

Autism Treatment Shifts Away from 'Fixing' the Condition

by Claudia Wallis, 2022

There are different ways to be happy and function well, even if your brain is not typical

- When I began reporting on autism about 15 years ago, therapists would talk about achieving the "optimal outcome" for children on the autism spectrum. What they meant was changing the classic behaviors associated with the condition—suppressing repetitive actions such as hand flapping, drilling young kids to make eye contact, rehearsing speech and social interactions—so that ultimately the children would no longer meet the diagnostic criteria for autism. It was an elusive goal that only a tiny percentage could reach. Today it is widely seen as wrong-minded.
- "We've moved away from thinking of autism as a condition that needs to be eliminated or fixed to thinking about autism as part of the neurodiversity that exists across humankind," says Geraldine Dawson, director of the Duke Center for Autism and Brain Development in Durham, N.C. "The question then becomes, How do we best support people who are autistic, and how would you measure improvement if you are conducting clinical trials?" Dawson, along with two colleagues, wrote about this shift in a recent article in JAMA Pediatrics. It reflects a widespread reevaluation of the goals of therapy and metrics for success, driven in part by the self-advocating voices of people on the spectrum. They have fostered a greater appreciation for what society gains from having different kinds of brains contribute to our world, as well as a greater awareness of the negative impacts of insisting that people with autism behave in ways that are unnatural for them.

- This **reassessment** doesn't mean that **early intervention** is any less important for young children diagnosed with autism. As in the past, therapies should aim to **remediate** the defining **impairments** of the condition, which include challenges communicating and establishing social relationships, and to reduce harmful and disruptive behaviors, such as head banging and **tantrums**. But today an optimal outcome will depend on the abilities and desires of the individual and the person's family and will not necessarily emphasize conforming to typical behavior.
- For example, therapists need not focus on changing behaviors that are essentially harmless. Dawson cites the case of a teenager who told his therapist he no longer wanted to work on sustaining eye contact. "That should be okay," she says. "If you think about the people you know, there are those who make a lot of eye contact and others who make less." Similarly, she adds, "if someone rocks back and forth because it makes them feel calmer, I feel that our society should be accepting of different ways of being in the world."
- The neurodiversity movement, which fights **stigma**, has encouraged scientists to study the high cost of forced **conformity** for people with autism. A 2018 paper, for example, found a link between trying hard to "pass" as nonautistic and a higher risk of suicide. The struggle to keep up a "neurotypical" appearance pulls attention from other things, says Ari Ne'eman, who co-founded the Autistic Self Advocacy Network. "If you're constantly policing where your eyes are pointing and second-guessing yourself about if you're talking too much about the things that interest you, all of that is energy and **cognitive** load that doesn't get spent elsewhere." Ne'eman, who is autistic and a Ph.D. candidate in health policy at Harvard University, remains concerned that bias against certain behaviors is built into the tools **clinicians** use. Too often therapists are "teaching to the test' of typical appearance," he wrote in a 2021 piece in the *AMA Journal of Ethics*.
- The watchwords of the neurodiversity movement are "nothing about us without us."

 That means autistic people and their families help to define therapy goals. "If you were a nonverbal six-year-old and at 12 you are able to speak, whether through an iPad or with your voice, that can be an optimal outcome," says autism researcher Connie Kasari of the University of California, Los Angeles, who often works with minimally verbal people on the spectrum. "They can be very happy," she observes. "They can be working. It comes down to how you define success within your world."
- The old goal of losing the autism diagnosis is not a priority for many people on the spectrum, Dawson says, and "when we follow people to see if losing the diagnosis is associated with a better quality of life, it just is not." What is a **priority**, she says, is having a meaningful job and relationships: "being as **independent**, joyful and productive as possible." Just like for any human being.