



The Grassroots Project

Engage. Connect. Advocate.

Administered by Human Services Research Institute
with funding from the Administration for Community Living



Today's webinar:

What to Know About the New 1915(c)(11) Waiver Authority

September 9th, 2026

Webinar Logistics

- Participants will be muted during this webinar. Please use the chat feature in Zoom to ask questions and communicate with the hosts.
- Toward the end of the webinar, panelists will have an opportunity to respond to questions that have been entered into the question-and-answer portal.
- The webinar will be live captioned in English and live interpreted in Spanish.
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 - Once in the Spanish channel, please silence the original audio.
 - Se puede acceder a la interpretación en español, en vivo haciendo clic en el botón "interpretation" en la parte inferior de la pantalla de Zoom (icono del mundo). 
 - Una vez en el canal español, por favor silencie el audio original.
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



Feedback and Follow-Up

- Follow-up questions and feedback about the webinar can be addressed to grassroots@hsri.org. This email address is not monitored during the webinar.
- Grassroots Project webinars are not officially approved for Continuing Education Units (CEUs). However, we do provide a confirmation of attendance in case an organization wishes to use participation in our webinars to grant credit for internal requirements. Zoom will automatically send attendees a confirmation of attendance one day after the webinar.
- All registrants will receive a link to the webinar recording and other materials such as slides and resources shortly after the webinar.
- Additionally, Grassroots Project webinars and associated materials such as plain language summaries and transcripts are archived on the Grassroots Project website: [Grassroots Project webpage](#).

Who's Here?

In what ways do you identify with the disability community? Please select all that apply.

1. Person with a disability/disabled person
2. Person with a disability who uses long-term services and supports and/or a home and community-based services waiver(s)
3. Advocate
4. Family member/loved one of a person with a disability/disabled person
5. Person working in a disability organization or state agency
6. Caregiver or staff supporting a person with a disability

Grassroots Project

The ACL Grassroots Project:
Engage. Connect. Advocate.
launched in 2023-2024 with the
goal of supporting national,
state, and local disability
advocates to build networks and
grow advocacy leadership, with
the intention of driving disability
policy and supports to serve
disabled people and
communities robustly and
wholly.

Project Approaches

- Develop **structures, processes, and relationships** necessary to build the next generation of **cross-disability, cross-generational, and culturally diverse leaders** within the disability community.
-
- **Connect, grow, and strengthen networks of grassroots disability focused people and coalitions** supporting each other to engage in improving disability support systems at the local, state, and national level.



Key Partners

- National Advocacy and Action Coalition (NAAC)
- State and Local Advocacy and Action Coalitions (StAACs and LAACs)
- An advisory State Agency Partnership Group (SAPG)

Today's Webinar

H.R. 1 creates a new Medicaid 1915(c)(11) waiver authority that allows states to offer home and community-based services (HCBS) to people who need support but do not yet meet an institutional level of care.

This session will explain what the new authority does, how it differs from traditional 1915(c) waivers, and what guardrails states must consider, including needs-based eligibility, cost limits, and protections against increasing wait times for people already seeking HCBS.

Speakers will explain the requirements for this new waiver authority and discuss how disability advocates, state councils, providers, and community partners, can engage early in state planning, elevate community priorities, and push for implementation that is consistent with federal requirements and expands access without weakening existing HCBS systems.



A circular inset image showing a field of lavender plants with purple flowers and green stems, set against a soft, warm-toned background.

Today's Agenda

- **Welcome and logistics**
- **ACL Welcome**
- **Overview of**
1915(c)(11): Elizabeth Zirker, National Health Law Program (NHeLP)
- **Opportunities for people with Brain Injury:** Zaida Ricker, National Association of Head Injury Administrators (NASHIA)
- **Advocacy Lens:** Whit Downing, Kansas (KS) Developmental Disabilities Council
- **Q+A with the Audience**
- **Wrap up**



Jennifer Johnson,
Deputy Commissioner
of the Administration
on Disabilities



Dr. Jennifer Johnson is the **Deputy Commissioner of the Administration on Disabilities (AoD)**, part of the **U.S. Department of Health and Human Services' Administration for Community Living**.

