

Medicaid and People With Disabilities

Education and Advocacy Toolkit

Millions of older Americans and individuals with disabilities rely on Medicaid for comprehensive health coverage and essential services that enhance their quality of life and independence.

As the nation's primary health insurance program for people with disabilities, Medicaid provides essential supports that enable individuals to live independently in their homes and communities.

While strides were made to provide adequate funding for these services during the COVID-19 public health crisis, there is more work to do. The Modern Medicaid Alliance is committed to advocating for a strong and sustainable Medicaid program in order to expand patients' access to quality services and support the essential workers and caregivers who provide these services.

Key facts about Medicaid and the disability community:

(additional facts can be found in the resources on the next page):

- All Medicaid programs [cover](#) long-term services and supports (LTSS), which are supportive services that help people with their activities of daily living (ADL), such as toileting, bathing, dressing, and eating meals.
- Demographic trends indicate that LTSS will only become more critical moving forward. More than [half of Americans 65+](#) are expected to develop long-term disabilities requiring LTSS in the future.
- Adult Day Services (ADS) cover a wide range of supports for patients, from personal care needs, such as bathing and eating, to daily life needs such as transportation, diet, and specialized supports.
- State Medicaid programs are required to provide LTSS in nursing facilities; however, states may also elect to provide services in people's homes and community settings. Services provided in this manner are referred to as home and community-based services (HCBS).
- Medicaid funds [more](#) than two-thirds (66%) of total spending on HCBS.
- More than [half of all states](#) deliver some or all HCBS through Medicaid managed care.

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Template Social Media Posts

We encourage Modern Medicaid Alliance partners to utilize the sample social media posts below to support your education and advocacy efforts, tailoring as you see fit.

#DYK ? #Medicaid is the nation's primary health insurance program for people with disabilities, providing essential supports and services that enhance their quality of life and independence.

#Medicaid covers Adult Day Services, a system of support that provides essential care to people with disabilities. Get the facts on Medicaid and Adult Day Services: <https://bit.ly/4bn5xsM>

👉 Long-term services and supports (LTSS) help people with disabilities complete activities of daily living such as eating and bathing. #Medicaid ensures people with disabilities have LTSS coverage and access. Learn more: <https://bit.ly/49SIDsX>

#Medicaid funds the majority of home and community-based services, which address both medical and daily living needs for older Americans and people living with disabilities. Check out this fact sheet for more: <https://bit.ly/494omz6>

Key Facts About Adult Day Services



Key Facts About Adult Day Services

Medicaid provides essential health services to millions of individuals living with disabilities, people with complex behavioral health needs, and older adults, including home and community-based Adult Day Services (ADS).

Below are some key facts about [ADS](#), a system of support that ensures seniors and people with disabilities receive the care they need.

1. ADS cover a wide range of supports for patients, from personal care needs, such as bathing and eating, to daily life needs such as transportation, diet, and specialized supports.
2. There are currently [over 4,000](#) adult day service centers in the United States, with more than 230,000 participants in any given day. These centers serve as the heart of programming and service assistance for those who rely on adult day care.
3. ADS are classified as a long-term service and support (LTSS) under Medicaid. Specifically, ADS are a type of LTSS provided in the home or community (known as "home and community-based services" or "HCBS"). Medicaid [funds](#) more than two-thirds (66%) of total spending on HCBS.
4. All [50 states and Washington D.C.](#) cover some form of adult day care through their Medicaid programs.
5. ADS have been shown to improve health outcomes for older adults and people with disabilities, such as [delaying institutionalization](#), as well as [social and behavioral outcomes](#) like increased patient independence.
6. ADS can provide welcome support to the [53 million people](#) in the United States who are working as unpaid caregivers. Research shows that ADS uptake is associated with [reduced caregiver burden and better quality of life](#).
7. ADS are designed specifically with patient and caregiver empowerment in mind.

"Adult day care has been a lifesaver for us. I know I could not do this myself."

– [Betty](#), Caregiver of an ADS participant

To learn more about the value of ADS and how Modern Medicaid Alliance partner National Adult Day Services Association (NADSA) is working to improve ADS quality and access, check out our recent [Spotlight piece](#).

