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Study on DSM-5 shows effects on autism diagnosis and prevalence

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A new study finds that the estimated prevalence of autism under the new DSM-5 criteria would decrease only to the extent that some children would receive the new diagnosis of social communication disorder (SCD). The study, funded in part by a research grant from Autism Speaks, the world's leading autism science and advocacy organization, appears online in the *Journal of the American Academy of Child and Adolescent Psychiatry*.

Overall, the researchers found that 83 percent of children who received a diagnosis of autism under the DSM-IV would also receive the diagnosis under DSM-5. The remaining 14 percent would be diagnosed with SCD. These results help answer questions raised by a Centers for Disease Control and Prevention study published last week. Last week's CDC study similarly concluded that DSM-5 would lower estimates of autism prevalence by around 10 percent. However, this study did not take into account SCD, nor did it directly evaluate children for either disorder. Rather, it attempted to apply the new criteria to old medical and educational records of children identified as having autism in 2008.

The new diagnosis of SCD was created along with revised criteria for autism in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), last May. SCD describes individuals who have social and communication difficulties without the repetitive behaviors or restrictive interests typical of autism. In addition, the DSM-5 combined earlier subtypes of autism into one diagnosis of autism spectrum disorder (ASD).

Both studies back earlier "field tests" of the DSM-5 criteria, which likewise suggested that the new category of SCD would apply to around 10 percent of children who would have previously received a diagnosis of autism. This sparked widespread concern among many families and autism advocates because, as yet, there are no treatment guidelines for SCD. Backing these concerns, Autism Speaks has received accounts from families who report their children losing autism services after an earlier diagnosis of ASD was changed to SCD.

"Autism Speaks is taking these reports of lost services very seriously," says Autism Speaks Chief Science Officer Rob Ring. "We advocate for all individuals affected by disabling symptoms that would benefit from autism-related services and supports."

The new findings were based on detailed, in-person ASD evaluations performed during an earlier Autism Speaks study by the same investigators. The earlier study looked at more than 55,000 children, ages 7 to 12 years old, in a South Korean suburb. Using DSM-IV criteria, it found an autism prevalence of 1 in 38 (2.6 percent). Importantly, this prevalence number included many children whose autism had gone previously undetected. As such, they would have been missed by estimating prevalence based on autism service records, as is done by the CDC.

In their new study, the investigators used DSM-5 criteria to re-assess the symptoms of 292 children diagnosed with autism during their earlier study. This lowered their estimate of ASD prevalence to 2.2, or 1 in 45. But the difference disappeared when they added back the children who fit the new diagnosis of SCD.

The researchers went further to determine which children would be most likely to have their diagnosis changed from autism to SCD. The old, DSM-IV guidelines categorized individuals with autism into subtypes.

These included autistic disorder, Asperger disorder and pervasive developmental disorder not otherwise specified (PDD-NOS).

Looking at these subtypes, Yale child psychiatrist and epidemiologist Young-Shin Kim and her colleagues found the following:

- Of children previously diagnosed with PDD-NOS, 71 percent would now be diagnosed with ASD, 22 percent with SCD and 7 percent with another non-autism disorder.
- Of those previously diagnosed with Asperger disorder, 91 percent would now be diagnosed with ASD, 6 percent with SCD and 3 percent with another non-autism disorder.
- Of those previously diagnosed with autistic disorder, 99 percent would now be diagnosed with ASD and 1 percent with SCD.

"Until proven otherwise, the treatments for ASD and SCD should remain the same or similar," says Dr. Kim. "It's important for children moving to a SCD diagnosis – and to their families – that they continue receiving the interventions they would have received with an autism diagnosis under the earlier DSM-IV criteria."

"Our research team also wants to thank Autism Speaks and its donors for supporting this important work," she adds. In addition to two grants from Autism Speaks, the study also received support from the Brain Research Foundation, the Simons Foundation, and the National Institutes of Health.

Provided by Autism Speaks