

Medicaid Home and Community-Based Services (HCBS) Toolkit

HCBS Overview

Millions of older Americans and individuals 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 funds [the majority](#) (57%) of HCBS in the U.S., and these services encompass [programs](#) that address both medical and daily living needs. Medical services include home health nursing services, physical/occupational/speech therapies, and more, while daily living services include but are not limited to personal care, transportation, meal programs, and adult day centers.

HCBS serve a [diverse population](#), including individuals with intellectual or developmental disabilities, physical disabilities, and/or mental illness. Without the critical services provided by HCBS, patients' family members often have to fill in the gaps to provide care. More than [1 in 5](#) Americans are caregivers who provide vital assistance to family members, including children or adults with disabilities, aging parents, and more.

Included in this toolkit is a suite of advocacy and educational resources to help your organization advocate for HCBS and their critical role within Medicaid.

While strides have been made to provide adequate funding for HCBS during the COVID-19 public health crisis, there is still much work to do. The Modern Medicaid Alliance is committed to advocating for adequate funding for HCBS in order to expand patients' access to quality services and support the essential workers who provide these services.

Resources included:

Advocacy Resources

2..... [Template letter to the editor](#)

3..... [Template social](#)

Educational Resources

4..... [Key Facts About Home and Community-Based Services](#)

5..... [Helping Seniors Age in Place Through Medicaid Access and Advocacy](#)

6..... [The Vital Role of Home and Community-Based Services: Q&A With the Arc](#)

8..... [Medicaid's Critical Role in Providing Long Term Services and Supports \(LTSS\)](#)

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Template HCBS LTE for Modern Medicaid Alliance Partners

We encourage Modern Medicaid Alliance partners to utilize the sample letter to the editor below to amplify the need to address HCBS funding, tailoring as you see fit.

Title: Congressional Action Needed to Strengthen Medicaid

Medicaid provides a critical safety net for millions of seniors and individuals with disabilities who rely on home and community-based services (HCBS). HCBS deliver essential supports that address both medical and daily living needs and allow Americans to live independently in their homes and communities.

As a member of [organization name] and the [Modern Medicaid Alliance](#), we represent [add details about your organization], and we know how essential Medicaid is for those in need of HCBS, as well as their caregivers and families.

However, more funding is needed to expand access to quality services for patients and to support the essential workers who provide these services. Nearly [820,000](#) Americans remain on waitlists to receive HCBS, oftentimes for years. With additional funding for HCBS, aging adults and people with disabilities in [your state/every state] would have the option to get the support they need at home and preserve their independence.

Congress must act now to provide adequate funding for HCBS to increase access to and improve the quality of these vital services.

Sincerely,

[Name]

[Organization]

Template HCBS Social for Modern Medicaid Alliance Partners

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

- Congress must act now to provide adequate funding for home and community-based services for the millions of people with disabilities and aging Americans who rely on them.
- Home and community-based services (HCBS) serve a diverse population, including individuals with intellectual or developmental disabilities, physical disabilities, and/or mental illness. Tell Congress: act now to provide adequate funding for #Medicaid HCBS.
- The #COVID19 crisis has been especially challenging for older adults and people with disabilities. Congress must act now to enhance funding for home and community-based services to support these at-risk communities.
- #DYK? #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.
- More than 800,000 Americans remain on waitlists to receive #Medicaid home and community-based services. We need Congress to increase access to these vital services for people living with disabilities and older Americans.

Sample social graphics:



1 in 10 Medicaid enrollees are Americans with disabilities.

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, families, and caretakers:

1. Medicaid funds [the majority](#) (57%) of HCBS.
2. HCBS encompass [services](#) that address both medical and daily living needs. Medical services include home health nursing services, physical/occupational/speech therapies, and more, while daily living services include but are not limited to personal care, transportation, meal programs, and adult day centers.
3. HCBS serve a [diverse population](#), including individuals with intellectual or developmental disabilities, physical disabilities, and/or mental illness.
4. Without the critical services provided by HCBS, patients' family members often have to fill in the gaps to provide care. More than [1 in 5](#) Americans are caregivers who provide vital assistance to family members, including children or adults with disabilities, aging parents, and more.
5. Nearly [820,000](#) Americans remain on waitlists to receive HCBS, oftentimes for years.
6. The American Rescue Plan provided an additional 10 percentage point increase in federal matching funds for state spending on HCBS from April 2021 through March 2022, which will lead to an increase in federal spending on HCBS. Medicaid HCBS spending is estimated to be [about \\$114 billion](#) in FY 2021.
7. The COVID-19 crisis has been especially challenging for older adults and people with disabilities. At the time of publishing, more than [186,000 residents and workers](#) in nursing homes and other congregate settings have died from COVID-19, representing nearly 1 in 3 deaths nationwide.
8. More than [half of all states](#) deliver some or all HCBS through Medicaid managed care.

Congress is currently considering providing additional funding for Medicaid HCBS. The Modern Medicaid Alliance and our partners will continue to advocate for these essential services and for a strong, sustainable Medicaid program.

For more information about how Modern Medicaid Alliance partners are raising awareness about the vital role HCBS play in the lives of people with disabilities, check out our latest [Medicaid Spotlight](#) piece on The Arc of the United States.

Helping Seniors Age in Place Through Medicaid Access and Advocacy

Medicaid plays a vital role in providing low-income seniors and seniors with disabilities across America with the care they need. Making up [9%](#) of those covered by Medicaid, [7.2 million seniors](#) depend on the program for essential health care and services.

