2025 DEVELOPMENTAL DISABILITIES LEGISLATIVE SYMPOSIUM

A National Call to Action for Intellectual and Developmental Disabilities Policy Reform

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SEATTLE, WASHINGTON, JUNE 11–13, 2025

FIRST BIPARTISAN NATIONAL GATHERING OF STATE LEGISLATORS

ORGANIZED BY THE ARC OF WASHINGTON STATE

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EXECUTIVE SUMMARY

The 2025 Developmental Disabilities Legislative Symposium, held in Seattle from June 11–13, 2025, was the first bipartisan national gathering of state legislators focused on addressing critical issues affecting individuals with intellectual and developmental disabilities (IDD) and their families. Organized by The Arc of Washington State, the symposium aimed to uncover and challenge barriers to belonging, inclusion, and well-being, while addressing policies that hinder full community participation and create challenges within existing care systems. This report summarizes the discussions, key takeaways, and commitments made during the event, emphasizing the need for collaborative action and policy reforms at both state and national levels.

KEY TAKEAWAYS

> **"It was a privilege to gather with so many dedicated community members and legislators to discuss issues and strategies to strengthen a responsive, community-based, person-centered system of care"**
>
> ***– Representative Darya Farivar***

- **Addressing Systemic Barriers**: Participants identified significant systemic barriers impacting individuals with IDD, including inadequate support for direct support professionals, complex service navigation systems, and insufficient access to behavioral and mental health services. These barriers often result in individuals with IDD facing unnecessary hardships, such as limited care options. Simplifying processes, increasing workforce development and compensation, and improving service accessibility are essential steps toward creating a more equitable system.
- **Collaboration Across States**: The symposium highlighted the critical need for cross-state collaboration to address shared challenges in supporting people with IDD. Legislators committed to sharing evidence-based strategies and working together on policy reforms that strengthen community-based

services and support systems. The goal is to establish a national network of legislators dedicated to advancing the rights and opportunities of people with IDD.

- **Cultural and Community Inclusion**: There is a pressing need for more inclusive decision-making processes that prioritize the voices and leadership of marginalized communities, particularly people of color with IDD and their families. Supporting BIPOC-led organizations and ensuring culturally responsive, linguistically appropriate services are fundamental to addressing systemic inequities within IDD systems.
- **Person-Centered and Flexible Planning**: Effective care and support for individuals with IDD must be rooted in person-centered planning, which prioritizes each person's preferences, goals, and auto-determination rather than fitting individuals into existing service models. Services must be flexible, responsive, and designed to promote autonomy, choice, and community inclusion.
- **Housing and Independence**: Affordable, accessible housing remains a major barrier to independence for people with IDD. The symposium called for expanding pathways to independent and supported living, overcoming zoning restrictions, and investing in innovative housing models that promote choice and community integration.
- **Funding Flexibility**: Symposium participants emphasized the need for more flexible funding models that "follow the person," ensuring individuals can access services that align with their chosen living arrangements and personal goals, whether in their own homes, with family, or in community settings of their choice.
- **Collaboration and Coalition Building**: Stronger collaboration across sectors, including agencies, service providers, advocacy organizations, and disability rights groups was identified as essential to address service gaps and system fragmentation. Effective coalitions ensure that the voices of self-advocates, families, and other stakeholders drive policy development and implementation.

Call to Action for National Engagement

The momentum generated at the symposium sets the stage for sustained national collaboration and policy advancement. Legislators are encouraged to leverage national organizations like the National Conference of State Legislatures, the Council of State Governments, and other national organizations as platforms to share evidence-based strategies, forge strategic partnerships, and champion comprehensive policy reforms that advance the rights of people with IDD. Legislators also discussed the importance of centering IDD expertise within these national organizations' work by engaging IDD leadership, policy experts, community organizations, and self-advocates as key partners in legislative education, decision-making, and policy development. This collaborative approach will ensure that the diverse perspectives and experiences of individuals with IDD and their families are at the center of national policy discussions. By working together, legislators can ensure that IDD issues remain a top priority, leading to lasting improvements in services, policies, and outcomes for this community.

