

Medicaid Home- and Community-Based Services for Older Adults with Disabilities: A Primer



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Amber Christ, Directing Attorney
Natalie Kean, Senior Staff Attorney

INTRODUCTION

When asked about where they want to live as they age, almost all older adults say they want to live in their homes and get the services they need in the community as opposed to moving into a nursing facility.¹ The COVID-19 pandemic has added an urgent need to honor this desire, as ongoing outbreaks and deaths demonstrate that residential congregate settings are the most dangerous places for anyone to live or work right now. And the more than year-long separation from family and friends that those living in nursing facilities and other congregate settings have experienced is leading to severe distress and, in some cases, early death. Unfortunately, the reality is that many older adults cannot make the choice to live at home because they do not have access to the necessary supports and services. While significant barriers to home- and community-based service

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(HCBS) exist for most individuals who need them, those barriers are even greater for older adults with limited income and wealth and people of color, due to historical and present-day discrimination.

Over one-third of adults age 65 and older have some form of disability² and many need assistance with daily activities such as bathing, eating, toileting, housework, medication management, financial management, and grocery shopping. In 2018, 21% of older adults reported difficulties moving from place to place, 8% had difficulties with self-care, 8% had difficulties with cognitive ability, and 14% reported difficulties with independent living.³ Over 20% of individuals age 85 and older and 8% of individuals age 75 and older reported needing help with personal care.⁴ In addition, racial disparities exist among older adults with disabilities. For example, Black older adults are nearly twice as likely, and Hispanic older adults are nearly 1.5 times as likely, as white older adults to have Alzheimer's and other dementias.⁵

To remain living at home and active in their communities, many of these older adults need caregiving, home modifications, and other supports that require significant financial resources, as well as caregiving from family and friends. While Medicaid can pay for these services and supports at home, state programs are not required to. At the same time, Medicare's coverage of long-term services and supports is limited in ways that re-enforce a bias towards institutional care.

“At the core of institutional bias is the fact that **federal Medicaid law requires states to cover nursing facility and other institutional care but does not require states to cover the full range of HCBS.**”

This primer provides an overview of Medicaid HCBS, the institutional bias, and how states are doing in terms of serving older adults with disabilities in the community. It also discusses the gaps and inequities in the HCBS system. The table in the appendix includes state-specific information about HCBS programs serving older adults with disabilities.

FIRST THINGS FIRST: WHAT IS THE INSTITUTIONAL BIAS?

Medicaid covers long-term services and supports (LTSS)⁶ provided in two categories of settings: institutional care, such as nursing homes, and home- and community-based services (HCBS). However, these two categories of settings are not equally accessible due to federal Medicaid law's historical and continued bias towards institutional care.⁷ At the core of the institutional bias is the fact that federal Medicaid law requires states to cover nursing facility and other institutional care but does not require states to cover the full range of HCBS to meet the needs of people with disabilities, including older adults, in the community.⁸ The result is a patchwork of HCBS programs within and across states that leaves people with disabilities of all ages vulnerable to losing access if they move or if their needs or income change. In addition, states often turn to reducing services or eligibility for HCBS when they face budget shortfalls since federal law permits cuts to HCBS and other a non-mandatory benefits.

Olmstead

In *Olmstead v. L.C.*, the Supreme Court decided that states must provide LTSS in the community in certain instances in order to be compliant with the Americans with Disabilities Act mandate that public entities administer programs in the most integrated setting appropriate to the needs of qualified individuals.⁹ The Department of Justice and several Circuit Courts expanded the *Olmstead* decision to apply to individuals who are at risk of being institutionalized, but are not currently living in nursing facilities.¹⁰

Over the years, there have been many different amendments to federal law and policy to increase coverage of and access to HCBS. This effort, sometimes referred to as “rebalancing,” has resulted in a significant shift in Medicaid spending. In 2018, over 56% of total Medicaid spending on LTSS went to HCBS, up from only 10% in 1988.¹¹ Yet, because states are not required to cover HCBS, there are significant inequities in access to HCBS based on where a person lives, as well as their age, disability, and race, as discussed in more detail below.

WHAT ARE HOME- AND COMMUNITY-BASED SERVICES?

Home- and community-based services (HCBS) is an umbrella term for long-term health care, services, and supports provided to an individual in their own home and in more integrated community-based settings, as opposed to institutional settings such as nursing homes and psychiatric hospitals. HCBS enable many people with disabilities of all ages to live independently and fully participate in their communities as they choose. HCBS include both health and human services to address an individual’s medical needs, daily living activities, and community integration.

Examples of HCBS

- Home health care (such as skilled nursing care; physical, occupational and speech therapy; and pharmacy services)
- Durable medical equipment (such as wheelchairs, oxygen, and assistive technology)
- Personal care (such as assistance with bathing, dressing, eating, transferring, and toileting)
- Caregiver training and respite
- Case management
- Hospice care
- Individual, group or center-based day supports, including senior centers and adult day centers
- Congregate meal sites and home-delivered meal programs
- Transportation
- Homemaker and chore services
- Financial and legal services
- Home repairs and modifications

