



Autism Society of North Carolina

Presentation to the Joint Legislative Oversight Committee on Medicaid

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Who We Are

For 56 years, we have been North Carolina's leading statewide nonprofit dedicated to improving the lives of individuals with autism and supporting their families throughout the lifespan.

Statewide Reach

- **Family & Community Support:** Information, navigation, crisis prevention, and parent to parent support
- **Education & Workforce Training:** Training for professionals, educators, first responders and caregivers
- **Direct Services:** Evidence-based clinical and behavioral supports, employment and skill-building services (via Innovations Waiver, Medicaid and commercial insurance), Camp Royall and Ignite program

What Autism Impacts



Autism is a Spectrum Disorder

- Challenges range from **mild** to **severe**
 - **Level 1** – Requiring support
 - **Level 2** – Requiring substantial support
 - **Level 3** – Requiring very substantial support
 - Other ways to describe the “spectrum”
 - **Level 1** = Independent in most environments
 - **Level 2** = Support needed in some environments
 - **Level 3** = High level of support needed across most or all environments
- *Source – DSM V, 2013*

Prevalence and Diagnostics

- CDC/ADDN Network cites the below changes over the past 20 years
 - 1 in 31 (2025)
 - 1 in 36 (2020)
 - 1 in 150 (2000)
- Boys more likely to be diagnosed than girls
- Nearly 2/3rd also reported to have Mild to Moderate Intellectual Disability

Source : CDC 2025

Policy Value to North Carolina

- With our statewide presence in all 100 counties, we are able to hear from families about their needs, barriers to services, and what is working well to support them in their communities
- We support **quality, accountability, and sustainability** in publicly funded autism services across all payors
- Provide real-time insight from families and providers to inform policy decisions
- A nonpartisan, solutions-focused partner advancing effective autism policy and systems that work for North Carolina families

Autism Treatment Coverage & Medicaid Policy Timeline North Carolina

- **2015 - SB 676** Commercial insurance required to cover autism treatment
- **2019 - NC Medicaid adds RBBHT** Autism services added to Medicaid benefit array
- **2019 to 2021 - Incremental growth** Gradual enrollment and provider expansion
- **2021 - SB 103 (BCBA Licensure)** Independent practice authorized; workforce expands (first license issued in 2023)
- **2023 - Medicaid Transformation** Shift to managed care; new dynamics
- **2023 - Medicaid Expansion** increased some access
- **2024 - Telehealth Updates/Networks opened** Clarified coverage standards; telehealth set in policy
- **2025 - Spending growth concerns** White paper issued by the **North Carolina Division of Health Benefits (DHB)**

Autism Coverage Preservation

We hear concerns and celebrations from families across the state about RBBHT and ABA service

We need to preserve access to quality ABA.

- We hope to continue collaborative work with DHHS and payors to ensure access happens
- We have provided policy proposals to NC DHHS to ensure the sustainability of RBBHT that promotes access and accountability while promoting quality

A story about Aaron and his family



Additional examples from parents who could not attend today...

- When we started serving a young girl two years ago, she had no communication system, meaning she had no way to interact with other people. She started using a PECS (Picture Exchange Communication System) and then quickly expanded to using an electronic communication device. Now, she can ask for what she wants and needs and can engage in conversational exchanges.
- Twin brothers were diagnosed with autism when they were 3 years old. The family sold everything so they could move from their rural NC community where they lived with their families to Raleigh to access therapy. At first, they were scared that they'd never be able to move back home because they would always need a high level of support. However, the boys graduated, and the family moved back to their hometown where they can be around their family and have the resources needed to care for them as they grow.
- Another child began working with ASNC to develop her limited communication skills, learn how to interact with others, and toilet train. Our Clinical Director wrote, "Now this little girl is learning to communicate, and her vocabulary grows daily! She especially loves coming to our clinic and having the opportunity to interact with same-aged peers... this was essential to making sure she could go to kindergarten and continue to grow and thrive in a classroom."

Thank you for your time today. Thank you as well for all you do for people with autism and their families in NC.

Questions?