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[Modern Medicaid Alliance](https://www.youtube.com/ModernMedicaid)

Download the fact sheet [here](#).

Medicaid's Critical Role in Providing Long-term Services and Supports (LTSS)



Medicaid's Critical Role in Providing Long-term Services and Supports (LTSS)

Millions of Americans, including a significant number of individuals 65+, need long-term services and supports (LTSS) due to disability and/or chronic illness. Medicaid is the primary provider for LTSS across a wide range of care settings.

1. Medicaid is the primary source of coverage for LTSS, providing [nearly half](#) of all national spending on these vital services.
2. LTSS [consist](#) of a wide range of medical and daily living support such as personal care assistance for people dealing with long-term conditions, disabilities, or frailty, provided by both paid and unpaid caregivers. Examples include nursing facility care, adult daycare programs, home health aide services, personal care services, transportation, and family caregiving services.
3. Demographic trends indicate that LTSS will only become more critical moving forward. More than [half of Americans 65+](#) are expected to develop long-term disabilities requiring LTSS in the future. As of 2022, the average person turning 65 is expected to incur \$120,000 for LTSS in their lifetime.
4. LTSS are provided across [3 main settings](#): nursing homes, peoples' homes, and residential facilities. The Medicaid share of nursing home care is particularly high. Of the people residing in nursing homes, an estimated [62%](#) have Medicaid as a payer source.
5. Community-based LTSS programs help Americans receiving care at home live as [independently and safely](#) as possible when they are no longer able to perform daily activities on their own.
6. [Nearly two-thirds](#) of all Medicaid spending for LTSS is now for services provided in the home or community (known as "[home and community-based services](#)" or "HCBS") that enable Americans 65+ and people with disabilities to live independently rather than in facilities.
7. [25 states](#) currently provide some or all LTSS benefits through Medicaid managed care. Managed LTSS (or MLTSS) [help improve](#) care coordination and access to HCBS for beneficiaries, lower costs, and improve health outcomes.



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Download the fact sheet [here](#).

Key Facts About Home and Community-Based Services



Key Facts About Home and Community-Based Services

Millions of Americans living with disabilities rely on home and community-based services (HCBS) for essential supports that enable them to live independently in their homes and communities. Medicaid is the primary source of coverage for HCBS.

Here are key facts you need to know about the vital role of HCBS for the disability community, their families, and caretakers:

1. More than **4 million people** use Medicaid home and community-based services (HCBS).
2. All Medicaid programs **cover** "long term services and supports" (LTSS), which are supportive services that help people with their activities of daily living (ADL), such as toileting, bathing, dressing, and eating meals. While state Medicaid programs are required to provide these services in nursing facilities, states also may elect to provide services in people's homes and community settings. Services provided in this manner are referred to as "home and community-based services" (HCBS).
3. All Medicaid programs **cover medical services in the home**, such as home health nursing services and physical/occupational/speech therapies. In contrast, HCBS are long-term, non-medical, supportive personal care services that enable people to remain living in their communities.
4. Medicaid funds **more** than two-thirds (66%) of total spending on HCBS.
5. More than **half of all states** deliver some or all HCBS through Medicaid managed care.
6. HCBS serve a **diverse population**, including individuals with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses.
7. Without the critical services HCBS provide, patients' family members often have to fill in the gaps to provide care. More than **53 million people** across the country serve as family caregivers who provide vital assistance to family members, including children or adults with disabilities and aging parents.
8. While some family caregivers can be **paid through Medicaid** for providing personal care, these payments are only authorized through certain waiver programs and are at the discretion of state Medicaid programs.
9. Nearly **692,000** Americans remain on waitlists to receive HCBS, oftentimes for years. Most people on waiting lists or interest lists have intellectual or developmental disabilities.
10. People who use HCBS are at heightened risk of serious illness or death from exposure to COVID-19. During the public health emergency (PHE), the federal government provided **states with new authorities** to maintain access to HCBS.
11. States leveraged these PHE authorities to **strengthen their HCBS programs** by expanding access to services and investing in the HCBS workforce. While some of those changes have transitioned into permanent policies, others have ended as the PHE authorities expired.
12. While strides were made to provide adequate funding for HCBS throughout the COVID-19 public health crisis, there is more work to do to expand patients' access to quality services and support the essential workers who provide these services.

