

Making HCBS Waitlists Count: Data Challenges and Opportunities Under the Access Rule

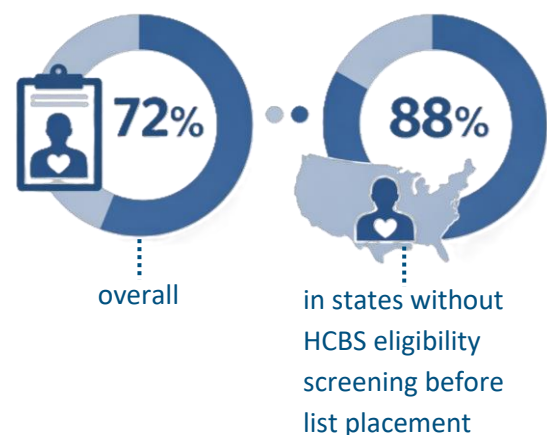
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What are HCBS waitlists? Why do they matter for people with intellectual and developmental disabilities?

Home- and community-based services (HCBS), such as personal care, employment supports, respite care, assistive technology, transportation, and supported living services can help people with intellectual and developmental disabilities (IDD) thrive in their communities. HCBS for people with IDD are largely delivered through section 1915(c) Medicaid waivers, which enable states to limit enrollment. As a result, many people with IDD who need services may have to wait to receive these services. Many states maintain a waitlist of people with IDD who are waiting to enroll in a waiver program. The list could be a formal waitlist when states have determined that an individual is eligible to receive HCBS under the waiver, or an interest list for people with IDD to indicate their need for HCBS and interest in enrolling when a waiver slot becomes available.

In 2024, it was estimated that more than **700,000**¹ people were on HCBS waitlists nationwide, the majority of them people with IDD, some of whom wait years to receive services. People with IDD comprise almost three-quarters (72%) of the total HCBS waiver waiting list population and an even larger share (88%) in states that do not screen for HCBS eligibility before waitlist placement. Delays in access to services limit opportunities for people with IDD to pursue their goals and participate fully in the community. When people with IDD are unable to access the services and supports needed, they experience poorer health and social outcomes, disparities in preventive care, and higher rates of emergency room visits and hospitalizations.²

People with IDD account for a large share of HCBS waiver waitlists.



Why is it important to collect accurate data about waitlists?

HCBS waitlists show the gap between how many people need services and how many the system can actually serve, making waitlists a useful measure of access. Accurate, cross-state, comparable data on who is waiting, what services they need, and how long they can expect to wait are important to track.

The data can help:

- self-advocates with IDD and their families better navigate and plan for the waiting period and potential gaps in services;
- states make decisions about HCBS waiver design, workforce planning, and identifying alternative community resources for people waiting for services;
- Centers for Medicare and Medicaid Services (CMS) compare HCBS access across states and design federal initiatives to improve transparency and reduce disparities in HCBS access; and
- researchers identify effective policies to reduce waitlists and improve HCBS for people with IDD.

However, current publicly available HCBS waitlist data are limited, difficult to interpret, and challenging to use for policy decision making or research.

What do publicly available HCBS waitlist data show?

There are two primary sources of publicly available HCBS waitlist data: KFF³ and the Residential Information Systems Project (RISP)⁴ datasets. Policy makers, advocates, and researchers use these data to examine HCBS waiver waitlists, understand the scope of waiting, measure access to HCBS, and examine changes in waitlists in response to state policy changes. KFF and RISP collect primarily information on the number of people waiting for HCBS. Neither source currently captures more granular details such as demographic characteristics, geographic areas, or service needs that could further inform policy decisions. Both aim to measure HCBS waitlists, but they reported notably different counts of individuals with IDD on waitlists in 2018, with KFF's estimate substantially higher than that from RISP.



589,940 individuals with
IDD on HCBS waitlists (KFF)



163,186 individuals with
IDD on HCBS waitlists (RISP)

Why are publicly available HCBS waitlist data insufficient for policy making, advocacy, and research?

HCBS waitlist data collected through KFF and RISP offer a starting point for understanding the scale of HCBS waitlists nationally. This is the current landscape of publicly available data, a foundation that policy makers, advocates, and researchers can build on. However, these data have important limitations for use in policy making, advocacy, and research.

Differences in data collection approaches can lead to vastly different waitlist counts.

In 2018, KFF reported substantially more individuals on HCBS waitlists than RISP. The difference reflects how variation in definitions and inclusion criteria can affect waitlist estimates. Both KFF and RISP aim to show how many people are waiting for services, but they collect information about waitlists in different ways:

- **Who the reporting entity is:** KFF collects waitlist information from state Medicaid agencies, whereas RISP collects waitlist information from state IDD agencies.
- **Whether people already receive services:** KFF may include people who are waiting for one service even if they already receive some HCBS waiver services. RISP counts only people with IDD who are not yet receiving any HCBS waiver services.
- **Who is counted:** KFF uses a broader definition that may include formal waiting lists, interest lists, and referral lists, regardless of whether applicants have been confirmed Medicaid-eligible. RISP uses a narrower definition focused on people with IDD living at home or with family who are waiting for Medicaid HCBS waiver services.

Waitlist data are not comparable across states because of differences in state waitlist policies.