AoD's mission is to equip individuals with disabilities of all ages with opportunities, tools, and supports to lead lives of their choice in their community. Its programs are working to create change and improve the lives of the estimated 61 million individuals with disabilities living in the US by advancing opportunities for inclusion and participation in the community, employment and financial well-being, and independence and self-determination.

Dr. Johnson has served as the Deputy Commissioner since September 2019, with a focus on improving the quality, accountability, and evidence base of AoD's programs and initiatives. She supports planning and oversight of AoD's \$355 million budget that funds a number of disability programs and projects across the US and its territories.

Her 30-year career in government, academia, national organizations, and school systems demonstrates a clear commitment to improving opportunities for people with disabilities to lead full lives in the community, with emphases on improving outcomes for people with disabilities.

Today's Presenters



Elizabeth Zirker

Senior Attorney

National Health Law Program



Zaida Ricker

Director of Strategic
Partnerships and Policy

National Association of State
Head Injury Administrators



Whit Downing

Vice President of Policy and
Programs

Kansas Council on
Developmental Disabilities

Overview of New 1915(c)(11) Waiver Option

Elizabeth Zirker, Senior Attorney, National Health Law Program



About the National Health Law Program

- National non-profit law firm committed to improving health care access, equity, and quality for underserved individuals and families State & Local Partners:
 - Disability rights advocates – 50 states + DC
 - Poverty & legal aid advocates – 50 states + DC
- National Partners
- Offices: CA, DC, NC

Contact us at:

www.healthlaw.org

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Overview of Traditional Home and Community-Based Services (HCBS) Waivers

- Home and Community Based Services (HCBS or 1915(c)) Waivers help people with disabilities live in the community.
- 1915(c) waivers are limited to people who are eligible for facility-based care but choose to live in the community.
- When you are eligible to live in a facility, this is called having an “institutional level of care”.

New 1915(c)(11) Option in H.R.1

- Creates new Waiver option for people who are not eligible for an institutional level of care.
- Available starting July 1, 2028.
- Allows people to get HCBS before they need facility-based care.

How is this the Same as a Traditional 1915(c) Waiver?

Because the 1915 (c)(11) is a type of 1915(c) waiver, many of the rules from traditional 1915(c) waivers still apply like:

- Person-centered service planning
- Same types of services
- Same rules for income and resources
- Same rules about settings
- Can be for people with certain types of disabilities
- Can be for only parts of a state

How is this the Same as a Traditional 1915(c) Waiver? (cont.)

- Have to have an annual eligibility check.
- Cost neutrality:
 - Average amount it costs per person cannot cost more than in a facility.
- States have to say the number of people who will be on the waiver.

What is Different about the 1915(c)(11) Waiver?

- Instead of using an institutional level of care, states will create “needs-based criteria”.
- The needs-based criteria must be based on what people can do, not on their age or on their type of disabilities.
- States can also consider risk factors as well as needs-based criteria.
- States cannot deny services to someone who has an institutional level of care.

What is Different about the 1915(c)(11) Waiver? (cont.)

- States get permission to run this program for three years at a time but can be renewed for 5 years after that.
- States cannot have a limit on needs-based criteria (they cannot say someone's needs are too high).
- States must make sure that people who are already on waiting lists for HCBS are do not have to wait longer because of a 1915(c)(11) waiver.

What are needs-based criteria?

Examples for children:

- Target group is children with disabilities.
- State defines needs-based criteria as needing help in at least two major life activities which include receptive and expressive language, self-care, learning, mobility, social skills, and health and safety.
- Could serve children with Autism Spectrum Disorder who need help with communication, behavioral support, and community integration.

What are needs-based criteria?

Examples for adults with I/DD:

- Target group is adults with an Intellectual or Developmental disability (I/DD).
- State defines needs-based criteria as needing help in at least two major life activities.
 - Major life activities include self-care, receptive and expressive language, learning, mobility, capacity for independent living, and economic self-sufficiency.
- Could serve adults with I/DD who:
 - Need help with meal preparation, medication management, and traveling in the community

Do all states have to use the same needs-based criteria?

