Celebrating 60 Years of Medicaid: Caring for Individuals with Disability

History: From the Social Security Act to Today

A disability can occur at any point of an individual's life, either present at birth or acquired later in life, and can be situational, temporary, or permanent.[1] A disability is defined as a physical, sensory, developmental, behavioral, or cognitive condition that may inhibit an individual's ability to perform one or more major life activities.[2] More than 15 million people in the United States have a disability; of those, 35% of them are enrolled in Medicaid. Nearly 60% of Medicaid enrollees with disabilities experience more than one difficulty, such as difficulties with living independently, self-care, and decision-making.[3] As a result, many of these individuals require additional medical care as well an array of supportive services, such as attendant care and nursing, known as long-term services and supports. Medicaid is the primary payer in the United States for LTSS, which are not covered under Medicare and are often not covered under employer-sponsored insurance.

Prior to the enactment of Medicare and Medicaid in 1965, the Social Security Act of 1935 was among the earliest pieces of legislation that addressed the needs of the aged, blind and disabled (ABD) population. Under the Social Security Act, the federal government established guidelines for three programs providing cash assistance: Old-

[1] Understanding Disability – Accessibility
[2] What is the definition of disability under the ADA? | ADA National Network ; Disability and Health Overview | Disability and Health | CDC
[3] 5 Key Facts About Medicaid Coverage for People with Disabilities | KFF

Age Assistance, Aid to the Blind, and Aid to the Permanently and Totally Disabled. States were responsible for administering the programs and implementing determination standards.[4] At the time of enactment in 1965, Medicaid did not explicitly cover individuals with disabilities as an eligibility group. In 1972, Congress created the Supplemental Security Income (SSI) program and linked Medicaid eligibility to SSI eligibility for the ABD population.[5] Eligibility determination responsibilities shifted from individual states to the federal government.[6] Through SSI, eligible individuals with disabilities are provided with a monthly income if they are unable to work or if their monthly income is below federal regulation. The Maximum Federal SSI is expected to increase by 2.8% in January 2026 and will provide eligible individuals with unrounded annual incomes of about $11,929.46 with $994.00 a month.[7]

Currently, 42 states allow for automatic enrollment of SSI beneficiaries into their Medicaid program, establishing them as categorically eligible. Eight states set more stringent criteria related to disability requirements or income[8] While the connection between SSI and Medicaid eligibility ensures Medicaid coverage for many low-income individuals with disabilities, about two-thirds of enrollees with disabilities do not receive SSI. In 2023, only 15% of disabled children ages 15 to19 receive SSI payments, but the rate is significantly higher for older populations, at 40% for adults 50 years and older.[9]

[4] III. The Supplemental Security Income Program
[5] Key Milestones in Medicare and Medicaid History, Selected Years: 1965-2003 - PMC
[6] III. The Supplemental Security Income Program
[7] 5 Key Facts About Medicaid Coverage for People with Disabilities | KFF ; SSI Federal Payment Amounts for 2026
[8] Supplemental Security Income (SSI) | SSI and Eligibility for Other Government and State Programs | SSA ; Are SSI Recipients Automatically Qualified For Medicaid? – Disability Attorneys of Michigan ; SSI Annual Statistical Report, 2023 - Background
[9] 5 Key Facts About Medicaid Coverage for People with Disabilities | KFF

Waivers

Congress passed the Omnibus Budget Reconciliation Act (OBRA) of 1981, which established the Home and Community-Based Services (HCBS) waiver program under Section 1915(c), through which states are given the option to provide services such as case management, personal care services, adult day healthcare services, and respite care, outside of the realm of institutionalized care. HCBS waivers continue to be a vital tool for states in the provision of comprehensive care services that are cost-effective and prioritize individualized healthcare[10].

Coverage of services for the disabled population has evolved through the introduction of waivers, commonly under Sections 1115 and 1915(c) of the Social Security Act. Waivers allow states to target specific populations and deliver additional services not otherwise covered under the Medicaid state plan in order to deliver specialized care to individuals tailored to their needs. States offer 1915(c) waiver services as a cost neutral alternative to institutional placement. In other words, waiver enrollees must otherwise require the level of care provided by a nursing facility, hospital, intermediate care facility, or inpatient mental health facility. States generally design waivers to target one or more groups that meet the level of care for one of these institutions. As part of their waiver design, states must ensure individuals seeking waiver services are assessed to establish that they meet an institutional level of care. Through 1915(c) waivers, Medicaid enrollees with disabilities are able to access specialized equipment and services and, importantly, receive such services in the home or other community setting.[11] Likewise, Section 1115 demonstration waivers may be leveraged for similar purposes.[12] States may use these waivers to provide additional HCBS for those already eligible for Medicaid. However, they may also use waivers to provide Medicaid coverage and HCBS for individuals whose income exceeds Medicaid eligibility standards. Because waiver services are not considered

[10] Home and Community-Based Services Waivers - PMC
[11] Home - Kids' Waivers
[12] Medicaid_Waivers_State_31797.pdf

entitlement services, states may place caps on waiver enrollment and impose stricter services limits or annual cost limits than are generally applicable to Medicaid state plan services. As a result, some states maintain waiting lists for those wanting to receive waiver services.

