Chapter 4:

Access to Home- and Community-Based Services

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Key Points

- Medicaid home- and community-based services (HCBS) are designed to allow people with long-term services and supports (LTSS) needs to live in their homes or a homelike setting in the community. HCBS encompass a wide range of services, such as personal care services provided in a community setting, supported employment, non-medical transportation, and home-delivered meals.
- HCBS are optional services for states, but all states cover some HCBS benefits. Variation exists in how benefits are delivered, the types of services covered, the populations served, and the criteria used to determine eligibility. Over the past decade, more than half of all spending on LTSS has been on HCBS compared to institutional care.
- Despite the array of HCBS programs, individuals needing community-based options can face barriers accessing these services. Some of the key challenges include limited provider availability, state budgetary constraints, waiver waiting lists, and gaps in beneficiary knowledge about the services that are available.
- States are frequently managing multiple HCBS programs and benefit packages, each with its own set of eligibility criteria, which creates administrative burdens for states. Additional challenges for states include budgetary constraints, limited staff capacity to manage HCBS programs, and limited state systems capacity, all of which reduce a state's ability to expand access to HCBS.
- Differences in access to HCBS for LTSS subpopulations may exist across a range of factors, including by race and ethnicity, by geographic location, and by age. However, the extent to which these differences occur is challenging to identify given that more data are necessary, particularly related to race and ethnicity.
- Over the next year, the Commission will work to identify policies that drive toward a more streamlined HCBS delivery system with increased access for beneficiaries and reduced administrative burden for states.

CHAPTER 4: Access to Home- and Community-Based Services

Medicaid home- and community-based services (HCBS) are designed to allow people with long-term services and supports (LTSS) needs to live in their homes or a homelike setting in the community. HCBS encompass a wide range of services, such as personal care services provided in a community setting, supported employment, non-medical transportation, and home-delivered meals. HCBS are optional for states, but all states cover some HCBS benefits.

States can cover HCBS in their state plans, which generally require such benefits to be made available to all Medicaid enrollees, or through various waiver authorities that can be targeted to certain populations.[1] Section 1915(c) waivers and Section 1115 demonstrations are some of the most common mechanisms through which states cover HCBS. In 2020, more than 3 million Medicaid beneficiaries received HCBS under these two authorities. In comparison, more than 2.5 million people received state plan benefits, including about 734,500 individuals who received mandatory home health services, which states are required to offer (O'Malley Watts et al. 2022a).

Despite the array of HCBS programs, individuals needing community-based options can face barriers accessing these services. Some of these barriers include limited provider availability, state budgetary constraints, waiver waiting lists, and gaps in beneficiary knowledge about the services that are available (MACPAC 2020a). Studies have also shown that the availability of HCBS fluctuates across populations, and the complexity associated with the range of HCBS authorities, such as varied eligibility requirements and differing benefit packages, can create barriers for beneficiaries to access these services and administrative burdens for states (Hayes et al. 2021, Sowers et al. 2016).

Over the past few years, MACPAC has examined ways to increase access to HCBS for beneficiaries. This work has included identifying potential opportunities for additional rebalancing of LTSS away from institutional settings, such as providing additional federal support for state rebalancing efforts and improving communication around care transitions. We have also explored HCBS waiver capacity and state management of waiting lists and summarized state efforts to address the primary drivers of Medicaid HCBS workforce shortages (MACPAC 2022a; Bernacet et al. 2021; MACPAC 2020a, 2020b). In addition, MACPAC contracted with the Center for Health Care Strategies (CHCS) to conduct an expert roundtable in December 2021 to consider the delivery of HCBS and the idea of establishing a core HCBS benefit.

Over the past year, MACPAC has conducted additional work on access to HCBS, including an environmental scan, stakeholder interviews, and two panels. In an effort to understand what HCBS are currently being offered by states, including for what populations and under what authorities, MACPAC conducted an environmental scan between May and July 2022. To further improve our understanding of the challenges that beneficiaries and states face in accessing and administering HCBS, we contracted with CHCS to conduct interviews with stakeholders. CHCS, with the support of its subcontractor RTI International, conducted 18 interviews between September and November 2022 with federal and state officials, beneficiary advocates representing a range of HCBS populations, and national experts.[2] In the fall of 2022, the Commission continued discussions on access by hosting a panel of experts to discuss streamlining delivery of HCBS. The Commission also hosted a panel in January 2023 on states' early experiences with implementation of the American Rescue Plan Act of 2021 (ARPA, P.L. 117-2).

This chapter synthesizes the findings from MACPAC's work and outlines an HCBS access framework that will guide the Commission's continued work in this area. The chapter begins with an overview of Medicaid coverage of HCBS, including eligibility, benefits, and spending. As part of this overview, we explain the range of federal HCBS authorities and describe the results of our environmental scan, which summarizes the number of states offering HCBS by certain taxonomy categories and type of population. Next, we introduce findings from our research, which are consistent with recent studies indicating that beneficiaries can face barriers to access HCBS and states can face administrative complexity when managing their HCBS programs. We map the findings

to four components of MACPAC's access framework for HCBS: (1) provider availability and accessibility, (2) use of services, (3) beneficiary perceptions and experiences of care, and (4) administrative complexity. The chapter concludes with next steps that will further the Commission's work to address access to HCBS and challenges experienced by states.

Medicaid Coverage of HCBS

Beneficiary preferences to remain in the community, along with growing demand for HCBS in recent decades, is both a response to the Americans with Disabilities Act of 1990 (P.L. 101-336) and the 1999 *Olmstead v. L.C.* decision that states must facilitate community integration for beneficiaries with disabilities (Chidambaram and Burns 2022, MACPAC 2019).[3] Medicaid is the primary payer for LTSS, which includes both institutional care and HCBS. States have been required to cover institutional LTSS, such as nursing facility care, since the program's enactment. In 1981, Medicaid coverage of HCBS was first authorized under Section 1915(c) of the Social Security Act (the Act) as an alternative to institutional LTSS. Since then, Congress has enacted various state plan authorities that states can use to cover HCBS. Medicaid beneficiaries who use LTSS are a diverse group, ranging in age from children to older adults, with varied cognitive and physical disabilities. People who use LTSS often receive services and supports for years or even decades. HCBS can be administered through fee-for-service (FFS) or managed LTSS (MLTSS) programs. These services and supports allow people to live in their homes or a homelike setting and remain integrated with the community.

Eligibility

To be determined eligible for Medicaid, individuals generally must fit into a specific eligibility category, meet certain income thresholds, and meet asset tests under certain circumstances. To qualify for LTSS, they must meet additional functional criteria that are based on an individual's physical or cognitive status.

Multiple Medicaid eligibility pathways exist for LTSS. States are required to cover beneficiaries who receive Supplemental Security Income (SSI) through the mandatory SSI-related pathway. All states choose to cover individuals through one or more optional pathways (Table 4-1).

TABLE 4-1. Overview of Selected Medicaid Eligibility Pathways and Criteria for Medicaid LTSS Coverage, 2022

Eligibility pathway	Definition	Number of states using pathway	Income thresholds	Asset limits
SSI-related	SSI is a federal income support program for people who have limited income and resources and are also age 65 or older, blind, or have disabilities. This is a mandatory pathway. In most states, individuals receiving SSI are automatically eligible for Medicaid.	50 states and DC; 8 states have elected the Section 209(b) option[1]	74% FPL ($841 per month for an individual and $1,261 for a couple in 2022)	$2,000 for an individual and $3,000 for a couple
Poverty-related	Optional pathway that allows a state to cover LTSS for individuals with incomes up to 100 percent FPL who have disabilities or are age 65 and older.	24 states and DC	Up to 100% FPL ($13,590 a year for an individual in 2022)	Typically same as SSI limits, but some states have higher limits

TABLE 4-1. (continued)

Eligibility pathway	Definition	Number of states using pathway	Income thresholds	Asset limits
Medically needy	Optional pathway that allows states to cover certain individuals who have high medical expenses relative to their income. These individuals would be categorically eligible but have income that exceeds the maximum limit for that pathway. Individuals become eligible for Medicaid once they have spent down their excess income on their medical expenses.	32 states and DC	At state discretion; median in 2022 was 43% FPL for an individual	Typically same as SSI limits, but some states have higher limits
Katie Beckett pathway for children with disabilities	Optional pathway that provides Medicaid services for at least some children with severe disabilities whose family income would otherwise be too high to qualify. Only the child's own income and assets are counted.	43 states and DC	300% of SSI benefit rate ($2,523 per month for an individual in 2022)	$2,000
Medicaid buy-in	Optional pathway that covers individuals with disabilities who work and have incomes too high to qualify for Medicaid via other pathways. Many states charge premiums for this group.	47 states and DC	At state discretion; median in 2022 was 250% FPL for an individual	Seven states do not have an asset limit for this group
Special income level	Optional pathway for individuals who have income up to 300 percent of the SSI benefit rate and who meet level of care criteria for nursing facility or other institutional care.	42 states and DC	Up to 300% of SSI benefit rate	Typically same as SSI limits
Section 1915(i) state plan HCBS	Section 1915(i) of the Social Security Act allows states to offer HCBS under the state plan to people who need less than an institutional level of care.	5 states	150% FPL for individuals who meet functional eligibility criteria, or 300% of SSI benefit rate for individuals receiving Section 1915(c) waiver services	None

Notes: LTSS is long-term services and supports. SSI is Supplemental Security Income. DC is District of Columbia. FPL is federal poverty level. HCBS is home- and community-based services. For married individuals, spousal impoverishment provisions are applied first (§ 1924 of the Social Security Act).

[1] Section 209(b) states may use eligibility criteria (related to income and assets, disability, or both) that are more restrictive than SSI program criteria, but they may not use more restrictive criteria than those in effect in the state on January 1, 1972.

Sources: SSA 2023, MACPAC 2022b, Musumeci et al. 2022, Colello and Morton 2019.

Once individuals are determined eligible for Medicaid, they are entitled to the full range of covered services in the state. HCBS are optional services, and all states choose to cover HCBS. Some states cover HCBS through an amendment to their state plan (e.g., 37 states covered personal care services under the state plan in 2020), but most states cover HCBS via Section 1915(c) waivers (47 states) and Section 1115 demonstrations (12 states) (O'Malley Watts et al. 2022b). Waiver authorities and demonstrations give states flexibility to limit the number of beneficiaries receiving HCBS, target services to particular populations, or provide services in certain parts of the state (Table 4-2). Section 1915(c) waivers also allow states to cover additional types of HCBS that are not available under the state plan as long as the spending under the waiver is cost effective compared to what the state would have spent if the beneficiary received institutional LTSS.[4] In contrast, HCBS that are covered under the state plan must be offered to all eligible beneficiaries; however, they are typically more limited in scope than those provided under waivers.