A Note About Medicare

Because Medicare is popularly known to cover older adults, many people believe that it will pay for nursing facility stays and other long-term care.¹² However, Medicare severely limits both the scope and duration of LTSS. For example, Medicare coverage of skilled nursing facility care is only available after hospital admissions of more than three days, and is limited to a maximum of 100 days, though often cut off much sooner.¹³ Similarly, Medicare does not pay for the full range of services and supports that Medicaid covers through HCBS. It specifically excludes 24-hour care, homemaker and chore assistance, and home-delivered meals and personal care aides. To be eligible for services at home, a Medicare enrollee must be certified by their doctor as “homebound” and need a health care service such as “intermittent” skilled nursing care, physical therapy, speech-language pathology, or continued occupational therapy services.¹⁴

Note that many older adults with disabilities eligible for Medicaid HCBS will have overlapping Medicare coverage for certain home health services and durable medical equipment. Individuals enrolled in Medicare Advantage plans may have additional overlapping coverage for services such as transportation and home-delivered meals. This overlapping coverage can present additional complexities and barriers to accessing HCBS.¹⁵

HOW IS ELIGIBILITY FOR HCBS DETERMINED?

Eligibility for HCBS requires an individual to meet both financial and functional criteria. Both criteria vary from state to state and program to program.

Financial Eligibility

Financial eligibility considers both income and assets and depends on the state and the particular HCBS program.¹⁶ Eligibility for state-plan HCBS programs usually follows the financial eligibility thresholds for the aged, blind, disabled Medicaid category (also known as the “poverty-related pathway”), which ranges from 74% to 100% of the federal poverty level, depending on the state.¹⁷ For assets, states typically apply limits of \$2,000/individual (\$3,000/couple), although some states have higher limits.¹⁸ Both the income and asset limits correspond to financial eligibility standards for Supplemental Security Income (SSI), a Social Security program that provides modest financial assistance to people who are unable to work enough to meet their basic needs, including older adults with low or no Social Security or pension income, and younger people with significant disabilities.¹⁹

Thirty-two states also allow seniors and people with disabilities to qualify for Medicaid through the “medically needy” pathway, which allows individuals with countable incomes above the aged, blind, disabled Medicaid limits to “spend down” their income by subtracting incurred medical-related expenses to reach the state’s medically needy income limit (between 48% and 74% of the federal poverty level depending on the state).²⁰ States can also expand financial eligibility limits for HCBS state-plan benefits under 1915(i) authority.

For HCBS waiver programs discussed below, most states follow the “special income rule,” which allows individuals to qualify with income up to 300% of the SSI rate.²¹ The dollar amount of the income limit changes every year and can vary within a state from program to program.²² States also have varying limits on how much income an individual receiving HCBS can keep as a “maintenance needs allowance” and varying rules about home equity as an asset.²³ States may also require HCBS enrollees to spend a percentage of their income on their care.²⁴ The higher income limits for HCBS waivers is a recognition that the aged, blind, and disabled Medicaid limits are too low for many people who need HCBS to qualify for Medicaid coverage and also be able to cover the expenses of living in the community.

“The expansion of spousal impoverishment protections for HCBS, while not yet permanent, helps mitigate the institutional bias by **ensuring married couples have the same financial protections whether or not care is provided in a facility or in the community.**”

In addition, Medicaid’s “spousal impoverishment protections” make it possible for an individual who needs a nursing home level of care to qualify for Medicaid and receive long-term services and supports, while allowing their spouse to retain a modest amount of income and resources to pay for rent, food, and medication. Congress established these protections first for spouses of individuals entering nursing homes and extended this protection to eligibility for HCBS in all states beginning in 2014. This expansion, which is not yet permanent, helps mitigate the institutional bias by ensuring married couples have the same financial protections whether or not care is provided in a facility or in the community.²⁵

Functional Eligibility

In addition to meeting financial criteria, individuals applying for HCBS must also undergo a functional assessment to determine eligibility and to establish a care plan. For most HCBS programs, the individual must have needs

that require an institutional level of care.²⁶ The threshold for institutional level of care, however, varies by state. For example, a state may require a person to have difficulties with three or four activities of daily living in order to be eligible.²⁷ HCBS offered under 1915(i) authority permits states to serve people who require less than institutional level of care.²⁸

While Medicaid covers a range of supports and services, HCBS are personalized based on what the individual needs and wants. Most states first determine whether an individual's functional capacity meets the "institutional level of care" eligibility standard and then determine what HCBS services are appropriate and necessary. For federally mandated home health services, eligibility must be based on medical necessity and they must include utilization controls. There are no federal eligibility requirements for optional services except that they must be equally available to all recipients who satisfy the state's service criteria.

These eligibility and service plan assessments are based on the individual's need for assistance with activities of daily living (bathing, dressing, transferring to or from bed/chair, toileting, eating) and instrumental activities of daily living (e.g., housework, taking medication, managing money, grocery shopping, using the telephone or other communications devices, caring for pets).²⁹

Many people receiving Medicaid HCBS also depend on "natural supports," that is caregiving and other support from family and friends as opposed to paid assistance. However, it is important to note that under federal Medicaid regulations, HCBS service plans cannot compel family members to provide unpaid assistance.³⁰

HCBS for American Indians and Alaska Natives

American Indians and Alaska Natives (AIANs) can enroll in Medicaid and receive HCBS if they meet the eligibility requirements in the state where they live, even if they reside on a reservation or are eligible for Indian Health Services (IHS) or other Tribal programs. Some Tribes provide direct care and HCBS through their state's Medicaid programs, IHS, and other Tribal and Urban Indian health programs.³¹ However, HCBS waiver services may not be available in areas of a state where AIANs reside, and access to providers may be an issue, especially in remote areas.