Through the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, Congress provided states the option to offer pediatric HCBS to children under 19 with complex medical needs through what is called a "Katie Beckett waiver." Prior to its passage, children with disabilities were often institutionalized due to the lack of resources available to take care of them at home or within their communities. Children are eligible if they meet a disability outlined under Social Security Administration (SSA) requirements. Currently 24 states offer the waiver and include services such as physical, occupational and speech therapy, prescription drugs, doctor visits, and medical supplies.[13]

Landmark Decisions

Legal case law, including significant Supreme Court opinions, have also played a significant role in shaping Medicaid coverage for individuals with disabilities. In 1990, President George H.W. Bush signed the Americans with Disabilities Act (ADA) into law, under which individuals with disabilities are protected from discrimination in five main domains: employment, public services, public accommodations, and telecommunications; ensuring they have equal access to the same resources and opportunities as able-bodied individuals. Included within this disability classification are physical, psychological, and emotional disabilities that prohibit an individual's ability to partake in major life abilities, such as PTSD, cancer, autism, diabetes, and intellectual disabilities.[14]

[13] Katie Beckett Waiver Explained: Eligibility, Benefits & Application ; Home - Kids' Waivers
[14] Introduction to the Americans with Disabilities Act | ADA.gov ; The Americans with Disabilities Act: A Brief Overview | Congress.gov | Library of Congress

In 1999, the ADA's impact on Medicaid was defined and expanded by the Supreme Court's decision in *Olmstead v. L.C.*, which interpreted the law to ensure individuals with disabilities have the right to live in and receive care from state funded programs, in their own communities, within institutions. Although the Court's decision was originally tied to psychiatric institutions, interpretation of the decision has expanded over time to cover other state and Medicaid funded institutions[15]

The *Olmstead* decision has spurred state Medicaid agencies' efforts at rebalancing, or ensuring individuals have a choice between institutional and community-based care.

Current State

Managed Long-Term Services and Supports

States have increasingly turned to managed care to deliver long-term services and support (LTSS) to individuals with disabilities and older adults.[16] In doing so, states may choose to include only acute care services for individuals with disabilities or may choose to contract with MCOs to deliver both acute care services and long-term care services and support. The latter option provides opportunities for tighter care coordination but may pose implementation and operational challenges. In 2025, at least 35 states include individuals with SSI in their Medicaid managed care program. States have been successful thus far in carving services for individuals who meet a Nursing Facility Level of Care (NF LOC) into managed care, including both institutional services and HCBS, with 22 states providing acute care services and/or LTSS for individuals who meet a NF LOC in managed care. Including both the institutional and HCBS under the same contract provides better opportunities for coordination and the ability for clearer choices for beneficiaries between care settings and removes any perverse incentives for the MCO that might influence decision-making around where

[15] Olmstead Decision
[16] MTLSS-Report.pdf

and how a beneficiary should receive care. Activity on including services for individuals who meet an Intermediate Care Facility for Individuals with Intellectual Disabilities Level of Care (ICF/IID LOC) has been slower. While many states include this population in their managed care program for acute care only, only 8 states deliver IDD waiver services in managed care; Arizona, Florida, Iowa, Kansas, New Jersey, New York (only in Fully Integrated Duals Advantage for Individuals with Intellectual and Developmental Disabilities [FIDA-IDD]), North Carolina, and Tennessee.

Within the realm of LTSS, self-direction is a powerful tool for both individuals with disabilities and older adults as it grants them the ability to make their own choices when it comes to the provision of care and resources, further promoting autonomy under waivers. In 2023, 46 states used 1915(c) waivers as a funding source to offer self-direction, and 14 funded it through an 1115 demonstration waiver. Currently, almost every state offers self-direction services for adults with physical disabilities, IDDs, or older adults.[17]

HCBS Settings Rule

In 2014, CMS released its final rule on HCBS. The rule shifts away from defining HCBS settings from physical characteristics such as location, instead focusing on an individual's outcome-related needs. The rule also prioritizes giving individuals autonomy and independence to make their own decisions regarding their lives and services, ensures access to their communities, and upholds their individual rights to privacy and respect. HCBS requirements now apply to all settings where these services are delivered, not just residential ones. Additionally, the final rule requires that HCBS program participants develop a person-centered plan that clearly identifies

[17] National Inventory of Self-Directed Long-Term Services and Supports Programs - AARP LTSS Choices Spotlight

their goals and preferences.[18] States were required to submit the person-centered plans to CMS plans to demonstrate compliance with these new requirements, and in many cases, were required to make significant program changes to their 1915(c) waivers.

