Long-Term Services and Supports: History of Federal Policy and Programs

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Long-term services and supports (LTSS) refer to a broad range of health and health-related services and supports needed by individuals who lack the capacity for self-care due to a physical, cognitive, or mental disability or condition. Often, an individual’s disability or condition results in the need for hands-on assistance or supervision over an extended period of time.

In 2021, the United States spent an estimated $467.4 billion on post-acute care and long-term services and supports (LTSS), representing 13.2% of the $3.6 trillion spent on personal health care. The majority of spending on LTSS is funded by public programs (71.4%), with the Medicaid program being the largest public payer of LTSS in the United States. In the absence of publicly funded LTSS, individuals must rely on private sources of funding (e.g., out-of-pocket spending and private long-term care insurance [LTCI]), which accounted for 28.6% of LTSS expenditures in 2021.

The cost of obtaining paid assistance for LTSS, especially over an extended period of time, may far exceed the financial resources of many individuals and their families. Large personal financial liabilities associated with paid LTSS can leave individuals needing LTSS and their families at financial risk. Moreover, the vast majority of uncompensated LTSS is provided by family members, friends, and neighbors. Thus, the above estimates of LTSS spending do not account for the total cost of LTSS to the economy. Accounting for the opportunity cost of caregivers’ time would add an additional $86 billion to $151 billion to the total cost of LTSS, according to some estimates, depending on various assumptions about the value of caregiver’s leisure time and forgone wages.

The Medicaid program is the largest public payer of LTSS in the United States. Medicaid is a joint federal-state program that is administered and partially financed by each state with additional financial assistance from the federal government. As a result, eligibility and covered services vary widely across the nation, particularly for LTSS. For example, states are required to cover nursing facility services and home health services. However, most Medicaid home and community-based services (HCBS), such as personal care, are optional services that states can choose to cover. Medicare, a federal program that pays for covered health services for older adults (aged 65 and over) and for certain younger individuals with disabilities, finances almost one-fifth of care in long-term care facilities (LTCFs) and home health care. Nevertheless, Medicare funding is predominantly for post-acute skilled nursing care services and is not intended to cover care over an extended period of time.

The projected growth of the elderly population combined with large and increasing federal expenditures for health care services has generated legislative interest among federal policymakers in the ways in which federal health care programs cover LTSS, as well as alternative financing approaches. Policy solutions addressing the federal government’s role in financing LTSS range from public to private to hybrid approaches that combine both public and private policies and resources.

To help Congress understand the current financing landscape for LTSS and evaluate the range of LTSS financing options and proposals, this report provides the history of federal policy development and the federal government’s role in financing LTSS. This legislative history focuses largely on the Medicaid program and legislative actions to expand coverage of HCBS, as well as actions to restrict Medicaid covered-LTSS to those with limited income and assets. The report also summarizes various federal legislative efforts to encourage and expand the take-up of private LTCI, educate consumers about the need to plan for their long-term care needs, and establish Achieving a Better Life Experience (ABLE) accounts as a new type of LTSS savings vehicle that qualifying individuals with disabilities can use for disability-related expenses. The Appendix includes a timeline of the legislation discussed in this report.
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Long-term services and supports (LTSS) vary widely in their intensity and cost depending on an individual’s underlying conditions, the severity of his or her care needs, the setting in which services are provided, and the caregiving arrangement (i.e., paid care versus uncompensated care). The cost of obtaining paid assistance for these services, especially over a long period of time, may far exceed the financial resources of many individuals and their families. Among adults aged 50 and older, 60% feel “mostly” or “somewhat anxious” about affording the cost of LTSS, such as a nursing home, assisted living facility, paid nurse or an aide to assist them in advanced age. Large personal financial liabilities associated with paid LTSS can leave individuals needing LTSS and their families at financial risk. Among older adults aged 65 with savings ranging from $171,000 to $1.8 million, those with greater long-term care needs were much more likely to deplete their savings than those who did not need long-term care.

What Are Long-Term Services and Supports?

Long-term services and supports (LTSS) refer to a broad range of health and health-related services and supports needed by individuals who lack the capacity for self-care due to a physical, cognitive, or mental disability or condition. Often, an individual’s disability or condition results in the need for hands-on assistance or supervision over an extended period of time. LTSS is provided to assist individuals in performing activities of daily living (ADLs), such as eating, bathing, dressing, toileting, and transferring (from a bed to a chair, etc.). LTSS may also include assistance with instrumental activities of daily living (IADLs), which facilitate independent living in the community, such as providing light housework, laundry, meal preparation, transportation, and grocery shopping. Assistance may be in the form of hands-on assistance (i.e., actually performing a task for an individual) or prompting an individual to perform the task by himself or herself. For individuals with cognitive impairments, such assistance may also include supervising or prompting an individual to perform the task.

LTSS includes a variety of services and supports that can be provided in an individual’s own home or in a community-based setting such as an assisted living facility, referred to as Home and Community-Based Services (HCBS). LTSS can also be provided in an institutional setting, such as a nursing home or Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/ID).

In the United States, an estimated 14 million adults are in need of LTSS, and over half (56%) are individuals aged 65 and older. Most individuals who need LTSS are cared for in their own homes with the assistance of informal caregivers such as family members or friends. An estimated 10.6 million people provide uncompensated care to older adults, and, among those, 30% provide care to individuals aged 85 and older. Moreover, there is unmet need among older adults who need daily assistance. Analysis of Health and Retirement Study data from 2000 to 2021 found that

1 In 2021, the median annual cost of nursing home care was $94,900 for a semi-private room and $108,400 for a private room. Assisted living facilities (ALFs) had a median cost of $54,000 annually, and the median annual cost for home health aide services (based on industry guidance that assumes 44 hours of care per week) was an estimated $61,800. See Genworth Financial, “Genworth 2021 Cost of Care Survey,” January 31, 2022, https://www.genworth.com/aging-and-you/finances/cost-of-care.html.


3 Ibid.


among the 8 million older adults who reported dementia or difficulty with one or more daily personal tasks, 3 million reported not receiving assistance.6

While the need for, use of, and costs associated with LTSS vary among individuals over their lifespans, the probability of needing LTSS increases with age. It is estimated that more than half (56%) of Americans who survive to age 65 develop a disability serious enough to need LTSS.7 Among those who develop a disability as an older adult, an estimated 10% will need care for less than a year and an estimated 22% will need care for five or more years.8 The average duration of LTSS needed is estimated to be 2.8 years overall, with the average duration of LTSS needed being higher for women, at 3.2 years, than for men, at 2.3 years.9 As the population ages, the aggregate demand for LTSS is expected to increase. In addition, advances in medical care and supportive care are enabling younger persons with disabilities to live longer lives, requiring the delivery of services and supports for longer periods of time.

The projected growth of the elderly population combined with large and increasing federal expenditures for health care services has generated legislative interest among federal policymakers in the ways federal health care programs cover LTSS, as well as alternative approaches to current financing systems. As the largest public payer of LTSS in the United States, Medicaid continues to be of interest and debate. For example, Medicaid effectively operates as a safety net program by providing LTSS for low-income persons. It also operates as a de facto public long-term care program in the absence of a comprehensive LTSS financing system in the United States. In addition, broader equity and access issues regarding community integration of publicly financed LTSS for individuals with disabilities continues to be a concern for federal policymakers.

Policy solutions addressing the federal government’s role in LTSS financing range from public to private to hybrid approaches that combine public and private spending. Some analysts suggest that individuals should assume greater financial responsibility for their own LTSS before relying on public funding to pay for care they could otherwise afford, suggesting the federal government’s role should focus on expanding the purchase of private LTCT.10 Others propose that federal health care financing programs, such as Medicare or Medicaid, should play a larger role in covering LTSS and advocate for greater LTSS coverage and more revenue and spending for these programs.11 Some have advocated for new public financing approaches that would provide

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8 Ibid.