- No
- Needs-based criteria are set by individual states, not CMS, so the waivers will be different depending on what a state chooses.

Who can get 1915(c)(11) waiver services?

- Examples:
 - Children with complex and varied support needs
 - Individuals with Intellectual or Developmental Disabilities (I/DD)
 - Individuals with mental health disabilities
 - Older adults with support needs below institutional level of care
 - Individuals with Traumatic Brain Injuries

Other things to know about the 1915(c)(11) Waiver

- States must give CMS data at least once a year:
 - Cost of service.
 - How long each person got the service?
 - How much the 1915(c)(11) waiver costs compared to a 1915(c) waiver?
 - How many people got 1915(c)(11) services in the year?

Funding from CMS

- 2026 \$50 million in funding for implementation.
- 2027 \$100 million to states for HCBS under section 1915(c) Waivers or section 1115 demonstrations.
- The \$100 million will be based on how many people in a state get HCBS through 1915(c) or 1115 Waivers.

How can I advocate with my state? (1 of 3)

- Ask your state to hold stakeholder meetings in developing the Waiver and include a broad range of people.
- Tell your state what you want to see for the target group and needs-based criteria.
- Ask your state to have ongoing stakeholder meetings to make sure the Waiver is working for the people who are getting the services.

How can I advocate with my state? (2 of 3)

- If your state proposes a 1915(c)(11) Waiver, you can comment on it.
- Public comment is a chance for people who want 1915(c)(11) Waiver services and others to tell the state what they need.
- Comments on HCBS waivers are simply people telling the state what does and does not work.
- They do not have to be formal letters.
- Comments from personal experience can be very helpful.

How can I advocate with my state? (3 of 3)

- A state does not have to make changes because of comments, but they are supposed to respond to comments in the waiver application they submit for approval.
- Even if the state does not make changes, comments may still affect the waiver or start conversations about waiver changes that should be made.

NHeLP Resources

- Improving Your HCBS Waiver Through Public Comment
- Commenting on Section 1915(c) HCBS Waivers: A Guide for Common Issues
- New 1915(c) Waiver Opportunity under OBBA

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Connect with National Health Law Program online:



www.healthlaw.org



@NHeLProgram



@nhelp.bsky.social

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9/15/2026



NATIONAL ASSOCIATION
OF STATE HEAD INJURY
ADMINISTRATORS

1915(c)(11)

**A New Option for
Community Support**

Support States.

Grow Leaders.

Connect Partners.

nashia.org

Vision: No matter where they live, people with brain injury can get the services and supports they need.



NASHIA

Mission: NASHIA helps state governments and their partners work together and build stronger supports for people with brain injury and their families.

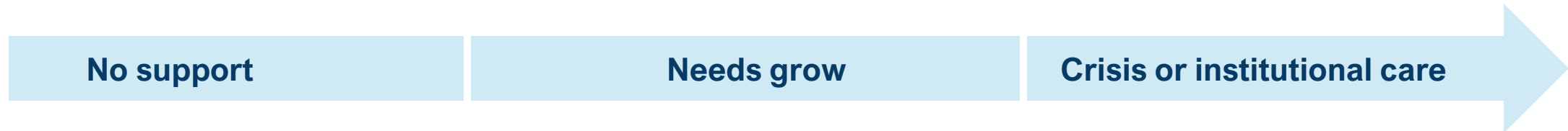
Support States.

Grow Leaders.

Connect Partners.

A new way to support people with disabilities

People should not have to qualify for institutional care before they can get meaningful support at home and in the community.