WHAT ARE THE TYPES OF HCBS PROGRAMS STATES OFFER?

States can choose to cover HCBS in one of two ways: through their state Medicaid plan or through a waiver program. Today, all 50 states and DC do provide HCBS to adults age 65 and older and certain other populations through combinations of state plans and waivers. However, what those supports and services are, who is eligible, and how many people are served varies significantly from state to state.

Medicaid & LTSS in the US Territories

While the U.S. territories all have Medicaid programs, Guam is the only territory that covered LTSS of any kind as of 2019. The U.S. Virgin Islands reported that it was working to implement a home health program for older adults.³² This lack of LTSS coverage is likely due to the caps on federal funding for Medicaid in the territories.

Medicaid State Plan

Under federal Medicaid law, all states must provide a minimum set of “home health” benefits under their state plan.³³ Home health is the only HCBS benefit that states are required to provide.³⁴ These mandatory services include nursing and home health aide services and durable medical equipment, and all states except Oklahoma also include physical, occupational, and speech therapy.³⁵ Only about 600,000 individuals receive mandatory home health benefits because these services overlap with Medicare home health, which is primary coverage for individuals dually eligible for Medicaid and Medicare, as well as services in other broader Medicaid HCBS programs.

States may amend their existing Medicaid plans to include personal care services³⁶ as well as a broader scope of HCBS, through authorities in Social Security Act Sections 1915(j) (Self-Directed Personal Assistant Services),³⁷ 1915(k) (Community First Choice),³⁸ and 1915(i) (State Plan HCBS).³⁹ Because these programs are offered through the state’s existing Medicaid plan, they must conform to the requirements that all state plan services are subject to. Stated simply, this means that these programs must be available to all individuals who meet the eligibility criteria in the state equally and cannot be limited to certain counties, for example. As shown in the table in the appendix, 34 states have amended their state plans to offer personal care services, eight states have implemented the Community First Choice, and three states offer Section 1915(i) services to older adults with disabilities.⁴⁰

Medicaid HCBS Waivers

The second avenue by which a state can offer HCBS is through what is known as a waiver program. Types of waiver programs include 1915(c) waivers⁴¹ and Section 1115 Research and Demonstration Project Waivers.⁴² These programs are aptly named because they allow states to waive certain federal requirements that are otherwise binding on Medicaid programs, including allowing states to provide care and supports in the home and community instead of institutional settings. Additional waived requirements include the comparability requirement to offer services in equal amount, duration, and scope to all eligible populations, the requirement to offer services statewide, and Medicaid’s strict income and asset limits, including extending higher eligibility limits available for institutional LTSS to HCBS. Therefore, HCBS waiver programs may only be available in certain counties and are typically targeted to specific populations, such as older adults and people with physical disabilities or people with intellectual and developmental disabilities.⁴³ Many waivers include caps on the number of people eligible for services, and often they have more relaxed financial eligibility requirements than state plan benefits.⁴⁴

All but three states have at least one 1915(c) waiver, and most states have multiple waivers targeted to specific populations. As shown in the table in the appendix, 42 states serve older adults through a 1915(c) waiver.⁴⁵ Section 1115 waivers are less common—only 12 states use them for HCBS, including the three states that do not have 1915(c) waivers.⁴⁶

Money Follows the Person Program

In addition to state plan amendments and waivers, Congress has also created other demonstration programs that aim to enhance access to HCBS.⁴⁷ One example that is especially important to older adults is the Medicaid Money Follows the Person (MFP) program.

MFP is a demonstration program that helps adults with disabilities of all ages move out of institutions and into the community and helps states develop infrastructure to expand HCBS.⁴⁸ MFP provides a year of HCBS for individuals who have been living in an institution for at least 60 days. In addition to supports and services

authorized through the state plan or waiver, MFP also authorizes payment for enhanced services and supplemental services not typically covered by Medicaid, such as household set up costs and security deposits.⁴⁹ As with most HCBS programs, the availability of MFP and the services it covers varies from state to state. Since the program began in 2007, 43 states and Washington, D.C. have implemented MFP to help more than 90,000 individuals transition out of institutions.⁵⁰

HCBS Settings Rule

In March 2014, new federal rules took effect that support the rights of people with disabilities of all ages to live and receive Medicaid services in integrated, community-based settings. The HCBS Settings Rule requires that all settings funded through HCBS waivers and state plan programs:

- Be integrated in and help provide full access to the greater community;
- Improve self-determination and independence in making life choices;
- Be chosen by the individual from among residential and day options, including settings that are not only for people with disabilities (called “non-disability specific settings”);
- Make sure of the right to privacy, dignity, respect, and freedom from coercion and restraint;
- Provide an opportunity to work in a typical job in the community (called “competitive integrated employment”);
- Provide people with an option to choose to live in their own unit or bedroom in the place where they live (called a residential setting); and
- Make sure there is a choice of services and providers.

The rules re-enforce the federal law that institutions, including nursing homes, are not allowed to receive funding through Medicaid HCBS programs.⁵¹

HOW DO STATES PAY FOR HCBS?