9 Ibid.


catastrophic coverage to protect against high LTSS costs.\textsuperscript{12} Still others have offered various hybrid approaches that combine new public financing programs with private insurance approaches such as a beneficiary-financed Medicare supplemental benefit.\textsuperscript{13} In the absence of a comprehensive approach to addressing the nation’s LTSS financing challenges, several states have established their own financing programs and initiatives.\textsuperscript{14}

To help Congress understand the current financing landscape for LTSS and evaluate both public and private LTSS financing options and proposals, this report provides the history of the federal government’s role in financing LTSS. This legislative history largely focuses on the Medicaid program and legislative actions to expand coverage of home and community-based services (HCBS), as well as actions to restrict Medicaid covered-LTSS to those with limited income and assets. The report then summarizes various federal legislative efforts to encourage and expand the take-up of private long-term care insurance (LTCI), educate consumers about the need to plan for their long-term care needs, and establish a new type of LTSS savings vehicle that qualifying individuals with disabilities can use for disability-related expenses. A timeline of the legislation discussed in this report is included in the Appendix.

**For More Information on Long-Term Services and Supports (LTSS)**

This report provides background and context for the summarized LTSS provisions in enacted legislation. CRS products and other resources are cited throughout this report, but select CRS products are listed below as particularly relevant for further information:

- CRS In Focus IF10427, Overview of Long-Term Services and Supports
- CRS In Focus IF10343, Who Pays for Long-Term Services and Supports?
- CRS Report R43328, Medicaid Coverage of Long-Term Services and Supports
- CRS Report R46111, Medicaid Eligibility: Older Adults and Individuals with Disabilities
- CRS In Focus IF11545, Overview of Federally Certified Long-Term Care Facilities
- CRS In Focus IF11544, Overview of Assisted Living Facilities
- CRS In Focus IF11614, Long-Term Care Insurance: Overview

**Role of Public Financing in LTSS**

With the enactment of Titles XVIII (Medicare) and XIX (Medicaid) of the Social Security Act in 1965, public financing for post-acute or rehabilitative care and LTSS in long-term care facilities (LTCFs) became part of the U.S. health care delivery system. Over time, states and the federal government became the largest payers of LTSS. In 2021, the United States spent an estimated $467.4 billion on post-acute care and LTSS, representing 13.2% of the $3.6 trillion spent on personal health care.\textsuperscript{15} The majority of spending on LTSS is funded by public programs (71.4%),

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\textsuperscript{15} CRS analysis of National Health Expenditure Account (NHEA) data obtained from the Centers for Medicare & (continued...)}
with the Medicaid program being the largest public payer of LTSS (see Figure 1). In 2021, over 44.3% of LTSS was financed by the Medicaid program (combined federal and state spending). Over the past 20 years, the share of public LTSS spending has increased (from 66.8% in 2001 to 71.4% in 2021), primarily due to increases in the proportion of Medicare funding.

**Figure 1. Long-Term Services and Supports Spending, by Payer, 2021**

<table>
<thead>
<tr>
<th>Total LTSS Spending (2021): $467.4 Billion</th>
<th>Public $333.6B (71.4%)</th>
<th>Private $133.8B (28.6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid $207.0B (44.3%)</td>
<td>Medicare $92.6B (19.8%)</td>
<td>Out-of-pocket $63.6B (13.6%)</td>
</tr>
<tr>
<td>Other Public $34.0B (7.3%)</td>
<td>Other Private Insurance $37.4B (8.0%)</td>
<td>Other Private $32.9B (7.0%)</td>
</tr>
</tbody>
</table>

**Source:** CRS analysis of National Health Expenditure Account (NHEA) data obtained from the Centers for Medicare & Medicaid Services, Office of the Actuary, prepared November 2022.

**Notes:** For more information, see CRS In Focus IF10343, *Who Pays for Long-Term Services and Supports?*

Because the vast majority of LTSS is provided by uncompensated caregivers such as family members, friends, and neighbors, these figures do not account for the total cost of LTSS to the economy. Researchers estimating the opportunity cost of uncompensated caregivers’ time found that the value of this care ranged from $86 billion to $151 billion, depending on various assumptions about leisure time and forgone wages.¹⁷

LTSS expenditures also make up a growing portion of the U.S. economy, rising from less than 1% of gross domestic product (GDP) in 1990 to more than 1.5% by 2011.¹⁸ Since that time, LTSS expenditures as a percentage of GDP have remained relatively flat, possibly due to policies and programs that have expanded access to less costly interventions that focus on care at home and in the community while restricting public program eligibility to those with low incomes and asset levels.

As the largest public LTSS payer, the joint federal-state Medicaid program is administered and partially financed by each state with additional financial assistance from the federal government.¹⁹ As a result, eligibility and covered services vary widely across the nation, particularly for LTSS. States are required to cover certain state plan services (mandatory services) and may choose to cover additional services (optional services). For example, states are required to cover nursing facility services and home health services, while most Medicaid HCBS (e.g., personal care) are optional services that states can choose to cover.⁰ Medicare, a federal program that pays for covered health services for older adults (aged 65 and over) and for certain younger

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¹⁶ Ibid.


¹⁸ Ibid.


²⁰ States are required to cover nursing facility services for beneficiaries aged 21 and over under their Medicaid plans. States have the option to cover nursing facility services for beneficiaries under age 21. According to CMS, all states provide this optional service. For more information see, CMS, “Nursing Facilities,” [https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/index.html](https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/index.html).
individuals with disabilities, finances almost one-fifth of care in LTCFs and home health care. However, Medicare funding is predominantly for post-acute skilled nursing care services and is not intended to cover care over an extended period of time.

Individuals who are not eligible for publicly funded LTSS must rely on private sources of funding, which accounted for 28.6% of LTSS expenditures in 2021 (see Figure 1). The largest component of private spending is out-of-pocket spending, followed by private long-term care insurance (LTCI). Individuals who seek paid LTSS but do not qualify for public assistance or do not have private LTCI must pay for these services directly out-of-pocket or rely on family and friends to provide needed care. Private LTCI provides some financial protection against the risk of the potentially high cost of LTSS.

Private LTCI policies can take different forms, from stand-alone or traditional LTCI policies to linked benefit products, also known as hybrid products, that combine life insurance or an annuity with long-term care coverage. Generally, the types of services covered under a LTCI policy are not covered under health insurance. And, unlike most health insurance policies, LTCI policies are subject to underwriting, which means that individuals who have preexisting conditions can be denied coverage or offered a policy with a high premium. As of 2020, about 7.5 million Americans have some LTCI coverage from either traditional or linked-benefit products, representing a small fraction of the potential market.

The LTCI market has changed significantly over the past two decades by becoming more concentrated, with fewer companies selling traditional LTCI. Over the past two decades, annual LTCI premiums in the stand-alone market have increased significantly for both current and new policyholders raising concerns about future market stability. For example, the Federal Long-Term Care Insurance Program (FLTCIP) for active and retired federal workers and eligible family members was suspended in 2022 for new enrollee applications and to assess premium rates for current policyholders. At the same time, linked-benefit products have become more popular, with the number of in-force policies at 600,000 in 2019 and growing annually.

Medicaid and LTSS Coverage

One important issue for Medicaid LTSS coverage is its perceived bias in favor of institutional care. The original 1965 Medicaid law established that eligible Medicaid beneficiaries are entitled to nursing facility care. However, increasing expenditures for institutional care and growing public demand for community-based alternatives spurred congressional action over time. This led to additional authority for states, as well as federal payment incentives, to expand state Medicaid

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21 CRS Report R40425, Medicare Primer.

22 Generally, Medicare covers up to 100 days of post-hospital care for skilled nursing facility services on a daily basis (after a three-day hospital stay). There is no beneficiary cost-sharing for the first 20 days. Days 21-100 are subject to a daily coinsurance charge of up to $200; see https://www.medicare.gov/coverage/skilled-nursing-facility-care.html.