TABLE 4-2. Statutory Authorities for Medicaid Home- and Community-Based Services

Type of authority	Authority	Description
Waiver	Section 1915(c)	Allows states to cover a wide range of HCBS as a cost-effective alternative to institutional care. Also allows states to forgo certain Medicaid requirements to target HCBS benefits to specific populations, cap the number of beneficiaries who receive these benefits, or create waiting lists for people who cannot be served under the cap.
	Section 1115	Not specific to HCBS, Section 1115 demonstration authority is a broad authority that allows states to test new delivery models that advance the goals of the Medicaid program.
State plan	Section 1905(a)(7)	States are required to cover home health care services, which include nursing; home health aides; and medical supplies, equipment, and appliances. States also have the option of covering additional therapeutic services, including physical therapy, occupational therapy, and speech pathology and audiology services.
	Section 1905(a)(24)	Allows states to cover personal care services but does not give beneficiaries using self-direction the authority to manage their own individual service budget.[1]
	Section 1915(i)	Allows states to offer HCBS to people who need less than an institutional level of care, the typical standard for Medicaid coverage of HCBS. States can also establish specific criteria for people to receive services under this authority.
	Section 1915(j)	Gives authority for self-directed personal assistance services (PAS), providing beneficiaries with the ability to hire and direct their own PAS attendant. States may also give beneficiaries the authority to manage their own individual service budget.
	Section 1915(k)	The Community First Choice option, established in the ACA, provides states with a 6 percentage point increase in the FMAP for HCBS attendant services.

Notes: HCBS is home- and community-based services. ACA is the Patient Protection and Affordable Care Act (P.L. 111-148, as amended). FMAP is federal medical assistance percentage.

[1] Under self-direction, beneficiaries, or their representatives if applicable, have decision-making authority and responsibility for managing all aspects of their service delivery in a person-centered planning process, with the assistance of a system of available supports. States may allow self-direction under Section 1915(c) waivers, Section 1115 demonstrations, and Sections 1915(i), 1915(j), and 1915(k) state plan options (CMS n.d.).

Sources: Sections 1115, 1905(a)(7), 1905(a)(24), 1915(c), 1915(i), 1915(j), and 1915(k) of the Social Security Act; 42 CFR 440.70(b).

To receive HCBS, beneficiaries must meet certain functional eligibility criteria. Eligibility determinations for LTSS generally focus on measures of functional status—referred to as "level of care" (LOC) criteria—rather than the existence of specific clinical conditions. To make these determinations, states use functional assessment tools, which are sets of questions that collect information on an applicant's health conditions and functional needs. Such tools may also be used to develop a care plan of specific services that an individual will receive upon being determined eligible. The tools that states use to measure the need for these services and supports can vary by service, program, and HCBS subpopulation (MACPAC 2016).

Benefits

Given the design flexibilities available to states, Medicaid benefits differ across states. This variation applies to HCBS, including how benefits are delivered, the types of services covered, the populations served, and the criteria used to determine eligibility. States often use different terminology to refer to the same or similar services. To organize unique state approaches, researchers developed the HCBS taxonomy, a uniform classification system composed of 18 service categories, including more than 60 specific services (Table 4A-1). States began using the HCBS taxonomy to report HCBS waiver claims in the Medicaid Statistical Information System (MSIS) in 2010, but the extent to which all states do so varies (Peebles et al. 2017). In a recent analysis of 2019 Transformed MSIS (T-MSIS) analytic files examining LTSS users, several data quality issues were documented across a number of states, such as challenges identifying Medicaid beneficiaries and the high number of claims reported to the T-MSIS analytic files (Kim et al. 2022).

MACPAC conducted an environmental scan in 2022 to identify the authorities that states use to cover HCBS. We included all 50 states and the District of Columbia in our scan. We reviewed Section 1915(c) waivers (47 states) and Section 1115 demonstration authority documents (13 states) and Section 1915(i) (14 states) and Section 1915(k) state plan authorities (9 states).[5] Every state plus the District of Columbia uses one or more of these authorities to cover HCBS.[6] We then mapped the services offered under each authority to the appropriate HCBS taxonomy category and population, where possible.

For Section 1915(c) waivers, the Centers for Medicare & Medicaid Services (CMS) provides a list of 12 populations from which states can choose their target HCBS populations (CMS 2022a).[7] The term "aged" is used in the Section 1915(c) waiver application, and to remain consistent, we used the same term for our environmental scan. The HCBS waiver technical guidance document notes that although generally, "aged" refers to individuals age 65 and older (aligning with § 1905(a)(iii) of the Act), states can identify a minimum age that is lower than 65 to align with state systems. In our review, we found that many waivers often serve more than one of these populations, so we consolidated them into seven population groupings. This mirrors other studies that used similar groupings and allows for easier comparisons across similar populations (O'Malley Watts et al. 2022b, Ross et al. 2021). The seven population groupings we used are:

- aged;
- individuals with intellectual disabilities or developmental disabilities (ID/DD), including autism;
- individuals with physical or other disabilities;
- individuals with brain injury;
- individuals with mental illness or serious emotional disturbance;
- individuals with HIV/AIDS; and
- individuals who are medically fragile or technology dependent.

These seven population groupings are not mutually exclusive; some beneficiaries may belong to two or more populations, such as being aged and having an intellectual disability. Furthermore, some states have developed separate programs targeting specific populations, while other states more recently have consolidated their waivers to target multiple populations under one authority.

Unlike Section 1915(c) waivers and Section 1915(i) state plan authority, for which all states identified their selected target groups to receive services, there is no defined list of target groups to indicate which populations are served under Section 1115 demonstrations and Section 1915(k) state plan

authority. This lack of consistency made summarizing which populations are covered across states challenging. For Section 1115 demonstration authority, if populations covered were not clearly identified in the waiver, we relied on an existing study to confirm or identify the populations (O'Malley Watts et al. 2022b). For Section 1915(k) state plan authority, services covered must be available statewide for eligible beneficiaries and may not be limited to a target group.

In our review of waivers and state plan authorities authorized under sections 1915(c), 1115, and 1915(i), we found certain commonalities among the populations states select to receive HCBS and the services states choose to cover (Table 4A-2). (HCBS covered under Section 1915(k) state plan authority are included in a separate table given that services are not directed to one particular HCBS population.) All states and the District of Columbia cover HCBS for individuals with ID/DD or autism as well as for the aged population. Forty-nine states cover HCBS for individuals with physical or other disabilities. About half of states cover HCBS for individuals with brain injuries or mental illness or those who are medically fragile or technology dependent. Ten states cover HCBS targeted specifically to individuals with HIV/AIDS.

Among the services in the HCBS taxonomy, caregiver support and home-based services are the most common and are covered for all seven populations based on our review of Sections 1115, 1915(c), and 1915(i). Equipment, technology, and modifications services are covered for six populations, and day services are covered for five populations. Rent and food expenses for live-in caregivers is the least common service and is covered for two populations. Across HCBS subpopulations, we found that certain services, such as supported employment, are covered for individuals with ID/DD or people with autism more often than for the aged population. We also identified the top five most common services covered for each target population (Table 4A-3).

Based on our review of Section 1915(k) authority, 11 different taxonomy services are covered among the 9 states. Home-based services; participant training; and equipment, technology, and modifications are the most common services (Table 4A-4).

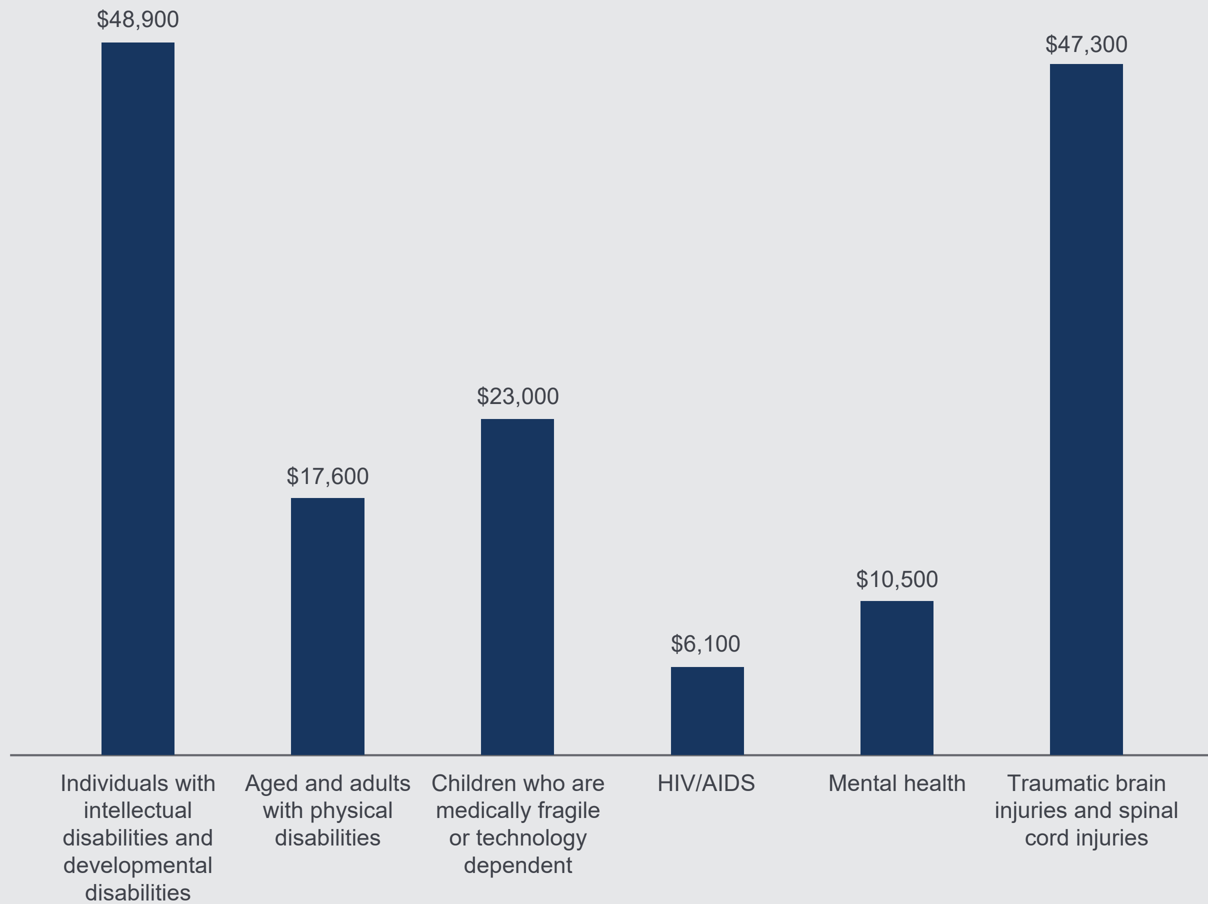
Spending

Nationally, since fiscal year (FY) 2013, spending on HCBS as a proportion of total LTSS expenditures has exceeded spending on institutional care. However, in some states and for some HCBS populations, spending on institutional care exceeds spending on HCBS. In FY 2019, nationally, HCBS expenditures as a share of total Medicaid LTSS reached 58.6 percent. In 29 states and the District of Columbia, HCBS made up 50 percent or more of total LTSS spending; among all states, rebalancing ratios ranged from 83 percent to 33 percent (Murray et al. 2021a).[8]

