'Diagnostic Substitution' Drives Autism Spike

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A child in New York taking part in a swim program funded by Autism Speaks, a nonprofit group. *Photo: Seth Wenig/Associated Press*

By

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The number of children diagnosed with autism has surged around the globe in the past two decades. But new research in Europe and the U.S. suggests much of the increase

occurred on paper.

In 2000, the U.S. Centers for Disease Control and Prevention estimated 1 in 150 children in its surveillance areas had autism spectrum disorder. By 2012, the figure had grown to 1 in 88. Last year, the agency estimated 1 in 68 children suffered from the disorder.

Compared with the 1970s, when only about 3 in 10,000 children was diagnosed with the complex neurobiological condition, it is no wonder talk of an epidemic took hold.

Parents, fearing for their children, were unnerved by the spread of a disabling condition whose symptoms ranged from social awkwardness to repetitive behaviors and an inability to speak. Researchers, seeking to prevent or treat the disorder, were flummoxed.

Desperate for an explanation, some blamed vaccines—a theory that has been discredited—while others suspected exposure to chemicals such as pesticides or phthalates.

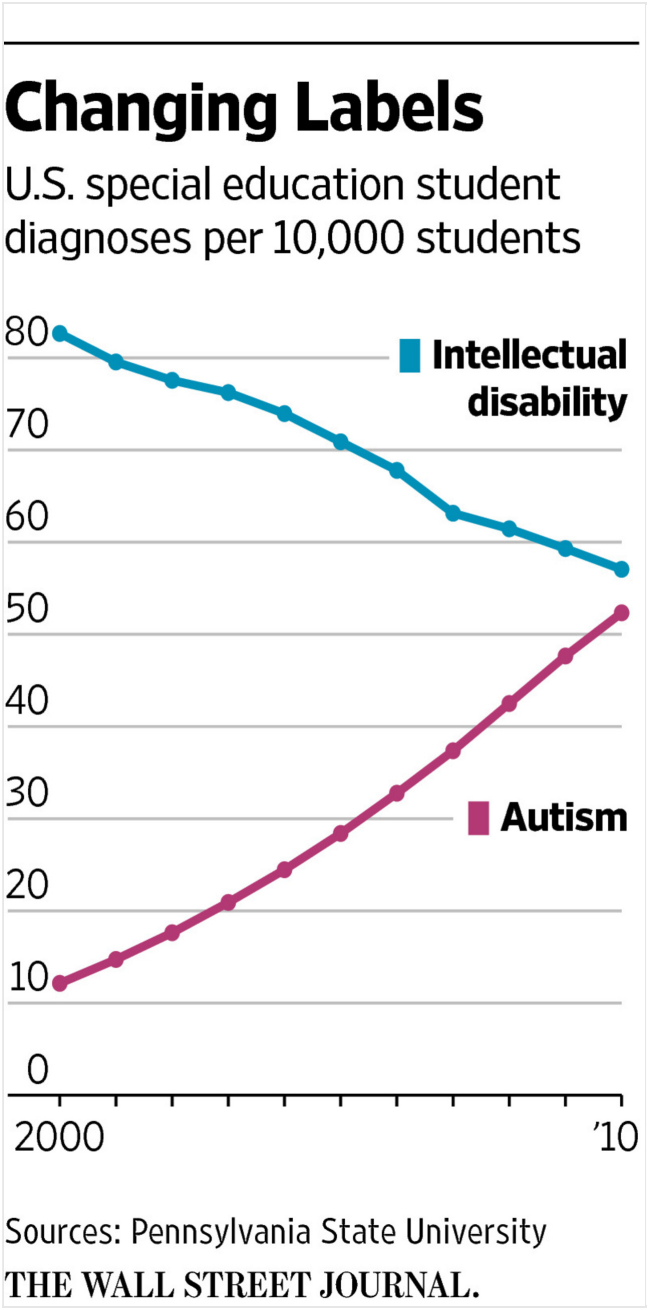
But studies in Sweden, Denmark and the U.S. suggest that a significant portion of the increase can be attributed to more diagnoses, rather than to more cases.

In other words, increasing numbers of children have been labeled autistic when in the past they might have received a different diagnosis, or in less severe cases, perhaps no diagnosis at all.

In scientific jargon, this is called diagnostic substitution: One label replaces another, causing an apparent decrease in the prevalence of the first condition and a corresponding increase in the prevalence of the second.

Most recently, researchers at Penn State University examined 11 years of U.S. special-education enrollment records from 2000 to 2010, with about 6.2 million children each year, to see how the students were categorized.

The Penn State researchers documented that the number of children diagnosed with



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intellectual disability in the U.S. declined as the number diagnosed with autism climbed. By 2010, the upward- and downward-sloping trend lines nearly converged, and the researchers estimate the shift accounted for 64.2% of the increase in autism diagnoses in the period.

"It's almost like a mirror image," said Andrew Polyak, the lead author on the study, which was published in July in the American Journal of Medical Genetics.

Other countries also have documented large increases in autism, and other researchers have found similar explanations for the change.

Danish investigators examined the prevalence of autism among 677,915 individuals born in Denmark between 1980 and 1991 and found that 60% of the increase was caused by changes to the criteria for diagnosing the disorder and the way diagnoses were recorded. The results were published in January in JAMA Pediatrics.

Swedish researchers examined the national patient register of 1 million children born in Sweden from 1993 to 2002 and survey data for 20,000 twins. They found the number of autism diagnoses had increased significantly even though the number of children displaying symptoms had remained stable.

The finding, which was published in April in the British Medical Journal, compared the prevalence of cases recorded in the national patient register with the prevalence of

children who had symptoms of autism based on survey data. Registered cases increased over the 10-year period, while cases reported in annual surveys didn't.

Some advocates and researchers suggest surveys provide a fuller accounting of autism than patient registers or special-education rolls because not all autistic individuals receive treatment or services. Because of these omissions in health and education records, advocates say studies like the one at Penn State don't account for everyone with autism and, as a result, they overestimate the effect of diagnostic substitution.

"What the studies insinuate is all of the increase can be explained by diagnosis," said Michael Rosanoff, the director of public health research for Autism Speaks. "There is absolutely some artificial increase due to changes in diagnostic criteria, but it can't explain all of the increase. About half is explained. About half is not yet explained."

Regardless of the exact figure, several things have contributed to the paper increase. For one thing, autism is a relatively new diagnostic option, and the definition of the condition has changed over time.

In the U.S., autism wasn't a unique category in the Diagnostic and Statistical Manual of Mental Disorders, which sets criteria for classifying mental disorders, until 1980. It wasn't included as special-education category until 1991. And initially, the diagnostic criteria were very strict.

"Only children exhibiting very specific behaviors had autism" according to the manual, said Daisy Christensen, an epidemiologist with the CDC.

The criteria were rarely met, but the definition changed in 1987 and again in 1994, when it was broadened to include a range of behaviors that varied in characteristics and severity. "Not only were there more possible behaviors, but fewer were required for a diagnosis," Dr. Christensen said.

The latest edition of the manual, which came out in 2013, revises the definition yet again —and this time, it is stricter than before.

Now, only individuals with both social communication and interaction disorders and restricted or repetitive behaviors will be diagnosed with autism, Dr. Christensen said. “Individuals who have all the symptoms without repetitive or restricted behaviors will no longer be diagnosed as autistic.”

The CDC is currently assembling data using the new definition. It expects to report the numbers in 2018, and it is likely the prevalence of autism will decrease.

At least on paper.

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