23 CRS analysis of National Health Expenditure Account (NHEA) data obtained from CMS, Office of the Actuary, prepared November 2022.


programs HCBS offerings, often referred to as “rebalancing.”

These legislative activities were also prompted by the U.S. Supreme Court decision in Olmstead v. L.C., which held that the institutionalization of people who could be cared for in community settings was a violation of Title II of the Americans with Disabilities Act (ADA). The following section describes legislative activity that established Medicaid and its coverage requirements for nursing facility services and home health, as well as various legislative efforts over time to provide additional coverage and financing for HCBS.

Nursing Facility Services

Prior to the enactment of Medicaid in 1965, homes for the aged and other public institutions were financed by a combination of direct payments made by individuals from their Old-Age Assistance benefits and vendor payments made by states with federal matching payments on behalf of individuals. In 1960, legislation established the Kerr-Mills Medical Assistance to the Aged program (P.L. 86-778), which allowed states to provide medical services, including skilled nursing care, to persons who were not eligible for Old-Age Assistance cash payments, thereby expanding the covered population.

In 1965, when Kerr-Mills was incorporated into the new federal-state Medicaid program, legislation to provide an entitlement to skilled nursing facility care for beneficiaries aged 21 and older was enacted, requiring states to offer this service under the expanded program. This legislation gave skilled nursing facility care the same priority status as hospital and physician services. Subsequent amendments allowed states to provide care in “intermediate care facilities” for persons who did not need skilled nursing facility care but needed assistance beyond room and board alone. In 1987, legislation was enacted to eliminate the distinction between skilled nursing facilities and intermediate care facilities in the Medicaid program (effective in 1990). Medicaid law now refers collectively to these settings as nursing facilities (NFs).

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28 For more information on the ADA, see CRS In Focus IF12227, The Americans with Disabilities Act: A Brief Overview.


32 Social Security Amendments of 1965 (P.L. 89-97). The term intermediate care facilities is still used to refer to residential facilities licensed and certified by Medicaid as Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/IDs).


34 Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203).
These early legislative developments helped stimulate growth in the nursing home industry. A significant increase in the number of nursing homes occurred between 1960 and 1970. Over that period, the number of nursing homes in the United States more than doubled, from around 9,600 to almost 23,000, and the number of beds more than tripled, from 331,000 to more than 1 million.\textsuperscript{35} Since 1970, the number of nursing homes nationwide has declined, but the number of beds has increased. As of September 2023, nearly 15,000 nursing homes participated in Medicare or Medicaid.\textsuperscript{36} Of this total, 94% of nursing homes were dually certified to participate in both Medicare and Medicaid, 4% were certified as Medicare only, and 2% were certified as Medicaid only. A daily average of 1,202,855 individuals resided in a nursing home.\textsuperscript{37}

### Home and Community-Based Services

Home care services also received congressional attention in Medicaid’s original authorizing statute. Under the 1965 law, home health care was established as one of the optional services that states could provide. In 1968, three years after Medicaid was established, legislation was amended that required states to provide home health care to persons entitled to skilled nursing facility care as part of their state Medicaid plans.\textsuperscript{38} Over time, states were authorized to cover other types of home and community-based services (HCBS) as optional benefits under the Medicaid state plan, which is the agreement between a state and the federal government that describes how that state will administer its Medicaid program. For example, the optional personal care benefit was first available in 1978 through federal regulation.\textsuperscript{39} Subsequent legislative efforts added an optional case management benefit in 1986, enabling states to make improvements in the management of care for their LTSS beneficiaries and other groups.\textsuperscript{40}

### Authorizing Medicaid HCBS Waiver Programs

During the 1970s, the U.S. Department of Health, Education and Welfare (HEW, now the Department of Health and Human Services [HHS]) considered alternatives to nursing home care through various federal research and demonstration efforts.\textsuperscript{41} These efforts were undertaken not only to find ways to offset the high cost of nursing facility care, but also to respond to older adults and individuals with disabilities who desired to remain in their homes and in community-based settings rather than in institutions. In 1981, Congress took significant legislative action to expand HCBS when it authorized the Medicaid Section 1915(c) of the Social Security Act (SSA), Home and Community-Based Services (HCBS) Waiver Program in response to general concerns about


\textsuperscript{36} CRS analysis of CMS, Nursing Home Compare, as of September 1, 2023, accessed October 12, 2023, available at https://data.cms.gov/provider-data/dataset/4pq5-npy.

\textsuperscript{37} Ibid.

\textsuperscript{38} Social Security Amendments of 1967 (P.L. 90-248).

\textsuperscript{39} Provided first in federal regulation (43 Federal Register 45228, September 29, 1978), legislation to add personal care to the list of optional services specified in the Medicaid statute was enacted under the Omnibus Budget Reconciliation Act of 1993 (P.L. 103-66). Personal care services include assistance with performing activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Assistance may be in the form of hands-on assistance (i.e., actually performing a task for an individual) or prompting an individual to perform the task by himself or herself. For individuals with cognitive impairments, such assistance may also include supervising or prompting an individual to perform the task.

\textsuperscript{40} The Consolidated Omnibus Reconciliation Act of 1985 (P.L. 99-272), effective on enactment (April 7, 1986).

the lack of federal funding for noninstitutional LTSS. The HCBS waiver program also responded to specific concerns that Medicaid provided far greater support for nursing facility care than home and community-based care.

Medicaid HCBS waiver program coverage allows states to waive certain Medicaid statutory requirements under the state plan to provide services that are not specified in Medicaid federal statute. Under the HCBS waiver program, states may choose to cover certain HCBS under one or more waiver programs subject to the terms and conditions of the waiver agreement and with approval from the Secretary of Health and Human Services. Prior to 1981, many of the nonskilled personal care and supportive services needed by chronically impaired persons to remain in the community were not covered under the Medicaid state plan. With approved HCBS waiver programs, states were permitted to waive certain Medicaid state plan requirements to allow coverage of a wide variety of nonmedical, social, and supportive services designed to assist individuals with independent living.

Community Integration: The Olmstead Decision

In 1999, the U.S. Supreme Court ruled on a landmark case for individuals with disabilities: Olmstead v. L.C. The Court held that institutionalization of people who could be cared for in community settings was a violation of Title II of the Americans with Disabilities Act (ADA). This case prompted federal administrative and legislative activities to provide expanded HCBS to persons with disabilities. Since this time, every state has taken up either the SSA Section 1915(c) HCBS waiver program option, or a comparable waiver under the authority of SSA Section 1115 (research and demonstration waivers), to offer HCBS to certain LTSS participants. To help states transform their Medicaid LTSS delivery systems toward HCBS, Congress in FY2001 provided appropriated funding for the Real Choice Systems Change Grants for Community Living Program. This program awarded grants to states to transform their Medicaid LTSS delivery systems. CMS awarded over 350 grants to states between FY2001 and FY2010, for a total of approximately $288.6 million.