States define and manage waitlists in a variety of ways. For example, Tennessee and Wisconsin evaluate eligibility for HCBS before placing people on waitlists. In Texas, Ohio, and New Mexico, individuals can join a waitlist simply by expressing interest, without prescreening for eligibility. Many states use a first-come first-served approach, which may encourage waitlist enrollment in anticipation of future needs rather than immediate service needs. States also vary in how they maintain their lists. Some regularly verify whether individuals still need or want services, whereas others rarely update their waitlists. These differences in state waitlist definitions and management policies can lead to significant under- or overestimation at the national level and make cross-state comparisons using waitlist data for policy making difficult.

Existing waitlist data are limited to waitlist counts, which limits understanding of HCBS needs.

Currently, publicly available waitlist data report only waitlist counts and minimal demographic information for people with IDD. Although some states may collect additional data about waitlists, these data are not reported publicly and cannot be used for advocacy, research, or federal policy making. To provide actionable information for research and policy making, data about demographic and social needs; HCBS service needs; and waiting time overall, by service, and across geographic areas within a state, are crucial. Lack of detailed information about waitlists renders these data inert for meaningful analysis and examining effective policies or state strategies to reduce waitlists and improve HCBS for people with IDD.

What does the Access Rule require states to report about HCBS waitlists? How can federal guidance improve waitlist data?

In May 2024, CMS finalized the [Ensuring Access to Medicaid Services rule](#) (Access Rule),⁵ which requires states to publicly report data on waitlists beginning in July 2027. Under the Access Rule, states must report annually the number of individuals on HCBS waiting lists, average wait times, and key waitlist management practices, including whether states screen for eligibility before waitlist placement and the frequency of rescreening. States must also report how long newly enrolled individuals waited before receiving services. The key goal of the Access Rule is to improve transparency about HCBS waitlists and reduce disparities in HCBS. The Access Rule, if accompanied by clear and actionable guidance, presents a tremendous opportunity to improve data collection about HCBS waitlists, which in turn can increase transparency, strengthen oversight, and support efforts to reduce disparities in access to HCBS.

However, the rule does not fully resolve long-standing differences in how states define, manage, and collect waitlist data. Without clearer standards, reported differences across states may reflect variations in reporting practices rather than meaningful differences in access to services. Therefore, the subregulatory guidance that CMS is expected to issue before the July 2027 reporting deadline presents a critical opportunity to establish consistent, actionable reporting standards. We have identified four areas that warrant particular attention as CMS develops this guidance:

OPPORTUNITIES TO IMPROVE WAITLIST DATA UNDER THE ACCESS RULE

Opportunity Area 1: Clarify who should be counted on HCBS waiting lists.

Guidance could improve data comparability by encouraging states to report waitlist counts separately for individuals who have been screened for HCBS eligibility and those who have not. In states that do not currently screen before list placement, CMS could use reporting to identify technical assistance needs and support phased improvements in waitlist maintenance practices.

Opportunity Area 2: Assess the feasibility of providing additional context on who is waiting.

Guidance could encourage states to assess the feasibility of reporting additional contextual information, such as demographics, geography, service needs, or waiver type, to better understand access gaps and disparities.

Opportunity Area 3: Improve the measurement of wait duration.

Guidance could standardize how wait duration is measured, including start and end points such as eligibility determination to waiver slot assignment. CMS guidance could encourage reporting of wait-time distributions (e.g., the proportion of individuals waiting less than 3 months, 3–12 months, 1–3 years, 3–5 years) to provide a clearer picture of waiting experience and improve cross-state comparability.

Opportunity Area 4: Connect waitlist reporting with broader access measures.

Guidance could help states interpret waitlist and service delivery measures together to provide a more complete picture of access to HCBS, from waiting for services to receiving authorized supports.

What is PATH-IDD doing to improve HCBS waitlist data?

The federal guidance opportunities outlined above are part of the broader work of the [Pathways from Waitlists to Person-Centered Supports for People with Intellectual and Developmental Disabilities \(PATH-IDD\) project](#) at the American Institutes for Research®. The project is working to improve transparency about HCBS waitlists as well as the HCBS waitlist data and outcomes of people with IDD by doing the following:



Analyzing **waitlist definitions, eligibility criteria, and waitlist management policies** across states to identify key gaps and opportunities for improving HCBS waitlist data collection.



Engaging with **state developmental disability agencies** to understand the strategies and challenges involved in collecting HCBS waitlist data.



Engaging with **individuals with IDD and their families** to better understand their needs and experiences while waiting for services.



Developing a **person-centered needs assessment tool** that states can use to better capture service needs during waiting, inform state waitlist policies, and improve HCBS for people with IDD.

¹ Waitlist estimates are based on the most recently available data and may vary across reporting sources.

² The Community Living Policy Center. (n.d.). *Care can't wait: How do inadequate home- and community-based services affect community living and health outcomes?* National Institute on Disability, Independent Living, and Rehabilitation Research. <https://heller.brandeis.edu/community-living-policy/images/pdfpublications/care-cant-wait.pdf>

³ Burns, A., Wolk, A., & O'Malley Watts, M. (2026, October 5). *Waiting lists for Medicaid home and community-based services programs*. KFF. <https://www.kff.org/medicaid/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2026/>

⁴ Larson, S. A., Neidorf, J., Begin, B. C., Pettingell, S., & Sowers, M. (2024). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2020*. University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. <https://ici.umn.edu/products/CFgCCl1FSn-AB52d1HrNaQ>

⁵ Centers for Medicare & Medicaid Services. (2024). *Medicaid program; Ensuring access to Medicaid services; Final rule*. Federal Register, 89(92), 40542–40839. <https://www.federalregister.gov/documents/2024/05/10/2024-08363/medicaid-program-ensuring-access-to-medicaid-services>