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Proposed Autism Diagnosis Changes Anger "Aspies"

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CHICAGO (AP) -- In the autism world, "Aspies" are sometimes seen as the elites, the ones who are socially awkward, yet academically gifted and who embrace their quirkiness.

Now, many Aspies, a nickname for people with Asperger's syndrome, are upset over a proposal they see as an attack on their identity. Under proposed changes to the most widely used diagnostic manual of mental illness, Asperger's syndrome would no longer be a separate diagnosis.

Instead, Asperger's and other forms of autism would be lumped together in a single "autism spectrum disorders" category. Some parents say they'd welcome the change, thinking it would eliminate confusion over autism's variations and perhaps lead to better educational services for affected kids.

But opponents - mostly older teens and adults with Asperger's - disagree.

Liane Holliday Willey, a Michigan author and self-described Aspie whose daughter also has Asperger's, fears Asperger's kids will be stigmatized by the autism label - or will go undiagnosed and get no services at all.

Grouping Aspies with people "who have language delays, need more self-care and have lower IQs, how in the world are we going to rise to what we can do?" Willey said.

Rebecca Rubinstein, 23, a graduate student from Massapequa, N.Y., says she "vehemently" opposes the proposal and will think of herself as someone with Asperger's no matter what.

Autism and Asperger's "mean such different things," she said.

Yes and no.

Both are classified as neurodevelopmental disorders. Autism has long been considered a disorder that can range from mild to severe. Asperger's symptoms can vary, but the condition is generally thought of as a mild form and since 1994 has had a separate category in psychiatrists' diagnostic manual. Both autism and Asperger's involve poor social skills, repetitive behavior or interests, and problems communicating. But unlike classic autism, Asperger's does not typically involve delays in mental development or speech.

The American Psychiatric Association's proposed revisions, announced Wednesday, involve autism and several other conditions. The suggested autism changes are based on research advances since 1994 showing little difference between mild autism and Asperger's. Evidence also suggests that doctors use the term loosely and disagree on what it means, according to psychiatrists urging the revisions.

A new autism spectrum category recognizes that "the symptoms of these disorders represent a continuum from mild to severe, rather than being distinct disorders," said Dr. Edwin Cook, a University of Illinois at Chicago autism researcher and member of the APA work group proposing the changes.

The proposed revisions are posted online at <http://www.DSM5.org> for public comment, which will influence whether they are adopted. Publication of the updated manual is planned for May 2013.

Dr. Mina Dulcan, child and adolescent psychiatry chief at Chicago's Children's Memorial Hospital, said Aspies' opposition "is not really a medical question, it's an identity question."

"It would be just like if you were a student at MIT. You might not want to be lumped with somebody in the community college," said Dulcan who supports the diagnostic change.

"One of the characteristics of people with Asperger's is that they're very resistant to change," Dulcan added. The change "makes scientific sense. I'm sorry if it hurts people's feelings," she said.

Harold Doherty, a New Brunswick lawyer whose 13-year-old son has severe autism, opposes the proposed change for a different reason. He says the public perception of autism is skewed by success stories - the high-functioning "brainiac" kids who thrive despite their disability.

Doherty says people don't want to think about children like his son, Conor, who will

never be able to function on his own. The revision would only skew the perception further, leading doctors and researchers to focus more on mild forms, he said.

It's not clear whether the change would affect autistic kids' access to special services.

But Kelli Gibson of Battle Creek, Mich., whose four sons have different forms of autism, thinks it would. She says the revision could make services now designated just for kids with an "autism" diagnosis available to less severely affected kids - including those with Asperger's and a variation called pervasive developmental disorder-not otherwise specified.

Also, Gibson said, she'd no longer have to use four different terms to describe her boys.

"Hallelujah! Let's just put them all in the same category and be done with it," Gibson said.