Providing Additional Medicaid HCBS State Plan Options

In response to pressure from states and other stakeholders for additional ways to expand Medicaid HCBS without the use of a waiver and to meet the community integration mandate under the Olmstead decision, federal lawmakers established two optional state plan Medicaid benefits under the Deficit Reduction Act of 2005 (DRA; P.L. 109-171), thereby providing states with additional statutory authority to provide HCBS. SSA Section 1915(i) gave states the authority under their state plan to cover new waiver-like HCBS for certain eligible individuals without requiring a Secretary-approved waiver for this purpose. The DRA also established a state plan option under a

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44 Specifically, the Court held that the Americans with Disabilities Act (ADA) requires states to transfer individuals with mental disabilities from institutions to less confining community settings when a state treatment professional has determined the latter is appropriate, the community setting is not opposed by the individual with a disability, and the placement can be reasonably accommodated by the state. A January 2000 Health Care Financing Administration (now Centers for Medicare & Medicaid Services, CMS) notice to state Medicaid directors indicated that the decision was applicable to all individuals with disabilities, not just those with mental disabilities. See https://downloads.cms.gov/cmsgov/archived-downloads/smdl/downloads/smd011400c.pdf.

new SSA Section 1915(j) to provide states with the authority to offer self-directed personal attendant services (PAS), with features such as individual budgets and the ability to purchase nontraditional goods and services. The DRA also included certain case management and targeted case management reforms that further defined these services under Medicaid.46

With limited take-up of HCBS state plan options under the DRA and continued calls for additional incentives for states to offer HCBS, Congress helped to enact new and revised HCBS authority under the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended). The ACA created a new LTSS state plan option under Medicaid for states to increase HCBS coverage. This optional benefit, the Community First Choice (CFC) state plan option under SSA Section 1915(k), authorizes states to receive an increase to the Federal Medical Assistance Percentage (FMAP) and to offer personal attendant services and supports to assist eligible individuals accomplish daily personal care activities and health-related tasks.47 In an effort to expand state participation, the ACA also amended the HCBS state plan option established under the DRA to offer additional flexibilities similar to Section 1915(c) HCBS waiver programs.

**Incentivizing HCBS Through Financing and Demonstration Programs**

In addition to offering states additional statutory authority and flexibility to cover HCBS in their Medicaid programs, new demonstration programs were established to increase HCBS access and coverage and to provide grant funding and other financing incentives to states for these activities. Beginning in 2006, the DRA established and appropriated a total of $1.75 billion in funding through FY2011 for the Money Follows the Person (MFP) Rebalancing Demonstration Program. The MFP program provided competitive grants to states to transition Medicaid participants who reside in institutional settings that provide LTSS, such as nursing facilities, into community-based settings.48

Since the passage of the ACA, the MFP program has been extended with additional mandatory funding under the ACA, as well as through subsequent legislation to extend certain health care-related provisions scheduled to expire since enactment. These expiring provisions are portions of law that are time-limited and will lapse once a statutory deadline is reached, absent further legislative action. Most recently, the Consolidated Appropriations Act, 2023 (P.L. 117-220),

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48 For more information, see CRS In Focus IF11839, Medicaid’s Money Follows the Person Rebalancing Demonstration Program.
extends the MFP program and appropriates $450 million in federal funding for each of FY2024 through FY2027, for a total of $1.8 billion for competitive grants to states.\textsuperscript{49} In addition to extending MFP, the ACA also established a new four-year incentive payment grant program, referred to as the Balancing Incentive Payments (BIP) Program. The BIP program authorized CMS to provide incentive payment grants to qualifying state Medicaid programs for increasing their share of LTSS spending on HCBS while reducing their spending on LTSS institutional care. The aggregate amount of incentive payments made by the HHS Secretary under the BIP program to states was not to exceed $3 billion over the BIP period, which began October 1, 2011, and ended on September 30, 2015. More recently, in an effort to provide additional support to states for Medicaid HCBS during the COVID-19 pandemic, the American Rescue Plan Act of 2021 (ARPA, P.L. 117-2) temporarily increased the FMAP rate for Medicaid HCBS expenditures by 10 percentage points for states that met the requirements during the program improvement period (i.e., April 1, 2021, through March 31, 2022).\textsuperscript{50}

**Medicaid and LTSS Eligibility**

Medicaid is intended to provide a safety net for those who cannot afford to pay the high cost of health care. Medicaid eligibility for adults aged 65 and over (i.e., aged) and individuals who are blind or disabled is of interest to lawmakers primarily for two reasons: (1) these groups are more likely to need LTSS, and (2) they account for a large share of Medicaid spending.\textsuperscript{51} The Supplemental Security Income (SSI) program rules, which include both an income and a resource or asset test, are the foundation of Medicaid eligibility for older adults and individuals with disabilities under mandatory and optional eligibility pathways.\textsuperscript{52} In addition, there are financial eligibility rules for receipt of Medicaid-covered LTSS that allow states to extend eligibility to those with incomes above the federal poverty level and to exclude certain assets in order to help them qualify for covered services.\textsuperscript{53} Other Medicaid provisions seek to recover the costs associated with Medicaid LTSS through estate recovery programs.\textsuperscript{54} Advocates argue that

\begin{footnotesize}
\textsuperscript{49} For more information, see CRS Report R47821, *Consolidated Appropriations Act, 2023 (P.L. 117-328): Medicaid and CHIP Provisions.*


\textsuperscript{52} SSI is a federal assistance program authorized under Title XVI of the Social Security Act that provides monthly cash payments to aged, blind, or disabled individuals who have limited income and resources. SSI is intended to provide a guaranteed minimum income to adults who have difficulty covering their basic living expenses due to age or disability and who have little or no Social Security or other income. It is also designed to supplement the support and maintenance of needy children under the age of 18 who have severe disabilities. Unlike Medicaid, SSI eligibility requirements and benefit levels are based on nationally uniform standards. For more information, see CRS Report R46111, *Medicaid Eligibility: Older Adults and Individuals with Disabilities.*

\textsuperscript{53} CRS Report R46111, *Medicaid Eligibility: Older Adults and Individuals with Disabilities.*

\textsuperscript{54} Section 1917(b) of the Social Security Act describes estate recovery provisions.
\end{footnotesize}
Medicaid essentially “loans” financial support for LTSS to participants; once the participant is deceased, assets that were otherwise not factored into the income or asset limits to gain eligibility, and were allowed to remain in the individual’s estate, may become due to the state and the federal government.55

Congress has increasingly focused on legislative efforts to expand options for individuals to access Medicaid-covered LTSS, primarily through options to cover HCBS, and has incentivized states to do so. However, federal policymakers have concurrently enacted legislation to ensure that the program remains focused on providing needed care to individuals who have limited income and assets. To this end, federal Medicaid law established requirements that non-Medicaid family members, such as spouses, are protected from financial hardship while discouraging would-be applicants from divesting their assets sooner than would occur otherwise to gain Medicaid-covered LTSS. The following section describes legislative activity concerning spousal impoverishment protections, the treatment of certain assets, and transfer of assets for less than fair market value (FMV) prior to Medicaid eligibility.56

Spousal Impoverishment Protections

The Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360)57 established new rules for the treatment of income and resources (i.e., assets) of married couples when one spouse needs LTSS provided in an institution, such as a nursing home. Commonly referred to as “spousal impoverishment protections,” these requirements attempt to equitably allocate income and assets to each spouse when determining Medicaid financial eligibility and are intended to prevent the impoverishment of the non-Medicaid spouse. These rules allow the Medicaid-spouse to transfer income and assets to the non-Medicaid spouse up to state-determined monthly income and asset thresholds within federal minimums and maximums, which are adjusted annually for inflation, referred to as the minimum monthly maintenance needs allowance (MMMNA) and the community spouse resource allowance (CSRA).58 Prior to enactment of P.L. 100-360, the non-Medicaid spouse could face financial hardship because the income and assets that belonged to the Medicaid-spouse or the couple were considered available for the cost of care. In addition, amounts that could be set aside for the non-Medicaid spouse were considered by some to be inadequate to cover basic living expenses and personal needs.

Over time, Congress has worked to amend these spousal impoverishment protections to address equity and other access issues. For example, under the DRA, states were required to apply the “income-first” rule in determining whether to allocate additional spousal assets above the CSRA for a non-Medicaid spouse with limited or no income to bring that spouse’s income up to the


56 This discussion of legislative history largely focuses on financial eligibility for Medicaid-covered LTSS, for more information about ways Medicaid has expanded to include additional optional eligibility pathways for working individuals with disabilities or working families who have a child with a disability under Medicaid Buy-In Groups, see CRS Report R46111, Medicaid Eligibility: Older Adults and Individuals with Disabilities. These proposals have been enacted under Section 201 of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA; P.L. 106-170) and Section 6061 of the DRA (P.L. 109-171), the Family Opportunity Act (FOA).

