August 2020



## State Management of Home- and Community-Based Services Waiver Waiting Lists

Medicaid home- and community-based services (HCBS) allow people with significant physical and cognitive limitations to remain in their homes or home-like settings rather than in an institution. While HCBS is not a mandatory benefit, all Medicaid programs currently provide some HCBS benefits. Moreover, over several decades, federal and state policies have encouraged rebalancing—shifting Medicaid long-term services and supports (LTSS) spending away from institutional services and toward HCBS (MACPAC 2019).

HCBS encompass a wide range of services and includes personal care, supported employment, and home-delivered meals. States can cover HCBS in their state plans, which require such benefits to be made available to all enrollees, or through various waiver authorities that can be targeted to certain populations. Waivers under Section 1915(c) and Section 1115 of the Social Security Act (the Act) are often used by states to cover HCBS and permit states to limit the number of individuals served and establish waiting lists. While waiting lists allow states to manage costs, they also restrict access to HCBS for some individuals who need them. Long wait times result in some people having to find other ways of meeting their LTSS needs.

States take different approaches to managing their HCBS waiver waiting lists and to date there has been no comprehensive analysis of state practices. To gain insight on these practices, MACPAC analyzed Section 1915(c) and Section 1115 waiver documents for all 50 states and the District of Columbia. We compiled selected information on waiver capacity and waiting list management in a *Compendium of Medicaid Home- and Community-Based Services Waiver Waiting List Administration*, and we describe the results of our analyses of these waivers in this issue brief (MACPAC 2020).

In addition, we conducted 16 stakeholder interviews to gain insight on state approaches to waiting list management, strategies to reduce waiting lists, and the experiences of individuals on waiting lists. These stakeholders included federal officials; state officials; state associations of directors of aging, physical disability, and developmental disability services; beneficiary advocacy organizations; and other experts.<sup>1</sup>

From our analysis of waivers and stakeholder interviews, we found:

 While waiting lists vary in their size, the length of a waiting list is not a precise measure of unmet need for HCBS waiver services. In particular, eligibility screening for waiver services happens at different times in different states, making it difficult to compare waiting lists across states.

- A state's waiting list management approach can influence the length of its waiting list. For example, a
  first-come, first-served approach—the most commonly used—can encourage individuals to seek
  enrollment in anticipation of future needs.
- Waiting list times vary among states and within some states by waiver. In states that we interviewed, estimates of wait times ranged from less than 1 year to 14 years.
- Stakeholders noted that 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 judge 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.
- State funding was cited as the most important factor in many states for increasing waiver capacity. In some states, explicit support from the governor or the state legislature has led to funding increases that helped reduce waiting lists.
- Many states are experiencing or anticipating a growing need for waiver services; some anticipate
  increasing difficulty meeting needs in the future.

This issue brief provides background on Medicaid coverage of HCBS through Section 1915(c) and Section 1115 waivers. It goes on to discuss HCBS waiver capacity, waiting list management practices, and wait times. Next, themes from stakeholder interviews are summarized on the experiences of individuals on waiting lists, strategies to reduce or eliminate waiting lists, and meeting the growing need for HCBS. Maintaining and augmenting federal and state rebalancing efforts is particularly relevant during the COVID-19 pandemic as it may increase demand for HCBS even further.

## **Medicaid Coverage of HCBS**

Medicaid coverage of HCBS was first authorized in 1981 through waivers made available under Section 1915(c) of the Act. Since that time, various state plan options have been added. States can also provide HCBS through demonstration waivers authorized under Section 1115 of the Act (see Appendix A).

#### **HCBS** waivers

Waiver authorities allow states to forego certain Medicaid requirements such as comparability, freedom of choice, and statewideness. While individuals must meet certain functional criteria to be eligible for HCBS waiver services, 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 waivers also allow waiting lists for HCBS.

