Supporting People with IDD While They Wait for Services

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State leaders and self-advocates share ideas for improving support while people wait for home and community-based services.

Why Support During the Wait Matters

People with intellectual and developmental disabilities (IDD) may wait months or even years for home and community-based services (HCBS). But life does not stop while people wait. They still have goals, relationships, health needs, and opportunities to learn, work, build independence, and participate in their communities. This raises an important question:

> **? Sometimes people have to wait for services. While they are waiting, how can we support them to live the life they want to live?**

The Pathways from Waitlists to Person-Centered Supports for People with Intellectual and Developmental Disabilities (PATH-IDD) project is exploring how Medicaid policies and practices can better support people with IDD while they wait for services. As part of this work, PATH-IDD brings together state leaders and self-advocates with disabilities to learn from both system and lived-experience perspectives.



Bringing Different Perspectives Together

In July 2026, PATH-IDD Advisory Board members came together for a World Café[1] discussion focused on this question. State leaders brought experience managing HCBS programs and waitlists, and self-advocates brought firsthand perspectives on what it means to wait for services and supports.



The World Café is a way to bring together a wide range of community members, such as professionals, civic leaders, families, and neighbors, to talk about important local issues and find solutions together.

Participants joined three moderated groups for a discussion, where they shared experiences, compared perspectives, and generated ideas for supporting people while they wait. The PATH-IDD team reviewed detailed notes from the discussions and identified common themes. This brief highlights **five themes** and the specific ideas state leaders and self-advocates shared for improving policies and practices.

1	**Clear, honest, and ongoing communication**
2	**Simpler steps and hands-on help**
3	**Life, growth, and independence**
4	**Flexible funding and a strong workforce**
5	**Current, easy-to-find resources**



Core Message: Waiting for services should not mean waiting for information, support, opportunity, or connection.

[1]Bumble, J. L., & Carter, E. W. (2021). Application of the World Café to disability issues: A systematic review. *Journal of Disability Policy Studies*, *32*(3), 193–203. https://doi.org/10.1177/1044207320949962

Findings

1. Waiting Without Answers

For many people with IDD and their families, the waitlist feels like a black box—they cannot see or understand how it works. They often do not know which waitlist they're on, whether they qualify for services, or what comes next. Some people end up on the wrong list. Others may not be notified when their status changes. Participants pointed out that states can't always say exactly when someone will get waiver services. When a person has an urgent need, they may be given the next open spot for services. But both state leaders and self-advocates agreed that even without a clear timeline, regular communication matters. States can still explain how the process works, communicate how long people usually wait for services, and be honest about what they can and can't predict.

State leaders and self-advocates shared ideas for improving communication and access to information.

The challenge	What state leaders and self-advocates suggested
People don't understand how the waitlist works. They often don't know which list they are on, who is eligible, or what happens next.	Give each person a plain-language workflow or outline showing which list they are on, the eligibility rules, what happens next, and which services they can use while they wait.
People rarely hear about changes to their status. Once on waitlists people rarely hear about changes in their status.	Send recurring written updates explaining whether the person's position has changed, how to report changed circumstances, and how to appeal or reapply if services are denied.
No one can say exactly when the person will get services. Urgent needs may affect which person receives the next available slot.	Explain honestly that urgent needs can change who receives the next opening and share what the state knows without promising a date it cannot guarantee.
People can't see the big picture. They don't have clear information about waitlist movement and trends.	Publish waitlist dashboards showing program growth and the number of people moving off the waitlist. Share useful trends, like the percentage of people expected to seek waiver services after age 22.
Families need someone who can answer practical questions. General information may not address each family's circumstances.	Assign a service coordinator or other knowledgeable contact to speak directly with the person and family, understand their circumstances, explain delays, and suggest support similar to what they are waiting for.
People need support while they wait. They may not know what they can do while waiting for services.	Connect people with targeted case management, peer navigators, and family networks that can help them find benefits and community supports while they wait. For example, some states' case managers help people explore Medicaid benefits, housing, and SNAP.