In addition to setting the scope of services and the populations who are eligible for HCBS, states also have choices in how they pay providers: fee-for-service or capitated payments for each covered person. Under traditional “fee-for-service,” the state pays providers directly according to payment rates it sets. Under capitated programs, states pay a managed care health plan an amount for each person enrolled in an HCBS program, and the managed care plan then contracts with and pays the providers. Currently, 25 states are operating managed long-term services and supports (MLTSS) programs to pay for HCBS for at least some populations.⁵²

Another capitated payment program some states have implemented is **PACE—Program of All-Inclusive Care for the Elderly**. PACE programs typically serve individuals who are dually eligible for Medicare and Medicaid and employ an interdisciplinary team to provide all covered services, both medical and LTSS, on-site at a day center.⁵³ Participants may also receive services at home or by referral as necessary. Nationwide, nearly 50,000 individuals are enrolled in PACE programs across 31 states.⁵⁴

HOW DOES ACCESS TO HCBS VARY ACROSS STATES?

As noted previously, every state provides HCBS beyond the mandatory home health care benefit. However, due to the optional nature of these benefits and the flexibility states have in designing their HCBS programs, not everyone

who needs or is eligible for Medicaid HCBS can access these benefits. The data is not available to fully assess the need, especially among people who are not enrolled in Medicaid or actively trying to access HCBS. What is known is how many people received HCBS in past years and some information about how many people are waiting for services.

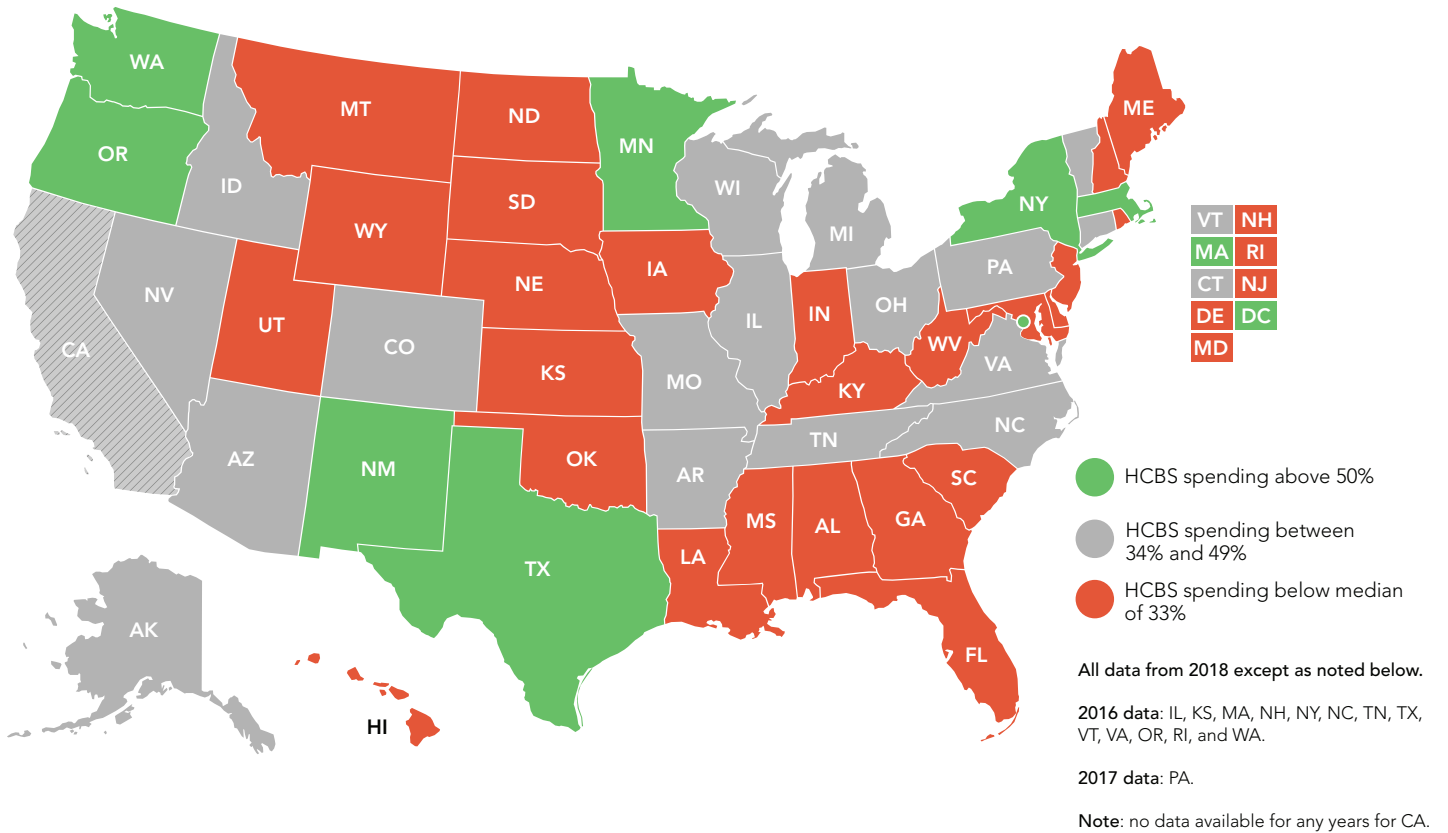
One measure of access is the number of people who are waiting for an opening in their state's HCBS waiver programs. Most states have waiting lists for some waivers because they have capped the number of "slots" available, but the size of the waiting lists ranged from 17 people in North Dakota to 385,000 people in Texas in 2018. In total, nearly 820,000 people were on a waiting list for HCBS in 2018, including more than 188,000 seniors and people with physical disabilities, as shown in the table in the appendix.⁵⁵ Older adults on those waiting lists wait an average of at least 28 months to begin receiving HCBS.⁵⁶ These numbers are likely only a fraction of the unmet need because there are many people who need HCBS and are in fact eligible but are not on waiting lists, particularly older adults who are less familiar with how to navigate the service system. For example, as of 2018, 33 states had no waiting lists for older adults and people with physical disabilities.⁵⁷ Yet, of these 33 states, 28 were spending more on institutional care than on HCBS for this population (see table in appendix). Moreover, the eligibility criteria for Medicaid HCBS are quite narrow, leaving many others who need services and supports to live independently ineligible for Medicaid coverage.