The most recently available data on Medicaid spending for HCBS are limited to services delivered through FFS and do not capture Medicaid spending on HCBS delivered through managed care. In FY 2021, total federal and state spending on Medicaid HCBS delivered through FFS was $88 billion (or about 62 percent of all LTSS FFS spending), compared to about $54.5 billion on institutional LTSS (38 percent of total LTSS FFS spending). Total federal and state spending on all Medicaid benefits was $717 billion, of which LTSS spending was 19.5 percent (12 percent of spending was on HCBS and 7.5 percent was on institutional services) (MACPAC 2022c). These figures do not account for spending in MLTSS, and as a result, total spending on HCBS is likely much higher. In FY 2019, the most recent year for which there are data on MLTSS expenditures, 65 percent ($30.9 billion) of total MLTSS expenditures were for HCBS (Murray et al. 2021a).[9]

There are limited data on spending by population; however, the data that we do have indicate that per-person spending on HCBS is highest for individuals with ID/DD. For example, one study of FY 2018 data that analyzed HCBS spending compared to institutional spending by population type found that for people with ID/DD, including autism spectrum disorder, about 79 percent of LTSS spending was for HCBS. In contrast, about one-third of LTSS expenditures for older adults and people with physical and other disabilities was for HCBS. For individuals with behavioral health conditions, it was just over 49 percent (Murray et al. 2021b).

FIGURE 4-1. Section 1915(c) Waiver Per-Person Spending by Target Population, FY 2020



Note: FY is fiscal year.

Source: O'Malley Watts et al. 2022a.

More recent data from FY 2020 that reflect per-person spending by target population among Section 1915(c) waivers show the highest spending is for the ID/DD population ($48,900 per person on average) (Figure 4-1). Spending on the ID/DD population, however, accounted for a disproportionate share of total Section 1915(c) spending (67 percent) compared to the share of people with ID/DD who received these services in FY 2020 (43 percent). In comparison, older adults and individuals with physical disabilities comprised 54 percent of total Section 1915(c) waiver users but accounted for 31 percent of total expenditures. The other populations combined accounted for about 3 percent of people served and about 3 percent of spending, although per-person spending among these groups varied widely: from $6,100 for individuals with HIV/AIDS to $47,300 on average for people with traumatic brain injuries and spinal cord injuries (O'Malley Watts et al. 2022a).

Access to HCBS

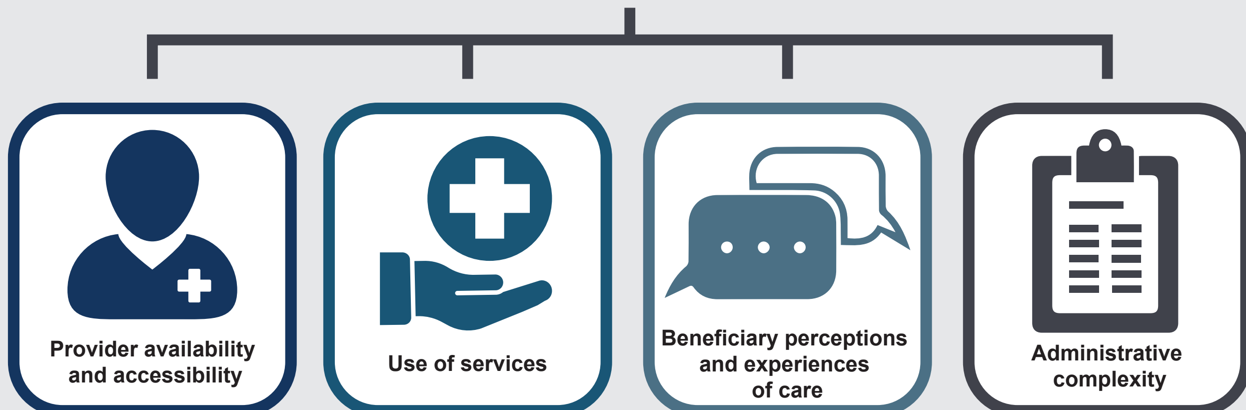
In its June 2022 *Report to Congress on Medicaid and CHIP*, the Commission discussed a new Medicaid access monitoring framework with three key domains of access: (1) provider availability and accessibility, (2) use of services, and (3) beneficiary perceptions and experiences of care (MACPAC 2022d). For purposes of analyzing access to HCBS for Medicaid beneficiaries, we mapped our findings to these three domains and added an additional category, administrative complexity, to capture the challenges that states face in operating their HCBS programs (Figure 4-2).

Provider availability and accessibility

Provider availability and accessibility measures capture potential access to providers and services, regardless of whether the services are used. Provider availability is a function of the presence of providers in the state or region (i.e., supply) as well as their participation in Medicaid and CHIP (MACPAC 2022d, 2011; Kenney et al. 2016). This domain also includes other measures of availability, such as timeliness of appointments, travel time, and accessibility for individuals with language barriers and disabilities.

HCBS provider capacity. HCBS providers include several types of workers—direct care workers (DCWs), direct support professionals, and independent providers—who assist beneficiaries with activities of daily living, such as mobility, personal hygiene, and eating.[10] In addition to these essential basic functions, HCBS workers also assist beneficiaries in community integration by providing support with instrumental activities of daily living such as grocery shopping and managing finances. The tasks they perform may be specialized, depending on the needs of the population (e.g., children, people with ID/DD, adults with physical disabilities, and people with dementia). HCBS workers are typically employed either by an agency that serves as a provider enrolled with the state Medicaid agency or as an independent provider working via self-directed waiver services.[11]

FIGURE 4-2. HCBS Access Framework



Notes: HCBS is home- and community-based services.

Source: MACPAC 2022d.

HCBS workers tend to earn low incomes, and many are Medicaid beneficiaries themselves. In 2021, the median home health and personal care aide hourly wage was $14.15 (BLS 2022). In 2020, 43 percent of DCWs lived in households with incomes under 200 percent of the federal poverty level (FPL), and more than half (53 percent) used public assistance programs, including 30 percent who were enrolled in Medicaid. The majority of DCWs are women (85 percent) and people of color (64 percent identified as being a race other than white in 2020) (PHI 2022). Additionally, wage disparities exist within the workforce; women earn less than men on average, and people of color earn less than white people (Campbell et al. 2021).

Roughly 2.6 million workers provided services to Medicaid beneficiaries in their homes and other community settings in 2021 (PHI 2022). Workforce shortages, however, limit the ability of Medicaid programs to serve more people in the community. The COVID-19 pandemic has exacerbated the workforce shortage and highlighted its drivers, including low wages, limited opportunities for career advancement, and high turnover (MACPAC 2022a).

Nearly all interviewees cited limited provider capacity and shortages of DCWs as key barriers to increasing access to HCBS. Persons with ID/DD and behavioral health needs may experience particular challenges due to the limited availability of HCBS workers because of the additional training required to serve these populations. One federal official shared that providers do not have workers available or financial capacity to meet population needs in states. A lack of HCBS funding coupled with limited provider capacity creates challenges for states to have a person-centered approach to HCBS delivery.

HCBS provider payment. Workforce shortages are an ongoing barrier to expanding services (Bernacet et al. 2021, MACPAC 2020a). Interviewees underscored how low wages for DCWs and high turnover rates lead to challenges delivering care and providing person-centered services. A state official shared that multiple wage increases were not sufficient to make wages competitive with other employment opportunities. Interviewees reported that additional funding could help states improve payment rates for HCBS providers, which would in turn improve the delivery of services.

Section 9817 of ARPA provided a temporary increase in the federal medical assistance percentage (FMAP) for state Medicaid programs to support the HCBS infrastructure.[12] States are using ARPA funds on activities that enhance, expand, or strengthen HCBS, such as initiatives to increase provider payment rates and expand provider capacity. Nearly all states have one or more ARPA-funded initiatives related to provider payment, such as rate increases (32 states), requirements for funds to be passed on to DCWs (20 states), and conducting studies on new rate structures (23 states) (ADvancing States 2023). For example, Maine used ARPA funds to provide two bonuses of $1,000 to existing DCWs and their immediate supervisors in 2021 and one-time bonuses of $1,500 for newly hired DCWs. Starting in 2022, Maine's state budget also provided permanent funding to sustain HCBS worker wages at 125 percent of the state's minimum wage (Manz 2022). Iowa gave one-time recruitment and retention bonuses to direct support professionals, including supervisors (IA DHS 2021). Iowa also used its ARPA funds to contract with a statewide crisis provider to assist DCWs serving individuals with co-occurring ID/DD and behavioral health conditions. The crisis provider operates a 24/7 helpline for workers to call if they need assistance deescalating a situation or advice on administering care. The state also offers mobile response specifically for this population (Matney 2023).

Some states are addressing gaps in the HCBS workforce by supporting natural caregivers, such as family members. For example, Washington established the Medicaid Alternative Care program and the Tailored Supports for Older Adults program, which support unpaid family caregivers. These programs are intended to address the health and wellness of the caregiver. Research has indicated that the stress and burden associated with caregiving can put the caregiver and the person receiving care at risk (WA DSHS 2018). The COVID-19 pandemic has further demonstrated the critical value of informal caregivers for beneficiaries requiring LTSS. During the COVID-19 public health emergency (PHE), more than half of states allowed family members to be paid providers (CMS 2023). The Administration for Community Living's report 2022 *National Strategy to Support Family Caregivers* emphasized the role of family caregivers in supporting individuals with disabilities and those age 65 and older (ACL 2022).