2. Too Many Steps, Too Little Help

Getting on a waitlist can mean filling out form after form, repeating the same information, and trying to understand unfamiliar rules. In some states, people join the waitlist before knowing if they qualify, creating uncertainty about whether they will eventually get services or whether they are on the right list. Gaps in services can also happen when a person changes providers. Both state and community participants agreed that joining a waitlist should not leave people on their own to find what they need. They need help identifying benefits, community resources, natural supports, and services that are available immediately.

Participants called for simpler steps and more hands-on help, both when people apply and while they wait.

The challenge	What state leaders and self-advocates suggested
People join a wait list without knowing whether they qualify. They may wait without knowing if they are on the right list.	Determine eligibility before placing someone on the waitlist. Then connect the person with targeted case management to identify immediate supports and keep plans current while the person waits.
People have to repeat the same information. Forms can be confusing, hard to complete, and often ask for information people have already provided on other state forms they've completed.	Shorten applications, use plain language, and delay questions that are not needed until later. Make forms electronic and usable on both iPhones and Android devices.
People can't track their status. They may not know where they stand in the process or what needs to happen next.	Create a secure portal where people can review their information, check their waitlist status, and submit required information.
Paperwork and benefits are hard to navigate alone. They may need help understanding their options and rights.	Have support coordinators, direct support providers, or provider agencies help people complete paperwork accurately and better understand how to reapply or appeal. Increase access to legal help for people whose cases require representation.
Information is spread across different systems. People need to receive coordinated information about available services and their progress in the application process.	With the person's permission, connect eligibility information to electronic health records so pediatricians and families receive age-specific prompts about wraparound services and updates about waitlist placement.
Changing providers can interrupt support. One provider may stop before the next is available.	Have the outgoing and incoming providers communicate before the handoff, including what the person needs immediately, so the person is not left without support between providers.

3. Waiting Should Not Put Life on Hold

Waiting should not put a person's life, growth, or independence on hold. Yet system rules and concerns about safety can limit those opportunities. Board participants felt that people with IDD and families may feel pressure to describe only the hardest parts of a person's life to show that they need support. That can leave out the person's strengths, goals, relationships, and what they can do with the right help.

State leaders and self-advocates called for approaches that start with the person, not the system. That means recognizing abilities, respecting choices, and helping people take reasonable risks with support when needed.

The challenge	What state leaders and self-advocates suggested
People have fewer chances to build autonomy and dignity of risk while waiting. Opportunities to try new activities, develop skills, or learn to live on their own may be put on hold.	Offer opportunities to try new activities, build skills, and practice independence while people wait—including supported opportunities to learn to live on their own and safely recover from mistakes.
The support a person already receives may not be fully recognized. Friends, family members, and others who know and care about the person may already be important parts of their support system.	Ask which friends, relatives, peers, and volunteers already know and support the person, and include those relationships in planning rather than treating paid services as the only source of support.
Assessments may focus on a person's challenges instead of considering the whole person. They can miss a person's goals, existing support system, and abilities.	Assess the person's goals, daily circumstances, existing relationships, and missing supports—not only the severity of the disability. Use tools such as Charting the LifeCourse to discuss life beyond services.
Technology may be out of reach without a waiver. People may miss tools that could help them now.	Give people opportunities to try assistive technology and remote supports before they receive a waiver. Tennessee's non-Medicaid Medicaid Alternative Pathways program was identified as one existing model.
System rules can limit person-centered practices. System requirements can take priority over a person's goals, abilities, choices, and right to take reasonable risks.	Use presumed competence and dignity of risk when discussing options with people and families. Help people take reasonable risks in a safe setting, with someone available to help if the experience does not go as planned.
People and families may feel pressured to describe only the hardest moments. They may think this is the only way to show a need for help.	Give people time to describe sensitive circumstances in a trusted relationship, including risks such as losing housing, without requiring families to portray the person only at their most challenging.