For more information about HCBS, check out the Alliance's [Medicaid Home and Community-Based Services \(HCBS\) Toolkit](#).

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Download the fact sheet [here](#).

The Vital Role of Home and Community-based Services: Q&A with The Arc

Modern Medicaid Alliance (MMA): Can you tell me more about The Arc and who the organization serves?

Nicole Jorwic (The Arc): The Arc is a national community-based organization advocating for and with people with intellectual and developmental disabilities. We work to advance our vision that every individual and family living with disabilities in the United States has access to the information, advocacy, and skills they need to support their full inclusion and participation in the community.

MMA: What is the importance of home and community-based services (HCBS) for individuals living with disabilities?

The Arc: HCBS are vital in several areas of life for individuals living with disabilities. First, HCBS are funded through Medicaid and provide essential support that many people don't realize, such as personal hygiene, getting out of bed, handling medications, supporting people to live independently and at their jobs.

Secondly, and why they are so important for individuals living with disabilities – HCBS mean independence. Without HCBS, family members have to step in to fill the gaps in care, or people end up in institutions that they might not want to be in.

MMA: What is Medicaid's role as it relates to HCBS?

The Arc: Medicaid is the main and only game in town when it comes to funding HCBS. When programs are in peril, we often get contacted by family members saying they had no idea the programs were funded by Medicaid. There is a need to continue educating people about Medicaid's role in the disability and aging communities and, critically, the general public.

MMA: How have the needs of Medicaid beneficiaries changed around HCBS and how has the pandemic shifted the HCBS landscape?

The Arc: The HCBS program faced major cuts five years ago, leading to an increase in public education and awareness around the needs of the disability community. That focus has led to greater attention on HCBS. The [Money Follows the Person](#) demonstration, a Medicaid program that seeks to increase the use of HCBS and reduce the use of institutionally-based services, was reauthorized for 3 years. More recently, the American Rescue Plan provided a one year 10% enhanced federal matching funds for states to increase access and improve provision of HCBS. Overall, funding threats have led to a better understanding from the general public and led to

further pushes from advocates for more legislative wins.

The COVID-19 public health emergency has shifted the focus on HCBS quite a bit. The government created a lot of flexibility in the program through the [1135 K Waivers](#), such as allowing for reimbursement for remote services. The pandemic has also exposed what advocates have always known: there is a public health hazard in larger care settings, such as nursing facilities, which are often an alternative to HCBS. Additionally, there has been the realization that we have unpaid family caregivers that are filling in the gaps of these services, and the system is falling short.

MMA: What are the most pressing current issues facing HCBS from your perspective?

The Arc: Access and infrastructure. Regarding infrastructure, we need to make sure there is enough funding for services, but also enough to support the workforce who provide those services. The average hourly wage for these individuals is less than \$11, so we need to have a workforce that is making a family-sustaining wage.

In regards to access, right now, 820,000 people are on waiting lists for HCBS and relying on unpaid family caregivers as well as facing the risk of institutionalization. The Arc has more than 600 chapters across the country, and a lot of them provide HCBS, wanting to support provision of those services and share their stories.

MMA: What are your current advocacy priorities regarding HCBS?

The Arc: HCBS received a historic commitment to new funding through the introduction of the [Better Care Better Jobs Act](#). The bill would address institutional biases in Medicaid programs that regard HCBS as optional services and help eliminate waiting lists. We are [rallying support](#) for the bill and calling on Congress to ensure its swift passage.

We are also currently leading [Medicaid Can't Wait](#), a nationwide campaign to raise awareness about the vital need for HCBS. Additionally, we recently joined [Care Can't Wait](#), a coalition committed to advocating for federal investment in HCBS so that more individuals living with disabilities can access these vital services.

Nicole Jorwic is the Senior Executive Officer for State Advocacy at The Arc. For more information about The Arc's Medicaid Can't Wait program, check out our recent Medicaid Spotlight piece.

View the Modern Medicaid Alliance's [blog post here](#).