

Study: Milder autism far outpacing 'profound' diagnoses

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An autistic boy holds the hand of his adoptive father as they prepare to leave for a family outing from their home in Springfield, Mass., on Saturday, Dec. 12, 2015. Traditionally, autism was diagnosed only in kids with severe language and social impairments and unusual repetitious behaviors. But the definition gradually expanded, and autism is now shorthand for a group of milder, related conditions, too. Credit: AP Photo/Charles Krupa, File

As autism diagnoses become increasingly common, health officials have wondered how many U.S. kids have relatively mild symptoms and how many have more serious symptoms, such as very low IQ and inability to speak.

A first-of-its-kind study released Wednesday shows the rate of such "profound" [autism](#) is rising, though far slower than milder autism cases.

"It's very important to know how many people have profound autism so that we can properly prepare for their needs," including more health and [education services](#), said Alison Singer, executive director of the advocacy and research group Autism Science Foundation.

Singer—the mother of a 25-year-old woman with profound autism—was a co-author of [the paper](#), which was published by the journal *Public Health Reports*. Scientists at the Centers for Disease Control and Prevention led the research.

Though autism has been diagnosed for at least 80 years, the new study is the first to put a number on the share of U.S. children who have the most severe version of it. It comes less than two years after an international commission of autism experts established [a definition of profound autism](#): children with an IQ of 50 or less, and/or kids who can't communicate through speaking.

Under that definition, about a quarter of U.S. children identified as having autism by age 8 fall into the profound category, the new study found. It means more than 110,000 elementary school-age children in the U.S. have profound autism.

There are no blood or biological tests for autism. It's identified by making judgments about a child's behavior. Traditionally, it was diagnosed only in kids with severe language difficulties, social

impairments and unusual repetitious behaviors. But the definition gradually expanded, and autism is now shorthand for a group of milder, related conditions, too.

The researchers looked at school and [medical records](#) from 2000 to 2016 for more than 20,000 8-year-olds identified as having [autism spectrum disorders](#).

They found that the rate of profound diagnoses grew from about 3 cases per 1,000 children in 2000 to about 5 cases per 1,000 in 2016. But the rate of kids diagnosed with milder forms of autism grew from 4 per 1,000 to 14 per 1,000 over those years.

Milder forms of autism were more common in boys and white kids, the researchers found. Profound autism was more common in girls than boys.

A CDC study published last month found that autism overall [is being diagnosed more frequently](#) in Black and Hispanic children than in [white kids](#) in the U.S., a change from previous years when white children were more likely to be diagnosed. Experts cite improved screening and services, and increased awareness and advocacy. Among 8-year-olds, 1 in 36 had autism in 2020, the CDC estimates.

The new research found a large racial gap in profound autism. Among Black children with autism, 37% had profound autism. The same was true for about one-third of Hispanic kids with autism and about one-fifth of [white children](#) with autism.

More research is needed to understand the reasons for those differences, said the CDC's Michelle Hughes, the study's lead author.

Singer said the study's publication marks a recognition by the CDC that

"autism spectrum disorder diagnoses is overly broad and that people who are diagnosed with (it) have very different needs." The data should help identify schooling and residential needs, she said.

Jan Blacher, an autism researcher at the University of California at Riverside, voiced mixed feelings about the report.

Using an IQ of 50 as a definition of profound autism can be problematic, she said. She has observed children with an IQ above 70 who had the kind of symptoms associated with profound autism, like spinning or a seemingly meaningless repeating of words.

"It's the symptoms of autism that make a difference," she said.

She worries that [children](#) who don't make the cut-off might not get the same attention and help as those who do.

"We have work to do at all levels of the continuum," she said.

More information: Michelle M. Hughes et al, The Prevalence and Characteristics of Children With Profound Autism, 15 Sites, United States, 2000-2016, *Public Health Reports* (2023). [DOI: 10.1177/00333549231163551](#)

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