4. Funding and Workforce Challenges Limit Support

States may want to offer more help to people on waitlists, but limited funding, federal match requirements, caps on waiver slots, and workforce shortages limit what they can offer. State participants noted that even when funding is available, there may not be enough workers to provide support. High turnover among support coordinators adds another challenge. Families may lose a familiar contact, and new staff may need time to learn about available resources and changing rules. Payment arrangements can also leave gaps when people move from one provider to another.

State leaders and self-advocates suggested ways to offer more flexible help while strengthening the funding and workforce needed to sustain it.

The challenge	What state leaders and self-advocates suggested
People need help with everyday costs while waiting. They may need help covering transit, private-pay support, medical expenses, support staff, and other needs while they wait.	Create a flexible annual fund that people can use for needs such as transportation, private-pay support, medical expenses, or support staff. A Georgia participant described an existing fund providing roughly $4,000–$5,000 per year.
Federal match requirements can constrain the support states offer. Requirements for federal matching funds can make some options harder to fund.	Consider options that do not depend entirely on waiver funding: a disabled worker tax credit to offset staffing or other expenses, budget-neutral interim supports, and state-funded technology programs such as Tennessee's non-Medicaid model.
There aren't enough funded waiver slots. Limited budgets and caps restrict access.	Show legislators how requested funding affects the number of available waiver slots and how funding reductions can create or worsen slot caps.
There aren't enough workers to provide services. Expanding services alone won't solve staffing shortages.	Pair plans for new services with enough funding and staff to deliver them. Keep resource information current so new or less-experienced support coordinators can still connect people with available help.
People may need some help without a full waiver service package. Funding and service structures may constrain what states can offer while a person waits.	Use supports that do not require a full waiver package—for example, state-plan or Medicaid-funded targeted case management, peer navigation, natural supports, or a non-Medicaid technology program. Also examine the participant-proposed "C-11" stopgap for help before assessment.
Wait times may lack reasonable limits or benchmarks. It can be hard to set expectations or hold systems accountable.	Consider a maximum wait-time benchmark that states can use when setting priorities and reviewing whether people have waited too long.

5. Help May Exist, but People Can't Always Find It

Many services and community resources already exist, but people may not know about them or may receive outdated information. Resources and eligibility requirements change frequently, making it difficult for families and support coordinators to identify current options. People waiting for services may have additional urgent needs, such as homelessness, job loss, food insecurity, or health care challenges. Support should address the person's full range of needs, not only waiver services.

Participants encouraged states to look beyond waiver services and help people connect with support that fits their lives right now.

The challenge	What state leaders and self-advocates suggested
Information about resources can be hard to find or out of date. People may spend time pursuing options that are no longer available.	Maintain a simple, regularly updated one-stop guide with direct links to Medicaid dentists, free clinics, food banks, shelters, clothing programs, independent living centers, and advocacy organizations. Use family-informed, age-specific checklists like Kentucky's employment checklists, and consider AI-assisted matching and application help.
Different needs call for different responses. Waiting for a wheelchair or communication device is not the same as waiting for a day program.	Help each person distinguish and prioritize immediate needs—for example, a wheelchair or communication device may require a different response than a day program—and match each need with an available resource.
Outreach does not reach all families and communities. Some families and communities may miss information about available help.	Use Individualized Education Program (IEP) meetings and pediatric visits to reach families of young children with IDD, and work with provider agencies and community organizations to share information with underserved communities.
Young people leaving school may have an incomplete picture of their options. Information may focus on waiver services only and leave out other available supports.	Before students leave school, give them an age-specific, plain-language checklist covering available services, self-advocacy, assistive technology, employment, and other supports beyond the waiver system. Include direct links and a contact who can connect the family with resources.



Looking Ahead

Supporting people while they wait does not depend on a single solution. Participants identified practical steps states can take now. These ideas will help guide the next phase of PATH-IDD. The project team will use what we heard from state leaders and self-advocates, alongside findings from other project activities, to inform the development of practical resources and person-centered tools for people with IDD, families, and states. As this work moves forward, PATH-IDD will continue to engage Advisory Board members to ensure that project products reflect both lived experience and the realities of state systems.

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