Another measure of access is the balance of spending on LTSS between HCBS and institutional care. While we know that of all Medicaid enrollees age 65 and older, only 10% reside in a nursing home or other institutional setting,⁵⁸ the balance is much different among older adults who need and are eligible for LTSS. Looking at LTSS spending, it is clear that the demand for HCBS is not being met because the average LTSS spending on HCBS is only 56%. In other words, 44% of LTSS spending is going towards institutional care despite 9 out of 10 older adults expressing a desire to live at home as they age. When we look specifically at spending on older adults and people with physical disabilities,⁵⁹ the balance is even further from the demand. In fact, as shown on the map below and the table in the appendix, only eight states spend above 50% of LTSS dollars on HCBS for older adults, and 25 states spend less than 35%. In other words, half of states spend twice as much on institutional care as on HCBS for older adults and people with physical disabilities.

“Half of states spend **twice as much on institutional care as on HCBS** for older adults and people with disabilities.



HCBS Spending on Older Adults and People with Physical Disabilities by State as a Percentage of LTSS Spending



Source: CMS Medicaid Long Term Services and Supports Annual Expenditures Report Federal Fiscal Years 2017 and 2018.

A Note About Data

Data on HCBS programs is lacking. California has not reported HCBS spending data at all in recent years and several other states were not able to report data in 2018, the most recent reporting year. It is also notable that all but one of the states that did not report data in 2018 are paying and delegating delivery of HCBS to managed care plans through their MLTSS programs. There is almost no demographic data on HCBS enrollees, including data by age, race, and ethnicity, making it impossible to fully understand age and race-based inequities in the system. Most states do report enrollment by “target population,” however those groupings usually combine older adults with people with physical disabilities of any age. Other changes to data reporting and categorization have led to some older adult HCBS enrollees being included in a “multiple populations” category.

WHAT ARE THE GAPS & INEQUITIES?

Although every state does offer HCBS, there are significant gaps in access to these programs. As demonstrated above, access to HCBS varies widely from state to state and even within states because many HCBS programs are operated through waivers of federal law. In addition, because federal Medicaid law does not require states to provide

HCBS to all populations who need LTSS, significant race and population-based inequities arise and often intersect.

For example, half of Michigan's population lives in 10 counties in the southeast part of the state. In one of those, Wayne County, 40% of older adults are non-white. However, only one-third of the state's total HCBS waiver slots are available in those 10 counties. In other words, there is only one waiver slot for every 58 eligible individuals in those counties compared to one slot for every 20 eligible individuals in the rest of the state.⁶⁰

Another example is inequitable access to HCBS for people with Alzheimer's and other dementias. At age 80, 75% of people with dementia live in a nursing home compared to 4% of the general population.⁶¹ This inequity compounds other race-based inequities because rates of dementia are higher among Black and Hispanic older adults.

Finally, an underlying barrier in access to HCBS that exists in every state and every community is affordable and accessible housing. When a Medicaid enrollee resides in a nursing home or other institution, Medicaid covers the costs of room and board, in addition to the health care and LTSS costs. However, aside from a few limited demonstration programs, Medicaid does not pay for housing or housing modifications for people who are receiving or need HCBS. Individuals who are unhoused, including a growing number of older adults, face the ultimate barrier to accessing HCBS and are more likely to be forced into an institution. Like other barriers to HCBS, the housing barrier is disproportionately greater among people of color with limited wealth.⁶²

CONCLUSION

Addressing these gaps and barriers will require fundamental systemic changes that are centered in equity. At the federal level, changing Medicaid law to end the institutional bias is key. This includes making HCBS a required benefit, enhancing the HCBS infrastructure, expanding the scope of covered services, and increasing eligibility. Improving data collection, modernizing eligibility rules and systems, and coordinating with housing and other agencies are also necessary steps that can and should be taken immediately.