Appendix K flexibilities. In an emergency, Section 1915(c) waivers can be modified with the submission of an Appendix K. In light of the COVID-19 PHE, CMS created a prepopulated template to modify Appendix K, referred to as the "Appendix K COVID Addendum," that highlighted the most common flexibilities requested by states (CMS 2020). During the PHE, states used the flexibilities available through Appendix K to bolster HCBS delivery and reimbursement. Some of these flexibilities include modifying services, payment rates, and eligibility criteria. CMS also permitted states to use virtual LOC determinations, pay for HCBS in institutional settings, and allow family caregivers to be reimbursed for care provided to an HCBS user (CMS 2023). Appendix K flexibilities may also be used to expand provider qualifications or the pool of providers who can deliver services. During the PHE, 29 states used the Appendix K COVID Addendum to request flexibility to allow spouses and parents of minor children to be paid providers, and 25 states requested to allow family members to be paid providers. CMS has indicated that continuing allowance of payment for family caregivers to render services may be approved in standard Section 1915(c) applications but not under Section 1905(a)(24) state plan personal care benefit, in which legally responsible individuals may not be reimbursed (CMS 2023, Teshale et al. 2021).

Every state with a Section 1915(c) HCBS waiver program submitted an Appendix K requesting flexibilities in HCBS delivery and services. Although Appendix K flexibilities are set to expire six months after the end of the PHE, states have the option to make some flexibilities permanent through their Section 1915(c) waivers, such as flexibilities around the use of telehealth in HCBS delivery (CMS 2023).

Use of services

This domain of the access framework measures realized access by examining use of services and, in some cases, use of specific providers or settings. Existing measures typically focus on medical care; relatively few standardized measures are available for other types of services, particularly for LTSS. Monitoring unmet need and particular access goals for HCBS can be a challenge. Service gaps, such as delivery of fewer HCBS hours than recommended in the person-centered service plan, are difficult to capture in administrative data, as authorized hours are not reported on claims. Furthermore, some beneficiaries in need of HCBS may not be receiving services because they are on a waiver waiting list. Administrative data also cannot capture information on the key goals of HCBS, such as an individual's ability to live independently, visit with family and friends, and participate in community activities.

Enrollment caps and waiting lists. States are allowed to set caps on the number of people served under a Section 1915(c) waiver and to establish waiting lists when demand exceeds the waiver's approved capacity. Some Section 1115 demonstrations also allow waiting lists for HCBS. In general, waiting lists are indicative of an unmet need for HCBS waiver services; however, they are an imperfect measure of access. For example, eligibility screening for waiver services happens at different times in different states, making it difficult to compare waiting lists across states.[13]

Although waiting lists allow states to manage costs, interviews with federal officials, national experts, and beneficiary advocates noted that they also restrict access to HCBS for some individuals who need them. In our previous work on waiting lists, state funding was cited as the most important factor in many states for increasing waiver capacity, such as the number of waiver slots. In some states, explicit support from the governor or the state legislature led to funding increases that helped reduce waiting lists (MACPAC 2020a).

Interviewees told us that some individuals with LTSS needs may apply to several waiver programs at once in an effort to gain access to HCBS, even when one waiver program would best suit their needs. Another waiver may not have a waiting list or may have a shorter wait time, and thus, individuals might apply to begin receiving some services while waiting for a slot in a different HCBS waiver with services that more appropriately meet their needs. Most states with waiting lists allow individuals to be on more than one waiting list at a time (O'Malley Watts et al. 2022b).

Long wait times for waiver services can also result in some people finding other ways to meet their LTSS needs. One study found that among all populations, in 2020, the average wait time for waiver services was 44 months, but substantial variation existed among

populations, with a range of 1 month for individuals with HIV/AIDS to 60 months for individuals with ID/DD (O'Malley Watts et al. 2022b). Among states that we interviewed in 2020, estimates of wait times ranged from less than 1 year to 14 years. Wait times also differed within states among their various waivers, often by differences of more than five years (MACPAC 2020a). As such, beneficiaries may get their LTSS needs met through state plan services or support from family caregivers while they wait for an HCBS waiver slot to become available. It is difficult to assess how many people on waiting lists are actually going without any HCBS because states do not track how individuals meet their care needs while waiting for waiver services (MACPAC 2020a).

States are using ARPA funding to expand beneficiary services, including efforts to reduce waiting lists. Six states—Alabama, California, New Mexico, North Carolina, Tennessee, and Texas—are proposing to eliminate or reduce waiting lists by adding more than 17,000 waiver slots (CMS 2021). For example, Texas is adding an additional 1,549 waiver slots distributed among 6 different waivers. The state is also proposing to update its waiting list management policies. In Texas, individuals are placed on waiting lists on a first-come, first-served basis but are not screened for eligibility for a waiver until a slot becomes available. The state proposed spending $13 million (including $6.5 million of federal ARPA funds and $6.5 million of state general revenue) to use a contractor to screen individuals on the waiting list for eligibility as well as make referrals to available services until a waiver slot opens up. The contractor is also tasked with creating an online portal for waiting list participants to see their place on the list, update their contact information, and update their needs assessment (TX HHS 2022).

Disparities in access. Disparities in access to HCBS for LTSS subpopulations may exist across a range of factors, including by race and ethnicity, by geographic location, and by age. However, several interviewees shared the challenge of identifying the extent to which these disparities occur given the lack of available data, particularly related to race and ethnicity. One study found that Medicaid HCBS spending is lowest for dually eligible Black males with multiple sclerosis as compared to white males with multiple sclerosis who had the highest HCBS spending (Fabius et al. 2018).

Other evidence points to disparities: among people with Alzheimer's disease and related dementias, higher HCBS expenditure was linked to a lower probability of institutional care for white individuals and not for Black individuals (Yan et al. 2021). Interviewees also noted geographic disparities in rural areas where it can be more difficult to find HCBS workers. In these cases, self-direction may be a useful tool for getting assistance to beneficiaries. Every state makes self-direction available as an option in at least one HCBS program in the state (O'Malley Watts et al. 2022c). Finally, interviewees told us that age can be a barrier to accessing HCBS. One interviewee shared that individuals supporting care plan development, such as social workers, may not engage in person-centered planning for older adults by asking beneficiaries about their preferences and instead may assume knowledge of their needs, which could affect access to services.

More data are necessary to identify potential disparities in HCBS access. The federal government and the states are working on obtaining better data; however, data limitations related to race and ethnicity continue to be an area the Commission has highlighted as a challenge given that some states have high rates of missing data (MACPAC 2022e). The Commission recently voted on several recommendations related to the collection of race and ethnicity data in Medicaid applications (MACPAC 2023). Other sources may also exist to supplement government data. For example, one state official pointed out that although the state does not stratify HCBS data on use and outcomes by race and ethnicity, the managed care organizations operating in the state regularly collect such data.

We also heard concerns about a lack of coordination on quality metrics across HCBS programs. CMS recently released a set of national standardized HCBS quality metrics that is intended to streamline state reporting on data for HCBS users. In a July 2022 letter to state Medicaid directors, CMS published the HCBS Quality Measure Set and strongly recommended that states stratify their data by race and ethnicity, sex, age, rural or urban location, disability, and language (CMS 2022b). Stratified data allow states to determine existing health disparities encountered by HCBS beneficiaries to inform targeted initiatives intended to address such differences. CMS notes that the goal of this effort is to encourage increased

use of standardized metrics within and across states for HCBS programs. This policy change may lead to more comparative quality data on HCBS programs that both states and CMS can use to enhance quality of care (CMS 2022b). Policymakers may be better able to monitor whether different LTSS populations are receiving the services they need if states collect HCBS data in a standardized manner and the data are stratified by subgroups.

Beneficiary perceptions and experiences

The third domain in MACPAC's access framework, beneficiary perceptions and experiences, is focused on barriers to accessing care, experiences with care, and beneficiaries' knowledge and understanding of available benefits. This includes their connection to the health care system, timeliness of care, unmet needs, and culturally competent care (MACPAC 2022d, Kenney et al. 2016). Our key interview finding in this domain centers on the barriers that largely relate to a lack of clarity and understanding of the available options and how to access them among individuals interested in accessing HCBS.

Beneficiary knowledge gaps. Medicaid waivers have complex requirements, which can create challenges for beneficiaries and for states. Interviewees explained that the range of waivers that cover HCBS, each with unique eligibility pathways and often managed by separate state agencies, can result in confusion among beneficiaries about which they qualify for. Given multiple waiver options, beneficiaries may apply for multiple waivers to increase their chance of being determined eligible and obtaining coverage.

Overall, consumers face knowledge gaps regarding available HCBS supports in their communities. Several interviewees noted that people who are eligible for HCBS can encounter confusing information about HCBS options and how to access them. Interviewees told us that information on state websites varies in terms of the level of detail, and the websites can be difficult to navigate.

One source of information for beneficiaries is information and referral/assistance (I&R/A) networks, which include a range of entities responsible for making available and coordinating services for persons with a disability, older adults, and caretakers (ADvancing States 2022). Some of the primary functions for I&R/A specialists include identification and referral to available services in the community and information sharing. Entities involved in these state-established networks vary; they include but are not limited to area agencies on aging (AAA), 211 call centers, aging and disability resource centers, and centers for independent living. Each entity also offers different services, ranging from providing a referral to essential supports (e.g., assistance with utilities) to options counseling. One key issue is a lack of training for and high turnover rates among information counselors, which are partly driven by low wages similar to the HCBS workforce challenges. For example, one state noted that it is experiencing a high turnover rate among its AAA counselors, which it depends on to serve as an HCBS resource for residents. These challenges are not unique to this particular state or to AAAs. Interviewees noted that states could also turn their attention to other areas that may create access barriers to seeking information; states can examine if information is accessible for those with limited English proficiency or for individuals who are visually impaired.

Services provided through I&R/A entities may also be operated through a no wrong door (NWD) system, in which state and local agencies coordinate to create a simplified process for people to access information, determine their eligibility, and provide one-on-one counseling on LTSS options (ADvancing States 2022, NCD 2022). The NWD system was initiated as part of a joint effort by the Administration for Community Living, CMS, and the Veterans Health Administration (NCD 2022). NWD initiatives have multiple funding streams, including federal, state, and local funding; however, the funding available to states to implement NWD systems is limited and has hindered their ability to implement NWD systems to their full capacity (NCD 2022, NCOA 2022). Some states have used ARPA funding to improve the availability of HCBS information

for individuals by allocating funding specifically to the state's NWD system.

