

New Definition of Autism Will Exclude Many, Study Suggests



Mary Meyer, right, of Ramsey, N.J., said that a diagnosis of Asperger syndrome was crucial for her daughter, Susan, 37. Todd Heisler/The New York Times

By **Benedict Carey** Jan. 19, 2012

Proposed changes in the definition of autism would sharply reduce the skyrocketing rate at which the disorder is diagnosed and might make it harder for many people who would no longer meet the criteria to get health, educational and social services, a new analysis suggests.

The definition is now being reassessed by an expert panel appointed by the American Psychiatric Association, which is completing work on the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders, the first major revision in 17 years. The D.S.M., as the manual is known, is the standard reference for mental disorders, driving research, treatment and insurance decisions. Most experts expect that the new manual will narrow the criteria for autism; the question is how sharply.

The results of the new analysis are preliminary, but they offer the most drastic estimate of how tightening the criteria for autism could affect the rate of diagnosis. For years, many experts have privately contended that the vagueness of the current criteria for autism and related disorders like Asperger syndrome was contributing to the increase in the rate of diagnoses — which has ballooned to one child in 100, according to some estimates.

The psychiatrists' association is wrestling with one of the most agonizing questions in mental health — where to draw the line between unusual and abnormal — and its decisions are sure to be wrenching for some families. At a time when school budgets for special education are stretched, the new diagnosis could herald more pitched battles. Tens of thousands of people receive state-backed services to help offset the disorders' disabling effects, which include sometimes severe learning and social problems, and the diagnosis is in many ways central to their lives. Close networks of parents have bonded over common experiences with children; and the children, too, may grow to find a sense of their own identity in their struggle with the disorder.

The proposed changes would probably exclude people with a diagnosis who were higher functioning. "I'm very concerned about the change in diagnosis, because I wonder if my daughter would even qualify," said Mary Meyer of Ramsey, N.J. A diagnosis of Asperger syndrome was crucial to helping her daughter, who is 37, gain access to services that have helped tremendously. "She's on disability, which is partly based on the Asperger's; and I'm hoping to get her into supportive housing, which also depends on her diagnosis."

The new analysis, presented Thursday at a meeting of the Icelandic Medical Association, opens a debate about just how many people the proposed diagnosis would affect.

The changes would narrow the diagnosis so much that it could effectively end the autism surge, said Dr. Fred R. Volkmar, director of the Child Study Center at the Yale School of Medicine and an author of the new analysis of the proposal. "We would nip it in the bud."

Experts working for the Psychiatric Association on the manual's new definition — a group from which Dr. Volkmar resigned early on — strongly disagree about the proposed changes' impact. "I don't know how they're getting those numbers," Catherine Lord, a member of the task force working on the diagnosis, said about Dr. Volkmar's report.

Previous projections have concluded that far fewer people would be excluded under the change, said Dr. Lord, director of the Institute for Brain Development, a joint project of NewYork-Presbyterian Hospital, Weill Medical College of Cornell University, Columbia University Medical Center and the New York Center for Autism.

Disagreement about the effect of the new definition will almost certainly increase scrutiny of the finer points of the psychiatric association's changes to the manual. The revisions are about 90 percent complete and will be final by December, according to Dr. David J. Kupfer, a professor of psychiatry at the University of Pittsburgh and chairman of the task force making the revisions.

At least a million children and adults have a diagnosis of autism or a related disorder, like Asperger syndrome or "pervasive developmental disorder, not otherwise specified," also known as P.D.D.-N.O.S. People with Asperger's or P.D.D.-N.O.S. endure some of the same social struggles as those with autism but do not meet the definition for the full-blown version. The proposed change would consolidate all three diagnoses under one category, autism spectrum disorder, eliminating Asperger syndrome and P.D.D.-N.O.S. from the manual. Under the current criteria, a person can qualify for the diagnosis by exhibiting 6 or more of 12 behaviors; under the [proposed definition](#), the person would have to exhibit 3 deficits in social interaction and communication and at least 2 repetitive behaviors, a much narrower menu.

Dr. Kupfer said the changes were an attempt to clarify these variations and put them under one name. Some advocates have been concerned about the proposed changes. "Our fear is that we are going to take a big step backward," said Lori Shery, president of the Asperger Syndrome Education Network. "If clinicians say, 'These kids don't fit the criteria for an autism spectrum diagnosis,' they are not going to get the supports and services they need, and they're going to experience failure."

Mark Roithmayr, president of the advocacy organization Autism Speaks, said that the proposed diagnosis should bring needed clarity but that the effect it would have on services was not yet clear. "We need to carefully monitor the impact of these diagnostic changes on access to services and ensure that no one is being denied the services they need," Mr. Roithmayr said by e-mail. "Some treatments and services are driven solely by a person's diagnosis, while other services may depend on other criteria such as age, I.Q. level or medical history."

In the new analysis, Dr. Volkmar, along with Brian Reichow and James McPartland, both at Yale, used data from a large 1993 study that served as the basis for the current

criteria. They focused on 372 children and adults who were among the highest functioning and found that overall, only 45 percent of them would qualify for the proposed autism spectrum diagnosis now under review.

The focus on a high-functioning group may have slightly exaggerated that percentage, the authors acknowledge. The likelihood of being left out under the new definition depended on the original diagnosis: about a quarter of those identified with classic autism in 1993 would not be so identified under the proposed criteria; about three-quarters of those with Asperger syndrome would not qualify; and 85 percent of those with P.D.D.-N.O.S. would not.

Dr. Volkmar presented the preliminary findings on Thursday. The researchers will publish a broader analysis, based on a larger and more representative sample of 1,000 cases, later this year. Dr. Volkmar said that although the proposed diagnosis would be for disorders on a spectrum and implies a broader net, it focuses tightly on “classically autistic” children on the more severe end of the scale. “The major impact here is on the more cognitively able,” he said.

Dr. Lord said that the study numbers are probably exaggerated because the research team relied on old data, collected by doctors who were not aware of what kinds of behaviors the proposed definition requires. “It’s not that the behaviors didn’t exist, but that they weren’t even asking about them — they wouldn’t show up at all in the data,” Dr. Lord said.

Dr. Volkmar acknowledged as much but said that problems transferring the data could not account for the large differences in rates.

Amy Harmon contributed reporting.

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