

VIEWPOINT

It's time to embrace 'profound autism'

BY ALISON SINGER

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Earlier this month, I attended the Autism-Europe International Congress in Kraków, Poland, where the theme was “Happy Journey Through Life.” Although this sounds like an admirable goal, I would not choose the word “happy” to describe my daughter Jodie’s life with profound autism, nor would many other families who struggle with the day-to-day challenges of life on the profound end of the autism spectrum, a reality that is largely invisible to mainstream society.

Jodie is minimally verbal and suffers from painful self-injurious behaviors, intellectual disability, aggression, anxiety, sleeplessness and seizures. Her frequent aggressive outbursts make it hard to involve her in community activities. Although she is often content and enjoys working on a farm, no one who witnesses her pulling her own hair or headbutting the wall would call her “happy” during those episodes. And my family and I are not “happy” that she will require 24-hour care and supervision for the rest of her life.

My experience at the Autism-Europe International Congress — and my experience as a parent of a child with profound autism — makes me more convinced than ever that we need to bifurcate the diagnosis of ‘autism spectrum disorder’ and add a new diagnosis of ‘profound autism’ to better serve this vulnerable and underserved population, which is consistently overshadowed by the higher-functioning members of the autism community.

The first mention of “profound autism” in the scientific literature came in 2021 in **The *Lancet* Commission on the Future of Care and Clinical Research in Autism** report. The commission was co-chaired by **Catherine Lord**, George Tarjan Distinguished Professor of Psychiatry at the Semel Institute of Neuroscience and Human Behavior at the University of California, Los Angeles. I also served as one of more than 30 commissioners. The report stated that the term “profound autism” is critical to distinguish people who have high dependency needs from the more verbally and intellectually able population of people with autism.

In reviewing several datasets of people with autism, the *Lancet* Commission estimated that close to 50 percent of the autism population falls into the category of profound autism. This means that for

every autistic person trying to get a job at Microsoft, there's also one who cannot grasp the abstract concept of what Microsoft even is or does.

Families like mine who face profound autism have advocated for this distinction for quite some time. We strongly believe that the breadth of the autism spectrum has become unwieldy, and the phrase "autism spectrum disorder" has become such a big-tent term that the people under that tent often have little in common with one another. Autism can mean genius or an IQ below 30. Autism can mean highly verbal or nonverbal. It can mean graduating from Harvard Law School or 'exiting' high school with a certificate of attendance. If we are going to be able to personalize our approach to care, as the *Lancet* Commission report suggested, we need terminology and language that are specific and meaningful, rather than terminology that lumps everyone together.

The neurodiversity community's success at drawing attention to its issues has led many without deep experience with autism to conclude that those issues are representative of everyone. To the broader public, the word "autism" now only describes the more verbal, traditionally skilled, visible end of the spectrum — because people who meet those criteria are able to have a voice, attend conferences, represent themselves at policymaking meetings and **appear in the media**. The result is that autistic people with severe intellectual disability and the most challenging behaviors have become invisible and been left behind.

This blind spot was painfully illustrated to me at the Autism-Europe International Congress, where the vast majority of delegates represented the higher-functioning end of the spectrum and yet claimed to speak for everyone with autism. Many delegates became visibly angry over some of the terms presenters used in their talks to describe autism traits, such as "patient," "disability" and even "intervention." Many took to social media to bash these scientists; others walked out of the room.

But these words are necessary and correct. My daughter consumes medical services; that makes her a patient. She has a disability; if she didn't, she wouldn't qualify for services. The same is true for so many other families who suffer (yes, suffer) from profound autism.

There were several instances at the conference in which the presenters gave evidence of this growing dichotomy. The most vivid was the keynote address by **Brian Boyd**, William C. Friday Distinguished Professor in Education at the University of North Carolina at Chapel Hill, titled "Reconceptualizing repetitive behavior in autism." Boyd presented two videos to represent different types of repetitive behaviors. The first showed an autistic adult who had parlayed his special interest into a job, and who spoke eloquently about the challenges of socializing and how he values his alone time. The second video was preceded by a trigger warning, greeted with "oohs" and gasps from the audience, and immediately criticized on Twitter, as it showed a profoundly autistic child engaging in self-injurious behavior.

This video reflected a normal day for many families with a profoundly autistic child, who can't, as

Boyd suggested the attendees might do, “cover their eyes and ears” to hide from what is happening around them. If those who purport to represent and speak for the full autism spectrum can’t even observe, for a few seconds, the daily behaviors many with profound autism experience, how can they advocate for their needs? Boyd rightly pointed out that these two people need vastly different types of interventions, as they face vastly different situations. What he described were, in fact, the two extremely different types of autism.

Similarly, in her keynote address, Lord showed data on the outcomes of people with autism, based on a 30-year longitudinal study. The outcomes of those with low IQ scores, who likely would qualify for the profound autism diagnosis, were drastically different — and far worse — than the outcomes of those who are higher functioning. And when asked how people in the study felt about their future, verbal young adults cited “mood, anxiety and depression” as core factors in their happiness, whereas the parents of less verbal young adults described “difficulties with aggression” as the key determinants. In short, if we are going to meet the needs of people with different types of autism, we need very different types of interventions based on their functional level.

One of the themes of the Autism-Europe International Congress was a call for greater participatory research. At the meeting, this meant research being done by and with input from high-functioning adults with autism, but not from parents. Much of the research the delegates called for focused on mental health and well-being. But when it comes to the type of research needed, there are dramatic differences in priorities between verbal autistic adults and parents of profoundly autistic people, as Lord articulated. According to several delegates and posts on Twitter, any “intervention” research — behavioral or pharmacological — is “ableist,” “neuronormative” and “pathological.” Yet this is exactly the type of research families of those with profound autism want, need and deserve. On the other hand, in the profound autism community, studies of determinants of “autistic flourishing” are viewed as luxuries, as families struggle to meet their children’s basic needs and keep them physically safe.

Another theme at the conference was the need to use “neutral,” non-threatening language. Several presenters actually amended their slides at the last minute to remove any trace of language that might get them called out by neurodiversity advocates on social media. Soon, they may be afraid to present scientific findings at all, for fear of being canceled. There is nothing beneficial or even neutral about cleansing the words needed to describe the scientific and practical realities of autism. Such so-called neutral language robs the community of the ability to even describe the day-to-day lives of people with profound autism.

Although it is regrettable that some people are triggered by reasonable terminology, no one should have the power to censor language to exclude the observable realities of autism. Scientists and advocates need a full semantic toolbox to describe what is happening in the real world. Pretending people with profound autism don’t exist by eliminating language to describe their symptoms is itself ableist. Unlike the attendees in Boyd’s presentation, we cannot cover our eyes and ears to the reality of profound autism.

After speaking to many of the congress' delegates and presenters, it seems clear to me that the broad autism community, as currently defined, will never agree on priorities, needs or language. It is time to admit that lumping everyone together along one spectrum has created rancor and ill will. There are real-world implications for people with profound autism when high-functioning advocates seek to defund and deprioritize medical research, block access to treatment and clinical care, censor necessary and accurate scientific language, and advocate for policies that cause real harm to those who will not and cannot ever live independently. Only by returning to at least two separate diagnoses can we begin to meet the highly diverse needs of both groups.

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