Redefining Autism: Will New DSM-5 Criteria for ASD Exclude Some People?

Experts call for small and easy changes to the Diagnostic and Statistical Manual, the "bible" of psychiatry, so that everyone with autism spectrum disorder qualifies for a diagnosis

By Ferris Jabr

By The Numbers: Autism Is Not a Math Problem

People have been arguing about autism for a long time—about what causes it, how to treat it and whether it qualifies as a mental disorder. The controversial idea that childhood vaccines trigger autism also persists, despite the fact that study after study has failed to find any evidence of such a link. Now, psychiatrists and members of the autistic community are embroiled in a more legitimate kerfuffle that centers on the definition of autism and how clinicians diagnose the disorder. The debate is not pointless semantics. In many cases, the type and number of symptoms clinicians look for when diagnosing autism determines how easy or difficult it is for autistic people to access medical, social and educational services.

The controversy remains front and center because the American Psychiatric Association (APA) has almost finished redefining autism, along with all other mental disorders, in an overhaul of a hefty tome dubbed the Diagnostic and Statistical Manual of Mental Disorders (DSM)—the essential reference guide that clinicians use when evaluating their patients. The newest edition of the manual, the DSM-5, is slated for publication in May 2013. Psychiatrists and parents have voiced concerns that the new definition of autism in the DSM-5 will exclude many people from both a diagnosis and state services that depend on a diagnosis.

The devilish confusion is in the details. When the APA publishes the DSM-5, people who have already met the criteria for autism in the current DSM-IV will not suddenly lose their current diagnosis as some parents have feared, nor will they lose state services. But several studies recently published in child psychiatry journals suggest that it will be more difficult for new generations of high-functioning autistic people to receive a diagnosis because the DSM-5 criteria are too strict. Together, the studies conclude that the major changes to the definition of autism in the DSM-5 are well grounded in research and that the new criteria are more accurate than the current DSM-IV criteria. But in its efforts to make diagnosis more accurate, the APA may have raised the bar for autism a little too high, neglecting autistic people whose symptoms are not as severe as others. The studies also point out, however, that minor tweaks to the DSM-5 criteria would make a big difference, bringing autistic people with milder symptoms or sets of symptoms that differ from classic autism back into the spectrum.

A new chapter

Autism is a disorder in which a child's brain does not develop typically, and neurons form connections in unusual ways. The major features of autism are impaired social interaction and communication—such as delayed language development, avoiding eye-contact and difficulty making friends—as well as restricted and repetitive behavior, such as repeatedly making the same sound or intense fascination with a particular toy.

The DSM-5 subsumes autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS)—which are all distinct disorders
in DSM-IV—into one category called autism spectrum disorder (ASD). The idea is that these conditions have such similar symptoms that they do not belong in separate categories, but instead fall on the same continuum.

Essentially, to qualify for a diagnosis of autistic disorder in DSM-IV, a patient must show at least six of 12 symptoms, which are divided into three groups: deficits in social interaction; deficits in communication; and repetitive and restricted behaviors and interests. In contrast, the DSM-5 divides seven symptoms of ASD into two main groups: deficits in social communication and social interaction; and restricted, repetitive behaviors and interests. (For a closer look at the changes, read the companion piece: "Autism Is Not a Math Problem". You can also compare DSM-IV and DSM-5 criteria for autism on the APA's Web site.)

The APA collapsed the social interaction and communication groups from DSM-IV into one group in the new edition because research in the last decade has shown that the symptoms in these groups almost always appear together. Research and clinical experience has also established that heightened or dulled sensitivity to sensory experiences is a core feature of autism, which is why it appears in DSM-5 but not in the preceding version. The psychiatric community has generally applauded these changes to the criteria for ASD.

What is in question is how many of the DSM-5 criteria a patient must meet to receive a diagnosis—too many and the manual excludes autistic people with fewer or milder symptoms; too few and it assigns autism to people who don't have it. Since the 1980s the prevalence of autism has dramatically increased worldwide, especially in the U.S. where the Centers for Disease Control and Prevention estimates that nine per 1,000 children have been diagnosed with ASD. Many psychiatrists agree that the increase is at least partially explained by loose criteria in DSM-IV.

"If the DSM-IV criteria are taken too literally, anybody in the world could qualify for Asperger's or PDD-NOS," says Catherine Lord, one of the members of the APA's DSM-5 Development Neurodevelopmental Disorders Work Group. "The specificity is terrible. We need to make sure the criteria are not pulling in kids who do not have these disorders."

Relaxed requirements
Three studies published between last summer and this month conclude that the DSM-5 criteria for ASD are too strict, but that a few small changes would make them appropriately inclusive. One might think that the APA would conduct such research themselves, but studies that explicitly compare DSM-IV and DSM-5 criteria are not an official part of the revision process. Rather, researchers who are not helping revamp the DSM, but were interested in how the new edition will change psychiatric diagnosis, decided to find out for themselves.

Marja-Leena Mattila of the University of Oulu in Finland conducted the only epidemiological study published so far that explicitly compared the two editions' criteria for autism. (Mattila used DSM-5 criteria posted to the DSM-5 Development Web site in February 2010; the criteria have the same basic structure as the new specifications posted in January 2011, but they are far less detailed and descriptive.) In her study, Mattila surveyed a sample of more than 5,000 Finnish schoolchildren and identified 26 eight-year-olds with an IQ of 50 or higher who qualified for autistic disorder in the DSM-IV. Of those 26, only 12 qualified for ASD in the DSM-5. But when Mattila lowered the threshold for ASD by requiring only two of the three symptoms in the social interaction and communication group, 25 of the

Similarly, Thomas Frazier of the Center for Autism at the Cleveland Clinic performed a series of statistical analyses on symptom reports from nearly 7,000 ASD children, looking for the symptoms that appeared together most frequently. When he programmed a computer to figure out what kind of diagnostic model best reflected the naturally occurring clusters of symptoms, Frazier found that a model with two groups of symptoms—just like the one in the DSM-5—captured how the symptoms clustered in the children better than the DSM-IV or any other model. He also found that the DSM-5 model misdiagnosed autism in only 3 percent of the children, whereas the DSM-IV model misdiagnosed autism in 14 percent. When Frazier relaxed the DSM-5 requirements from five out of seven criteria to four out of seven, he brought back about 12 percent of ASD children that the model originally neglected.

William Mandy of University College London also used statistical analyses to evaluate the DSM-5 criteria and concluded that the two-group DSM-5 model is overall more accurate than the three-group DSM-IV model, but a little too restrictive. Both Frazier's study and Mandy's study are published this month in the Journal of the American Academy of Child and Adolescent Psychiatry.

"They got the major changes right," Mandy says of the APA. "But recent evidence shows that borderline people might miss out on a diagnosis in DSM-5 because they don't have clinical levels of some symptoms, such as repetitive behavior. The real issue is threshold." Not all psychiatrists agree that the stricter DSM-5 criteria should be relaxed, because they think that many people currently diagnosed with Asperger's or PDD-NOS do not in fact have autism and that the new definition of ASD should not include these people. Some parents of children with severe autism are also in favor of stricter criteria, arguing that children who are most in need should receive state services over others with milder symptoms.

Darrel Regier, vice chair of the DSM-5 Task Force, says that he is well aware of the recent studies and that the committee will consider whether they need to revise the DSM-5 criteria for ASD even further. The APA is supposed to finalize all changes to the DSM this year and publish the new edition in May 2013. When asked if he thinks the APA can adjust the revisions to criteria not only for ASD, but for all the other disorders in the DSM-5 by the end of this year, Regier says "there is plenty of time."