THE IMPERATIVE FOR ACTION

Overview of Chronic Systemic Challenges

Individuals with IDD face persistent and widespread systemic challenges that impact nearly every aspect of their lives. These challenges vary across regions and states, but some of the primary barriers include:

- **Fragmented Service Systems and Educational Barriers**: Many individuals with IDD encounter significant obstacles in accessing quality education, healthcare, and community-based services due to siloed systems, restrictive eligibility criteria, and chronic underfunding. Geographic disparities can exacerbate these challenges, with rural and under-resourced communities facing particularly severe service gaps and limited provider networks. As one participant noted, "There are huge gaps in services across counties—especially rural ones." Participants flagged geographic disparities in access to essential community-based services such as employment, transportation, and specialized providers. In rural counties, gaps in service delivery and a lack of flexible funding options contribute to long-term instability and crisis cycles for individuals with IDD.
- **Workforce Shortages**: The caregiving workforce is often underpaid and overworked, leading to high turnover rates and a lack of consistent, quality care for individuals with IDD. These workforce challenges are felt differently across regions, with rural areas experiencing more severe shortages and higher levels of turnover.
- **Barriers to Community-Based Care**: Individuals with complex support needs face substantial obstacles accessing appropriate community-based services, particularly specialized behavioral health, assistive technology, and medical supports. Families navigate labyrinthine bureaucratic processes, encounter extensive waitlists, and are sometimes forced to resort to inappropriate institutional placements due to community service gaps. The availability and quality of care can differ widely across states and communities.
- **Systemic Inequities**: These systemic failures contribute to a cycle of marginalization, where individuals with IDD and their families are left without the necessary resources to thrive. Regional

variations in housing accessibility, integrated employment programs, and inclusive community support further entrench inequities, particularly impacting communities of color and rural populations.

These are just some of the chronic systemic challenges that individuals with IDD face, and the nuances of these issues can differ depending on the specific region or state. The variations in access to services, resources, and care highlight the importance of addressing these barriers through a coordinated, nationwide effort.

The Imperative for Cross-State Collaboration

Addressing these challenges requires a coordinated effort across state lines. The symposium underscored that isolated state-level efforts cannot adequately address the scale and complexity of systemic barriers facing the IDD community. Critical challenges faced by individuals with IDD are common across states, from workforce shortages to the lack of culturally competent community-based services. Cross-state collaboration creates powerful opportunities for legislators to exchange evidence-based practices, replicate successful policy innovations, and develop coordinated advocacy strategies for federal-level reform. By fostering this collaboration, states can create a unified voice in advocating for change, strengthening the impact of their efforts, and ensuring that solutions are informed by a broad range of experiences and expertise.

Challenge of the Moment: Urgency and Opportunity

The IDD community faces a critical moment where longstanding systemic challenges converge with immediate threats to essential federal programs and protections. The ongoing national conversation about healthcare, , and state responsibilities provides a unique moment for legislators to push for systemic change that could have a lasting, positive impact on the IDD community. The symposium underscored the need for immediate action, especially in light of the gaps in community-based services and the increasing demand for better care options. At the same time, the collective commitment from legislators to bring about change offers a rare opportunity to break through the barriers that have historically hindered progress. Now is the time to transform the way we care for individuals with IDD and create a more inclusive and supportive system.

CONVENING FOR CHANGE: THE 2025 SYMPOSIUM

Participating States and Legislators

The Symposium was designed with careful thought and intentionality to bring together a diverse group of legislators, community leaders, and advocates to address the most pressing issues facing individuals with IDD. Representative Jamila Taylor was instrumental in organizing the event, ensuring a collaborative and impactful gathering.

Legislators were invited by Representative Taylor, with out-of-state participants selected for their work in disability-related legislation and in-state legislators from the DD Legislative Advocacy Caucus or beyond. Community members were chosen based on their expertise in areas like education, housing, community-based services, and self-advocacy, ensuring balanced interactions with legislators. The process involved two Community Advisory Meetings to help identify community stakeholders and shape the Day 3 agenda, fostering collaboration and strategic solutions for individuals with IDD.

The symposium saw participation from approximately 40 legislators from both state and federal levels, including members of both the House and Senate. The group included Democrats and Republicans from 14 states across the U.S. While Republican representation was more limited, this marked the first bipartisan national gathering focused specifically on IDD policy, establishing important precedent for cross-party collaboration on disability issues.

States Represented by Legislators

Alaska (1)	Georgia (1)	North Carolina (1)
Arizona (1)	Idaho (1)	Utah (1)
Arkansas (1)	Iowa (1)	Washington (25)
Colorado (1)	Kansas (2)	West Virginia (2)
Florida (1)	Nevada (1)	

In addition to legislators, over 70 community members participated, including self-advocates, parent advocates, and representatives from policy advocacy organizations, community groups, and community-based services. These community members played a critical role in shaping the discussions, ensuring that the “nothing for us without us” principle was central to the symposium. On the third day, they joined Washington State legislators in collaborative conversations that translated national learnings into state-specific priorities and actionable solutions grounded in lived experience.