EVV

In 2016, Congress mandated the use of Electronic Visit Verification (EVV) through the 21st Century Cures Act for personal care services (PCS) and home health services. Under EVV, providers must use a system to "check in" for home visits to ensure services are delivered in accordance with an individual's care plan. The EVV system seeks to reduce fraud and ensure improvement in patient care and delivery, as well as ensure accurate reimbursement to care providers.[19]

Future Directions and Outlook

Budget Reconciliation

On July 4, 2025, President Trump signed H.R.1, the "One Big Beautiful Bill Act" (OBBBA, or the Act) into law. Section 71121 of the bill expands the population eligible for 1915(c) HCBS waivers to include individuals who may not meet the "institutional level of care" criteria that is otherwise required in order to enroll under this type of waiver.[20] Increased eligibility could increase the demand for services, which could mean longer waitlists in states that implement this option.[21] In 2024, those on HCBS interest lists or on wait lists accessed services after waiting an average of 40

[18] DEPARTMENT OF HEALTH & HUMAN SERVICES ; Self-Directed Personal Assistance Services State Plan Option
[19] Direct Care Innovations | The Role of Electronic Visit Verification and Medicaid Compliance
[20] Congressional-Approved-Reconciliation-Bill_July-10-2025.pdf
[21] Medicaid HCBS wait lists are getting longer: report

months.[22] Workforce shortages remain a crucial issue in the home healthcare sector, with many states struggling to recruit enough nurses, home health aides, and personal care attendants to meet demand.

Aging Population and Workforce Challenges

The aging population will place additional strain on the system of care for individuals with disabilities. An estimated 1 in 5 Americans will be age 65 or over by 2030.[23] While medical schools have increased enrollment by about 40% since 2002, by 2036, the United States is expected to face a physician shortage of about 86,000.[24] A factor that exacerbates the issue is that providers are aging out of the workforce faster than they can be replaced. A large amount of the current physician workforce is already nearing the standard retirement age, with 22% of physicians being between the ages of 55 and 64.[25] By 2037, 47 states are expected to experience a shortage of primary care physicians, rates of which are higher in physician specialties such as geriatrics, primary care, and pediatrics.[26] An insufficient health workforce can cause delays in care, both increasing healthcare costs due to people seeking emergency care instead of primary care and leading to higher rates of mortality and worsened health conditions due to trouble accessing services.[27] Direct Support Professionals (DSPs) are key players in providing support services for individuals with disabilities, such as emotional support, job coaching, advocacy, and caregiving.[28] Due to low Medicaid reimbursement rates, employers are unable to attract nor retain workers within the DSP workforce.[29] While many states have taken action to bolster the direct care workforce through increasing

[22] A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2024 | KFF
[23] 1 in 5 Americans to be 65 years old or older by 2030 | S&P Global
[24] New AAMC Report Shows Continuing Projected Physician Shortage | AAMC
[25] New AAMC Report Shows Continuing Projected Physician Shortage | AAMC
[26] Addressing Health Care Workforce Shortages
[27] Addressing Health Care Workforce Shortages
[28] Direct Support Professionals (DSPs) | U.S. Department of Labor
[29] New Report: Access to Disability Care Has Dropped to Dangerous Levels Nationwide as Workforce Shortage Grows More Severe - United Cerebral Palsy

provider rates, increasing the minimum wage, or creating direct care provider registries, much work remains to be done to ensure the workforce is sufficient to meet the challenge of caring for a growing aged and disabled population in the coming decades.

Conclusion

Medicaid constitutes a key part of the safety net for individuals living with disabilities. That safety net has evolved over the last 60 years, expanding from initial ABD programs to SSI, waiver programs, the expansion of HCBS, implementation of the ADA, and development of MLTSS delivery systems. Today, Medicaid provides services for 35% of Americans with disabilities and is vital to their long-term healthcare needs. As the Medicaid program moves into future, workforce shortages and funding constraints present challenges, but the program will continue to provide the care needed by individuals with disabilities.