

## **Transforming Care for Individuals with Intellectual and Developmental Disabilities (IDD) and Autism: Insights from the IDD/Autism Summit 2025**

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### **Abstract**

The Intellectual and Developmental Disabilities (IDD) and Autism Summit, a cornerstone event of the TUFH 2025 Conference held from September 14-15, 2025, in Langhorne, Pennsylvania, convened more than 450 participants from 29 countries. The two-day event, co-hosted by the Woods System of Care (WSOC), the Mollie Woods Hare Global Center of Excellence, and The Network: Towards Unity for Health (TUFH), an official non-state actor of the WHO, brought together physicians, clinicians, researchers, policymakers, educators, self-advocates, and families to collectively advance and transform care for individuals with IDD and autism.

The summit provided a platform to examine pressing systemic challenges such as fragmented healthcare delivery, workforce shortages, diagnostic overshadowing, overreliance on medication, and structural barriers to inclusion. Discussions highlighted promising innovations, including integrated and interdisciplinary care models, data-informed behavioral interventions, precision medicine, technology-enabled supports, and community-driven approaches that prioritize family engagement and lived experience. Participants developed key recommendations centered on workforce development, standardized data collection, lifespan care planning, policy reform, and enhanced cross-system collaboration. By bridging research, policy, and lived experience, the IDD/Autism Summit 2025 advanced a global dialogue on inclusive, person-centered care and charted a transformative path toward supporting individuals with IDD and autism to thrive and participate fully in their communities.

### **Introduction**

According to the World Health Organization (WHO), in 2021, about 1 in 127 people<sup>1</sup> worldwide were identified with autism, while a 2019 WHO-UNICEF report estimated that 317 million<sup>2</sup> children and young people are affected by conditions contributing to developmental disabilities, many of whom face stigma, exclusion, and barriers to quality care. In the U.S., Centers for Disease Control and Prevention (CDC) data show that about 1 in 31 children aged 8 years (3.2%) are identified with autism, with 1 in 6 children aged 3–17 having a developmental disability<sup>3</sup>. These striking figures highlight the pressing need for inclusive, accessible, and high-quality care for neurodiverse populations.

In response to this urgent need, the Woods System of Care (WSOC), in partnership with the Mollie Woods Hare Global Center of Excellence and The Network: Towards Unity for Health (TUFH)—an international nonprofit affiliated with the WHO, advancing equitable, community-focused health services, education, and research through global collaboration and social accountability—convened the Intellectual and Developmental Disabilities (IDD) and Autism Summit 2025 (IDD/Autism Summit) from September 14-15 in Langhorne, Pennsylvania, drawing over 450 participants from 29 countries<sup>4</sup>. This two-day summit was a key component of the TUFH 2025 Conference, an annual international, intersectoral, and intergenerational event held since 1979 that brings together academic institutions, global health providers, policymakers, and advocates to promote inclusive health, education, and research worldwide. The summit brought together physicians, clinicians, researchers, policymakers, self-advocates, and families to use these stark statistics to drive real-world solutions, sharing research, lived experience, and policy strategies to advance integrated, innovative healthcare systems for individuals with IDD and autism—locally and globally.

With a mission to break down silos, implement person-centered care, and promote family-first, inclusive approaches, the summit provided a platform for cross-disciplinary collaboration and forward-thinking solutions. Central to the discussions was a call to action: to see the whole person, not just the diagnosis, reflecting **Mark Williams, Board Chair of WSOC**, assertion that, “Our mission is bold but simple: to change the way people with behavioral health complexities, autism, intellectual and developmental disabilities access care across the entire lifespan.” This emphasis on coordinated, lifespan-oriented care, moving “from silos to symphonies” and “from episodic to lifespan”, echoed through panel after panel, highlighting the need for comprehensive, continuous support.

Sessions focused on bridging systems and honoring lived experiences to create more person-centered approaches. Innovative approaches to medication management were discussed, emphasizing data-driven solutions tailored to the unique needs of individuals with autism and IDD. The summit also examined collaborative leadership and strategies for building unified systems of care to achieve sustainable change, alongside perspectives from policy leaders on the policy landscape for complex care, highlighting the need for stronger and more coordinated services. Addressing stigma in mental health, IDD, and autism care was another critical theme, emphasizing cultural competence and public awareness. Participants explored root cause care approaches to foster hope and healing for the autism community, alongside the importance of training healthcare professionals to ensure informed, compassionate care. Innovative discussions on redesigning care pathways focused on community-based solutions for complex behavioral and medical challenges, while sessions on policy and family support examined systemic strategies to address health, advocacy, and quality-of-life needs for neurodiverse communities.