APPENDIX

HCBS Programs Serving Older Adults and HCBS Spending by State

State	1915(c) waivers	1115 waiver	1915(k) Community First Choice	1915(i) state plan HCBS	State plan personal care	HCBS Spending on Older Adults & People with Physical Disabilities (as % of LTSS spending)	HCBS Spending on All Populations (as % of LTSS spending)	Older Adults & People with Physical Disabilities on Waiting lists for Waivers
Alabama	yes					16.1	42.8	5,080
Alaska	yes				yes	44.4	62.3	0
Arizona^		yes				39.9	75.2	0
Arkansas^	yes				yes	36	51.9	234
California^	yes	yes	yes		yes	NR	NR	4834
Colorado	yes				yes	40.4	55.3	0
Connecticut	yes		yes	yes		36.9	55.5	0
Delaware^		yes				22.2	47.5	0
District of Columbia	yes			yes	yes	55.6	61.6	0
Florida^	yes				yes	21.4	37.1	49,798
Georgia	yes					29.8	48.5	820
Hawaii^		yes				20.2	45.5	0
Idaho^	yes				yes	38.7	60	0
Illinois^	yes					45.8	49.3	0
Indiana	yes					20	34.8	0
Iowa^	yes					10.2	41.5	0
Kansas^	yes				yes	30.9	56.6	0
Kentucky	yes					13.5	42.8	0
Louisiana	yes				yes	21.6	34.2	36,743
Maine	yes				yes	32.6	57.6	0
Maryland	yes		yes		yes	18.2	60.9	20,500
Massachusetts^	yes				yes	62.4	71.5	0
Michigan^	yes				yes	34.2	42.7	3,021
Minnesota^	yes				yes	71.9	77.4	0
Mississippi	yes					29.1	32.6	10,224
Missouri	yes				yes	45.2	60.2	0
Montana	yes		yes		yes	25.7	56.1	233
Nebraska	yes				yes	28.6	52.7	0
Nevada	yes			yes	yes	36.2	61.3	781
New Hampshire	yes				yes	11.4	42.6	0
New Jersey^		yes			yes	20.9	34.4	0
New Mexico^		yes			yes	63.5	75.7	15,325
New York^	yes	yes	yes		yes	52.2	61	NR
North Carolina^	yes				yes	41	45	3,397
North Dakota	yes				yes	17.5	41.7	0

State	1915(c) waivers	1115 waiver	1915(k) Community First Choice	1915(i) state plan HCBS	State plan personal care	HCBS Spending on Older Adults & People with Physical Disabilities (as % of LTSS spending)	HCBS Spending on All Populations (as % of LTSS spending)	Older Adults & People with Physical Disabilities on Waiting lists for Waivers
Ohio [^]	yes					44.5	57.7	0
Oklahoma	yes				yes	27.7	48	0
Oregon	yes		yes		yes	80.3	81.4	0
Pennsylvania [^]	yes					41.9	52.6	0
Rhode Island [^]		yes			yes	24.4	55.4	0
South Carolina [^]	yes					32.8	47.2	0
South Dakota	yes				yes	22.2	49.8	0
Tennessee [^]		yes				34.7	53.5	0
Texas [^]		yes	yes		yes	55.7	58	35,224
Utah	yes				yes	21.6	51.4	253
Vermont ^{^^}		yes			yes	45.3	70.3	0
Virginia [^]	yes					48.4	57.3	0
Washington	yes	yes	yes		yes	71.1	68.5	0
West Virginia	yes				yes	22.6	41.4	30
Wisconsin [^]	yes				yes	48.6	75.3	1,635
Wyoming	yes					24.9	50.3	0
United States	42	12	8	3	34	Median 33.5	Median 53.1	188,132

Table Key

- yes = state has a program serving older adults, or older adults and people with physical disabilities.
- [^]state uses MLTSS program; ^{^^}VT has a non-risk based MLTSS program as of September 2017.
- NR = data not reported.

All spending data from 2018 with the following exceptions: 2016 data used for Illinois, Kansas, Massachusetts, New Hampshire, New York, North Carolina, Tennessee, Texas, Vermont, and Virginia due to unavailability or unreliability of 2017 or 2018 data. 2017 data used for Pennsylvania because 2018 data was not available. 2016 data used for Oregon, Rhode Island, and Washington because changes in CMS's methodology showed a large decrease in HCBS spending on older adults and people with physical disabilities between 2016 and 2018 that we cannot verify is accurate. No data is available for any years for California.

Waiting list data are for seniors/physical disabilities only from FY 2018, with the exception of DC and FL, which are for 2017. CA data include § 1915 (c) waivers only; CA did not report waiver waiting list enrollment for its § 1115 waiver for seniors and adults with physical disabilities.

Sources: Kaiser Family Foundation, Key State Policy Choices About Medicaid Home and Community-Based Services; CMS Medicaid Long Term Services and Supports Annual Expenditures Report Federal Fiscal Years 2017 and 2018.