**Section 1915(c) waivers.** Section 1915(c) waivers are the primary waiver authority used by states to cover HCBS; as of March 2020, there were 254 Section 1915(c) waivers operating in 47 states and the District of Columbia. States typically offer multiple Section 1915(c) waivers in order to target a specific population or multiple populations, such as individuals with intellectual or developmental disabilities (ID/DD) or people age 65 and older, or to provide a different set of services (Table 1).<sup>2</sup>

TABLE 1. Number of Section 1915(c) Waivers by Population Targeted, March 2020

Population targeted	Number of waivers
Age 65 and older	64
Autism	54
Brain injury	27
Developmental disability	86
Disabled (other)	27
Disabled (physical)	73
HIV/AIDS	8
Intellectual disability	91
Medically fragile	25
Mental illness	9
Serious emotional disturbance	9
Technology dependent	12

Source: MACPAC analysis of approved Section 1915(c) waivers, March 2020.

Many different services may be provided under Section 1915(c) waivers; these vary widely by state. Examples include personal care services, adult day services, supported employment, respite, occupational therapy, and transportation, although states often use different terms for similar services.

Some states also use a tiered waiver structure in which multiple waivers serve the same populations but offer varying types and intensities of services. This approach facilitates the ability of states to place individuals in the waiver most appropriate for their needs. For example, a state may have multiple waivers targeting individuals with ID/DD, but they may not all provide personal care services. States may also tier waivers using monetary caps, such that multiple waivers may provide the same or similar services, but individuals with lesser needs may be placed in a capped waiver (e.g., an individual may use up to \$30,000 of services per year) whereas other individuals with greater needs may be enrolled in a waiver without a cap. The package of waiver services also differs by population served (e.g., services available to individuals age 65 and older may be quite different than services for individuals with brain injury).

Under Section 1915(c) waivers, providers can be paid under fee-for-service arrangements. These waivers can also be combined with Section 1915(b) waivers to provide HCBS under managed care arrangements. Under managed long-term services and supports (MLTSS) programs, states contract with managed care organizations to provide LTSS in exchange for a capitated payment.

**Section 1115 waivers.** Section 1115 waivers are also used to cover HCBS. Fourteen states use Section 1115 waivers to provide HCBS, including three states—Arizona, Rhode Island, and Vermont—that use Section 1115 as their sole HCBS authority. Section 1115 waivers for HCBS are often used for MLTSS programs; of the 14 states using such waivers for HCBS, 12 use MLTSS (MACPAC 2020b). Many Section 1115 waivers provide services for individuals who are aged, blind, or disabled, but a few states also target

individuals with autism, traumatic brain injury, HIV/AIDS, or behavioral health needs.<sup>3</sup> Section 1115 waivers typically cover all or a broad range of a beneficiary's Medicaid benefits in addition to HCBS.

**Use of waiting lists under HCBS waivers.** States are allowed to set caps on the number of people served under a Section 1915(c) waiver, and may establish waiting lists when demand exceeds the waiver's approved capacity. Some Section 1115 waivers also allow waiting lists for HCBS. In fiscal year (FY) 2018, 41 of 51 states reported having an HCBS waiver waiting list for at least one population, with total waiting list enrollment of 819,886 and an average wait time of 39 months (KFF 2020a).

Eligibility screening for waiver services happens at different times in different states, making it difficult to measure unmet need and compare waiting lists across states. According to the Kaiser Family Foundation, 33 of 41 states with waiting lists screen individuals for waiver eligibility before placement on a waiting list (KFF 2020a). Some states use specific screening tools to determine waiver eligibility, taking into consideration factors such as financial eligibility and functional status (e.g., the need for assistance with activities of daily living). These tools may also be used to determine placement on waiting lists in states that prioritize waiting lists by need.

## State plan HCBS

Many states provide HCBS through several state plan authorities (Appendix A). For example, Section 1915(i) allows states to offer HCBS to people who need less than an institutional level of care (which is typically required to receive Medicaid-covered HCBS). Services offered under state plan HCBS are typically more limited in scope than those provided under waivers (e.g., fewer services or limitations in service hours). States may not create waiting lists for state plan services, as such services must be available to all Medicaid enrollees if they are deemed medically necessary. Thus, offering state plan HCBS puts states at greater financial risk than HCBS waivers.