SHARED CHALLENGES AND ASPIRATIONS

Over the course of the three days of the symposium, participants heard from leading experts, community members, families, and self-advocates on the challenges and opportunities facing individuals with IDD. These experts and advocates shared valuable insights and experiences, highlighting systemic issues and promising solutions. At the end of each day, facilitated sessions provided participants with the opportunity to reflect on the information shared, discuss learnings, and identify next steps for moving forward. These sessions helped participants distill the key themes and insights from the symposium and focus on actionable ideas.

Common Barriers Raised

Several systemic barriers were identified throughout the symposium, with experts and community advocates highlighting the following key challenges:

- **Workforce Shortages**: One of the primary concerns discussed was the shortage of direct care workers, which is exacerbated by low wages, insufficient training, and high turnover rates. These workforce issues significantly impact the quality and consistency of care provided to individuals with IDD. Participants highlighted the fragility of the direct service provider (DSP) workforce, with one noting, "50% turnover among careworkers." This high turnover is compounded by the reliance on family caregivers, especially aging ones, who are providing the majority of support without adequate systems for transition or relief. These workforce issues significantly impact the quality and consistency of care provided to individuals with IDD.

- **Navigating the System**: Participants expressed frustration with the complexity of the service systems. Families and individuals with IDD often struggle to understand how to access providers of community-based services, which leads to delays and confusion. There was a strong call for simplified processes and better information to help families navigate the system more easily.

> **"With our national debate about the role of Medicaid and state responsibilities coming to heightened levels, Washington state's DD Advocacy Caucus is leading the national conversation about how we can collectively call out systemically ableist, arbitrary, and oppressive policies that keep people with IDD and their families from thriving. I am proud of the work we've done and am ready to move this cohort and our country forward from talk into action."**
>
> ***- Representative Jamila Taylor***

- **Access to Appropriate Care**: Accessing care, especially for individuals with complex needs, was another major barrier. Many families find it difficult to locate providers who can meet the specialized needs of individuals with IDD. Participants also pointed out that housing is deeply intertwined with access to support services. As one participant noted, “Housing is inextricably linked to support services.” When community-based services and supports are fragmented or constrained by funding structures, the availability of appropriate housing becomes unstable or inadequate for the individual's needs. This reinforces the importance of integrated solutions that provide both housing and community-based services in a cohesive, person-centered manner.

Common Policy Barriers

In addition to systemic challenges, several policy barriers were highlighted as significant obstacles to progress. These barriers include:

- **Fragmented Funding Models**: Participants discussed how funding structures for IDD services often create silos and make it difficult to provide comprehensive care. The lack of coordinated funding across agencies results in fragmented services, with families needing to navigate multiple programs that don’t always communicate with each other.
- **Complex Eligibility Requirements & Digital Inequity**: There was widespread frustration over the complexity of eligibility criteria for services such as the Department of Developmental Disabilities (DDA) enrollment. Participants expressed that the current system is burdensome for families and creates unnecessary barriers to accessing essential community-based services. As one participant noted, “There are so many steps to even figure out what you’re eligible for.” Additionally, structural barriers like racism, ableism, and underfunding were identified as root causes of ongoing digital inequity. Families are forced to navigate outdated websites, complex login systems, and red tape just to access basic services.
- **Lack of Cross-Agency Collaboration**: A lack of coordination between different state agencies, such as DDA, Medicaid, and mental and behavioral health services, was identified as a significant policy barrier. This lack of coordination leads to gaps in care and duplication of efforts. Participants called for

stronger cross-agency collaboration and for policies that ensure services are aligned to better support individuals with IDD.

Emerging Aspirations

Despite these barriers, several aspirations emerged during the symposium discussions. These aspirations were centered around ensuring that policies and practices promote inclusivity, collaboration, and meaningful involvement of those directly impacted by the system, with a core focus on the guiding principle of "Nothing for Us Without Us":

- **Human-Centered Approach**: The central theme throughout the symposium was the importance of centering the humanity of individuals with IDD. Participants stressed the need for policies and community-based services that prioritize the dignity, autonomy, and voices of individuals with IDD. This aligns with the foundational belief that no decisions should be made about individuals with IDD without including them directly in the process.

