

A rift over ‘profound autism’ reveals a community’s deeper divide

Amid a burgeoning neurodiversity movement, some say autistic children who are nonverbal and intellectually disabled are being left behind

By Katherine Ellison

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Public perceptions of autism have come far in the 80 years since Austrian American scientist Leo Kanner first described a neurodevelopmental childhood disorder causing “an innate inability to form the usual, biologically provided contact with people.”

Against a backdrop of a burgeoning neurodiversity movement portraying wide variations in human behavior as differences, not deficits, many autistic adults have come to see their traits as a gift and source of pride.

Yet parents such as Maria Leary, the mother of two autistic, nonverbal sons — one of whom frequently injured himself and others before his death in 2018 — fear the neurodiversity revolution is leaving her family behind.

“You see happy videos of the great accomplishments of people with autism who get to go to work and play in basketball games,” says Leary, who is also a New Jersey disability consultant. “And, of course, that’s what I want for my kids. But that’s not my reality.”

Leary is on one side of a debate that probably will heat up in coming months as advocates seek different outcomes from Congress’s review of the Autism Collaboration, Accountability, Research, Education and Support (Autism Cares) Act of 2019.

At the heart of the divide is a deceptively simple phrase: “profound autism.”

Parents such as Leary believe recognizing some people as having profound autism would help target more research and support for children like theirs who are nonverbal, intellectually disabled and in need of constant supervision. In a paper in the journal *Public Health Reports* this year, researchers estimated that nearly 27 percent of 20,000 autistic 8-year-olds whose records they analyzed could be categorized as having profound autism.

Leaders of the Autistic Self Advocacy Network (ASAN), however, reject the phrase, calling it dangerous and misleading.

“We are concerned about the human and legal rights of the people who would be so labeled,” ASAN Executive Director Julia Bascom said in an email. Devoting funds to “profound autism,” she wrote, “would result in research aiming to ‘prevent’ or ‘cure’ autism, and a focus on more restrictive services.”

The Centers for Disease Control and Prevention estimates that 1 in 36 U.S. children (roughly 2 million) and some 5.4 million adults have autism spectrum disorder. While the causes aren’t well understood, some scientists believe it runs in families. No link has been found between autism and vaccines.

Until 2013, clinicians diagnosed people with any one of four distinct categories of autism, including Asperger’s syndrome, called high-functioning autism by some, and childhood disintegrative disorder, a rarer and more debilitating condition. But following a major revision that year in the Diagnostic and Statistical Manual of Mental Disorders, a key clinical guidebook, these separate diagnoses were consolidated as “autism spectrum disorder.”

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As co-founder and president of the Autism Science Foundation, former network TV executive Alison Singer is a leader in the effort to distinguish these points on the spectrum.

Singer says there’s an urgent need for more specialized care for people like her daughter, Jodie, 26, who has been diagnosed with autism. Her mother says she also is intellectually disabled, minimally verbal, and often pulls her hair, bangs her head and lashes out at others.

Alison Singer also wants to see more research into the genetic causes of autism, which she says could help spur early interventions. ASAN vigorously opposes this, however. “We do not believe that any autistic person needs to be “cured,” the organization’s website says. “This includes autistic people with the highest support needs. Autistic people with the highest support needs are some of the most vulnerable members of our community. They deserve good lives with the right to make their own decisions, not yet another round of ‘cures’ that will not work.”

An often blunt speaker, Singer has become a leading lightning rod in the emotional debate, in which she says she has been threatened and denounced as an “ableist” and worse. It hasn’t deterred her activism.

“Autism can be an identity or way of being for some, but for others, it’s a debilitating medical condition,” she says.

‘Nothing about us without us’

Horrible history predates ASAN’s perspective.

Less than 100 years ago, the American Journal of Psychiatry published a debate on the merits of using “eutanasia” for “feeble-minded people.” In the 1980s, autistic Americans were still being shut away in overcrowded, unsanitary and abusive institutions such as Willowbrook State School on Staten Island.

In 1993, the autistic self-advocate Jim Sinclair’s landmark essay, “Don’t Mourn for Us,” advised parents of autistic children who “pray for a cure” to let go of their “grief over the loss of a fantasized normal child.”

Sinclair helped pioneer neurodiversity activism, including the demand that people with autism have input into decisions about scientific research and policy. ASAN’s motto is “nothing about us without us.”

The civil rights battle has brought progress in understanding, although at some cost. Some scientists have declined opportunities to speak about autism for fear of being heckled for using terms such as “risk,” “problem behavior” and “symptoms,” which some advocates call offensive.

Parents speaking about their struggles have been branded “mommy martyrs.” Singer showed The Washington Post several threatening texts she says she received. At the same time, ASAN’s Bascom says her organization has received bomb threats and won’t print its physical address because of security concerns.

Parents including Leary and Singer insist that, while they respect the achievements of autistic adults able to advocate for themselves, they need to speak on behalf of children unable to do so.

Leary’s firstborn son, David, who was born with autism and a rare genetic condition, suffered epileptic seizures, couldn’t speak and often banged his head on the floor. He was treated for behavioral problems at the Kennedy Krieger Institute in Baltimore before his death at age 12, which was believed to be due to a seizure.