Despite state efforts to establish NWD systems, we heard from several national experts that these systems are not widely available. Some states are working to improve their NWD systems. For example, Iowa is further developing its warm handoff and referral system, which enables individuals to access the information they need regardless of which entity they seek information from. California, through ARPA funding, is investing $5 million in its NWD system to improve communication between entities in the system. This investment is intended to facilitate access to information for beneficiaries on the availability of HCBS in the state, irrespective of what "door" an individual uses (Kashen and Knackstedt 2022). Advance education and knowledge for beneficiaries is critical before the need for HCBS presents itself. Some individuals wait to access HCBS until they are experiencing an immediate need for services. NWD systems can make information more widely available.

Administrative complexity

The final domain in MACPAC's HCBS access framework, administrative complexity, examines the following: state burden in administering multiple HCBS programs often under different federal authorities, constraints on state capacity and resources, the implications of system complexity for beneficiaries, and the concept of establishing a core set of services. Our interviews revealed themes consistent with this domain, including administrative complexity for beneficiaries involved in navigating the Medicaid statutory authorities for providing HCBS as well as challenges for states, including budgetary constraints, a lack of staff with knowledge of HCBS, and limited state systems capacity, all of which reduce a state's ability to expand access to HCBS.

State administration of HCBS. Interviewees shared that states can experience challenges providing access to HCBS given the complexity associated with administering HCBS waiver programs as well as state capacity challenges. States may cover HCBS via different waiver and state plan authorities. States' decisions regarding their administrative approach can be driven by varying reporting and renewal requirements, which can consume state resources.

HCBS waiver reporting requirements are more prescriptive than those for state plan options, but the use of a waiver may provide additional programmatic flexibility for states. States with a Section 1915(i) state plan option must make the estimated number of persons to be enrolled and the count of enrollees from the prior year available to CMS annually (42 CFR 441.745(a)(1)(i)). For Section 1915(c) waivers and per federal regulation, states are required to submit an annual form CMS-372(S) for each approved waiver (42 CFR 441.302(h)). This reporting requirement includes data on expenditures and service utilization of individuals participating in the waiver as well as information about the effect of the waiver on the "health and welfare" of HCBS users (CMS 2019). Several state officials and national experts considered the waiver reporting requirements excessive and unnecessary to determine the effectiveness of a program. They suggested reducing the number of requirements as a way to support states and their ability to effectively administer HCBS programs. One state official suggested that the waiver renewal process could be better aligned with the state plan renewal process to remove the additional work involved with waiver renewals, which require different and more information than the state plan renewal process. However, compared with HCBS state plan options, waivers give states enhanced flexibilities, such as waiving the statewideness requirement, that may justify additional reporting requirements.

Through interviews with stakeholders and panels of experts, we identified various suggestions to streamline HCBS administration. They include consolidating HCBS authorities, aligning reporting requirements and renewal processes for waivers with those required for state plan amendments to decrease administrative requirements, rethinking the design of HCBS programs to better align with beneficiary needs, and encouraging the use of managed care to provide HCBS. We have provided some state examples that reflect innovative approaches to restructuring administration of HCBS (Box 4-1).

BOX 4-1. Innovative State Approaches to Restructuring Administration of Home- and Community-Based Services

Florida. Florida operates the iBudget waiver program to provide home- and community-based services (HCBS) to individuals with intellectual disabilities or developmental disabilities (ID/DD). Previously, Florida used a prior authorization system. A support coordinator was responsible for creating a list of services with input from the individual or family, and services were reviewed by an authorizing agent. However, challenges related to the prior-authorization system and the costs associated with it led the state to transition to a budget-based program. Together with stakeholders, the Florida Agency for Persons with Disabilities established the iBudget program as a cost control mechanism for the state while simultaneously allowing persons with ID/DD and their families autonomy and flexibility to choose the services they need to reside in the community. The individualized budget is based on an algorithm, and participants, with the support of a coordinator, have budget and employer authority to allocate funds to services and direct who furnishes their care (AHCA 2021). In its recent American Rescue Plan Act (ARPA, P.L. 117-2) spending plan, Florida included funding to expand the iBudget waiver slots to move individuals off the waiting list.

Minnesota. Minnesota used ARPA funds to launch a Waiver Reimagine Advisory Committee that is supporting the second phase of the state's efforts to consolidate its four disability waiver programs, each associated with varying diagnoses and populations served, into two waivers based on an individual's level of need and one set of eligibility requirements (MN DHS 2023). The advisory committee solicits insights from individuals with disabilities and their families to inform the development of the two waivers. During the first phase of the initiative that ended in 2021, the state worked to align services across waivers to enable a seamless transition from four waivers to two in the second phase of the project, which was authorized to begin in 2021 at the conclusion of Phase 1 (MN DHS 2023).

Tennessee. Tennessee operates a Section 1115 demonstration program, which offers Medicaid managed care for the majority of the Medicaid population in the state. Tennessee had numerous Section 1915(c) waivers that it consolidated into a single Section 1115 demonstration program by offering the CHOICES program. CHOICES provides HCBS through managed care for older adults and individuals with physical disabilities based on their eligibility for one of three population groups, as defined by certain medical and functional criteria, and their TennCare eligibility group. Tennessee also has the Employment and Community First CHOICES program, which provides employment supports for individuals with ID/DD based on their eligibility for one of five population groups. The state is using ARPA funding to increase access to HCBS by serving additional individuals with ID/DD in the Employment and Community First CHOICES program.

Interviewees also provided feedback on the use of tiered waivers. Some states use a tiered waiver structure in which multiple waivers serve the same populations but offer varying types and intensities of services. A state may have multiple waivers targeting individuals with ID/DD, but they may not all cover personal care services. Louisiana has a tiered benefit system for individuals with ID/DD through use of several Section 1915(c) waivers (Box 4-2). One state official suggested allowing for tiered benefit packages within one Section 1915(c) waiver program rather than having a separate waiver for each tier (i.e., redesign within existing authorities).

BOX 4-2. Louisiana's Tiered Home- and Community-Based Services Waiver System

In 2018, Louisiana's Office for Citizens with Developmental Disabilities (OCDD), with help from stakeholders, launched its Tiered Waiver program. With this new program, the state moved away from operating on a first-come, first-served basis to meet the home- and community-based services needs of more than 10,000 persons with intellectual disabilities or developmental disabilities (ID/DD) on a waiting list (LDH 2018). The goal was to consolidate the waiting lists associated with its four existing Section 1915(c) waivers. Individuals were screened and stratified into five groups based on level of need, with a goal to set priorities for access to the next available OCDD waiver slot for persons most at risk of institutionalization (LDH 2022). This screening process continues at the time of publication. The state uses a person-centered planning process, in which the Louisiana Plus assessment tool is used to identify the type of ID/DD waiver best suited to the person's needs and for which they are eligible.

State capacity. States are operating with limited capacity and resources amid competing priorities and tight budget constraints. State administrative capacity limitations can restrict states' ability to fulfill program requirements, such as timely eligibility determinations, as well as to carry out initiatives that improve quality and outcomes (MACPAC 2014). Further, state administrative staffing shortages may hinder efforts to establish more robust HCBS systems. Interviewees noted that some states with multiple HCBS waivers are managed by different state agencies. Interviewees also shared that the technological investments that states must implement to comply with new CMS requirements create challenges. States used ARPA funds to enhance state platforms responsible for billing, reporting, and tracking data; improve administration of HCBS programs; and invest in systems that promote cross-sector integration, such as between Medicare and Medicaid HCBS (Kashen and Knackstedt 2022, Sullivan 2021).

Many interviewees pointed to budgetary constraints as limiting state ability to expand access to HCBS. They indicated that states may cut services to meet budgetary demands when they arise. States have leveraged one-time ARPA funding to mitigate budget constraints and increase access to HCBS. In Illinois, ARPA funding is being directed to assistive technology as well as vehicle and home modifications that support community living. Other initiatives targeted expanding access to specific HCBS populations, such as persons with behavioral health needs and the workers who support this population (Kashen and Knackstedt 2022).

Complex requirements. National experts and federal officials said that the complexity of income and resource eligibility criteria may deter some individuals from applying for HCBS. In particular, we heard this feedback about the medically needy pathway. This pathway provides coverage to people with modestly higher incomes than the Medicaid limit in the state with an opportunity to become Medicaid eligible, if they meet spend-down requirements. Specifically, states establish a medically needy income level (MNIL) to which a beneficiary must spend down within a certain time frame, referred to as a "budget period," which varies from one to six months. This spend down typically occurs when beneficiaries incur medical expenses and pay for them out of pocket. Once individuals spend down their income to their states' MNIL, they are eligible for Medicaid.

A proposed rule in 2022 looked to address differential treatment in current Medicaid regulations by making the medically needy pathway more accessible to individuals applying for Medicaid and in need of HCBS by accounting for the projected expenses of individuals who are not institutionalized and are receiving HCBS when determining Medicaid eligibility for a given budget period (CMS 2022c).[14] The proposed rule is intended to do the following: (1) decrease Medicaid churn among noninstitutionalized individuals whose

Medicaid eligibility often begins after a new budget period is initiated, resulting in coverage gaps; (2) decrease states' administrative costs because of an expected decline in Medicaid churn; and (3) improve outcomes with continuity of care.

Medicaid-eligible individuals enrolling through the medically needy pathway must spend down their income to their state's MNIL. In 2020, the median MNIL across the 32 states and the District of Columbia with this pathway was $478.50 per month or 45 percent of the FPL for an individual. Asset limits for this pathway generally align with SSI levels, which are $2,000 for an individual and $3,000 for a couple (MACPAC 2021).[15] Given the income limit they would have to spend down to, eligible individuals may be hesitant to apply for HCBS out of a concern that they would have insufficient income to maintain their community living expenses.

The process of being determined eligible for Medicaid HCBS is complex and can take considerable time. State and federal officials raised concerns about the lengthy process and noted that individuals have to navigate both functional and financial assessment processes. For example, one state official said that waiver applicants with ID/DD have to be determined medically eligible twice through a state developmental disability system determination and an HCBS medical eligibility determination. Interviewees suggested it would be helpful to streamline eligibility and enrollment processes—for example, by allowing for medical and financial eligibility determination processes to occur concurrently. Florida, along with several other states, has web-based and automated eligibility systems that link the medical and financial eligibility processes, resulting in simultaneous eligibility determinations. Another mechanism to streamline eligibility is to use more refined and consolidated assessment tools. A number of states have looked to ARPA funding to reexamine their assessment tools. For example, Rhode Island is working to move from six functional assessment tools to one tool for all HCBS programs in the state (RI EOHHS 2021).