57 Most of the Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360) was repealed under the Medicare Catastrophic Coverage Repeal Act of 1989 (P.L. 101-234), but the spousal impoverishment provisions were retained.

MMMNA. The income-first rule requires Medicaid programs to consider whether all income of the Medicaid-spouse that could be made available to the non-Medicaid spouse has been made available prior to allocating any additional resources. Likewise, prior to enactment of the ACA, spousal impoverishment rules applied only in situations where the Medicaid participant was receiving LTSS in an institution. States had the option to extend these protections to certain HCBS participants under a Section 1915(c) HCBS waiver program. The ACA temporarily required states to apply the spousal impoverishment rules to all married individuals who are eligible for HCBS under certain specified authorities, not just those receiving institutional care. This modified provision expired under the ACA on December 31, 2018. However, Congress has helped extend the authority for these protections several times. Most recently, the Consolidated Appropriations Act, 2023 (P.L. 117-328), extends these protections through FY2027.

Asset Transfer Rules

For persons seeking Medicaid eligibility and coverage of LTSS, federal law requires states to apply rules regarding the transfer of assets prior to qualifying for Medicaid. These rules attempt to ensure that Medicaid applicants apply their assets toward the cost of their care and do not divest them sooner than would occur otherwise to gain Medicaid eligibility. Medicaid may require states to delay Medicaid eligibility for applicants seeking institutional LTSS and certain HCBS who have disposed of assets for less than fair market value (FMV) on or after a “look-back period,” or period of time prior to application for services. In other words, transfers for less than FMV may be, but are not always, prohibited during a look-back period prior to application for Medicaid. Federal Medicaid law also prohibits spouses of applicants from transferring assets for less than FMV during this same period as a condition of the applicant’s eligibility for Medicaid.

Initially, states were required to take into account the FMV of asset transfers within the preceding 24-month period in determining SSI eligibility, and it was optional for states to impose restrictions with respect to Medicaid LTSS eligibility, provided it was not more restrictive than SSI, with certain exceptions. Subsequent legislation required state Medicaid programs to prohibit transfers of assets for less than FMV (rather than giving them the option to do so) and extended the look-back period from 24 months to 30 months. Further legislative efforts lengthened the look-back period from 30 months to three years (36 months). The DRA of 2005

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60 These HCBS recipients are eligible under the “special home and community-based services waiver eligibility group” or “217 Group” in reference to the specific regulatory citation for this group at 42 C.F.R. §435.217. Prior to Section 2404 of the ACA, states that chose to apply spousal impoverishment protections as an option for the 217 Group also had the option to treat married HCBS recipients in the 217 Group as institutionalized for the purposes of post-eligibility treatment of income (PETI) rules.

61 States that cover the 217 Group must also apply the post-eligibility treatment of income rules.


63 See Section 1917(c) of the SSA for requirements regarding the transfer of assets for less than fair market value.

64 SSI’s look-back period was initially 24 months when the asset transfer penalty was established in 1980. The SSI asset transfer penalty was later eliminated in 1988. However, Congress worked to reimpose the SSI asset transfer penalty in 1999 and extended the penalty period to 36 months, which, at the time, was the same length as Medicaid’s asset transfer penalty period; see Social Security Administration, Annual Statistical Supplement, 2023, “Transfer-of-Resources Penalties” at https://www.ssa.gov/policy/docs/statcomps/supplement/2023/si.html.

65 Section 303(b) of the Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360).

continued this policy trend and lengthened the look-back period that applies under current law, from three years to five years. Under this change, asset transfers for less than FMV of all kinds made within five years of application to Medicaid are subject to review by the state, which then applies asset transfer penalties in the form of a penalty period or months of program ineligibility. This provision further changed the start date of the ineligibility period, or penalty period, for all transfers made on or after the date of enactment, as well as how states calculate the ineligibility period. The DRA also added requirements for states to approve undue hardship requests when the asset transfer penalty would deprive an individual of critical medical care or basic necessities, such as food, clothing, and shelter.

**Treatment of Assets**

For the purposes of Medicaid asset transfer rules, all resources (and income) of an individual or couple are evaluated to determine whether the establishment, purchase, sale, or transfer of an asset has occurred for less than FMV. Generally, states follow federal SSI program rules concerning the treatment of most asset types that individuals possess at the time of application to Medicaid. Although Medicaid law does not contain provisions specifying how all assets should be treated, it does include special rules about how states must treat certain types of assets, such as annuities, fees for Continuing Care Retirement Communities (CCRCs), the value of a primary residence, life estates, promissory notes, loans, mortgages, and trusts. Also, the HHS Secretary has the authority to issue guidance to states on other categories of transactions that may be treated as transfers of assets for less than FMV.

The DRA added requirements concerning the treatment of annuities for purposes of Medicaid eligibility. It also restricted Medicaid LTSS eligibility if an applicant’s equity interest in the home exceeds a statutorily determined amount. DRA also allowed CCRCs and life care communities to require residents to spend their resources—declared when applying for admission—on their care before they apply for Medicaid. It further required states to consider certain entrance fees for CCRCs or life care communities as countable resources or assets when determining an individual’s eligibility for Medicaid. The DRA also specified that the purchase of a life estate is considered a transfer of assets for less than FMV unless the purchaser resides in the home for at least one year after the date of purchase. It further made funds used to purchase a promissory note, loan, or mortgage subject to the look-back period, and thus result in a penalty period unless the payment terms meet certain specifications.

**Long-Term Care Insurance, Planning, and Savings**

Federal policymakers have also sought to address private LTSS financing in several ways: by making the purchase of private LTCI more accessible and attractive to consumers through the Medicaid Partnership Program, by providing certain tax benefits and consumer protections for the

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68 Initially, the home equity limit amount a state could elect was a minimum of $500,000, not to exceed $750,000. Beginning in 2011, these dollar amounts were increased from year to year, based on the annual percentage increase in the Consumer Price Index for All Urban Consumers (CPI-U), rounded to the nearest $1,000 (currently $713,000, not to exceed $1,071,000). CMS, 2024 SSI and Spousal Impoverishment Standard, https://www.medicaid.gov/sites/default/files/2023-11/cib11142024.pdf.
69 Entrance fees for CCRCs can range from several thousand dollars to hundreds of thousands of dollars and vary by occupancy, setting size, and contract type; for more information, see GAO, Older Americans: Continuing Care Retirement Communities Can Provide Benefits, but Not Without Some Risk, GAO-10-611, June 2010, https://www.gao.gov/assets/gao-10-611.pdf.
purchase of private LTCI, and by establishing the Federal Long-Term Care Insurance Program (FLTCIP) for federal workers, retirees, and certain qualified relatives. Other programs have sought to educate consumers about the need to save for their LTSS needs by providing resources and information to consumers about long-term care planning through the creation of a National Clearinghouse for Long-Term Care Information. Policymakers have also established ways for individuals with disabilities and their families to save for LTSS expenses through Achieving a Better Life Experience (ABLE) accounts, which are a type of tax-favored savings account for individuals with qualifying disabilities.

With respect to broader LTSS financing initiatives, the ACA established a new publicly administered LTSS financing program, the Community Living Assistance Services and Supports (CLASS) Independence Benefit Plan, for the purchase of LTSS for individuals with certain functional limitations, which was repealed prior to implementation. Subsequent legislation created a bipartisan commission tasked with developing a plan and legislative recommendations for an LTSS financing system in the United States; however, commissioners did not reach an agreement on LTSS financing recommendations. The following section describes these long-term care insurance, savings, and planning provisions in greater detail.