## Early and periodic screening, diagnostic and treatment benefit

The early and periodic screening, diagnostic, and treatment (EPSDT) benefit is an entitlement for all children under age 21 enrolled in Medicaid through the categorically needy pathway. This group must receive any Medicaid-coverable benefit in any amount that is medically necessary, even if it is not in the state plan. EPSDT's purpose is to discover and treat childhood health conditions before they become serious or disabling. For children with HCBS needs such as those with ID/DD, the EPSDT benefit provides access to a broad array of services that includes personal care services and other HCBS.

## Waiver Capacity and Waiting List Management

To gain insight into how state management of waiver capacity can affect access to HCBS, MACPAC compiled information on how states manage waiting lists in Section 1915(c) and Section 1115 waivers.<sup>6</sup>

## **HCBS** waiver capacity

Section 1915(c) waivers are approved by the Centers for Medicare & Medicaid Services (CMS) for up to five years, and specify the maximum waiver capacity for each year of the waiver's operation. Once the waiver has been approved, a state must submit a waiver amendment to CMS to raise or lower a waiver's capacity.

States do not always serve the maximum capacity of their waivers, sometimes leaving slots open to accommodate individuals who meet the definition of a reserved capacity designation at any time without placing them on a waiting list. In states with a waiting list, this means that although a waiver may be otherwise full, an individual whose circumstances fall under a reserved capacity purpose can enroll in the waiver immediately. In our review we found that reserved capacity was most often used for individuals in institutions seeking to transition back to the community, such as through the Money Follows the Person program.<sup>8</sup>

## Waiting list management

CMS provides high-level guidance on waiting list management, but states retain a great deal of flexibility. Section 1915(c) waiver instructions say that if a waiting list is implemented states must have policies in place to govern how individuals are selected for the waiver when a slot becomes available, and that these policies should be objective and applied consistently across the waiver's service area (CMS 2019). These instructions give examples of appropriate and inappropriate policies and states can choose among the appropriate examples given or select alternative options; for example, entry to the waiver may be "offered to individuals based on the date of their application for the waiver", or "prioritized based on the imminent need for services that is determined through an assessment process" (CMS 2019).

Of the 254 approved Section 1915(c) waivers we reviewed as of March 2020, 199 document how waiting lists are managed. Of the 14 Section 1115 waivers we also reviewed as of March 2020, 11 document this. It is important to note, however, that some of these waivers may not have reached maximum capacity and thus may not have a waiting list. We do not have information on which specific waivers have operational waiting lists.

We characterized waiting list management practices into seven categories based on the criteria for waiver entry found in the waiver (Table 2). The method used most often for Section 1915(c) waivers is first come, first served, that is, an individual's placement on a waiting list is determined by how long they have been waiting, with the longest-tenured individual at the top of the list receiving the next available waiver slot (62 waivers). Priority, which is based on factors such as health status or a critical need due to the loss of a caregiver, was used in 46 waivers. For these waivers, assessment and screening tools are often used to determine an individual's need for services, taking into account factors such as level of care requirements, natural supports available to them, or risk of institutionalization. Another 21 waivers used a combination of priority and wait time, such as by assigning people to priority categories but ordering them by wait time within those categories.

**TABLE 2.** Waiting List Management

Waiting list management	Category definition	Number of 1915(c) waivers	Number of 1115 waivers
First come, first served	Individuals are offered waiver slots based on how long they have been on the waiting list and the order in which they have been waiting. Waivers may explicitly say they operate their waiting lists on a first-come, first-served basis, or they may mention the order is based on other criteria, such as chronological order or the date of request for services.	62	2
Priority	States may prioritize individuals based on age, diagnosis, or situational factors. States may base priority on needs assessments or criticality, such as loss of a primary caregiver. States may also use screening tools.	46	4
Priority and wait time	States combine use of priority categorizations and time spent waiting.	21	0
No waiting list	The state does not have a waiting list for that waiver. All who are eligible for services receive them.	59	2
No mention of waiting list	Waiver documents do not mention waiting lists and thus the existence of a waiting list for that waiver is unknown, as is how a state manages capacity and unmet need for services.	55	3
Unspecified	Waiver documents mention a waiting list exists but does not specify how it is managed.	4	2
Other	Waivers that do not fit into another category.	7	1

Notes: Category definitions created by MACPAC staff.

Source: MACPAC analysis of available Section 1915(c) and Section 1115 waivers, March 2020.