Core benefit. MACPAC convened a roundtable in December 2021 to discuss ways to streamline and increase access to HCBS. The roundtable discussed the idea of establishing a core set of services across all HCBS programs, referred to as a "core benefit." A core benefit could provide a basic set of HCBS designed to increase access to care while recognizing that some beneficiaries may need additional services or a higher level of services to meaningfully live in the community. To flesh out the roundtable discussion, we included this idea in the interviews that CHCS conducted for us in 2022. We asked interviewees for feedback at a conceptual level on the idea of a core benefit, including a range of design considerations and implications for the current HCBS delivery system. For example, interviewees explored several design considerations related to standardizing a core benefit or allowing state flexibility in the design. Other considerations included having one basic core benefit as opposed to multiple population-based core benefits and whether services should be offered in a tiered approach from least intensive to most intensive or should be allocated based on costs.

Overall, interviewee responses were mixed on the idea of establishing a core benefit and its potential to streamline and increase access to HCBS. Interviewees cautioned that the potential success of a core benefit as a way to increase access to services would depend on how the benefit is designed and implemented. They also noted that increases in access would likely vary across states because of the differences that exist in state policies and systems for determining HCBS eligibility and enrolling eligible beneficiaries and for the benefits covered. One state official predicted changes to provider payment rate structures to bolster provider networks in the event of implementing a core benefit. The state official also expressed apprehensions related to state staff capacity to implement a new benefit. Some individuals raised concerns related to design and implementation, questioning if such a benefit would add more complexity to the system. Almost all interviewees agreed that for a core benefit to streamline and increase access to HCBS, it would need to be a mandatory Medicaid benefit.

Interviewees raised several concerns around implementing a core benefit. Potential issues included limited workforce availability, the need for increased federal financial support, constraints on state capacity to enhance current infrastructure to accommodate new enrollees, the time it would take to initiate the benefit, and supports that beneficiaries would need to prevent disparities in access to the new core benefit. The primary concerns expressed by states we interviewed were the ongoing workforce shortages

and limited state staff capacity to implement a new benefit. Many interviewees also noted that states would need additional federal financial support to implement a new core benefit, particularly if it was mandatory. Some interviewees noted that low state take-up of the optional Section 1915(k) program, which includes an enhanced 6 percent federal match, might suggest that states would require greater support. One state official noted that states could struggle with the investments in infrastructure that would likely be needed to support implementation of a new benefit, such as updating state information technology systems and developing more user-friendly systems to process and track applications.

Several interviewees mentioned that states would require substantial time to implement a core benefit—for example, to engage stakeholders in the process and secure funding from the state legislature. Interviewees also noted that implementation of the core benefit should include beneficiary supports such as options counseling to help individuals make informed choices about their coverage. Interviewees told us that although the core benefit could allow individuals to more easily access services, it could also exacerbate disparities in access if it does not account for the varying levels of support that different beneficiaries might need, such as information in a language other than English.

Given the challenges that states are facing with the unwinding of the continuous coverage requirement established for Medicaid under the PHE and with implementation of ARPA-funded initiatives, introducing a core benefit, whether optional or mandatory, would be a substantial change to the HCBS system. The impact of such a change on access is unknown, particularly with the limited availability of workers to provide services, but may warrant further study in the future as the landscape changes.

Next Steps

States have been investing in HCBS as evidenced by the growth of HCBS expenditures relative to institutional care in recent decades. However, our summary of existing HCBS authorities and flexibilities, analysis of state coverage of HCBS by taxonomy categories, and extensive interviews indicate that access to and management of HCBS programs are complex and challenging to navigate for beneficiaries and states. HCBS worker shortages and limited state staff capacity further exacerbate these challenges. For beneficiaries, lack of familiarity with available options, complex and lengthy eligibility processes, and state use of enrollment caps and waiting lists for some waivers can mean delays in access to services. States also face challenges; they are administering multiple HCBS programs with limited resources and competing priorities for staff already juggling multiple responsibilities. Our findings show that policy and operational challenges persist.

The Commission is committed to exploring ways to expand access to HCBS within each domain of our HCBS access framework, taking into account state needs. In the coming year, we will work to identify policies that drive toward a more streamlined HCBS delivery system with increased access for beneficiaries and reduced administrative burden for states. The findings summarized in this chapter serve as the basis for upcoming Commission work, including projects that will examine HCBS spending and use, HCBS payment rates, and administrative requirements for HCBS programs.

Endnotes

[1] Most Medicaid-covered services are described in the Medicaid state plan, which is an agreement between states and the federal government about how the state will administer its Medicaid program. Services provided under the Medicaid state plan are statutorily required to be available statewide to all Medicaid-eligible beneficiaries.

[2] CHCS and RTI International conducted interviews with representatives from the Administration for Community Living, Centers for Medicare & Medicaid Services (CMS), Wisconsin, Florida, Tennessee, Washington, Louisiana, New York, Justice in Aging, The Council on Quality and Leadership, Autistic Self-Advocacy Network, National Association of State Mental Health Program Directors, Brain Injury Association of America, AIDS United, Family Voices, Topeka Independent, Community Living Policy Center, and ADvancing States.

[3] *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999).

[4] Section 1115 demonstrations also provide states with the authority to pay for services that cannot otherwise be covered under the state plan as long as spending on the demonstration is projected to be budget neutral to the federal government.

[5] MACPAC staff searched the CMS database of state waivers between May and July 2022 to identify current, approved Section 1915(c) and Section 1115 demonstrations. The U.S. territories were not included in this review. Pending, expired, and terminated waivers also were not included. Additionally, only Section 1115 demonstrations that cover HCBS were reviewed and included. Staff also searched CMS's database of Medicaid state plan amendments and state Medicaid websites for Section 1915(i) and 1915(k) state plan authorities. In the Section 1915(c) waiver application, states can identify the HCBS taxonomy category for each service they choose to cover, but not all states filled this out. For states that did fill this out, we relied on those classifications. For the states that did not, we read the service descriptions and relied on CMS guidance to assist us in choosing the most appropriate category (CMS 2014). We were able to map each service to a taxonomy category; therefore, we did not include the "unknown" HCBS taxonomy category in our results. Additionally, Section 1115 demonstrations and state plan documents do not identify the HCBS taxonomy categories the state is using, so we assigned categories for services listed in those documents. Another limitation of our review is the inability to summarize our findings for specific age groups. For example, in Section 1915(c) waivers, states can choose to limit services to a certain age range (e.g., age 0 to 21 or age 18 and older), but other waivers cover both children and adults, so it is not possible to catalog services by age.

[6] We excluded state plan authorities under Section 1905(a)(24) and Section 1915(j) from our review. Section 1905(a)(24) allows states to cover personal care services under the state plan but does not give beneficiaries the authority to manage a personal budget. These services are also not directed to one particular population and are made available to any eligible beneficiary in a state with this benefit. Section 1915(j) provides authority for self-directed personal assistance services (PAS), giving beneficiaries the ability to hire and direct their own PAS attendant. States may also give beneficiaries the authority to manage their own individual service budget. Often, self-direction is offered through other Medicaid authorities, and the Section 1915(j) option is not frequently implemented by states. Furthermore, Section 1915(j) authority may not target a particular population, unless combined with a 1915(c) waiver (Randi et al. 2021). This authority can also allow for self-directed services via the state plan optional personal care services.

[7] The 12 HCBS target groups included in Section 1915(c) waivers include: (1) aged, (2) disabled (physical), (3) disabled (other), (4) brain injury, (5) HIV/AIDS, (6) medically fragile, (7) technology dependent, (8) autism, (9) developmental disability, (10) intellectual disability, (11) mental illness, and (12) serious emotional disturbance (CMS 2022a).

[8] Rebalancing ratio refers to the share of total LTSS spending devoted to HCBS, expressed as a percentage (Murray et al. 2021a).

[9] In FY 2019, 25 states had MLTSS programs, but the total expenditures include data from only 20 states.

[10] DCWs include personal care aides, home health aides, and certified nursing assistants. Direct support professionals assist individuals with ID/DD, providing a broader range of services than personal care aides, such as employment support (PHI 2022). Independent providers are those who are employed directly by beneficiaries through consumer direction.

[11] There are additional types of HCBS providers, such as those that provide adult day services.

[12] ARPA increased the FMAP by 10 percent for the one-year period of April 1, 2021, through March 31, 2022. States had to submit spending plans to CMS on how they would spend this new money. All 50 states and the District of Columbia have received approval from CMS, and, at the time of publication, are implementing the initiatives included in their plans. States have until March 31, 2025 to spend the increased FMAP earned during the one-year period.

[13] Seven states do not screen for eligibility before placing people on waiting lists; individuals on waiting lists in these states account for 59 percent of the national total waiting list population in FY 2020 (O'Malley Watts et al. 2022b).

[14] The medically needy income eligibility determination process under current regulation (§ 435.831(g)(1)) only permits deduction of projected medical expenses from the income of individuals in institutions, which serves as part of their spend down for a designated budget period for purposes of determining Medicaid eligibility. Other expenses, such as those incurred by the individual's family members, may also be included in deductions from the countable income.

[15] The medically needy pathway allows states to cover individuals with high medical expenses relative to their income once they have spent down to a state's MNIL. The income threshold and the budget period used in medically needy eligibility determinations are state specific. States may offer full Medicaid services or a more limited set of state-specified benefits to this group. They may also provide institutional LTSS and HCBS waiver benefits to those meeting level of care criteria.

References

Administration for Community Living (ACL), U.S. Department of Health and Human Services. 2022. *2022 National strategy to support family caregivers*. Washington, DC: ACL. https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf.

ADvancing States. 2023. *ARPA HCBS spending plan analysis*. Arlington, VA: ADvancing States. http://www.advancingstates.org/sites/nasuad/files/u34188/3-28-2023 Updated ARPA Spending Plan Analysis 3.pdf.

ADvancing States. 2022. What is I&R/A? Arlington, VA: ADvancing States. http://www.advancingstates.org/initiatives/information-and-referralassistance/what-ira.

Agency for Health Care Administration (AHCA). 2021. Application for a §1915(c) home- and community-based services waiver. Tallahassee, FL: AHCA. https://ahca.myflorida.com/medicaid/hcbs_waivers/docs/ibudget_Waiver_Document_07012021.pdf.

Bernacet, A., C. Kordomenos, S. Karon, et al. 2021. *Examining the potential for additional rebalancing of long-term services and supports: Final report. MACPAC contractor report.* Research Triangle Park, NC: RTI International, and Trenton, NJ: Center for Health Care Strategies. https://www.macpac.gov/wp-content/uploads/2021/05/Examining-the-Potential-for-Additional-Rebalancing-of-Long-Term-Services-and-Supports.pdf.