**Medicaid Partnership Program**

In the late 1980s, several state Medicaid programs began to collaborate with private long-term care insurance (LTCI) companies to “create a bridge between Medicaid and private insurance for LTSS.” Initial planning grants were provided to states by the Robert Wood Johnson Foundation to design, market, and operate programs that would integrate public-private partnerships in LTSS financing. At the time, these partnerships aimed to create more affordable LTCI policies and provide enhanced consumer protections against the large financial risk associated with the high costs of LTSS. These planning grants resulted in the development of the State LTCI Partnership Program (referred to as the Partnership Program), a collaborative program between state Medicaid programs, the former Health Care Financing Administration (now the Centers for Medicare & Medicaid Services (CMS)), and the private LTCI industry.

The Partnership Program allows individuals who purchase a private LTCI policy to qualify for Medicaid covered-LTSS without meeting the same Medicaid financial eligibility rules regarding asset limits that other Medicaid LTSS applicants must meet, as long as they meet other Medicaid eligibility criteria. Generally, Partnership Program policyholders would seek Medicaid for extended coverage of LTSS after their private LTCI benefits have been exhausted. For these individuals, Medicaid financial eligibility requirements for the treatment of certain assets are relaxed at (1) the time of application to Medicaid and (2) the time of the beneficiary’s death,

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71 Ibid.

when Medicaid estate recovery is generally applied. Most Medicaid LTSS applicants may protect no more than $2,000 in assets for an individual and $3,000 for a married couple. In general, Partnership Program policyholders may protect amounts equivalent to the value of the benefits paid by the LTCI policy purchased (e.g., $100,000 of nursing home or assisted living benefits paid enables that individual to retain up to $100,000 in assets and still qualify for Medicaid coverage in that state).

Under the Long-Term Care Insurance Partnership Program, individuals who purchase certain private LTCI policies may qualify for Medicaid without the same financial eligibility requirements that other applicants must meet. The Omnibus Budget Reconciliation Act of 1993 (OBRA 1993; P.L. 103-66) amended Medicaid law to require that all 50 states and Washington, DC, seek recovery of payments from a deceased Medicaid participant’s estate for certain medical assistance provided to persons aged 55 or older. At the time, states operating Partnership Programs were permitted to disregard from countable assets certain LTSS benefits paid for by private LTCI policies when determining Medicaid financial eligibility. Under OBRA 1993, states with an approved state plan amendment for a Partnership Program as of May 14, 1993, were grandfathered in and could continue existing asset disregard practices and waive the new requirements for Medicaid estate recovery of those assets. While OBRA 1993 did not prohibit states from attempting to establish new Partnership Programs, states establishing new programs on or after May 14, 1993, were precluded from waiving these estate recovery requirements. By that date, five states (California, Connecticut, Indiana, Iowa, and New York) had received CMS approval.

The DRA expanded the Partnership Program under a new set of conditions that allowed any state with an HHS Secretary-approved Medicaid state plan amendment to operate a qualified state LTCI Partnership Program if specified conditions were met. Under these new conditions, states were required to exclude one dollar of asset for every dollar paid out under a qualified LTCI policy issued under the state’s new Partnership Program when determining Medicaid financial eligibility and protecting assets subject to Medicaid estate recovery. The DRA also required that a qualified LTCI policy, as defined in Section 7702B(b) of the Internal Revenue Code (IRC), meet new uniform standards for LTCI policies under qualified Partnership Programs. Among these requirements are consumer protections related to inflation protection, unintentional lapses in coverage, disclosure of certain policies, and contingent nonforfeiture requirements that protect consumers against increases in policy rates.

**Tax Benefits and Protections for Long-Term Care Insurance**

Federal law provides tax benefits and minimum consumer protection standards for purchasers of “tax-qualified” LTCI policies, as authorized by the Health Insurance Portability and

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73 Medicaid estate recovery requires states to seek recovery of payment from the estates of deceased Medicaid participants for certain benefits paid on their behalf. For individuals aged 55 or older, states are required to seek recovery of payments for nursing facility services, home and community-based services, and related hospital and prescription drug services. States have the option to recover payments for all other Medicaid services provided to these individuals, except Medicare cost-sharing paid on behalf of Medicare Savings Program beneficiaries. For more information, see CRS Report R43506, *Medicaid Financial Eligibility for Long-Term Services and Supports.*

74 Ibid.

75 HHS, “State Long-Term Care Partnership Program: Reporting Requirements for Insurers,” 73 Federal Register 76960-76969, December 18, 2008.

Accountability Act of 1996 (HIPAA, P.L. 104-191). These provisions are established in the Internal Revenue Code (26 U.S.C. §7702B). Most traditional LTCI policies sold after enactment of HIPAA are tax-qualified policies. Linked-benefit LTCI policies with a separately identifiable premium component can also qualify for tax benefits.

HIPAA tax-qualified LTCI products are required to have defined benefit triggers for when the policy begins to pay benefits. These triggers require policyholders to meet the definition of a “chronically ill” individual who has been certified by a licensed health care practitioner as

- being unable to perform (without substantial assistance) at least two ADLs for a period of at least 90 days due to a loss of functional capacity;
- having a level of disability similar (as determined by the Secretary of the Treasury in consultation with the Secretary of Health and Humans Services) to the level of disability described above; or
- requiring substantial supervision to protect the individual from threats to health and safety due to severe cognitive impairment.

Federal law provides tax advantages for some aspects of private LTCI. The dollar value of benefits from a HIPAA tax-qualified LTCI product are excluded from the gross income of the taxpayer (i.e., they are exempt from federal taxation). In general, LTCI premiums are allowed as itemized deductions to the extent that they and other unreimbursed medical expenses exceed 7.5% of adjusted gross income. LTCI premium deductions are subject to age-adjusted annual maximum amounts. In 2023, these amounts ranged from $480 for those aged 40 and younger to $5,960 for those aged 71 and older. Under current law, employer contributions toward the cost of tax-qualified LTCI, while not typical, are excluded from the gross income of an employee. Self-employed individuals may include LTCI premiums in calculating their deductions, along with other health insurance premiums. Only amounts less than or equal to the age-adjusted limits may be deducted or excluded from taxable income.

Federal Long-Term Care Insurance Program

The Long-Term Care Security Act (P.L. 106-265) authorized the Office of Personnel Management (OPM) to offer a federal long-term care insurance program (FLTCIP), which was established in 2002. Under the FLTCIP, active and retired federal workers and eligible family members who are approved for coverage may voluntarily purchase an LTCI policy. FLTCIP premiums may be deducted from an individual’s salary or pension benefit, but they are not pretax contributions, and workers pay 100% of the premiums. Eligible workers receive no premium assistance from the federal government. Since enactment, amendments to this legislation have primarily addressed eligibility. OPM has suspended new enrollee applications for FLTCIP coverage, as well as current enrollee’s coverage increases, to allow time to assess benefit offerings and premium rates. The suspension period began on December 19, 2022, and is scheduled to remain in effect for 24 months unless OPM decides to end or extend the suspension period.77

National Clearinghouse for Long-Term Care Information

To help individuals plan for their potential LTSS needs, the DRA required the HHS Secretary to establish the National Clearinghouse for Long-Term Care Information (the Clearinghouse) to

77 For more information, see the Federal Long-Term Care Insurance Program at https://www.ltcfeds.com/.
• educate consumers about the availability and limitations of coverage for long-term care under Medicaid,
• provide objective information to help consumers decide whether to purchase LTCI, and
• maintain a list of states with State LTCI Partnership Programs under Medicaid.