> **"In order to ensure that we are building solutions that center the humanity of people with IDD, we must first start by sharing our stories and creating space for authentic connection and dialogue. I look forward to working alongside our legislative champions to address the community's top priority issues in 2026 and beyond."**
>
> ***– Stacy Dym, Executive Director of The Arc Of Washington State***

- **Building Meaningful Partnerships**: There was a shared desire to build strong, meaningful partnerships across sectors; between legislators, service providers, self-advocates, and families. Participants expressed the importance of collaboration and coalition-building to create sustainable change. These partnerships are seen as essential for fostering inclusive, community-based solutions that prioritize the needs of individuals with IDD and their families. There was also a strong call to move beyond scarcity-driven decision-making by building trust and uniting across disabilities. As one participant stated, “Create a united front—we need to have the hard conversations.” This highlights that meaningful partnerships are not just about collaboration but also about having the hard conversations and working together toward a common goal to create lasting, systemic change.
- **Inclusion of Marginalized Communities**: A key theme was the inclusion of marginalized and BIPOC communities in the decision-making process. Historically, many communities of color have been excluded from critical conversations, and participants advocated for supporting BIPOC-led organizations to ensure that these voices are represented and heard in shaping IDD policy. As one participant stated, “We need to support BIPOC-led orgs. Once these organizations are at the table, we can learn from them & support their direction/vision.” This sentiment underscores the importance of creating space for BIPOC-led organizations to lead and contribute to policy development, ensuring that solutions are truly inclusive and reflective of diverse perspectives.
- **Prioritizing Community-Based Care**: Many participants voiced the need to shift towards community-based care, ensuring that individuals with IDD have opportunities to live independently and thrive within their communities. This shift would involve prioritizing flexibility and choice, allowing people with IDD to decide where and how they want to live. However, participants emphasized that many individuals are currently stuck in inappropriate or overly restrictive settings, such as hospitals, due to a lack of community-based care options. As one participant noted, “Siloed funding and geography

make it hard to find care that matches people's preferences." This highlights the need for integrated provider networks and flexible, person-centered care that can meet the diverse needs of individuals with IDD.

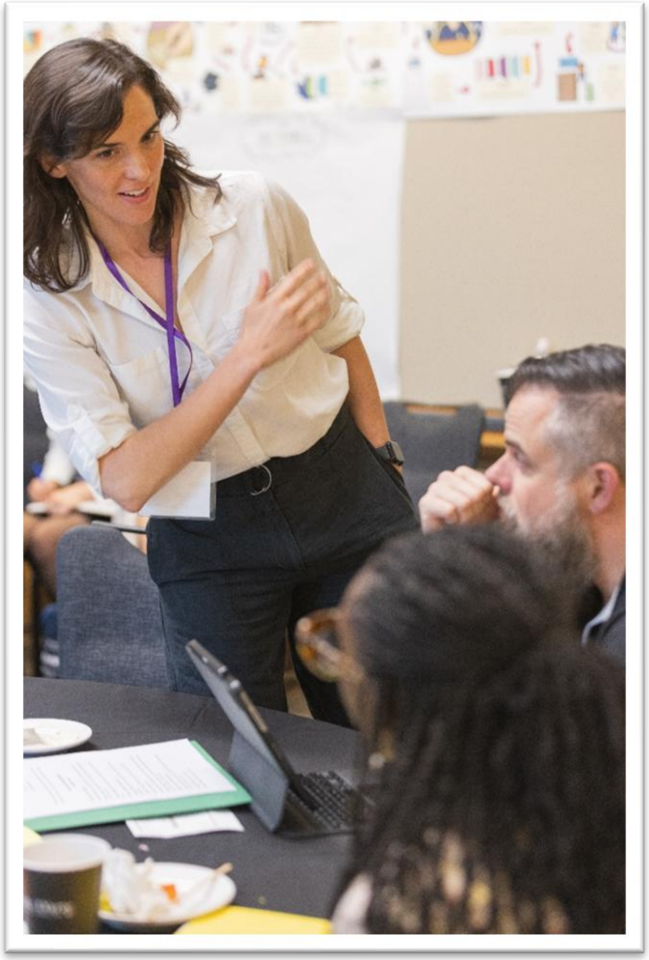
- **Systemic Reform for Person-Centered Services**: Participants emphasized the need for systemic reform to create flexible, person-centered services that meet the diverse needs of individuals with IDD. This includes restructuring funding models to allow resources to follow the person and ensuring cross-agency collaboration to provide holistic, integrated support. As one participant stated, "Money should follow the person—not the program, not the house, not the location." There was strong support for transitioning away from rigid, siloed systems toward a more flexible, menu-based approach. This would empower families to choose community-based services based on evolving needs, rather than forcing individuals to conform to fixed categories, ensuring that community-based services can better accommodate individual preferences and circumstances.