Bureau of Labor Statistics (BLS). 2022. Occupational outlook handbook: Home health and personal care aides. Washington, DC: BLS. https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm.

Campbell, S., A. Del Rio Drake, R. Espinoza, and K. Scales. 2021. *Caring for the future: The power and potential of America's direct care workforce*. Bronx, NY: PHI. http://phinational.org/wp-content/uploads/2021/01/Caring-for-the-Future-2021-PHI.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2023. Unwinding home and community based services (HCBS) public health emergency (PHE) flexibilities. CMS webinar presentation, February 8, 2023. https://www.medicaid.gov/home-community-based-services/downloads/unwind-hcbs-phe-flexbles-feb2023.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2022a. Application for a §1915(c) home and community-based services waiver. Baltimore, MD: CMS. https://wms-mmdl.cms.gov/WMS/help/version_36_1915c_Waiver_Application_and_Accompanying_Materials.zip.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2022b. Letter from Daniel Tsai to state Medicaid directors regarding "Home- and community-based services quality measure set." July 21, 2022. Baltimore, MD: CMS. https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2022c. Streamlining the Medicaid, Children's Health Insurance Program, and basic health program application, eligibility determination, enrollment, and renewal processes: Proposed rule. *Federal Register* 87, no. 172 (September 7); 54760–54855. https://www.govinfo.gov/content/pkg/FR-2022-09-07/pdf/2022-18875.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2021. *American Rescue Plan Act of 2021 (ARP) section 9817: Overview of state spending plans (as of November 30, 2021)*. Baltimore, MD: CMS. https://www.medicaid.gov/medicaid/home-community-based-services/downloads/arp-sec9817-overview-infographic.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2020. 1915(c) waiver Appendix K COVID-19 prepopulated template instructions. Baltimore, MD: CMS. https://www.medicaid.gov/state-resource-center/downloads/covid-19-appendix-k-instructions.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2019. Application for a §1915(c) home and community-based waiver [version 3.6, January 2019]: Instructions, technical guide and review criteria. Baltimore, MD: CMS. https://wms-mmdl.cms.gov/WMS/faces/portal.jsp.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2014. *Medicaid home and community-based services (HCBS) taxonomy category and subcategory definitions*. Baltimore, MD: CMS. https://wms-mmdl.cms.gov/WMS/help/TaxonomyCategoryDefinitions.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. n.d. Self-directed services. Baltimore, MD: CMS. https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html.

Chidambaram, P., and A. Burns. 2022. 10 things about long-term services and supports. Washington, DC: KFF. https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/.

Colello, K.J., and W.R. Morton. 2019. *Medicaid eligibility: Older adults and individuals with disabilities*. Report no. R46111. December 9. Washington, DC: Congressional Research Service. https://crsreports.congress.gov/product/pdf/R/R46111.

Fabius, C.D., K.S. Thomas, T. Zhang, et al. 2018. Racial disparities in Medicaid home- and community-based service utilization and expenditures among persons with multiple sclerosis. *BMC Health Services Research* 18, no. 773. https://doi.org/10.1186/s12913-018-3584-x.

Hayes, K., G.W. Hoagland, L. Harootunian, et al. 2021. *Streamlining and simplifying Medicaid HCBS authorities*. Washington, DC: Bipartisan Policy Center. https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2021/10/BPC-HBCS-Report_R02.pdf.

Iowa Department of Human Services (IA DHS). 2021. *Iowa spending plan for implementation of the American Rescue Plan Act of 2021, section 9817*. Des Moines, IA: DHS. https://www.medicaid.gov/sites/default/files/2022-06/IA%20Medicaid%20ARPA%20HBCS%20Spending%20Plan%20and%20Narrative.pdf.

Kashen, J., and K. Knackstedt. 2022. How three states made COVID-relief investments in improving home- and community-based services. New York, NY: The Century Foundation. https://tcf.org/content/report/how-three-states-made-covid-relief-investments-in-improving-home-and-community-based-services/.

Kenney, G.M., K. Gifford, J. Wishner, et al. 2016. *Research report: Proposed Medicaid access measurement and monitoring plan*. Washington, DC: Urban Institute. https://www.urban.org/sites/default/files/publication/88081/2001143-medicaid-access-measurement-and-monitoring-plan.pdf.

Kim, M., E. Weizenegger, and A. Wysocki. 2022. *Medicaid beneficiaries who use long-term services and supports: 2019*. Chicago, IL: Mathematica. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-user-brief-2019.pdf.

Louisiana Department of Health (LDH). 2022. *Tiered waiver: Questions & answers*. Baton Rouge, LA: LDH. https://ldh.la.gov/assets/docs/OCDD/TieredWaiverFAQ.pdf.

Louisiana Department of Health (LDH). 2018. New approach to home and community based services ends wait for thousands of citizens with developmental disabilities. Baton Rouge, LA: LDH. https://ldh.la.gov/news/4687.

Manz, J. 2022. States use American Rescue Plan Act funds to strengthen home and community-based service workforce. Washington, DC: National Academy for State Health Policy. https://nashp.org/states-use-american-rescue-plan-act-funds-to-strengthen-home-and-community-based-service-workforce/.

Matney, E. 2023. Presentation before the Medicaid and CHIP Payment and Access Commission, January 26, 2023, Washington, DC. https://www.macpac.gov/public_meeting/january-2023-public-meeting/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2023. Chapter 1: Medicaid race and ethnicity data collection and reporting: Recommendations for improvement. In *Report to Congress on Medicaid and CHIP*. March 2023. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2023/03/MACPAC_March-2023-Report-WEB-Full-Booklet_508.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022a. *State efforts to address Medicaid home- and community-based services workforce shortages*. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2022/03/MACPAC-brief-on-HCBS-workforce.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022b. 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, 2022. In *MACStats: Medicaid and CHIP Data Book*. December 2022. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2022/12/MACSTATS_Dec2022_WEB-508.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022c. Exhibit 17: Total Medicaid benefit spending by state and category, FY 2021 (millions). In *MACStats: Medicaid and CHIP Data Book*. December 2022. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2022/12/MACSTATS_Dec2022_WEB-508.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022d. Chapter 1: A new Medicaid access monitoring system. In *Report to Congress on Medicaid and CHIP*. June 2022. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2022/06/Chapter-1-A-New-Medicaid-Access-Monitoring-System.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022e. *Availability of race and ethnicity data for Medicaid beneficiaries*. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2022/03/MACPAC-brief_Race-and-Ethnicity-Data-Availability.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2021. Chapter 3: Medicaid estate recovery: Improving policy and promoting equity. In *Report to Congress on Medicaid and CHIP*. March 2021. Washington, DC: MACPAC. https://www.macpac.gov/publication/medicaid-estate-recovery-improving-policy-and-promoting-equity/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2020a. State management of Medicaid home- and community-based services waiver waiting lists. Washington, DC: MACPAC. https://www.macpac.gov/publication/state-management-of-home-and-community-based-services-waiver-waiting-lists/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2020b. Compendium of Medicaid home- and community-based services waiver waiting list administration. August 2020. Washington, DC: MACPAC. https://www.macpac.gov/publication/compendium-of-medicaid-home-and-community-based-services-waiver-waiting-list-administration/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2019. *Twenty years later: Implications of Olmstead v. L.C. on Medicaid's role in providing long-term services and supports*. Washington, DC: MACPAC. https://www.macpac.gov/publication/twenty-years-later-implications-of-olmstead-v-l-c-on-medicaids-role-in-providing-long-term-services-and-supports/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2016. Chapter 4: Functional assessments for long-term services and supports. In *Report to Congress on Medicaid and CHIP*. June 2016. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2016/06/Functional-Assessments-for-Long-Term-Services-and-Supports.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2014. Chapter 4: Building capacity to administer Medicaid and CHIP. In *Report to Congress on Medicaid and CHIP*. June 2014. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2014/06/Building-Capacity-to-Administer-Medicaid-and-CHIP.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2011. Chapter 4: Examining access to care in Medicaid and CHIP. In *Report to Congress on Medicaid and CHIP*. March 2011. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2011/03/March-2011-Report-to-Congress-on-Medicaid-and-CHIP.pdf.

Minnesota Department of Human Services (MN DHS). 2023. Waiver reimagine FAQs. St. Paul, MN: DHS. https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/waiver-reimagine/faq/.

Murray, C., A. Tourtellotte, D. Lipson, and A. Wysocki. 2021a. *Medicaid long term services and supports annual expenditures report: Federal fiscal year 2019*. Chicago, IL: Mathematica. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures2019.pdf.

Murray, C., A. Tourtellotte, D. Lipson, and A. Wysocki. 2021b. *Medicaid long term services and supports annual expenditures report: Federal fiscal years 2017 and 2018*. Chicago, IL: Mathematica. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures-2017-2018.pdf.

Musumeci, M., M. O'Malley Watts, M. Ammula, and A. Burns. 2022. *Medicaid financial eligibility in pathways based on old age or disability in 2022: Findings from a 50-state survey*. Washington, DC: KFF. https://www.kff.org/report-section/medicaid-financial-eligibility-in-pathways-based-on-old-age-or-disability-in-2022-findings-from-a-50-state-survey-appendix/.

National Council on Aging (NCOA). 2022. *No wrong door: A guide for community organizations*. Arlington, VA: NCOA. https://ncoa.org/article/no-wrong-door-a-guide-for-community-organizations.

National Council on Disability (NCD). 2022. *Strengthening the HCBS ecosystem: Responding to dangers of congregate settings during COVID-19*. Washington, DC: NCD. https://ncd.gov/sites/default/files/NCD_Strengthening-HCBS-Ecosystem_508.pdf.

O'Malley Watts, M., M. Musumeci, and M. Ammula. 2022a. *Medicaid home & community-based services: People served and spending during COVID-19*. Washington, DC: KFF. https://www.kff.org/report-section/medicaid-home-community-based-services-people-served-and-spending-during-covid-19-issue-brief/.

O'Malley Watts, M., M. Musumeci, and M. Ammula. 2022b. *State policy choices about Medicaid home and community-based services amid the pandemic*. Washington, DC: KFF. https://www.kff.org/report-section/state-policy-choices-about-medicaid-home-and-community-based-services-amid-the-pandemic-issue-brief/.

O'Malley Watts, M., A. Burns, and M. Ammula. 2022c. *Ongoing impacts of the pandemic on Medicaid home & community-based services (HCBS) programs: Findings from a 50-state survey*. Washington, DC: KFF. https://www.kff.org/medicaid/issue-brief/ongoing-impacts-of-the-pandemic-on-medicaid-home-community-based-services-hcbs-programs-findings-from-a-50-state-survey/.