ENDNOTES

- 1 AARP Research, “2018 Home and Community Preferences: A National Survey of Adults Ages 18-Plus” (July 2019), <https://www.aarp.org/research/topics/community/info-2018/2018-home-communitypreference.html>.
- 2 ACL, 2019 Profile of Older Americans, at 19 (May 2020), <https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2019ProfileOlderAmericans508.pdf>.
- 3 *Id.*
- 4 *Id.*
- 5 Alzheimer’s Ass’n, “Fact Sheet: Race, Ethnicity, & Alzheimer’s” (March 2020), <https://www.alz.org/aaic/downloads2020/2020-Race-and-Ethnicity-Fact-Sheet.pdf>.
- 6 See 42 C.F.R. § 438.2 (“Long-term services and supports (LTSS) means services and supports provided to beneficiaries of all ages who have functional limitations and/or chronic illnesses that have the primary purpose of supporting the ability of the beneficiary to live or work in the setting of their choice, which may include the individual’s home, a worksite, a provider-owned or controlled residential setting, a nursing facility, or other institutional setting.”)
- 7 When Medicaid was enacted in 1965, funding for long-term care was limited to paying for skilled nursing facility (SNF) stays for individuals 21 or older. At the time, states were given an option to cover home health and private duty nursing services. In 1970, due to the high cost of SNFs, Congress made home health services for individuals who need a nursing facility level of care a mandatory benefit.
- 8 42 U.S.C. §§ 1396a(10)(A), 1396d(a)(4)(A); *see also, e.g.*, 42 USC §§ 1396n(c), (j), (k).
- 9 See *Olmstead v. L.C.*, 527 U.S. 581 (1999) (holding that a state must allow a person to receive long-term care services in the community if the person does not oppose living in the community, a professional has deemed community living to be appropriate, and provision of such services can be reasonably accommodated by the state).
- 10 U.S. Dep’t of Justice, “Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*” (2011), www.ada.gov/olmstead/q&a_olmstead.htm.
- 11 CMS, “Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018” (Jan. 2021), www.medicare.gov/sites/default/files/2021-01/ltssexpenditures-2017-2018.pdf.
- 12 *See, e.g.*, Associated Press-NORC Ctr. for Public Affairs “Research, Long Term Care: Perceptions, Experiences, and Attitudes Among Americans 40 or Older 7” (2013), <https://apnorc.org/projects/long-term-care-perceptions-experiences-and-attitudes-among-americans-40-or-older/> (survey shows Americans “overestimate the long-term care services that Medicare will cover”).
- 13 42 C.F.R. §§ 409.30(a), 409.31(b), 409.32, 409.61(b). In 2018, the average length of stay in a nursing facility under Medicare was only 25 days. Medicare Payment Advisory Commission (MedPAC), “A Data Book: Health Care Spending and the Medicare Program”, at 100, Chart 8-4 (July 2020), www.medpac.gov/docs/default-source/data-book/july2020_databook_entirereport_sec.pdf?sfvrsn=0.
- 14 See CMS, Medicare.gov: Home Health Services, www.medicare.gov/coverage/home-health-services; Homebound means “You have trouble leaving your home without help (like using a cane, wheelchair, walker, or crutches; special transportation; or help from another person) because of an illness or injury, or leaving your home isn’t recommended because of your condition. You’re normally unable to leave your home, but if you do it requires a major effort.” CMS, “Medicare and Home Health Care”, at 5, www.medicare.gov/sites/default/files/2020-10/10969-Medicare-and-Home-Health-Care.pdf.
- 15 *See, e.g.*, Integrated Care Resource Center, “Strategies to Support Dually Eligible Individuals’ Access to Durable Medical Equipment, Prosthetics, Orthotics, and Supplies” (Jan. 2019), www.integratedcareresourcecenter.com/resource/strategies-support-dually-eligible-individuals%E2%80%99-access-durable-medical-equipment.
- 16 Kaiser Family Foundation, “Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey”, www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-findings-from-a-50-state-survey-issue-brief/.
- 17 *See*, MACPAC, “MACStats: Medicaid and CHIP Data Book”, at Exhibit 37 (Dec. 2020), www.macpac.gov/wp-content/uploads/2015/01/EXHIBIT-37-Medicaid-Income-Eligibility-Levels-as-a-Percentage-of-the-Federal-Poverty-Level-for-Individuals-Age-65-and-Older-and-Persons-with-Disabilities-by-State-2020.pdf. Note: States have flexibility in what income is counted towards eligibility including flexibility to disregard income in determining whether an individual’s income is at or below the income eligibility limit. Most states disregard income 5% or less above the eligibility limit, but some states disregard more. For example, in California,

the state disregards any countable income above 100% FPL up to 138% FPL, in effect making the income eligibility limit 138% FPL In California.