States often have specific reasons for policies governing waiting list management. In our interviews we gained insight into the factors that led states to select one approach over another, or to change their approach. For example, officials from one state said they began using a first-come, first-served approach due to a lawsuit, and considered it the fairest method of waiting list administration. Another state that moved from a priority-based waiting list to a first-come, first-served list said that it allowed them to equalize their county-level allocations of waiver slots.

In contrast, another state that switched from a first-come, first-served to a priority approach for one of its waivers indicated that they changed their approach due a fairly large waiting list, saying it made the most sense to serve those with the highest need first. They also noted that the tiered waiver structure in the state allows those with lesser needs to get on another waiver that provides a lower level of services.

#### Wait time

According to a state survey conducted by the Kaiser Family Foundation, in FY 2018, the average wait time across 30 states for HCBS waivers with waiting lists was 39 months (KFF 2020a). Wait time varied by target population. The survey did not report data at the state level, and this information is not reported to CMS. We probed on wait times in our interviews.

**Waiting list time varies by state and by waiver.** Some states we interviewed provided estimates of how long individuals remain on waiting lists, with the length of time ranging from 291 days for one state's waiver to 14 years in another state. For these states, wait times also differed among their various waivers, often by differences of more than five years.

**Management approach can influence waiting list length.** Stakeholders explained how first-come, first-served approaches can encourage waiting list enrollment in anticipation of future need. This would be particularly true in states that do not screen for eligibility prior to waiting list placement. For example, in some states, families add their children at a young age to waiting lists for services offered to individuals with ID/DD, anticipating the long wait time, assuming that by the time they reach the top of the waiting list, they will have developed the need for services.

## Experiences of individuals on waiting lists

It is not clear the extent to which waiting lists demonstrate unmet need for HCBS waiver services, given that not all of those on waiting lists may be determined eligible and because individuals may be able to access other services while they wait for an HCBS waiver slot. States indicated that they do not track how people may be getting their needs met as they wait for services (e.g., accessing other Medicaid state plan services or family caregivers). We sought to gain insight into these issues in our interviews.

It is difficult to measure unmet need and compare waiting lists across states. Several stakeholders noted that the true level of unmet need for HCBS is hard to measure because not all states screen for eligibility before placing people on waiting lists. As noted earlier, eight states do not screen for eligibility; individuals on waiting lists in these states account for 61 percent of the national total (KFF 2020a). While some individuals on waiting lists in these states may not qualify for waiver services, a few interviewees said that the likelihood that individuals with ID/DD would be eligible for waiver services if they were screened was high.

In some states, waiting lists may contain inaccurate or outdated data, further complicating comparisons. A few states that had significantly reduced waiting lists told us they did this by removing duplicate applications, as well as applications for those who had moved out of state, died, or no longer needed

services. Some states periodically reassess the needs of individuals on waiting lists, and sometimes find individuals who are eligible for state plan services that would meet their needs in lieu of waiver services.

Many individuals may be receiving some Medicaid services while waiting for waiver services. Because states may use multiple authorities to cover HCBS, it is difficult to judge how many people on waiting lists are actually going without any HCBS. For example, states can:

- tier waivers so that different waivers provide varying types and intensities of services, and beneficiaries can receive waiver services from one waiver and still be on the waiting list for a different waiver.
- use state plan services as a tool to serve more individuals with LTSS needs, particularly to provide services to people before they need an institutional level of care. Although state plan services typically provide a more limited benefits package than HCBS waivers, they provide some services to those who are eligible for HCBS waivers but remain on waiting lists.
- use the EPSDT benefit as a way to provide services to children on waiting lists.

Many individuals have natural supports, such as family caregivers, who provide care. When asked how individuals manage their needs while waiting for services, interviewees most frequently cited support provided by family caregivers. Many caregivers are unpaid, although some may be paid in waivers that allow for self-direction of services. One state said that they use state-only funding for a caregiver respite benefit. Given the key role of family caregivers for many people in need of HCBS, the loss of a caregiver can change a person's level of need for waiver services to urgent.