Peebles, V., M. Kim, A. Bohl, B. Morales, and D. Lipson. 2017. *HCBS claims analysis chartbook: Final report*. Report to the Medicaid and CHIP Payment and Access Commission. Chicago, IL: Mathematica Policy Research. https://www.macpac.gov/publication/hcbs-claims-analysis-chartbook-final-report/.

Peebles, V., and A. Bohl. 2013. *The HCBS taxonomy: A new language for classifying home- and community-based services*. Chicago, IL: Mathematica Policy Research. https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/Downloads/MAX_IB19_Taxonomy.pdf.

PHI. 2022. Workforce data center. 2022. Bronx, NY: PHI. https://phinational.org/policy-research/workforce-data-center/.

Randi, O., E. Girmash, and K. Honsberger. 2021. *State approaches to reimbursing family caregivers of children and youth with special health care needs through Medicaid*. Washington, DC: National Academy for State Health Policy. https://www.nashp.org/wp-content/uploads/2021/01/Family-Caregivers-for-CYSHCN-PDF-1-15-2021.pdf.

Rhode Island Executive Office of Health & Human Services (RI EOHHS). 2021. *Spending plan narrative for implementation of American Rescue Plan Act of 2021, section 9817*. FY 2023 Q1. Cranston, RI: EOHHS. https://eohhs.ri.gov/media/35891/download?language=en.

Ross, J., K. Liao, and A. Wysocki. 2021. *Medicaid section 1915(c) waiver programs annual expenditures and beneficiaries report, 2017–2018*. Chicago, IL: Mathematica. https://www.mathematica.org/publications/medicaid-section-1915c-waiver-programs-annual-expenditures-and-beneficiaries-report.

Sowers, M., H. Claypool, and M. Musumeci. 2016. Streamlining Medicaid home and community-based services: Key policy questions. Washington, DC: KFF. https://www.kff.org/report-section/streamlining-medicaid-home-and-community-based-services-key-policy-questions-issue-brief/.

Sullivan, J. 2021. *States are using one-time funds to improve Medicaid home- and community-based services, but longer-term investments are needed*. Washington, DC: Center on Budget and Policy Priorities. https://www.cbpp.org/sites/default/files/9-24-21health.pdf.

Teshale, S., W. Fox-Grage, and K. Purington. 2021. *Paying family caregivers through Medicaid consumer-directed programs: State opportunities and innovations*. Washington, DC: National Academy for State Health Policy. https://nashp.org/paying-family-caregivers-through-medicaid-consumer-directed-programs-state-opportunities-and-innovations/.

Texas Health and Human Services (TX HHS). 2022. *Texas: Home and community based services spending plan narrative: Quarterly update—February 16, 2022*. Austin, TX: TX HHS. https://www.medicaid.gov/media/file/tx-hcbs-spendn-pln-nartv-update.pdf.

U.S. Social Security Administration (SSA). 2023. Supplemental Security Income (SSI) eligibility requirements. https://www.ssa.gov/ssi/text-eligibility-ussi.htm.

Washington State Department of Social and Health Services (WA DSHS). 2018. Aging and long-term support administration long-term care manual: Chapter 30b initiative 2: Long term services & supports—MAC & TSOA. Olympia, WA: DSHS. https://www.dshs.wa.gov/altsa/aging-and-long-term-support-administration-long-term-care-manual.

Yan, D., S. Wang, H. Temkin-Greener, and S. Cai. 2021. HCBS service spending and nursing home placement for patients with Alzheimer's disease and related dementias: Does race matter? *Journal of Applied Gerontology* 41, no. 3: 638–649. https://doi.org/10.1177/07334648211048187.

APPENDIX 4A: Environmental Scan of Home- and Community-Based Services Authorities

To address state variation in names of services and to make it easier to report on home- and community-based services (HCBS) use and spending, researchers developed the HCBS taxonomy—a uniform classification system that includes 18 categories, each associated with a set of subcategories (Table 4A-1) (Peebles et al. 2017). The HCBS taxonomy is used in Section 1915(c) waivers, in which there are designated fields for states to select an HCBS taxonomy category and subcategory for each service covered in the waiver.

TABLE 4A-1. HCBS Taxonomy Categories

HCBS taxonomy category	Examples of HCBS taxonomy services
Case management	Case management
Round-the-clock services	Group living, shared living, in-home habilitation, and in-home round-the-clock services
Supported employment	Job development, ongoing supported employment (individual or group), and career planning
Day services	Prevocational services, day habilitation, education services, day treatment or partial hospitalization, adult day health, adult day services, community integration, medical day care for children
Nursing	Private duty nursing and skilled nursing
Home-delivered meals	Home-delivered meals
Rent and food expenses for live-in caregivers	Rent and food expenses for live-in caregivers
Home-based services	Home-based habilitation, home health aide, personal care, companion, homemaker, chore
Caregiver support	Respite (in home and out of home) and caregiver counseling or training
Other mental health and behavioral services	Mental health assessment, assertive community treatment, crisis intervention, behavior support, peer specialist, counseling, psychosocial rehabilitation, clinic services
Other health and therapeutic services	Health monitoring; health assessment; medication assessment and/or management; nutrition consultation; physician services; prescription drugs; dental services; occupational therapy; physical therapy; speech, hearing, and language therapy; respiratory therapy; cognitive rehabilitative therapy; other therapies
Services supporting participant direction	Financial management services in support of participant direction and information and assistance in support of participant direction
Participant training	Participant training
Equipment, technology, and modifications	Personal emergency response system, home and/or vehicle accessibility adaptations, equipment and technology, supplies
Non-medical transportation	Non-medical transportation
Community transition services	Community transition services
Other services	Goods and services, interpreter, housing consultation, other
Unknown	Unknown

Note: HCBS is home- and community-based services.

Sources: CMS 2014, Peebles and Bohl 2013.

MACPAC conducted an environmental scan in 2022, in which we reviewed Section 1915(c) waivers and Section 1115 demonstrations and Section 1915(i) state plan authority, to determine which categories of services states are covering for each target population (Table 4A-2). We also illustrate the number of states that cover any HCBS by target population as well as the number of states covering each HCBS taxonomy category.

TABLE 4A-2. State Coverage of HCBS Under Sections 1915(c), 1915(i), and 1115 by Target Population, July 2022

HCBS taxonomy categories	Count of Medicaid HCBS authorities and states offering HCBS, by target population						
	Intellectual disabilities and developmental disabilities[1]	Physical and other disabilities	Aged	Brain injury	Mental illness and serious emotional disturbance	Medically fragile and technology dependent	HIV/AIDS
Total number of waivers and authorities in use	**129**	**86**	**76**	**33**	**28**	**27**	**10**
Total number of states	**51**	**49**	**51**	**26**	**23**	**23**	**10**
Caregiver support	48	44	46	17	15	16	8
Case management	27	32	33	12	10	11	4
Community transition services	32	28	30	11	7	5	1
Day services	48	44	47	17	12	7	7
Equipment, technology, and modifications	48	45	46	20	12	15	7
Home-based services	46	48	48	22	14	15	9
Home-delivered meals	14	38	39	6	8	4	6
Non-medical transportation	40	32	32	15	10	7	4
Nursing	33	29	27	6	7	13	6
Other health and therapeutic services	43	30	29	19	11	10	5
Other mental health and behavioral services	42	18	17	15	18	5	5
Other services	37	26	24	10	14	8	3
Participant training	25	13	13	10	12	2	2
Rent and food expenses for live-in caregivers	7	0	0	0	1	0	0
Round-the-clock services	44	32	34	13	10	3	2
Services supporting participant direction	23	20	21	6	6	6	3
Supported employment	48	21	13	18	15	6	4

Notes: HCBS is home- and community-based services. The number of states includes all 50 states and the District of Columbia for a total of 51. We were able to map each service to a taxonomy category; therefore, we did not include the "unknown" HCBS taxonomy category in our results.

[1] The intellectual disabilities and developmental disabilities category also includes autism.

Source: MACPAC analysis of approved Section 1915(c) waivers and Section 1115 demonstration authority and Section 1915(i) state plan authority, July 2022.

The most commonly covered HCBS among all states by target population are reported in Table 4A-3.

TABLE 4A-3. Top Five Most Common HCBS by Target Population, July 2022

Target population	HCBS taxonomy categories
Aged	• Home-based services • Day services • Caregiver support • Equipment, technology, and modifications • Home-delivered meals
Intellectual disabilities and developmental disabilities[1]	• Caregiver support • Day services • Equipment, technology, and modifications • Supported employment • Home-based services
Brain injury	• Home-based services • Equipment, technology, and modifications • Other health and therapeutic services • Supported employment • Caregiver support • Day services
Physical and other disabilities	• Home-based services • Equipment, technology, and modifications • Caregiver support • Day services • Home-delivered meals
Mental illness and serious emotional disturbance	• Other mental health and behavioral services • Caregiver support • Home-based services • Supported employment • Other services
HIV/AIDS	• Home-based services • Caregiver support • Day services • Equipment, technology, and modifications • Home-delivered meals • Nursing
Medically fragile and technology dependent	• Caregiver support • Equipment, technology, and modifications • Home-based services • Nursing • Case management

Notes: HCBS is home- and community-based services. For some populations, we included six services instead of five due to a tie in the number of states covering one or more services.

[1] The intellectual disabilities and developmental disabilities category also includes autism.

Source: MACPAC analysis of approved Section 1915(c) waivers and Section 1115 demonstration authority and Section 1915(i) state plan authority, July 2022.

At the time of our environmental scan, nine states covered HCBS via Section 1915(k) state plan authority. Table 4A-4 presents the range of HCBS made available to all eligible beneficiaries by tallying the number of states that cover each service.

TABLE 4A-4. HCBS Covered under Section 1915(k) State Plan Authority, July 2022

HCBS taxonomy categories	Number of states covering service
Caregiver support	0
Case management	3
Community transition services	3
Day services	1
Equipment, technology, and modifications	7
Home-based services	9
Home-delivered meals	4
Non-medical transportation	1
Nursing	2
Other health and therapeutic services	1
Other mental health and behavioral services	0
Other services	0
Participant training	7
Rent and food expenses for live-in caregivers	0
Round-the-clock services	0
Services supporting participant direction	4
Supported employment	0

Notes: HCBS is home- and community-based services. Section 1915(k) is also known as the Community First Choice option. We were able to map each service to a taxonomy category; therefore, we did not include the “unknown” HCBS taxonomy category in our results.

Source: MACPAC analysis of Section 1915(k) state plan authority, July 2022.