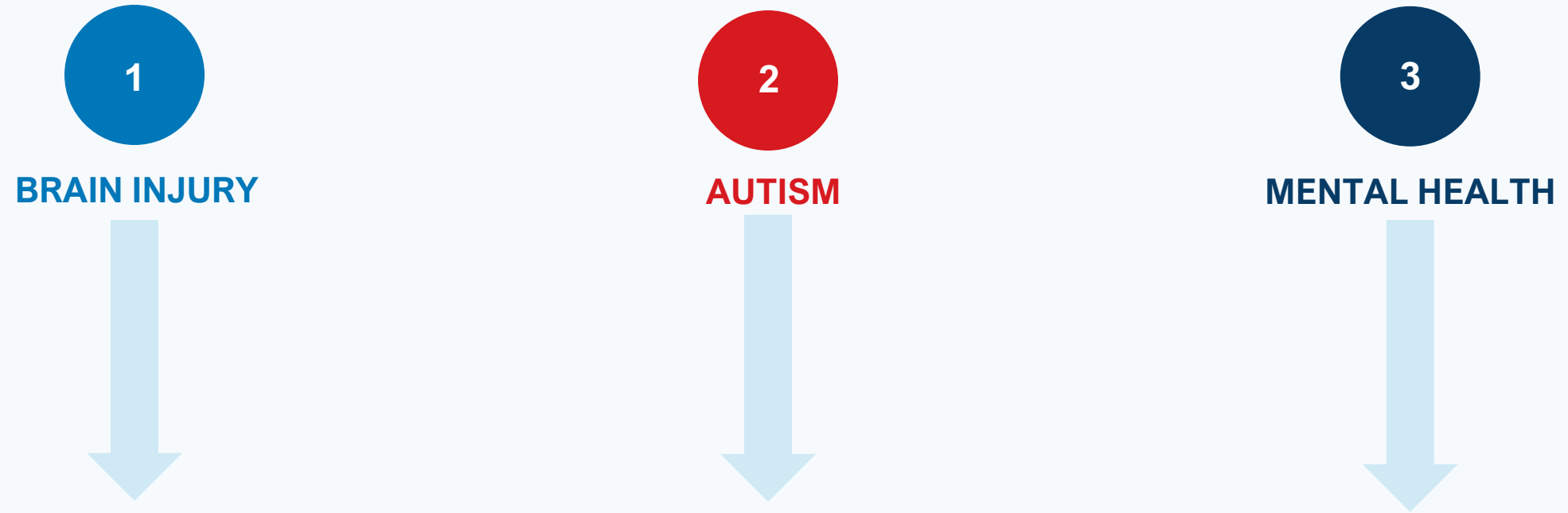


1915(c)(11) can open access

- Serve people with significant needs who do not qualify for institutional care
- Reach people left out of traditional HCBS programs
- Provide support before needs grow or a crisis occurs
- Design services around the needs of specific groups

Ask: What does this person need to live successfully in the community?

1915(c)(11) can help people get support earlier



THE SHARED GAP

People may need help with housing, work, relationships, appointments, or daily tasks even if they do not qualify for institutional care.

Brain injury support needs can be serious and easy to miss

A person may look independent but still face major challenges with thinking, emotions, and daily life.



How states could use 1915(c)(11)

Support people earlier to prevent or delay crises and more costly institutional care

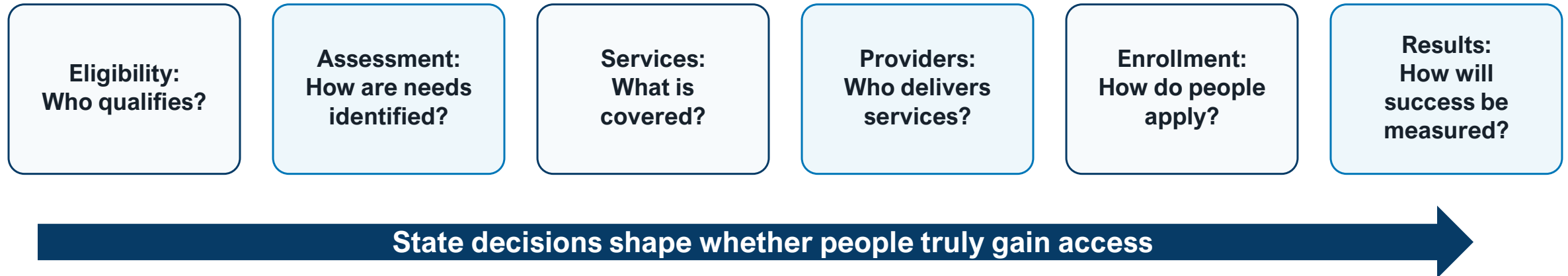
Reach people with complex needs who do not qualify for a traditional 1915(c) waiver

Support people with more than one condition, such as brain injury and mental health needs

Use screening to find people whose repeated brain injuries make independent living harder

States must make key decisions

The state decides how the waiver will work. These choices determine who can find, enter, and use it.



