



State Management of HCBS Waiver Waiting Lists

**Medicaid and CHIP Payment and Access
Commission**

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Introduction to MACPAC

- Non-partisan, independent legislative branch agency
- Provide analyses and advice to Congress, HHS, and the states on Medicaid and CHIP policy issues
 - Report annually on March 15 and June 15
 - Provide technical assistance to Congress
 - Serve as an information resource to the broader health policy community
- 17 commissioners appointed by GAO to three-year terms
 - Meet 6–8 times per year in public
 - Permanent staff of 30 based in DC
- Began work in 2010

Overview of Presentation

- Medicaid coverage of home- and community-based services (HCBS)
- HCBS waivers
- Waiting list management practices
- Experiences of individuals on waiting lists
- Strategies to reduce or eliminate waiting lists
- Growing need for HCBS
- Conclusions

Medicaid Coverage of HCBS

- HCBS is not a mandatory benefit, but all Medicaid programs currently provide some HCBS benefits
- States can cover HCBS through state plan options or through waiver authorities under Section 1915(c) and Section 1115 of the Social Security Act
 - State plan services are available to all enrollees
 - Section 1915(c) and Section 1115 waivers are permitted to have waiting lists

Use of Waiting Lists under HCBS Waivers

- According to a Kaiser Family Foundation survey, in fiscal year 2018:
 - 41 states had an HCBS waiver waiting list for at least one population
 - total waiting list enrollment was 819,886
 - average wait time was 39 months
 - 33 of 41 states with waiting lists screen individuals for waiver eligibility before placement on a waiting list

Why We Did This Work

- To gain a comprehensive view of the use of HCBS waivers and waiting list management practices in all 50 states and DC
- To understand concerns about HCBS access and the level of unmet need
- To understand factors affecting states' ability to reduce or eliminate waiting lists

Methodology

- Analyzed approved Section 1915(c) and Section 1115 waivers from all 50 states and DC and compiled select information into compendium
 - Summarized by populations served and waiting list management practices
- Conducted 16 stakeholder interviews with:
 - Federal officials
 - State officials
 - State associations of directors of aging, physical disability, and developmental disability services (including ADvancing States)
 - Beneficiary advocacy organizations
 - Other experts

HCBS Waivers

- As of March 2020, there were:
 - 254 Section 1915(c) waivers operating in 47 states and the District of Columbia
 - 14 Section 1115 waivers operating in 14 states
 - Arizona, Rhode Island, and Vermont use Section 1115 as their sole HCBS authority

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

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

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

Waiting List Management Practices

Waiting list management	Number of Section 1915(c) waivers	Number of Section 1115 waivers
First come, first served	62	2
Priority	46	4
Priority and wait time	21	0
No waiting list	59	2
No mention of waiting list	55	3
Unspecified	4	2
Other	7	1

Notes: First come, first served policies offer individuals waiver slots based on how long they have been waiting. Priority lists give precedence to individuals based on age, diagnosis, or situational factors. Priority and wait time is a combination of priority categorizations and time spent waiting. No waiting list means all who are eligible for services receive them. No mention of waiting list is for waivers that do not mention waiting lists and thus their existence or how a state manages waiver capacity is unknown. Unspecified is for waivers that mention a waiting list exists but does not specify how it is managed. Other is for waivers that do not fit into another category.

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

Experiences of Individuals on Waiting Lists

- It is difficult to measure unmet need and compare waiting lists across states
 - Not all states screen for eligibility before placing people on waiting lists
- Many individuals may be receiving some Medicaid services while waiting for waiver services, such as through:
 - Tiered waivers, in which different waivers in a state provide varying types and intensities of services for the same populations
 - State plan services, such as those provided under Sections 1905(a)(24), 1915(i), 1915(j), and 1915(k)
 - Early and periodic screening, diagnostic, and treatment benefit

Experiences of Individuals on Waiting Lists (continued)

- Many individuals have natural supports, such as family caregivers, who provide care
- Some individuals may enter institutions or have supports available from other sources such as schools
- Individuals and families may be confused by waiting lists or unaware of how long they will have to wait to receive services

Strategies to Reduce or Eliminate Waiting Lists

- State funding and prioritization of HCBS by the governor or state legislature were the most important determinants of waiting list size
- Stakeholder views differed on whether state adoption of managed long-term services and supports affects waiting lists
- Some stakeholders spoke about how making HCBS a mandatory benefit would make the biggest difference in eliminating waiting lists

Growing Need for HCBS

- Many states are experiencing or anticipating a growing need for waiver services
 - Increasing demand for HCBS waiver services for children in some states
 - Concerns about state capacity
- Increasing lifespan and service intensity affect states' ability to meet the needs of individuals with intellectual and developmental disabilities
- Provider capacity can be a limiting factor

Conclusions

- Waiting lists are an imperfect proxy for unmet need, as they are not comparable across states due to differences in the timing of eligibility screenings, the populations served, and the services provided
- Our interviews suggested a growing need for HCBS even though waiting list enrollment trends imply that states are unable to meet current need
- States that had waiting lists generally sought to reduce or eliminate them, but often said there were financial barriers
- The Commission plans to consider future demand for HCBS and how federal and state efforts toward rebalancing can be sustained and expanded

Resources

- August 2020 issue brief: *State Management of Home- and Community-Based Services Waiver Waiting Lists*.
<https://www.macpac.gov/publication/state-management-of-home-and-community-based-services-waiver-waiting-lists/>
- August 2020 compendium: *Compendium of Medicaid Home- and Community-Based Services Waiver Waiting List Administration*.
<https://www.macpac.gov/publication/compendium-of-medicaid-home-and-community-based-services-waiver-waiting-list-administration/>
- Additional resources:
 - <https://www.macpac.gov/topics/long-term-services-and-supports/>
 - <https://www.macpac.gov/subtopic/home-and-community-based-services/>



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