

Autism Speaks: From Criticism To Inclusion And A Future Of Listening

Autism Speaks is working to evolve — shifting from controversy to inclusion with a renewed focus on autistic voices, lifespan support, and community-driven change.

By Jennifer Jay Palumbo

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That experience was personal for Keith Wargo, the current President and CEO of Autism Speaks, whose own son was diagnosed more than two decades ago.

“When he was diagnosed, we were given a diagnosis and little else. No roadmap. No coordinated support system,” Wargo explained. Like many families at the time, his support came from informal parent networks rather than institutional guidance. “Our shared journey, grounded in the experiences of our children and as parents, is what originally drew me to this work—and is what continues to keep the voices of the autism community at the center of all we do at Autism Speaks.” That hasn’t always been the case.

The Criticism of Autism Speaks And The Lessons Learned



A Circle from colorful figures and sign neurodiversity.

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Over the years, Autism Speaks has faced significant criticism—most notably from self-advocates—regarding its early focus on curing autism, portraying [autistic individuals](#) through a lens of fear, and failing to include autistic voices in leadership and decision-making.

But Wargo says that the feedback wasn't ignored—it was transformative. "This is not a PR effort—it's fundamental to how we operate and make decisions. If we're serious about impact, we need to build solutions with, not just for, the people we're working to support."

This perspective has catalyzed a shift in the organization's core mission—from one focused on early diagnosis and awareness to one that

addresses support across the entire lifespan. As Wargo notes, “Autism is a lifelong condition, yet the support available to autistic adults is lacking.”

The data backs him up. According to the [CDC](#), autistic individuals face a life expectancy of just 54 years, and only one in five people with disabilities—including autism—is employed. Autistic people are [twice as likely](#) to experience homelessness, and one in four families raising a child with autism faces food or housing insecurity.

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Focusing On The Core Areas Where Autistic People Face Disparities



Concept of the diversity of talents and know-how, with profiles of male and female characters ... More associated with different brains.

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Autism Speaks is now focusing on three core areas where these disparities are most acute: [healthcare](#), employment, and housing. And within each of those domains, the organization is elevating the voices of autistic individuals to help drive its agenda forward.

Dr. Andy Shih, Chief Science Officer at Autism Speaks, believes that meaningful progress for autistic adults will require long-term scientific investment. “We urgently need longitudinal studies that follow autistic people across their lifetimes,” he said, noting the absence of research on how autism intersects with chronic health conditions like cardiovascular disease, diabetes, and dementia. As the autistic population ages, Shih

says, there's a growing need to understand better how these conditions impact quality of life and life expectancy.

Despite recent advancements in early screening and evidence-based interventions, research on adulthood and aging in autism lags significantly behind. According to the [2021 National Autism Indicators Report](#), autistic adults frequently encounter healthcare systems that are ill-equipped to meet their needs, especially when it comes to coordinating care for co-occurring conditions. “We need to ensure that these studies are inclusive,” Dr. Shih adds, “especially of those with intellectual disabilities and individuals from underrepresented communities so that the results can drive equitable outcomes for everyone.”

True Equity And Representation of Autistic People



World Autism Day, held on 2 April.

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That emphasis on equity and representation is echoed by [Eileen Lamb](#), Director of Social Media and Influencer Marketing at Autism Speaks—and an autistic self-advocate herself. Lamb is also the mother of two autistic children, including her eldest son, Charlie, who is nonverbal and has profound autism. “To me, true acceptance means including everybody—it doesn’t stop at level 1 autism or when it’s hard,” she said. For Lamb, meaningful inclusion means building systems that support both the gifted and the differently abled.

“Charlie has no sense of danger, which manifests in different ways like running in front of cars and eating non-edible items,” she shared. “He requires extensive support and will continue to as he gets older, but his life still has great value.” Through her dual lens as a parent and self-advocate, Lamb is helping guide Autism Speaks’ initiatives in expanding mental and physical healthcare resources, educating employers on inclusive hiring practices, and advocating for technologies that foster communication and independence.

Lamb also recognizes the importance of caregiver voices, particularly when those being served are nonverbal. “We need to invest in services and supports that allow all autistic people to be integrated into society—not just those who are able to advocate for themselves.”

Tonya and Tyler Haynes offer a generational view of how support systems have changed over time. When Tonya’s eldest son, Tyler, was diagnosed with autism, the family was overwhelmed and isolated. “We were met with little guidance—only a diagnosis, a pamphlet, and a referral,” she recalls. “It often felt like we were navigating a vast sea of uncertainty alone.”

Years later, their younger son received the same diagnosis, but the experience was different. “We were aware of organizations like Autism Speaks,

which provided invaluable support throughout our journey. We were better positioned to advocate for him and were able to access early intervention and support services more swiftly.”

Tyler, now a college graduate and employed, shared that although he still needs support in certain areas, he hopes others can see beyond stereotypes. “I am autistic, but I am also a son, brother, friend, graduate, and employee with an exciting life ahead of me. I think every person with autism should have the opportunity to contribute in ways important to them.”

His mother agrees—and believes that change begins with systems, not just sentiment. “As someone with a background in healthcare, I believe this vision begins with translating scientific discovery into tangible real-world impact,” she said. “That includes inclusive employment pathways, integrated healthcare, supported housing, and opportunities for connection at every level of society.”

How Autism Speaks Is Learning From It's Past



Autistic rainbow eight infinity symbol. Autism awareness day symbol

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Autism Speaks has not escaped its past—but its current leaders seem determined to learn from it. Its new strategic focus prioritizes autistic inclusion, not only in theory but in practice, with goals aimed at improving quality of life and extending opportunity across the spectrum. From leadership changes to investments in lifespan research and grassroots advocacy, the organization is working to rebuild trust where it once faced skepticism.

As Wargo puts it, “We can’t allow progress in early childhood to be where the story ends. Our responsibility is to make sure that every autistic person, regardless of their support needs, has the opportunity to live a full and supported life—at every age.”

That future, according to Autism Speaks, will be built not on speaking louder—but on listening better.