States can start by finding who is being left out

OKLAHOMA

**One state is
exploring how this
option could close
gaps for people with
brain injury**

Every state can ask these questions.

- Who is being left out now?
- Who needs HCBS but does not meet institutional level of care?
- What services could preserve independence?

Services to explore

Respite

Family
caregiving

Peer support

Employment

States must weigh real challenges as they consider this option.

- 1 States still don't have all the federal guidance they need
- 2 States are managing other Medicaid changes
- 3 States are managing other budget pressures
- 4 There aren't enough people and providers to support people right now
- 5 States are focusing on a lot of other things right now

Federal guidance is still developing.

States and advocates can begin planning together now.

States should engage communities before writing the waiver

States can use data and community knowledge to make better early decisions.

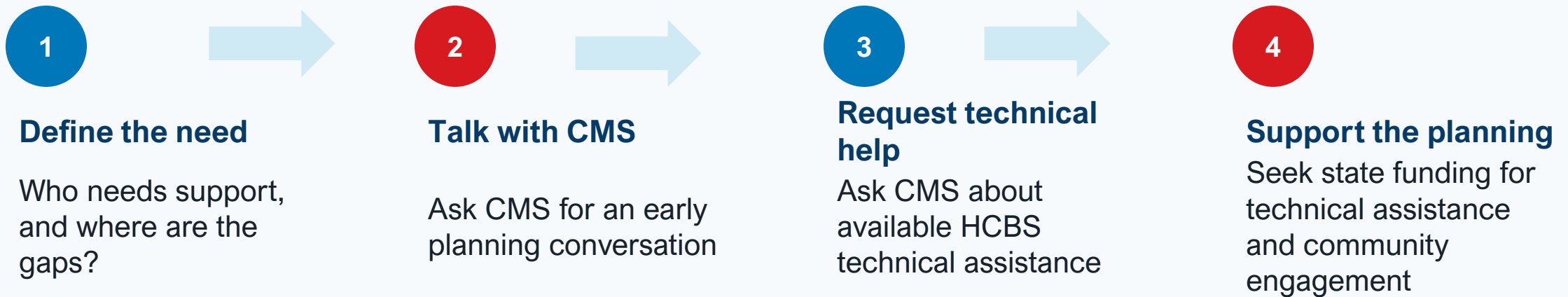
- 1 Identify** Use data to find gaps
- 2 Listen** Hear directly from people with disabilities, families, and caregivers
- 3 Map** Compare current services with unmet needs
- 4 Review** Different tools to identify needs
- 5 Define** Choose services that can support independence
- 6 Prepare** Ask providers how they can support people
- 7 Connect** Coordinate Medicaid with disability, aging, behavioral health, housing, and workforce systems

Key Brain Injury Partners



Technical assistance can help states move from idea to action

States do not have to plan this waiver alone.



Advocates Can Request:

Use state resources to get technical assistance and engage with the community to develop strong waivers.

Plan with advocates from the start

The Path to Strong State Systems of Care



Start with Advocacy

Advocacy is the essential first step required to generate good policy.



Develop Good Policy

Effective policy is the direct output of successful advocacy efforts.



Strong State Systems of Care

Good Policy serves as the foundation for building strong state-level care systems.

NotebookLM

People who will use the waiver should help design it



The toolkit can help states:

- Include the right people
- Make participation accessible
- Go beyond traditional meetings
- Gather useful input
- Explain how that input changed decisions

How advocates can support state planning

Disability advocates, state councils, providers, and community partners can help shape the waiver before key decisions are made.

