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The Autism Wars

By **AMY HARMON**

THE report by the Centers for Disease Control and Prevention that one in 88 American children have an autism spectrum disorder has stoked a debate about why the condition's prevalence continues to rise. The C.D.C. said it was possible that the increase could be entirely attributed to better detection by teachers and doctors, while holding out the possibility of unknown environmental factors.

But [the report](#), released last month, also appears to be serving as a lightning rod for those who question the legitimacy of a diagnosis whose estimated prevalence has nearly doubled since 2007.

As one person commenting on The New York Times's [online article](#) about it put it, parents "want an 'out' for why little Johnny is a little hard to control." Or, as another skeptic posted on a different Web site, "Just like how all of a sudden everyone had A.D.H.D. in the '90s, now everyone has autism."

The diagnosis criteria for autism spectrum disorders were broadened in the 1990s to encompass not just the most severely affected children, who might be intellectually disabled, nonverbal or prone to self-injury, but those with widely varying symptoms and intellectual abilities who shared a fundamental difficulty with social interaction. As a result, the makeup of the autism population has shifted: only about a third of those identified by the C.D.C. as autistic last month had an intellectual disability, compared with about half a decade ago.

Thomas Frazier, director of research at the Cleveland Clinic Center for Autism, has argued for diagnostic criteria that would continue to include individuals whose impairments might be considered milder. "Our world is such a social world," he said. "I don't care if you have a 150 I.Q., if you have a social problem, that's a real problem. You're going to have problems getting along with your boss, with your spouse, with friends."

But whether the diagnosis is now too broad is a subject of dispute even among mental health professionals. The group in charge of autism criteria for the new version of the Diagnostic and

Statistical Manual of Mental Disorders has proposed changes that would exclude some who currently qualify, reducing the combination of behavioral traits through which the diagnosis can be reached from a mind-boggling 2,027 to 11, [according to one estimate](#).

Biology, so far, does not hold the answers: there is no blood test or brain scan to diagnose autism. The condition has a large genetic component, and has been linked to new mutations that distinguish affected individuals even from their parents. But thousands of different [combinations of gene variants](#) could contribute to the atypical brain development believed to be at the root of the condition, and the process of cataloging them and understanding their function has just begun.

“When you think about that one in 88, those ‘ones’ are all so different,” said Brett Abrahams, an autism researcher at Albert Einstein College of Medicine. “Two people can have the same mutation and be affected very differently in terms of severity. So it’s not clear how to define these subsets.”

Some parents bristle at the notion that their child’s autism diagnosis is a reflection of the culture’s tendency to pathologize natural variations in human behavior. Difficulty in reading facial expressions, or knowing when to stop talking, or how to regulate emotions or adapt to changes in routine, while less visible than more classic autism symptoms, can nonetheless be profoundly impairing, they argue. Children with what is sometimes called “high functioning” autism or Asperger syndrome, for instance, are [more likely to be bullied](#) than those who are more visibly affected, a recent study found — precisely because they almost, but don’t quite, fit in.

In a [blog entry](#), Christa Dahlstrom wrote of the “eye-rolling response” she often gets when mentioning her son’s autism by way of explaining his seeming rudeness: “The optimist in me wants to hear this as supportive (Let’s not pathologize differences!) but the paranoid, parent-on-the-defensive in me hears it as dismissive.”

There are, Ms. Dahlstrom acknowledges, parents of children with autism whose challenges are far greater. And perhaps it stands to reason that at a time when government-financed services for such children are stretched thin, the question of who qualifies as autistic is growing more pointed. “‘You don’t get it; your kid is actually toilet trained,’ ” another mother told her once, Ms. Dahlstrom recalled. “And of course she was right. That was the end of the conversation.”

But Zoe Gross, 21, whose autism spectrum disorder was diagnosed at age 4, says masking it can take a steep toll. She has an elaborate flow chart to help herself leave her room in the morning (“Do you need a shower? If yes, do you have time for a shower?”). Already, she had to take a term off from Vassar, and without her diagnosis, she says, she would not be able to get the accommodations

she needs to succeed when she goes back.

According to the C.D.C., what critics condemn as over-diagnosis is most likely the opposite. Twenty percent of the 8-year-olds the agency’s reviewers identified as having the traits of autism by reviewing their school and medical records had not received an actual diagnosis. The sharpest increases appeared among Hispanic and black children, who historically have been less likely to receive an autism diagnosis. In [South Korea, a recent study](#) found a prevalence rate of one in 38 children, and a study in England found autism at roughly the same rate — 1 percent — [in adults](#) as in children, implying that the condition had gone unidentified previously, rather than an actual increase in its incidence.

Those numbers are, of course, dependent on the definition of autism — and the view of a diagnosis as desirable. For John Elder Robison, whose memoir “Look Me in the Eye” describes his diagnosis in middle age, the realization that his social awkwardness was related to his brain wiring rather than a character flaw proved liberating. “There’s a whole generation of people who grew up lonelier and more isolated and less able to function than they might have been if we had taken steps to integrate them into society,” he said.

Yet even some parents who find the construct of autism useful in understanding and helping children others might call quirky say that in an ideal world, autism as a mental health diagnosis would not be necessary.

“The term has become so diffuse in the public mind that people start to see it as a fad,” said Emily Willingham, who is a co-editor of [“The Thinking Person’s Guide to Autism.”](#) “If we could identify individual needs based on specific gaps, instead of considering autism itself as a disorder, that would be preferable. We all have our gaps that need work.”

Amy Harmon is a national correspondent for The New York Times who has written extensively on autism.



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