Under the DRA, $3 million in mandatory funding for the Clearinghouse was provided for each fiscal year between FY2006 and FY2010. The ACA then amended Section 6021(d) of the DRA to extend mandatory funding for the Clearinghouse to $3 million per year for FY2011 through FY2015.78 The ACA also required the Clearinghouse to include information regarding how benefits provided under a CLASS benefit plan differ from disability insurance benefits. ACL continues to operate the Clearinghouse at LongTermCare.gov.79

Community Living Assistance Services and Supports (CLASS) Act

The ACA created a federally administered voluntary LTCI program under Title XXXII of the Public Health Service Act (PHSA) titled “Community Living Assistance Services and Supports,” or the CLASS Act. Subsequent legislation repealed the CLASS Act prior to program implementation. If established, the CLASS program would have provided a cash benefit that eligible enrollees could use to purchase LTSS, such as personal assistance services, home care aides, homemaker services, nursing support, respite care, home modifications, assistive technology, and accessible transportation. The stated purpose of the CLASS program was to

• provide individuals with functional limitations various services and supports to allow them to maintain their personal and financial independence and live in the community through a new financing strategy for community living assistance services and supports;
• establish an infrastructure to help address the nation’s community living assistance services and support needs;
• alleviate burdens on family caregivers; and
• address institutional bias by providing a financing mechanism that supports personal choice and independence to live in the community.

Furthermore, the CLASS program would have provided employed individuals aged 18 and older the option to enroll in the voluntary program. The ACA specified two processes for enrollment into the CLASS program. The first was an automatic enrollment process. Within the automatic enrollment process, employers who chose to participate would be responsible for withholding CLASS premiums through payroll deductions. Employees would then have the opportunity to opt out if they did not want to participate. These enrollment procedures for employers in the CLASS program were intended to be similar to those established for 401(k) and other similar retirement plans by the Internal Revenue Service. The second was an alternative enrollment process developed for self-employed individuals, individuals with more than one employer, and individuals who had an employer that did not elect to participate in the automatic enrollment process.

78 The American Taxpayer Relief Act of 2012 (ATRA, P.L. 112-240) rescinded the unobligated balance of ACA’s funds to the National Clearinghouse for Long Term Care Information.
Premiums for the CLASS program were to be determined by the HHS Secretary based on 75-year actuarial estimates of expected future use and expenditures. Premiums would vary by age at enrollment. The ACA also included premium subsidies for workers with incomes below the federal poverty level and full-time students aged 18 to 21 who were currently working. To be eligible to receive benefits, an individual must have been an active enrollee who met the five-year vesting and minimum earnings requirements. In addition, an eligible individual must have had a functional limitation, as certified by a licensed health care practitioner, that was expected to last for at least 90 days. Benefits to eligible recipients included a cash benefit of at least an average of $50 per day. Other benefits included advocacy services and advice and assistance counseling on accessing and coordinating LTSS.

A number of concerns were raised about the long-term sustainability of the program and, as a result, HHS concluded in a letter to Congress in the fall of 2011 that the agency did not see a viable path forward for implementation. With administrative implementation of the CLASS program stalled, the 112th Congress passed legislation to repeal the CLASS program provisions under the American Taxpayer Relief Act of 2012 (ATRA, P.L. 112-240).

**Bipartisan Commission on Long-Term Care**

With the repeal of the CLASS Act, legislation was included under ATRA creating a bipartisan commission to develop a plan and legislative recommendations for the establishment, implementation, and financing of an LTSS system in the United States. Section 643 of the ATRA established a Commission on Long-Term Care (the Commission), composed of 15 members representing the interests of certain LTSS stakeholders and organizations, appointed by the President and specified congressional leaders. The Commission was required to vote on a report based on the developed plan and any proposals for legislative action, referred to as the commission bill, no later than six months after the Commission’s appointment. If approved by a majority of commission members, the commission bill would have been required to be introduced in the Senate and the House. The Commission was scheduled to terminate 30 days after a vote on the plan and proposed commission bill.

Formally established on June 10, 2013, the Commission held four public hearings and met in nine working group sessions over the next three months. During that time, the Commission solicited stakeholder and general public comments. On September 30, 2013, the Commission issued a final report to Congress that made consensus recommendations regarding service delivery and workforce; however, the Commission did not reach an agreement on LTSS financing recommendations. Rather, the final report outlined different LTSS financing approaches offered by members.

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81 Section 642 of ATRA repealed PHSA Title XXXII.
82 For information about the Commission on Long-Term Care including commissioners, press releases, hearings, and public comments, see http://www.ltccommission.org/.
84 Ibid.
Achieving a Better Life Experience (ABLE) Accounts

The Stephen Beck, Jr., Achieving a Better Life Experience (ABLE) Act of 2014 was enacted as part of Division B of the Tax Increase Prevention Act of 2014 (P.L. 113-395). The ABLE Act created Section 529A of the IRC, which allows states to establish and maintain a type of tax-favored savings program for individuals with qualifying disabilities.\(^8\) The stated purpose of the act is to

- encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life, and
- provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Medicaid, SSI, the beneficiary’s employment, and other sources.

Under a state’s qualified ABLE program, contributions may be made to the investment account of an eligible individual with a disability, known as the designated beneficiary.\(^8\) Funds from an ABLE account may be used for the short-term needs or long-term benefit of the designated beneficiary to pay for “qualified disability expenses,” including those related to education, housing, transportation, employment training and support, assistive technology and personal support services, and health and wellness (including LTSS), among other expenses. To establish an ABLE account, an individual must have a qualifying disability that began before age 26 (or, beginning in 2026, before age 46).\(^8\)

ABLE programs are modeled loosely on 529 college-savings plans, also known as qualified tuition programs, and have two distinct benefits for eligible individuals with disabilities. First, assets in an ABLE account can grow tax-free annually, and distributions from the account for qualified disability expenses are not included in the designated beneficiary’s gross income for federal income tax purposes. Second, assets in an ABLE account and distributions from the account for qualified disability expenses are excluded when determining a designated beneficiary’s eligibility for most federal means-tested programs, including Medicaid.\(^8\) Under the SSI program, however, only the first $100,000 in an ABLE account is excluded.\(^9\)

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\(^8\) For information on the implementation of state ABLE programs, see the ABLE National Resource Center, at https://www.ablenrc.org/select-a-state-program/.

\(^8\) Contributed to ABLE accounts are subject to both annual and cumulative limits. For more information on ABLE accounts, see U.S. Congress, Senate Committee on the Budget, Tax Expenditures: Compendium of Background Material on Individual Provisions, committee print, prepared by the Congressional Research Service, 115th Cong., 2nd sess., December 21, 2018, S.Prt. 115-28 (Washington: GPO, 2019), pp. 1037-1045, https://www.govinfo.gov/content/pkg/CPRT-115SPRT34119/pdf/CPRT-115SPRT34119.pdf#page=1053.

\(^7\) Section 124 of the SECURE 2.0 Act of 2022 (Division T of the Consolidated Appropriations Act, 2023 [P.L. 117-328]) amended IRC Section 529A to increase the disability onset age limit for an ABLE account from age 26 to age 46, effective for tax years after December 31, 2025; see Social Security Administration, “President Signs the Consolidated Appropriations Act, 2023,” Social Security Legislative Bulletin, no. 117-14, January 4, 2023, https://www.ssa.gov/legislation/legis_bulletin_122922.html.