- 1 Organize** Bring together people with disabilities, families, providers, and community groups
- 2 Document** Share stories and data that show who lacks support and why
- 3 Engage** Ask to join advisory groups, listening sessions, and waiver workgroups early
- 4 Propose** Offer clear priorities for the waivers
- 5 Connect** Help state agencies coordinate across Medicaid and other systems
- 6 Test** Review proposals for plain language, accessibility, and real-world barriers
- 7 Stay involved** Comment on the draft waiver and monitor implementation after approval

What advocates should ask states to protect

- 1 Add access** Use the new waiver to reach people who are not served today
- 2 Protect services** Do not cut, replace, or weaken existing HCBS waivers and services
- 3 Follow the rules** Meet federal HCBS requirements, including person centered planning
- 4 Center choice** Protect choice and services based on individual needs
- 5 Build capacity** Set realistic provider rates, training, and workforce plans
- 6 Track equity** Use data to find and address gaps
- 7 Be accountable** Publish goals, timelines, results, and responses to public input

Reach people earlier.
Support independence.
Plan with communities.



1915(c)(11) can reach people before their needs grow into a crisis. Early, meaningful partnership will help states expand access while protecting existing HCBS.

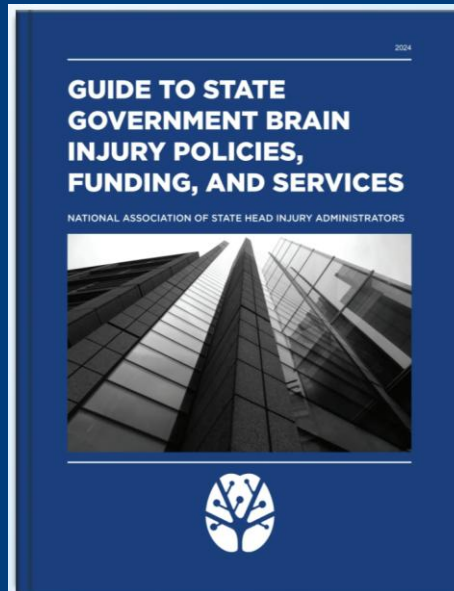


NATIONAL ASSOCIATION
OF STATE HEAD INJURY
ADMINISTRATORS

Building Systems of Care in Every State

NASHIA's State Program Directory lists state and territory brain injury programs, BIAA affiliates, Medicaid waivers, services, and brain injury advisory councils.

[NASHIA State Program Directory](#)



The background is a solid dark blue. In the top right and bottom left corners, there are light blue circular graphics containing a network diagram with nodes and connecting lines. Two solid red squares are positioned on the left and right sides of the slide, partially overlapping the blue background.

Thank you!

Zaida Ricker
zricker@nashia.org



KCDD
Kansas Council on
Developmental Disabilities



Whit Downing
Vice President of
Policy & Programs



My Passions

1.

**Mental Health
Advocacy**

2.

Writing

3.

Rubik's Cubes

4.

**Being a Proud Cat
Mom**



My 20's:



IDD Waiver Waitlist for
8 years...



Psychiatric hospitalized
over 15 times...



Risking
institutionalization...



KCDD
Kansas Council on
Developmental Disabilities

1. **Comprehensive Waiver**
2. **Community Supports Waiver**
3. **Non-IDD Waivers**



**We are advocating for
the elimination of the KS
IDD Waiver Waitlist.**

There are currently over 5,000 individuals
with IDD waiting for services on the IDD
waiver waitlist.



KCDD
Kansas Council on
Developmental Disabilities

**What advocacy currently
surrounds the 1915(c)(11)
waiver in KS?**



KCDD
Kansas Council on
Developmental Disabilities

**What gaps could the new
waiver authority
potentially fill in KS?**

Questions & Answers



Thank you

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Engagement Survey:**

[Open the engagement survey](#)

Contact Us:

Grassroots@HSRI.org

Stay tuned for ...

- The recording and PowerPoint for this webinar will be available for download at:

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