

Guideline changes have Asperger's community on edge

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Change in psychiatric manual will fold it into autism spectrum disorders, leaving many unsure about getting needed services

(HealthDay)—People with Asperger's syndrome—mild autism with normal or sometimes superior verbal ability and intelligence—are at a crossroads: Their diagnosis is about to disappear.

In 1994, Asperger's was recognized as its own disorder in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-4*). For some people, realizing that they fit into the Asperger's [diagnosis](#) was a "eureka" moment of sorts.

In mid-May, however, the [American Psychiatric Association](#) (APA) will unveil the latest edition of the diagnostic manual. In the *DSM-5*, the Asperger's term will not exist—and many people with Asperger's are

upset.

[Hallmark symptoms](#)—significant impairment in work and social functioning, inability to understand [nonverbal communication](#), [repetitive behaviors](#) and restricted routines—will be folded into the term "autism spectrum disorders," ranging from the mildest to most severe autism.

The APA says that with the change, diagnosis will become more accurate and consistent.

"The intent was that it would make diagnosis more straightforward," said Catherine Lord, a member of the APA group that updated the diagnoses. "They're not necessarily different disorders because, at least biologically, nobody can differentiate Asperger's from autism."

"One of the good things that the idea of Asperger's syndrome did was make people aware that somebody can have quite significant [social deficits](#) but be a very intelligent person," said Lord, director of the Center for Autism and the Developing Brain at New York-Presbyterian Hospital. "The goal of our committee is not to lose those people but to say they can be recognized within this broader concept of [autism spectrum disorders](#)."

But many with Asperger's believe they will fall off the spectrum and lose access to needed services. And they fear that their very identity is at stake.

Some people with Asperger's syndrome "formed their first identity of normality within the group," said Liane Holliday Willey, senior editor of the *Autism Spectrum Quarterly* and an autism consultant in Grand Rapids, Mich. She has Asperger's.

So does Brian King, an Illinois-based relationship coach and licensed

clinical social worker. With the change, he said, "people who have embraced the Asperger's label are now thinking, 'I have an Asperger's support group. I call myself an Aspie. If you take that from me, who am I?'"

It's not clear how many people have Asperger's. Estimates vary anywhere from three in every 1,000 to one in every 200 people. But experts say the impact of the change will be widespread.

In the United States, *DSM* diagnoses are closely aligned with health insurance billing. Internationally, governments and social agencies use the manual to approve funding for services and research.

"[The *DSM*] has repercussions throughout the world, especially the English-speaking world," said Tony Attwood, an adjunct professor at the Minds & Hearts clinic in Brisbane, Australia.

"I think the banning of the term Asperger's syndrome is too premature," Attwood said. "They're very upset [in Australia]. So they have to explain to, for example, employers, that they are now to be called autistic and have mild autism."

In October, APA member Lord published a study that found only about 10 percent of children would lose their autism diagnosis under the new criteria. Attwood, however, said estimates of people who will lose funding eligibility range anywhere from 10 percent to 75 percent.

King said people who are not obviously struggling may lose out.

"If there is some kid in college who's an intellectual juggernaut—they can pass socially, who can think his or her way through social situations—but is so in need of services on campus, in need of accommodations, that's the person I'm worried about," King said. "The

one who, underneath it all, is suffering, but is so good at passing that they're off the radar of a lot of diagnosticians."

For children with Asperger's, early intervention, which includes parent training, is considered ideal. One question is whether early intervention will be easier or harder to obtain under the new criteria.

"In California, for example, if you have an Asperger's diagnosis, you are not eligible for the autism services as a young child," Lord said. But Attwood said he's concerned that with the change, "parents may not be eligible for early intervention services before the child goes to school."

Lord said a family "must be ready if they meet someone who doesn't understand the new criteria to be able to say, 'Look, one principle is a lack of social reciprocity. And even though my son is 12 years old and very bright and does go to school and does love his teacher and does take turns well, he still really struggles with ... understanding what a friend is even though he has play dates and does do things.'"

Eric Lipshaw, 21, a student at Oakland University in Rochester, Mich., is "110 percent" against the diagnosis change.

"I get disability support services, assistance on campus," Lipshaw said. "They give me a scribe for my handwriting—that's illegible. They have note-takers and anything else we need."

Some job seekers with Asperger's turn to agencies that specialize in people with disabilities. Other adults need social security benefits or residential services. Some will lose these services along with the Asperger's diagnosis, Attwood said.

Karen Rodman, president and founder of Families of Adults Affected with Asperger's Syndrome, said although the Asperger's listing in *DSM-4*

was inadequate it was better than not using the term at all.

Rodman, whose husband has Asperger's and Tourette syndrome, said people with the diagnosis and their family caregivers already have unmet needs for assistance that will only get worse with the change.

One undercurrent in the debate has been the suspicion that the change was made to cut costs. Attwood and King both said that although that might or might not have been an intention, it will be an effect.

"The medical insurance companies and other agencies will save money," Attwood said. "I can't say that this has been the driving force of the change; all I know is that this is the highly probable outcome. With fewer people being diagnosed, it's going to be less expensive for the agencies that support such individuals—either government or private."

Some people with Asperger's may fit under "social communication disorder" in the new *DSM-5*.

The manual also is adding "sensory sensitivity" to the autism spectrum criterion. This involves extreme sensitivity to a person's environment, including the touch of other people, the sensation of the clothing they wear, and sights, smells and sounds around them. Attwood praised this addition.

"The ultimate impact of the *DSM* is going to be wait-and-see," King said. "It's a guideline, not an absolute end-all and be-all of how to treat this. A clinician can use their own judgment based on their own experience."

More information: The U.S. National Institute of Neurological Disorders and Stroke has more about [Asperger's syndrome](#).

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