The facilitated sessions at the end of each day provided a valuable space for participants to reflect on these challenges and aspirations, identify next steps, and create actionable plans for moving forward. These sessions helped participants to deepen their understanding of the issues and focus on solutions that center humanity, foster partnerships, and ensure that individuals with IDD are empowered to live fully included and independent lives.

NATIONAL-LEVEL OPPORTUNITIES

During Day 2 of the symposium, legislators discussed key opportunities for improving the way states collaborate and learn from each other. The facilitated discussions highlighted the importance of peer support and how a cohort of legislators and stakeholders could provide a foundation for cross-state collaboration and ongoing learning.

Core Needs and Opportunities



- **Peer Support and Cross-State Collaboration**: A primary opportunity identified was the creation of a cross-state cohort and network that could provide ongoing peer support for legislators and stakeholders facing similar challenges related to IDD. This network would function as a space for shared learning, where participants can exchange ideas, offer feedback, and support each other in addressing common barriers. The cohort would be critical in ensuring sustained engagement and continuous improvement across states.
- **Ongoing Dialogue and Learning**: Participants expressed the need for regular opportunities to connect, enabling states to learn from one another in real-time. This could include regular meetings or forums where states can share best practices, resources, and policy solutions. The goal would be to create a community of practice that helps states tackle shared challenges and improve their systems by leveraging the collective knowledge and experiences of the cohort.

- **Role of the Cohort in National Advocacy**: The cohort could play a vital role in national-level advocacy, coordinating efforts to address systemic issues such as service access, workforce development, and cross-agency collaboration. By coming together, the cohort could amplify its voice and advocate for policy reforms that benefit the entire IDD community. This could include presenting at national conferences like those organized by the National Conference of State Legislatures (NCSL). Participants emphasized the need to reimagine the system, with one stating, "Unstack the bricks (without harm) to rebuild the system." This highlights the importance of intentional restructuring that prioritizes the needs of the IDD community while avoiding the creation of new barriers.
- **Shared Resources for Continued Support**: A key opportunity for the cohort would be to provide shared resources that support ongoing dialogue and problem-solving. These could include contact lists, case studies, toolkits, and access to experts. By having these resources readily available, states can connect easily and access the knowledge needed to tackle specific challenges without having to reinvent the wheel each time.
- **Inclusive Policy Design**: Another crucial aspiration was the importance of designing policies and solutions with individuals with lived experience. The cohort could advocate for self-advocates to be involved in the policy-making process, ensuring that decisions reflect the real needs of individuals with IDD. Inclusive decision-making would be a core principle of the cohort, ensuring that individuals with IDD are not just consulted but are central to shaping the systems that impact their lives.

These national-level opportunities highlight the importance of peer support, collaboration, and mutual learning among states. By establishing a cohort and fostering cross-state dialogue, states can more effectively address the systemic challenges faced by individuals with IDD and create lasting, meaningful change.

LEGISLATOR COMMITMENTS

Throughout the symposium, there was clear enthusiasm among legislators to continue collaborating on pressing issues facing individuals with IDD. The discussions sparked a strong commitment to ongoing engagement, recognizing that the challenges require collective action and sustained attention.

- **Commitment to Continued Collaboration**: Legislators committed to connecting over Zoom within the next few months to ensure the momentum from the symposium continues. These virtual meetings will provide a platform for sharing updates, collaborating on solutions, and building peer support across states.
- **Shared Learning and Advocacy**: Legislators expressed eagerness to expand the conversation nationally, building a cross-state network to exchange best practices and advocate for systemic change. They are eager to continue learning from one another and strengthen policy initiatives that benefit individuals with IDD.
- **Centering the Voices of Those Most Affected**: A key aspiration shared was to design inclusive, human-centered policies with self-advocates at the table. Legislators committed to ensuring that future reforms reflect the lived experiences of those most impacted by the IDD system.

In sum, there was a strong collective commitment to ongoing collaboration and action. Legislators are determined to keep pushing forward, ensuring that the energy and insights from the symposium lead to lasting systemic change for individuals with IDD.

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To view conference materials, presentation recordings, and the photo gallery, visit

https://arcwa.org/advocacy/ddsymposium/

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