Autism Leaders United in Call for Action Following Roundtable in Washington D.C.

As Congress scrutinizes sweeping HHS budget proposals, advocates demand inclusion, protection, and person-centered reform

“We don’t need to divide our community. We need to come together to protect those of us who are at risk of being harmed by the changes. It is not just the concept of whose Autism is more valid…or who is more worth protecting. Because it is all of us.” — Jules Edwards, Autistic advocate and parent of Autistic children.

May 15, 2025, Washington, D.C. — This week, as Congress examined the Administration’s proposed restructuring of the Department of Health and Human Services (HHS) in hearings on May 14th, a powerful coalition of Autism organizations convened a first-of-its-kind roundtable to address the state of Autism services, civil rights, scientific integrity, and representation of disability in federal policy. Robert F. Kennedy Jr., Secretary of the Department of Health and Human Services, was invited to participate, however did not respond to the request to attend; Mary Lazare, Principal Deputy Administrator at the Administration for Community Living, was in attendance.

Hosted by the Autism Society of America (ASA), the Autistic Self Advocacy Network (ASAN), the Association of University Centers on Disabilities (AUCD), the Autistic People of Color Fund (APOC Fund), the Autistic Women & Nonbinary Network (AWN), the American Association of People with Disabilities (AAPD), The Arc, and the National Association of Councils on Developmental Disabilities (NACDD), the roundtable brought together Autistic self-advocates, parents, caregivers, researchers, and service providers to discuss the urgent needs faced by our community and to chart a united path forward.

These organizations, along with the roundtable participants, coalesced around the urgent need for our nation’s policies, systems, services and research to reflect the reality that autistic lives are lives worth living. Whether someone has complex needs, is non-speaking, has co-occurring disabilities, or is navigating daily life with non-apparent disabilities — every person deserves dignity, support, and opportunity.

“Something that hurts me a lot isn’t my Autism, it’s other people’s assumptions,” shared Perri Spencer, an Autistic self-advocate and a user of augmentative and alternative communication (AAC). “I’m more like their child than they realize. I hit my head, I struggle with verbal and non-verbal communication, I need a lot of sensory input, because my presentation is very dynamic and my abilities vary from day to day.”

The roundtable centered on six interwoven themes:

- The danger of proposed, and enacted cuts, to services and programs, like Medicaid
- The lack of comprehensive services for Autistic individuals with complex needs
- The urgent need for accessible, inclusive education
- A call for research that reflects community priorities—especially services and support
- Recognition of communication access as a fundamental human right
- Rejection of divisive narratives within the Autism community in favor of unity and inclusion

Participants emphasized that meaningful policy must reflect the full spectrum of Autistic experience—including those with high support needs, intellectual disabilities, co-occuring mental health and medical conditions, non-speaking individuals, and those multiply marginalized by race, gender, and poverty. The convening reaffirmed a unifying message: the path forward must be built on solidarity, dignity, and action rooted in lived experience.

"In terms of functioning labels – the functioning label can actually depend on what type of supports I have available, both informal and formal," said Gyasi Burks-Abbott, an Autism self-advocate, educator, and author. "My functioning has changed over the years. I can do things I can do now that I couldn't do in the past. But also, there are things that I can do now because I have certain help. I have assistance."

The convening took place amid the Administration's controversial plan to cut up to 20,000 HHS staff, reduce funding by 25%, and reorganize agencies under a new "Administration for a Healthy America." Advocates warned that these so-called 'cost-saving measures' include cuts to key disability-specific programs and civil rights enforcement. These cuts are further compounded by Congressional efforts to overhaul Medicaid and end marketplace subsidies, which could strip coverage from at least 13.7 million Americans.

"If Medicaid cuts were to happen, my son's life would be in danger," said Dr. Robert Naseef, a psychologist and father to an Autistic son. "The tragedy in my life would be if my son didn't have around-the-clock care – that he couldn't be alive today."

Additionally, there are concerns about how HHS intends to sustain meaningful, ongoing Autism research through the NIH and CDC, given the significant budget cuts to these agencies. While the majority of funding continues to be directed towards studying the causes of Autism, only a small fraction—estimated at around 8%—goes towards research into services and supports that impact and improve daily life. This misalignment is particularly troubling given that most Autistic people spend the majority of their lives in adulthood, yet funding remains disproportionately focused on early childhood.

"There's a misalignment between the types of shifts in research funding that are being proposed by HHS versus what autistic people have said that they want, which in my understanding is heavily focused on services research," shared Anne Roux, Researcher at Drexel University

At the Senate Health, Education, Labor, and Pensions (HELP) Committee hearing, Secretary Kennedy described the proposed Autism registry as opt-in with opt-out protections, framed as a tool to better understand Autism and evaluate therapies. Autism community members stressed the need for greater transparency, particularly regarding data use, consent processes, ethical oversight, and concerns that a registry could support harmful or unfounded research priorities. Any attempt to repurpose personal data in service of controversial theories or experimental interventions, without full community oversight, risks further erosion of trust.

In the aftermath of Secretary Kennedy's budget hearings and as Congress considers FY 2026 appropriations, roundtable organizers call on Congress to listen to those directly affected by systemic neglect and harmful cuts, alongside qualified and credentialed experts.

"We are not fighting about ideology. We are fighting for our lives, our families, and our future," said a parent and self-advocate. "We won't accept division in our community or in our policies. We must protect everyone, especially those with the most significant needs."

The participating organizations reaffirm their shared commitment to solidarity, inclusion, and the transformation of public policy to reflect the full spectrum of Autistic experience. This roundtable reaffirmed that partnership with government is possible—but it must be paired with accountability. As we look ahead to what happens in Congress, in the Administration, and in actual implementation, we are committed to continuing this dialogue. It is critical that Autistic people and the supporting community are not just invited to the table—but that the table is reshaped to reflect their priorities, leadership, and rights.

Joint Statement Signatories

Autism Society of America
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Association of University Centers on Disabilities
Autistic People of Color Fund
Autistic Women & Nonbinary Network
American Association of People with Disabilities
The Arc
National Association of Councils on Developmental Disabilities

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