Modern Medicaid Alliance partner [Justice in Aging](#) is a non-profit legal advocacy organization that advocates to strengthen safety net programs like Medicaid. Their work focuses on supporting older adults who are marginalized and excluded from justice, such as women, people of color, LGBTQ+ individuals, and people with limited English proficiency.

Not only does Medicaid cover six out of ten nursing-home residents, but Medicaid Home and Community Based Services (HCBS) also allow low-income seniors to “age in place” and continue to live in their own homes and communities. HCBS include both medical services and [assistance with daily activities](#) such as eating and getting dressed.

Justice in Aging advocates for Medicaid HCBS to be accessible to people with disabilities of all ages. In [Medicaid Home and Community Based Services for Older Adults with Disabilities: A Primer](#), Justice in Aging highlights the disparities in access to home-based care across states, by age, and for people of color.

Justice in Aging creates and shares additional resources on the importance of importance of expanding access to HCBS and addressing barriers to home-based care for older adults, such as [Why Older Adults Need Bold Investment in Medicaid Home and Community-Based Services](#). These resources emphasize the need for expanded access to quality HCBS services and support for the essential workers who provide these services. With increased investment in HCBS, aging adults and people with disabilities in every state would have the option to get the support they need at home.

Justice in Aging advocates for other important Medicaid policies that increase access, such as preserving the [Medicaid retroactive coverage policy](#) and the [harm of Medicaid work requirements](#) for seniors. Their organization highlights the necessity for a strong, sustainable Medicaid program that continues to serve millions of seniors and people with disabilities.

To learn more about Justice in Aging, click [here](#). For more information about Justice in Aging’s resources on Medicaid, click [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](#).

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) because of disability and chronic illnesses. 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 [more than half](#) of all national spending on these vital services.
2. LTSS [consist](#) of a wide range of medical and personal care, provided by both paid and unpaid caregivers, needed by people dealing with long-term conditions, disabilities, or frailty.
3. Demographic trends indicate that LTSS services will only become more critical moving forward. More than [half of Americans 65+](#) are expected to develop disabilities and require LTSS in the future. As of 2015, the average person turning 65 is expected to incur \$138,000 for LTSS services in their lifetime.
4. LTSS are provided across [3 main settings](#): nursing homes, home/community-based care, and residential facilities. The Medicaid share of nursing home care is particularly high. Of the people residing in nursing homes, an estimated 63% have Medicaid as a payer source.
5. Community-based LTSS programs help Americans 65+ receiving care at home live as [independently and safely](#) as possible when they are no longer able to perform all of their daily activities on their own.
 - [More than half](#) of all Medicaid spending for LTSS is now for services provided in the home or community (also known as “home and community-based services” or “HCBS”) that enable Americans 65+ and people with disabilities to live independently rather than in facilities.
6. [Managed care options](#) for LTSS services are becoming increasingly popular for Medicaid beneficiaries. Managed LTSS (or MLTSS) provide an opportunity to improve care coordination and access to HCBS for beneficiaries, as well as lower costs and improve health outcomes.
 - In 24 states, some or all LTSS benefits are provided through managed care. Currently more than [7 million people](#) receive LTSS through Medicaid managed care organizations.

[Download the factsheet here](#)

Advocating for Home and Community-Based Services

For millions of Americans living with disabilities, home and community-based services (HCBS) provide essential services that vastly improve their lives and enable them to live independently in their communities. As one of the key sources of funding for HCBS outside of private long term care coverage, Medicaid helps ensure that people with disabilities have the support they need to live independently in their homes and communities.

Medicaid and private health insurance provide coverage meet medical needs like skilled nursing care, dietary management, and case management. But HCBS encompass other services that address daily living needs, such as personal care, transportation, and meal programs. Without the critical services provided by HCBS, patients' family members often have to fill in the gaps to provide care, or patients may unwillingly end up in an institution.

The Arc of the United States, a Modern Medicaid Alliance partner, is currently leading [Medicaid Can't Wait](#), a nationwide campaign to raise awareness about the vital need for HCBS for people with disabilities. As part of this campaign, The Arc is providing resources to help educate lawmakers on the importance of investing in HCBS. Some of those resources include testimonials from people with disabilities explaining why living in their communities matters to them.



While Medicaid covers HCBS for millions of Americans, over 800,000 individuals remain on waiting lists — often as long as 8 to 10 years — before they can receive HCBS.

The COVID-19 pandemic has reinforced how essential HCBS are for millions of Americans with disabilities. In response to the COVID-19 crisis, changes to state Medicaid programs across the country have helped expand and strengthen HCBS, allowing individuals with disabilities to remain at home instead of in nursing homes, minimizing their exposure to the virus.

Ensuring that people with disabilities continue to live independently in their chosen community setting is a top priority for The Arc as they work to strengthen and expand HCBS. Learn more about how The Arc is raising awareness on the importance of HCBS through [Medicaid Can't Wait](#).

Fast Facts on HCBS

- Around [5 million people](#) rely on HCBS through Medicaid.
- [HCBS recipients](#) are diverse and include individuals with intellectual or developmental disabilities, individuals with physical disabilities, individuals with mental illness, and seniors.
- Medicaid HCBS spending totaled [\\$92 billion](#) in 2018.
- HCBS support [daily living needs](#) including services like personal care, transportation, and home-delivered meals.