**Supports may be available from other sources.** School supports were another commonly cited resource for families with school-age children. Some of these services (e.g., speech or occupational therapy, counseling, and assistive technology) are similar to what might be received under an HCBS waiver. A few states told us they prioritize young adults leaving school for waiver services, so as not to have a lapse in services during that transition. Individuals with HCBS needs may also pay out of pocket for services, or may receive services through state funded programs or block grant services from other agencies or community organizations.

Several stakeholders said some individuals may enter institutions to receive LTSS while waiting for an HCBS waiver slot. Medicaid beneficiaries are entitled to receive nursing facility services, and all states cover intermediate care facilities for individuals with intellectual disabilities through their state plan. Many interviewees said it was possible that individuals enter institutions in order to receive LTSS while waiting for a slot in an HCBS waiver; however, nearly 94 percent of individuals on waiting lists live in the community (KFF 2020a).

Individuals and families may be confused by waiting lists or unaware of how long they will have to wait to receive services. One advocate emphasized that states should disseminate better information to individuals and families. In the absence of information from a trusted source (e.g., the state), the advocate said families may get inaccurate advice from others regarding when they should get on a waiting list. Another advocate said that there could be greater transparency around waiting lists, such as one's

position on the waiting lists. Officials from one state we interviewed said individuals can check their waiting list status online.

## Strategies to reduce or eliminate waiting lists

Stakeholders consistently cited state funding as the driver of HCBS waiver capacity and waiting list size. Funding increases have contributed to the reduction or elimination of waiting lists, but litigation and state administrative processes have also played a role.

**Funding and prioritization of HCBS largely influence waiting list size.** State funding was cited as the most important factor in many states for increasing waiver capacity, with the number of waiver slots dependent on the state funding that the Medicaid or other operating agency receives. In some states, explicit support from the governor or the state legislature has made an important difference in states' abilities to move people from waiting lists into waiver services. One advocacy organization also noted that it is important for states to know who is on their waiting list(s) and the unmet need in order for operating agencies to request adequate funding. Some states cited the assistance of advocacy organizations in securing increased funding for HCBS waiver programs.

**Litigation also plays a role in waiting lists.** In 1999, the Supreme Court ruled in *Olmstead v. L.C.*<sup>10</sup> that the unjustified institutionalization of individuals with disabilities violates the Americans with Disabilities Act of 1990 (ADA, P.L. 101-336). There have been a number of actions at the federal and state level and in the courts to enforce *Olmstead v. L.C.* and the ADA (MACPAC 2019). For example, one state we interviewed told us that they prioritized moving nursing home residents onto the waiver due to an Olmstead-related settlement agreement.

**Stakeholder views differed on whether state adoption of MLTSS affects waiting lists.** On the one hand, interviewees told us that Tennessee has been able to use MLTSS to serve everyone who is eligible. On the other hand, all states that have adopted MLTSS have not achieved this result. Representatives from one state association said that in general, MLTSS adoption alone is not likely to reduce waiting lists, but it may be part of a larger rebalancing strategy. One state we interviewed reported that in its initial transition to managed care it had been able to serve more people, but that it did not make a significant reduction in their waiting list. Similarly, a state planning to move to MLTSS did not anticipate it would affect the size of their waiting list. One advocate also agreed that managed care has not had an impact on waiting list size.

Some stakeholders spoke about the potential of making HCBS a mandatory benefit. Several interviewees said that making HCBS a mandatory Medicaid benefit would make the biggest difference in eliminating waiting lists. As a mandatory benefit, HCBS would be treated the same as institutional services and therefore available to everyone who is eligible. One state official said that given that HCBS are optional, they are always more vulnerable to budget cuts than nursing facility services. One advocate proposed that even if some waiver services remained optional, it would still be beneficial to make a subset of HCBS an entitlement.

## Meeting growing need for HCBS

Stakeholders told us that an increasing need for HCBS and limited provider capacity both influence waiting lists and the ability to meet HCBS demand.

Many states are experiencing or anticipating a growing need for waiver services. Both states and advocacy organizations have expressed concern over the impact an aging population will have on state capacity. In recent years, several states have added waiver capacity for people age 65 and older, which they are able to do given the relatively low cost of serving this population through HCBS in comparison to what would be spent in an institution.

