NEWS

New U.S. data show similar autism prevalence among racial groups

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Autism prevalence in the United States continues to rise, according to a new study of 8-year-old children in 11 states¹. Boys are 4.3 times as likely as girls are to have autism, a ratio that is **consistent with previous estimates**.

The report, released today by the Centers for Disease Control and Prevention (CDC), shows that 1 in 54 children had autism in 2016. This represents a 10 percent increase over the 2014 prevalence of 1 in 59 children.

An accompanying report on 4-year-old children suggests that more autistic children are being identified earlier². If the trend continues, experts say, the prevalence among 8-year-olds will continue to rise.

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Part of the increase in overall prevalence could be due to a growing awareness among healthcare providers of the need for autism screening and treatment. But experts see some contribution from greater inclusion of children from different racial and ethnic groups.

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For the first time, the CDC report shows a nearly identical prevalence in black and white children. Researchers had long suspected that the previously seen differences reflected a **bias against non-white groups** rather than a true difference in prevalence, and the new study supports that idea. However, autism prevalence in Hispanic children still lags behind those of other groups.

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"Those indicators, I think, could be taken as signs of progress that more is being done to identify and diagnose and evaluate children early," says **Matthew Maenner**, epidemiologist and surveillance team lead for the Developmental Disabilities Branch of the CDC's National Center on Birth Defects and Developmental Disabilities. "But there's still work to be done, too."

Cumulative incidence:

The prevalence estimates are based on health and educational records collected at 11 sites by the CDC's Autism and Developmental Disabilities Monitoring Network.

As such, the data are a good indication of the number of children who appear to have autism based on those records — but they also reflect awareness and diagnosis of the condition, rather than true prevalence, says **Radley Sheldrick**, research associate professor of health law, policy and management at Boston University in Massachusetts, who was not involved in the analysis. "We have to be super concrete that it's more about the ascertainment than it is about true prevalence," he says.

The CDC report also includes the 'cumulative incidence' of autism in the sample population, a measure that was not included in previous reports. Cumulative incidence is an indicator of the proportion of all children with autism who are diagnosed by a certain age.

The national cumulative incidence is 13.2 per 1,000 children at age 8 compared with 10.2 at age 4.

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The figure for children who were 4 years old in 2016 is higher than the 8.3 cumulative incidence for children who were 4 years old in 2012. That's because clinicians are starting to diagnose autism at younger ages, says Kelly Shaw, epidemiologist in the Developmental Disabilities Branch of the CDC's National Center on Birth Defects and Developmental Disabilities.

The cumulative incidence also provides a more granular measure than simple prevalence for how

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effectively each state is identifying children, Maenner says.

Problematic trend:

For example, New Jersey's prevalence — 1 in 32 children — does not give as precise a picture of early identification and diagnosis in the state as its cumulative incidence of nearly 23 in 1,000 for 8-year-olds. The latter shows that clinicians in New Jersey diagnosed more children at an early age than any of the other sites.

The cumulative incidence for New Jersey is a matter of concern, says **Eric Fombonne**, director of autism research at the Institute on Development and Disability at Oregon Health and Science University in Portland, who was not involved in the study. New Jersey's cumulative incidence for 8-year-old children is almost twice the national average, with about half of the children being diagnosed after age 4.

The slope does not plateau, either; if the trend continues, Fombonne says, the autism prevalence in 18-year-olds would be as high as 6 percent.

"Autism occurs and shows up in the first three years of life," Fombonne says. "I'm just concerned why there has been such a delay in identification of these children and whether or not the diagnoses are accurate."

The numbers in New Jersey may not be particularly representative of the true prevalence in the U.S., Fombonne says, and may partly result from more "cooperative" schools participating in the study.

Follow-up studies to confirm the children's diagnoses in their teenage years could help clarify the numbers, he says.

State matters:

Autism prevalence among children of both age groups varies widely among states, as it did in the 2014 data. For children aged 4 and under, for example, the prevalence ranges from 8.8 per 1,000 children in Missouri to 25.3 per 1,000 in New Jersey; for children aged 8 and under, the range is 13.1 in Colorado to 31.4 in New Jersey.

The variability across sites is "mind-boggling," Fombonne says. "This average is on a background of extreme geographical diversity in the estimates, and that is also something which is troubling."

The disparity could be the result of differences in diagnostic practices and availability of services, but Sheldrick says it may also represent a true variability in prevalence from some environmental cause.

"It really raises the question of whether and how state-level policy might be influencing the lives of kids with autism," Sheldrick says. "The fact is we really just don't know."

New Jersey, for example, is known to have one of the strongest systems in the country for identifying and **evaluating children with developmental conditions**. That may spur both parents and clinicians to be more proactive about evaluating children, compared with states where being diagnosed does not immediately open a door to more services, Sheldrick says. Parents in those states may be more inclined to take a "wait-and-see" approach.

"There might be a theoretical benefit to early intervention," he says, "but if you can't actually access that high-quality early intervention, then what's the rush?"

The increasing prevalence in children indicates that autistic adults also need more consideration, says **Catherine Rice**, director of the Emory Autism Center in Atlanta, Georgia. According to the new estimates, nearly 75,000 autistic adolescents will become adults each year, she says, confirming that autism is an "important public health condition."

"Most communities are not prepared to inclusively and respectfully address the many quality-of-life challenges unique to those on the spectrum," Rice says. "As a society, we need to consider the long-term health and wellness of adults across the autism spectrum."

REFERENCES:

- 1. Maenner M.J. et al. MMWR Surveill. Summ. 69, 1-12 (2020) Full text
- 2. Shaw K.A. et al. MMWR Surveill. Summ. 69, 1-11 (2020) Full text