\(^9\) Legislation enacted in subsequent Congresses made amendments to IRC regarding ABLE programs. Specifically, Section 303 of the Protecting Americans from Tax Hikes Act of 2015 (the PATH Act), which was enacted as part of the Consolidated Appropriations Act, 2016 (P.L. 114-113), removed the requirement that a state’s qualified ABLE program allow the establishment of an ABLE account only for a designated beneficiary who is a resident of that state or (continued...)
Concluding Observations

The need for LTSS in the future will depend on a number of factors, including demographic changes in the nation’s population, economic conditions that affect an individual’s ability to pay for LTSS, levels of disability and care needs, and advances in medical technology and innovation in the prevention and treatment of chronic conditions. Although Congress has debated both incremental and comprehensive policy approaches regarding how LTSS is financed, policymakers have taken a cautious approach to establishing any new federal commitments to LTSS financing. In particular, concern about cost has been central to the debate, at a time when the federal government continues to experience large budget deficits and increasing outlays for the Medicare and Medicaid programs. At the same time, the United States spends less on long-term care as a share of GDP than most other wealthy countries. The COVID-19 pandemic revealed the weaknesses and fragmentation of care underlying the current system, which continues to face challenges in recruiting and retaining direct care workers to meet current demand. As the federal government continues the difficult work of improving individuals’ access to long-term care, new strategies that build on and strengthen LTSS financing and delivery systems will likely continue to be a critical issue for states and federal policymakers, especially as the current system relies on family members to provide the bulk of care and Medicaid is the largest payer and payer of last resort for LTSS in the United States.

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of a contracting state. The following three changes, effective for January 1, 2018, through December 31, 2025, under Sections 11024 and 11025 of the 2017 Tax Revision (P.L. 115-97), (1) increased the amount of contributions allowed to an ABLE account for certain employed designated beneficiaries, subject to specified contribution limits; (2) permitted designated beneficiaries who meet certain requirements to claim the saver’s credit on non-rollover contributions made to their ABLE accounts during the year; and allowed a limited tax-free rollover from a 529 qualified tuition program account of the designated beneficiary or certain family member to the ABLE account of the designated beneficiary. For more information, see CRS Report R47846, Reference Table: Expiring Provisions in the “Tax Cuts and Jobs Act” (TCJA, P.L. 115-97), and U.S. Department of the Treasury, Internal Revenue Service, “Guidance Under Section 529A,” 85 Federal Register 74010-74047, November 19, 2020, https://www.federalregister.gov/documents/2020/11/19/2020-22144/guidance-under-section-529a-qualified-able-programs.

Appendix. Timeline of Long-Term Services and Supports (LTSS) Legislative Activity

This appendix provides a historical timeline, by decade, of the major legislative actions that first established and then amended various LTSS programs and policies, beginning with the Kerr-Mills Medical Assistance to the Aged program in the 1960s, a precursor to the Medicaid program that was established in 1965 (see Figure A-1). This history of LTSS legislative activity is not meant to be comprehensive; rather, it summarizes the federal legislative actions and amendments discussed in this report to provide a historical timeline of federal LTSS policy development in chronological order.
Figure A-1. Long-Term Services and Supports (LTSS) Legislative Activity by Decade
(1960 to 2023)

1960s

The Kerr-Mills Medical Assistance to the Aged program (P.L. 86-778)
• Authorized states to provide medical services, including skilled nursing care, to persons who were not eligible for Old-Age Assistance cash payments.

Social Security Amendments of 1965 (P.L. 89-97)
• Established a hospital insurance program for the aged and a voluntary supplementary medical insurance program (Medicare), and an improvement and extension of the Kerr-Mills Medical Assistance program for needy individuals (Medicaid).

Social Security Amendments of 1967 (P.L. 90-248)
• Required states to provide home health care to persons entitled to skilled nursing facility care as part of their state Medicaid plans.

1970s

Social Security Amendments of 1972 (P.L. 92-603)
• Replaced Old-Age Assistance and certain other adult assistance programs with the newly created federal Supplemental Security Income (SSI) program; SSI program rules linked to Medicaid categorical and financial eligibility criteria for older adults and individuals with disabilities.

1980s

“Social Security Act Amendments of 1980” (P.L. 96-611)
• Required states to take into account the fair market value (FMV) of asset transfers within the preceding 24-month period in determining SSI eligibility, and authorized states to impose a similar restriction with respect to Medicaid eligibility, provided it was not more restrictive than SSI, with certain exceptions.

Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35)
• Authorized Section 1915(c) of the Social Security Act (SSA), Home and Community-Based Services (HCBS) Waiver Program.

Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203)
• Reformed the statutory authority applying to nursing homes participating in Medicare and/or Medicaid to address new quality of care requirements; altered the survey process to reflect these requirements; and provided an enforcement response for noncompliance with federal regulations.

The Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360)
• Established spousal impoverishment protections for non-Medicaid spouses to preserve income and assets.
• Required states to prohibit transfers of assets for less than FMV (rather than giving them the option to do so) for Medicaid LTSS eligibility and extended the look-back period from 24 months to 30 months.
**1990s**

Omnibus Budget Reconciliation Act of 1993 *(OBRA 1993; P.L. 103-66)*
- Added personal care to the list of optional state Medicaid plan services.
- Extended the look-back period from 30 to 36 months for transfers of assets for less than FMV and 60 months for trusts for Medicaid LTSS eligibility, among other asset rule changes.
- Required states to seek recovery of payments from a deceased Medicaid participant’s estate for certain medical assistance provided to persons aged 55 or older.
- Grandfathered states with an approved Medicaid Partnership Program (as of May 14, 1993) to continue existing asset disregard practices and to waive Medicaid estate recovery; precluded new Partnership Program states from waiving estate recovery requirements.

Health Insurance Portability and Accountability Act of 1996 *(HIPAA, P.L. 104-191)*
- Provided tax benefits and minimum consumer protection standards for purchasers of “tax-qualified” private long-term care insurance (LTCl) policies.

**2000s**

The Long-Term Care Security Act *(P.L. 106-265)*
- Authorized the Office of Personnel Management to offer a federal long-term care insurance program (FLTCP).

- Created a new Medicaid state plan optional benefit for HCBS under Section 1915(i) of the SSA to allow states to provide HCBS under a state plan authority with some HCBS waiver-like features.
- Created a new Medicaid state plan optional benefit for self-directed LTSS under Section 1915(j) of the SSA.
- Established a new Medicaid LTSS demonstration grant program under the Money Follows the Person (MFP) Rebalancing Demonstration Program.
- Amended asset rules that determine eligibility for Medicaid-covered LTSS to extend the look-back period from three years to five years for transfers of less than FMV, among other asset transfer rule changes.
- Restricted eligibility to Medicaid-covered LTSS for home-owner applicants whose equity interest in their home exceeds certain limits specified in statute, among other changes to the treatment rules regarding certain types of assets.
- Expanded the Medicaid Partnership Program.
- Established the National Clearinghouse for Long-Term Care Information.
2010s

Patient Protection and Affordable Care Act (ACA, P.L. 111-148)

- Amended SSA Section 1915(i) HCBS State Plan Option to provide additional flexibilities similar to HCBS waiver programs.
- Established the SSA Section 1915(k) Community First Choice (CFC) State Plan Option authorizing states to provide home and community-based attendant services; states receive a six percentage point increase in their Federal Medical Assistance Percentage (FMAP) for CFC expenditures.
- Extended with additional funding the Medicaid MFP Rebalancing Demonstration Program.
- Established a new Medicaid grants program, the Balancing Incentive Program (BIP).
- Established the Community Living Assistance Services and Supports (CLASS) program to design and implement a federally administered voluntary LTCI program that would provide a cash benefit for LTSS.

The American Taxpayer Relief Act of 2012 (ATRA, P.L. 112-240)

- Repealed the CLASS program provisions under the ACA.
- Created a bipartisan commission to develop recommendations for a LTSS financing system in the United States.


- Allowed states to sponsor tax-advantaged savings programs through which contributions can be made to the investment account of an eligible individual with a disability to meet qualified disability expenses (including LTSS); ABLE accounts receive preferential treatment under most federal means-tested programs, including Medicaid.

2020s

American Rescue Plan Act of 2021 (ARPA; P.L. 117-2)

- Included a temporary increase to the FMAP rate for Medicaid HCBS expenditures for states that meet certain requirements.

Author Information

Kirsten J. Colello
Specialist in Health and Aging Policy
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