The summit’s multidisciplinary design encouraged attendees to actively participate in a global dialogue linking clinical innovation, education, service delivery, family voices, and policy reform, creating a roadmap to empower individuals with IDD and autism to live healthy, independent, and full lives.

## **Key Challenges Identified**

A recurring theme throughout the summit was the **fragmentation of healthcare systems**. Primary care, specialty care, behavioral health, and dental services often operate in isolation, creating gaps that lead to delayed interventions, miscommunication between providers, and preventable hospitalizations. Another critical issue highlighted was **diagnostic overshadowing**, when medical or behavioral symptoms are incorrectly attributed to a person's disability. This misattribution frequently delays accurate diagnosis and appropriate support.

The summit also addressed **workforce challenges**. Too few medical, dental, and nursing programs provide specialized training in IDD and autism care, which leaves many clinicians unprepared to deliver person-centered, interdisciplinary support. This knowledge gap contributes to diagnostic errors, mismanagement of co-occurring conditions, and caregiver distress. Meanwhile, **direct support professionals (DSPs)**, who are the cornerstone of community-based care, continue to face low wages, high burnout, and limited career development, which erodes the stability of care networks for families.

**Medication polypharmacy** emerged as another area of concern. Psychotropic drugs are often used as first-line interventions without adequate behavioral or medical assessment, which increases the risks of overmedication, metabolic side effects, and reduced quality of life. These issues are further compounded by **gaps in early identification**, which prevent children from accessing crucial supports during formative years.

Beyond clinical issues, the summit spotlighted the pervasive **social and systemic barriers** that isolate individuals and families. **Stigma, cultural bias**, and lack of inclusive infrastructure frequently lead to disengagement from care. As **Dr. William Burdick** emphasized, "Every one of us has bias; the key is not to deny it, but to recognize it and choose not to act on our instant System 1 thinking."

Participants pointed out that **inadequate transition planning** from pediatric to adult services and limited community-based housing and employment options leave many adults with autism and IDD vulnerable to institutionalization and social exclusion. Finally, it was discussed that the **underutilization of technology and data** is a missed opportunity. Despite the potential of AI, electronic health records, and predictive analytics to enhance coordination and prevent crises, these tools remain inconsistently applied across systems of care.

Collectively, these discussions underscored an urgent message: the need for **systemic reform, workforce investment, and holistic, person-centered care**. The summit made clear that progress depends not only on clinical innovation but on reimagining how society sees, values, and supports individuals with IDD and autism, across every stage of life.

## **Innovative Solutions for Autism and IDD Care**

Summit participants identified a variety of innovative solutions aimed at improving care quality, integration, and outcomes for individuals with autism and IDD. A central theme was the **implementation of integrated care models**, in which primary care, behavioral health, dental services, and specialty care operate within a coordinated system. **Dr. Sailaja Musunuri** emphasized, “Integrated care improves quality, enhances access, and can cut overall healthcare costs.” The Woods System of Care was highlighted as a leading example, using shared electronic health records, weekly interdisciplinary team meetings, and individualized treatment plans to create a more **patient-centered approach**.

**Data-driven behavioral interventions** were another focus of discussion. Participants emphasized the importance of Functional Behavior Assessment (FBA) and ABC (Antecedent-Behavior-Consequence) tracking as tools for proactive care. They shared practices in applying Positive Behavioral Interventions and Supports (PBIS) and Applied Behavior Analysis (ABA) to reinforce positive behaviors, reduce challenging behaviors, prevent crises, and minimize unnecessary reliance on medication. **Dr. Musunuri** noted, “Medication should always be the last step; first, thoroughly assess medical issues, sleep, diet, environment, and collect behavioral data.”

The summit also underscored the importance of **workforce development and training** in creating skilled, compassionate providers. Participants described programs that use reflective journaling, mentorship, peer-to-peer learning, and lived experience to help staff connect meaningfully with the people they serve. **Dr. Daniel Balboni** emphasized that “Training helps professionals see these individuals as people first, not just diagnoses,” illustrating how structured learning builds empathy and human-centered care. Complementing this, **Tine Hansen-Turton**, President & CEO of Woods System of Care, explained that Woods supports its direct support professionals (DSPs) by offering clear career pathways, such as moving into teaching, healthcare, nursing, social work, or administration. She emphasized that this focus on “growing our own talent” helps staff develop both professional skills and compassion.