“I’d felt like I was failing because other kids I knew were getting better and he was getting worse,” his mother says. “Then I saw 15 other kids in his unit just like him, and I realized this is something other people don’t even know about. ... we need services to cover these children as well as others.”

Julie Greenan, a nurse from Buffalo, met Leary a decade ago at the Kennedy Krieger Institute, where Greenan’s son Sam, then 11, was also being treated for behavioral issues, including kicking, scratching and biting himself and others.

Greenan has an unusual perspective, in that all five of her children have been diagnosed with autism, yet they have a range of abilities and needs. Now 21, Sam is living in a group home while her oldest, at 24, is a college graduate with a job in his chosen field of musical theater.

Greenan blames the 2013 change in diagnostic rules for the discord in the autism community. “Before that, we didn’t have to fight each other about who gets services,” she says. “Saying there can’t be different levels of autism is like saying ... other people’s experiences don’t matter.”

Many parents of children like Greenan’s son Sam, whom she says can be violent or self-injurious and needs 24/7 supervision, say they desperately need more specialized services including long-term housing options. ASAN insists that autistic people should be able to live “in the same places as non-disabled people,” instead of restrictive institutions, yet other observers say the small-scale, community-based formula is failing because of a lack of resources and staff.

Some 656,000 Americans, most with intellectual and developmental disabilities, were on wait lists for state-paid home and community-based services in 2021, according to KFF, and emergency department visits and long hospital stays by people with severe autism skyrocketed between 2009 and 2014, as Kaiser Health News has reported.

“A lot of people with profound autism in acute psychiatric and behavioral crises wouldn’t be in that position if there were sufficient high-quality, dignified, well-staffed and well-run residential facilities and congregate living options across the United States,” says Lee Wachtel, medical director of the Neurobehavioral Unit at Kennedy Krieger Institute. She said the institute has a wait list 150 names long for its inpatient treatment program.

Parsing ‘profound autism’

The term “profound autism” was proposed in 2021 by the Lancet Commission on the future of care and clinical research in autism, which specified traits including a substantial intellectual disability (such as an IQ below 50) and very limited language (“e.g., limited ability to communicate to a stranger using comprehensible sentences”).

“It came from a concern that there are a lot of people who need help and are getting lost in the shuffle,” says Catherine Lord, the report’s lead author and a psychiatry professor at UCLA School of Medicine.

Ten years after autism was presented as a spectrum, reestablishing a category for more severely impaired people might help earmark resources for people unable to care for themselves, Lord adds. Yet she concedes that the backlash following her report surprised her.

Steve Silberman, author of “NeuroTribes: The Legacy of Autism and the Future of Neurodiversity,” summed up the objections in an interview. “‘Profound autism’ may seem like useful shorthand for parents struggling with their children’s behavior, but it raises more questions than it answers,” he says. “These debates are unfolding as if a child who receives the ‘profound autism’ label might not be deemed as having ‘mild autism’ after receiving better support and accommodations.”

A case in point is the celebrated animal behavior expert Temple Grandin, who didn’t speak until she was 3½ years old. Instead, she screamed, hummed and threw tantrums. Much later, she explained that she had acted out because her petticoats itched and scratched. Grandin’s website now says: “I like the logical way that I think and I do not want to be cured.”

‘Tearing each other apart’

Bascom characterizes the controversies as the result of a power shift.

“For many, many years, autism advocacy was dominated by nonautistic voices, and they could say whatever they wanted about autistic people without any pushback,” she wrote. “Now, autistic people have pushed ourselves into many of these conversations and are talking back. People in power often experience that sort of dynamic as uncivil.”

Others worry about potential fallout from the charged conversation.

A “toxic competition” may discourage members of Congress considering the Autism Cares Act, says Craig Snyder, a lobbyist for Singer’s foundation and supporters.

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Federal support for autism is already relatively limited, with \$369.7 million in annual Autism Cares funding vs. \$7.8 billion to the National Cancer Institute alone and \$28 billion annually for HIV, and the adult self-advocates and parents’ groups have conflicting goals.

“Whatever position (the legislators) take, some will applaud and others will loudly and vigorously oppose them,” Snyder says. “So what could well happen is there will be no major changes in the Act, but rather minor tweaks. They’ll follow the path of political least resistance.”

Stanford University undergraduate Lucy Kross Wallace was diagnosed with autism at age 18 after what she has described as years of out-of-control anxiety, obsessions, compulsions and failed treatment, including nearly a year of hospitalization before enrolling in college. While she depicts her diagnosis as revelatory and says she plans to study psychology after graduating, she says she won’t focus on autism because “I just don’t have the stomach for it.”

Wallace has criticized the “black and white thinking” she sees in the neurodiversity movement and calls on advocacy groups, clinicians, providers and researchers to denounce “anti-parent bullying” and other harassment.

“It’s really frustrating that people are getting so worked up with their terminology when there are so many real problems to deal with,” she says. “You’d think the common diagnosis should have people supporting each other, but people are tearing each other apart.”