At the same time, some states are experiencing increasing demand for HCBS waiver services for children. In one state, an increase of young families whose children were in need of, or anticipating need for, waiver services contributed to a growing waiting list; even as the state was moving many children off its waiting list, the number of people applying was outpacing their efforts.

**Increasing lifespan and service intensity also affect states' ability to meet the needs of individuals with ID/DD.** Several interviewees noted that people with ID/DD receive waiver services for many years and thus waiver slots do not open up as frequently as they do for older adults. As more individuals with ID/DD live longer and maintain community placements, this may result in longer wait times for waivers serving individuals with ID/DD. There are more waiting lists for individuals with ID/DD, and often more people on those waiting lists, than those for older adults or individuals with physical disabilities (KFF 2020a). Two states also noted that people are entering state HCBS systems with greater needs than those leaving the system.

**Provider capacity is another limiting factor.** Stakeholders suggested that even if waiting lists were eliminated or reduced, there may not be adequate capacity to meet the increased demand for HCBS. Several stakeholders noted that in some places, the workforce is already having trouble meeting existing demand, and states are considering how to handle growing needs, particularly since the inability to find a provider can impede an individual's ability to start receiving services. Differences in payment between institutional and HCBS settings may also be contributing toward a shortage of HCBS providers, as workers in institutional settings are often paid more than HCBS providers.

## **Conclusion**

Although they are often cited as an indicator of unmet need for Medicaid-covered HCBS, waiting lists are an imperfect proxy, as they are not comparable across states due to differences in the timing of eligibility screenings, the populations served, and the services provided. For example, particularly large waiting lists with long wait times sometimes reflect states' decisions to use a first-come, first-served approach, which encourages waiting list enrollment in anticipation of later need. The use of state plan options and tiered waivers also means that states may be trying to serve the greatest number of people possible, even though they may not meet all the needs of people with the most intense needs.

Our interviews suggested a growing need for HCBS due to factors such as the aging population and increased longevity among people with ID/DD. Thus, although waiting lists may not be a truly accurate measure of need, growth in waiting list enrollment may still signal that state capacity is lagging behind those trends. States that had waiting lists generally sought to reduce or eliminate them, but often said there were financial barriers at the state level. As the Commission continues to examine Medicaid's role in funding LTSS, it plans to consider future demand for HCBS and how federal and state efforts toward rebalancing can be sustained.

#### **Endnotes**

- <sup>1</sup> From January to March 2020, MACPAC conducted interviews with representatives from Indiana, Louisiana, New Mexico, North Carolina, Pennsylvania, Texas, West Virginia, ADvancing States, Justice in Aging, Kaiser Family Foundation, National Association of State Directors of Developmental Disabilities Services, The Arc, and the Centers for Medicare & Medicaid Services (CMS). We also interviewed researcher Dr. Sheryl Larson at the University of Minnesota. In two states, we spoke separately with the aging and developmental disabilities operating agencies.
- <sup>2</sup> We found the number of Section 1915(c) waivers per state ranged from 1 in Delaware, Hawaii, and New Jersey, to 10 in Colorado, Connecticut, Massachusetts, and Missouri.
- <sup>3</sup> Unlike Section 1915(c) waivers, there is no defined list of target groups to indicate which populations are served under Section 1115 waivers. This makes summarizing populations targeted by Section 1115 waivers challenging.
- <sup>4</sup> The states that do not screen for eligibility prior to placing individuals on waiting lists are Iowa, Illinois, North Dakota, Ohio, Oklahoma, Oregon, South Carolina and Texas (KFF 2020a).
- <sup>5</sup> Generally, a person must fall into a specific population group, referred to as categorical eligibility, and meet income thresholds in order to be eligible for Medicaid. Under the optional medically needy pathway, individuals who are categorically eligible but who have higher incomes can become eligible for Medicaid after incurring a certain amount in medical expenses. EPSDT is optional for children enrolled through the medically needy pathway.
- <sup>6</sup> Staff searched CMS's database of state waivers between September 2019 and March 2020 to identify current, approved Section 1915(c) and Section 1115 waivers. The U.S. territories were not included in this review. Pending, expired and terminated waivers also were not included. Additionally, only Section 1115 waivers that provide home- and community-based services were reviewed and included. All information contained in the compendium was taken verbatim from publicly available waivers, with the exception of the waiting list management categorizations. Staff categorized the approaches to waiting list management based on prior work and information gathered in our review (Cooper 2017).
- <sup>7</sup> Information on capacity by state and waiver can be found in the compendium. The waiver capacity specified may vary across operational years if the state chooses to phase-in enrollment over several years.
- <sup>8</sup> Money Follows the Person is a demonstration program focused on moving Medicaid beneficiaries living in institutions to a less restrictive community setting. It is a voluntary program that provides supportive services to beneficiaries who have resided in an institution for at least 90 days and want to return to the community.
- <sup>9</sup> State Medicaid agencies may designate another state agency to operate one or more HCBS waivers; typically, these include offices on aging, developmental disabilities agencies, and mental health authorities (MACPAC 2014).
- <sup>10</sup> Olmstead v. L.C., 119 S. Ct. 2176 (1999)