- 18 For a summary of Medicaid asset limits by state, see KFF, “Medicaid Financial Eligibility,” *supra* note 17 at App. Table 2 and Table 3.
- 19 Justice in Aging, “Fact Sheet: Supplemental Security Income (SSI)” (2019), www.justiceinaging.org/wp-content/uploads/2017/03/FSSI-Fact-Sheet.pdf.
- 20 KFF, “Medicaid Financial Eligibility,” *supra* note 17 at App. Table 2.
- 21 *Id.* at App. Table 5.
- 22 In 2021, 300% of the SSI benefit rate is \$2,382.
- 23 45 C.F.R. § 435.726.
- 24 42 C.F.R. § 435.217.
- 25 Justice in Aging, “Fact Sheet: Make the Expanded Spousal Impoverishment Protection Permanent,” (Feb. 2019), <https://justiceinaging.org/fact-sheet-make-the-expanded-spousal-impoverishment-protection-permanent/>.
- 26 MACPAC, “Chapter 4: Functional Assessments for Long-Term Services and Supports”, at 70 (2016), <https://www.macpac.gov/wp-content/uploads/2016/06/Functional-Assessments-for-Long-Term-Services-and-Supports.pdf>.
- 27 *Id.*
- 28 *Id.*
- 29 Administration for Community Living, “What is Long-Term Care”, <https://acl.gov/ltc/basic-needs/what-is-long-term-care>.
- 30 Justice in Aging, “Voluntary Means Voluntary: Coordinating Medicaid HCBS with Family Assistance” (2016), <http://justiceinaging.org/voluntary-means-voluntary-coordinating-medicaid-hcbs-with-family-assistance/>.
- 31 See CMS, LTSS Information: IHS, Tribal, and Urban Indian LTSS Programs, www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ihs-tribal-and-urban-ltss-programs.
- 32 Kaiser Family Foundation, “Medicaid in the Territories: Program Features, Challenges, and Changes” (Jan 25, 2019), www.kff.org/report-section/medicaid-in-the-territories-program-features-challenges-and-changes-issue-brief/.
- 33 42 USC §§ 1396a(10)(D); 1396d(a)(7); see 42 C.F.R. § 440.210(a)(1).
- 34 See 42 C.F.R. § 440.70. Note that mandatory home health services are more limited in scope compared to optional home and community-based services, and can include service caps and other utilization controls.
- 35 Kaiser Family Foundations, “Medicaid Home & Community-Based Services Enrollment & Spending” (Feb. 4, 2020), www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-appendix-tables/.
- 36 42 C.F.R. § 440.167.
- 37 CMS, Self-Directed Personal Assistant Services 1915 (j), www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/self-directed-personal-assistant-services-1915-j/index.html.
- 38 CMS, Community First Choice (CFC) 1915 (k), www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/community-first-choice-cfc-1915-k/index.html.
- 39 CMS, Home & Community Based Services 1915(i), www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915i/index.html.
- 40 KFF, “HCBS Enrollment & Spending”, *supra* note 35.
- 41 CMS, Home & Community-Based Services 1915(c), www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html.
- 42 CMS, About Section 1115 Demonstrations, www.medicaid.gov/medicaid/section-1115-demonstrations/about-section-1115-demonstrations/index.html.
- 43 A waiver typically targets one of several categories of people with disabilities: older adults and people with physical disabilities (often combined), people with intellectual and developmental disabilities, people who are medically Fragile/Tech Dependent Children, people with HIV/AIDS, people with mental health needs, and people with traumatic brain injuries or spinal cord injuries (TBI/SCI).

- 44 See Kaiser Family Foundation, “Key State Policy Choices about Medicaid Home & Community Based Services” (Feb. 4, 2020), www.kff.org/report-section/key-state-policy-choices-about-medicaid-home-and-community-based-services-appendix-tables/.
- 45 *Id.* at App. Table 5.
- 46 *Id.*
- 47 Another example is the Balancing Incentive Program that provided federal grants from 2011 to 2015 to 21 states that were spending less than 50% of their total Medicaid LTSS expenditures on HCBS. The grants were used to increase access to HCBS by establishing “no wrong door” systems in Medicaid, using core standardized assessment instruments, and implementing conflict-free case management systems. CMS, Balancing Incentive Program, www.medicaid.gov/medicaid/long-term-services-supports/balancing-incentive-program/balancing-incentive-program/index.html.
- 48 CMS, Money Follows the Person Program, www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html.
- 49 Kaiser Family Foundation, “Medicaid’s Money Follows the Person Program: State Progress and Uncertainty Pending Federal Funding Reauthorization” (Nov. 25, 2019), www.kff.org/medicaid/issue-brief/medicaids-money-follows-the-person-program-state-progress-and-uncertainty-pending-federal-funding-reauthorization/.
- 50 *Id.*
- 51 Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2948, 3030-31 (Jan. 16, 2014) (codified at 42 C.F.R. § 441.301(c)(4)).
- 52 This includes the 10 states that have operated Financial Alignment Initiative demonstrations, which covered Medicaid LTSS for individuals dually enrolled in Medicare. ADvancing States, Managed Long-Term Services & Supports Map, <http://www.advancingstates.org/initiatives/managed-long-term-services-and-supports/mltss-map>.
- 53 CMS, Programs of All-Inclusive Care for the Elderly Benefits, www.medicaid.gov/medicaid/long-term-services-supports/pace/programs-all-inclusive-care-elderly-benefits/index.html.
- 54 Enrollment by PACE program and state is available at www.integratedcaresourcecenter.com/resource/program-all-inclusive-care-elderly-pace-total-enrollment-state-and-organization-7.
- 55 KFF, “Key State Policy Choices”, *supra* note 45, at App. Table 9.
- 56 *Id.* at Table 11.
- 57 *Id.*
- 58 CMS, “Medicaid & CHIP Beneficiaries at a Glance,” (Feb. 2020), www.medicaid.gov/sites/default/files/2020-02/beneficiary-ataglance.pdf.
- 59 The data sources combine spending for adults age 65+ with spending for younger adults with physical disabilities.
- 60 AARP Michigan, “Disrupting Disparities: A Continuum of Care for Michiganders 50 and Older”, at 17 (Apr. 2019), <https://aarp-states.brightspotcdn.com/e1/01/462cbadceb72654cd57b63bb407e/aarp-report-disrupting-disparities.pdf>.
- 61 Alzheimer’s Ass’n, “Fact Sheet: Race, Ethnicity, and Alzheimer’s” (March 2020), www.alz.org/aaic/downloads2020/2020_Race_and_Ethnicity_Fact_Sheet.pdf.
- 62 Justice in Aging, “Low-Income Older Adults Face Unaffordable Rents, Driving Housing Instability and Homelessness” (Feb. 2021), <https://justiceinaging.org/wp-content/uploads/2021/02/Older-Adults-Rental-Housing-Burdens.pdf>.