**Precision medicine and individualized treatment** emerged as another area of innovation. **Dr. John Gaitanis** discussed the use of biomarker-driven care, genetic and metabolic testing, and AI-assisted data analysis to identify tailored treatment strategies for subgroups of patients. This approach allows interventions to account for biological differences, improving outcomes while reducing trial-and-error treatments.

Participants also emphasized **community-based and family-centered innovations**, such as sensory-friendly environments, inclusive recreation programs, life-sharing housing models, and in-home skilled nursing support. **Family engagement and advocacy** were consistently highlighted as essential. **Lisa Dressner** noted, “No one should be living in a hospital for months and years; integrated models in the community can truly change lives.” Similarly, **Nina Wall** reflected, “Extraordinary things can happen when there’s vision, when you find community, when there’s support from the top down and the push from the bottom up.”

**Technology** was recognized as a complementary tool to enhance care. Participants discussed AI-driven monitoring, smart home technologies, and video-based provider training as methods to improve safety and skill development, stressing the need for ethical implementation and privacy protections.

Finally, summit discussions highlighted the importance of **cross-system collaboration** among healthcare, education, child welfare, and human services. **Sherry Landis** emphasized, “Collaboration allows us to get stuff done that none of us could do alone. Even when we don’t fully agree, working together turns ideas into action”. This approach ensures that diverse perspectives and resources can be leveraged to create more effective, coordinated support for individuals and families.

### **Recommendations for Improving Care Systems**

Building on the solutions discussed at the summit, several practical approaches can guide policymakers, clinicians, families, and organizations toward more effective, sustainable systems of care for individuals with IDD and autism.

Central to these approaches is **strengthening the workforce through standardized training and ongoing professional development**. Medical, dental, nursing, and behavioral health providers, along with direct support professionals (DSPs) and interdisciplinary teams, must gain the knowledge and skills needed to deliver high-quality neurodiverse care. Experiential learning, mentorship, and reflective practice can help providers better understand the lived experiences of individuals with autism and IDD. At the same time, fair compensation, career growth opportunities, and the involvement of families and self-advocates in training programs can create a skilled, resilient, and inclusive workforce.

**Integrated care models can be expanded** to coordinate medical, behavioral, dental, and specialty services within co-located, interdisciplinary teams. Shared records, data-driven treatment planning, and collaborative practices can make care more holistic and seamless. **Policymakers and funders** can support these models by offering incentives for collaboration and investing in interoperable systems that track outcomes across the lifespan.

**Early identification and proactive interventions** can make a real difference, with consistent screening from birth through early childhood and functional assessments allowing providers to implement personalized strategies before behavioral or medical crises arise. **Advances in precision medicine and AI-driven analytics** can further help tailor care plans to address root causes rather than just symptoms.

**Family engagement and advocacy** must be built into the very fabric of care systems. Families must gain access to peer networks, educational resources, and hold real decision-making power in care planning. **Policymakers** should support this by funding programs that include family voices, creating incentives for meaningful participation, and designing systems that reflect the

lived experiences of those they serve. **Dr. Poki'i Balaz** emphasized, effective policy advocacy starts with clarity: "Identify the problem, provide a national statistic, show what's happening in your state, tie it to a meaningful story, and then clearly call for a policy change." This approach reinforces the principle of "Nothing about us without us," ensuring that families and self-advocates are not just consulted, but are active partners in shaping the policies that affect their lives.

**Lifespan planning and community integration** should also be strengthened. Care systems can support smooth transitions from childhood to adulthood, including vocational training, housing supports, social inclusion programs, and step-down services. Respite care and life-sharing arrangements can help prevent unnecessary institutionalization while promoting independence and quality of life.

Finally, **standardized data collection and outcome measurement** can help drive accountability and continuous improvement. By tracking health outcomes, costs, and quality of life, providers and policymakers can identify what works, scale effective practices, and design care systems that respond to the evolving needs of individuals with IDD and autism.

By combining workforce development, integrated services, family engagement, technology, and data-driven policies, these approaches can create care systems that are both effective and sustainable.

## **Conclusion**

The summit underscored that meaningful progress in IDD and autism care requires a holistic, coordinated approach that integrates clinical innovation, workforce development, family engagement, and policy reform. By embracing person-centered, data-driven, and community-focused strategies, stakeholders can break down systemic barriers, reduce disparities, and ensure that individuals with IDD and autism receive the support they need throughout their lives. The path forward calls for collaboration, sustained investment, and a commitment to seeing the whole person, so that every individual can thrive and participate fully in their communities.

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