•••

#### References

Burwell, S.M. 2015. *Community First Choice: Final report to Congress as required by the Patient Protection and Affordable Care Act of 2010 (P.L. 111–148)*. Washington, DC: U.S. Department of Health and Human Services. https://www.medicaid.gov/sites/default/files/2019-12/cfc-final-report-to-congress.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.

Cooper, R.E. 2017. Waiting lists and Medicaid home and community-based services. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services. https://www.nasddds.org/resource-library/general-information-on-administering-state-programs/state-waiting-list-information/waiting-lists-and-medicaid-home-and-community-based-servicesmainly-focus-on/.

Kaiser Family Foundation (KFF). 2020a. *Key state policy choices about Medicaid home and community-based services*. Washington, DC: KFF. https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/.

Kaiser Family Foundation (KFF). 2020b. *Medicaid home and community-based services enrollment and spending*. Washington, DC: KFF. https://www.kff.org/medicaid/issue-brief/medicaid-home-and-community-based-services-enrollment-and-spending/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2020. *Compendium of Medicaid home- and community-based services waiver waiting list administration*. 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/wp-content/uploads/2019/07/Twenty-Years-Later-Implications-of-Olmstead-on-Medicaids-Role-in-LTSS.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2018. *Medicaid home and community-based services:*Characteristics and spending of high-cost users. Washington, DC: MACPAC. https://www.macpac.gov/publication/medicaid-home-and-community-based-services-characteristics-and-spending-of-high-cost-users/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2016. EPSDT in Medicaid. Washington, DC: MACPAC. https://www.macpac.gov/subtopic/epsdt-in-medicaid/.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2014. Chapter 2: Medicaid's role in providing assistance with long-term services and supports. In *Report to Congress on Medicaid and CHIP*. June 2014. Washington, DC: MACPAC. https://www.macpac.gov/publication/ch-2-medicaids-role-in-providing-assistance-with-long-term-services-and-supports/.

# APPENDIX A: Statutory Authorities Used for Medicaid Home- and Community-Based Services

Medicaid-covered home- and community-based services (HCBS) include personal care services delivered both in an individual's private residence and in residential care settings such as assisted living facilities, adult day services, supported employment services, home-delivered meals, and transportation. States cover HCBS through one or more statutory authorities (Table A-1).

Waiver authorities allow states to forego certain Medicaid requirements. State plan authorities generally provide less flexibility from Medicaid requirements, particularly as they do not allow states to use waiting lists.

TABLE A-1. Statutory Authorities Used for Medicaid Home- and Community-Based Services

Type of authority	Authority	Description
Waiver	Section 1915(c)	Allows states to forego 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 waiver authority is a broad authority that allows states to test new delivery models.
State plan	Section 1905(a)(24)	Allows states to cover personal care services under the state plan, but does not give beneficiaries using self-direction the authority to manage their own individual service budget.
	Section 1915(i)	Allows states to offer HCBS under the state plan 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 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 Patient Protection and Affordable Care Act (P.L. 111-148, as amended) provides states with a 6 percentage point increase in the federal medical assistance percentage for HCBS attendant services provided under the state plan.

Notes: HCBS is home- and community-based services. PAS is personal assistance services.

Sources: Sections 1115, 1905(a)(24), 1915(c), 1915(i), 1915(j), and 1915(k) of the Social Security Act.