

Q&A

Questions for Stephen Blumberg: Tracking autism's transience

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Estimating autism's **prevalence** is tricky. No strategy is perfect, so researchers rely on a combination of approaches, such as sweeping national surveys and smaller pockets of meticulous monitoring.

These different tactics have all led to the same general conclusion: Autism is on the rise. Between 2012 and 2014, the prevalence rose from **1 in 88 to 1 in 68** children at age 8 — an increase of about 30 percent. But a new study from the U.S. Centers for Disease Control and Prevention (CDC) reveals an interesting twist. Roughly 13 percent of children with autism eventually **lose their diagnosis**, either because they outgrow it or because they never had autism to begin with.

The findings, published 20 October in *Autism*, highlight a pitfall of the tracking techniques that epidemiologists use. Surveys and medical-record reviews provide a snapshot of autism's frequency that may fail to capture these 'lost' diagnoses, inflating the prevalence. There is also value in understanding which children lose their diagnosis and why.

We spoke to lead researcher Stephen Blumberg, associate director for science at the CDC's **National Center for Health Statistics**, about the study's findings and what they mean.

Spectrum: How does the CDC track autism prevalence?

Stephen Blumberg: The CDC monitors the prevalence of autism in two primary ways. Through the Autism and Developmental Disabilities Monitoring Network, experts review medical and educational records from select sites across the U.S. to identify children who have an autism diagnosis or behaviors that would strongly suggest an autism diagnosis. It is in many ways considered a gold-standard measure of autism prevalence, but it takes a long time to compile that information. The most recent report — the one that says 1 in 68 children have autism spectrum disorder — is based on 2010 data for 8-year-old children in 11 communities.

The other way is through nationwide surveys that ask parents whether their children have ever been diagnosed with autism spectrum disorder by a doctor or other healthcare provider. The surveys have large sample sizes and are of high quality, but are limited by the knowledge parents have and their ability to recall their children's diagnoses. In addition, some children with autism may not have received a diagnosis from a healthcare professional because they have limited access to the healthcare system, or they're in a school system that has limited resources to conduct or share diagnostic evaluations.

Each system has its strengths and weaknesses. Together, they help us to understand the prevalence of autism, and both show that the prevalence has been increasing over time.

S: Why did you conduct this study?

SB: I think researchers have recognized that autism diagnoses sometimes change due to misdiagnoses, maturation or treatment. The purpose of our study was to better understand which of those reasons is most common and to learn who's most likely to lose an autism diagnosis.

S: What did you find?

SB: Approximately one out of eight children ever diagnosed with autism had lost their diagnosis. And of the children who had been diagnosed with autism but no longer had a diagnosis, the parents of 74 percent said a doctor changed their child's diagnosis because of 'new information.' This translates to 9 percent of school-age children ever diagnosed with autism having lost their diagnosis due to new information.

S: What is this new information?

SB: We don't have a clear answer. We didn't ask what the new information was or what guided the doctor's decision-making. What we did find is that when a doctor changed the diagnosis, attention deficit hyperactivity disorder (ADHD) was the most common replacement diagnosis. But children who lost their autism diagnosis were no more likely to have ADHD than children currently diagnosed with autism.

S: Why ADHD?

SB: Symptoms of hyperactivity, impulsivity and inattention are common in children who have autism. For some children with ADHD, these symptoms may initially receive less attention because of social communication issues that they eventually grow out of.

S: What were some other reasons for a lost diagnosis?

SB: Sometimes a doctor may give an autism diagnosis so that a child with other developmental issues can receive necessary services. In about one in four children who lost an autism diagnosis, the parents said the initial diagnosis was given for this reason. In addition, for about one in five children, the parents gave an answer suggesting that early intervention, treatment or maturity resulted in the child's behaviors changing or the autism symptoms going away.

S: What do your findings say about the rise in autism?

SB: Our finding that autism diagnoses are not necessarily permanent can complicate the use of surveys to estimate the prevalence of autism. However, our estimated prevalence of lost diagnoses — about 13 percent of children who are diagnosed — is still too low to explain the recent increase in the estimated prevalence of autism.

S: Should researchers change the way they track autism prevalence?

SB: As a result of the findings here, we're adding a question about current autism [diagnosis] to the **National Health Interview Survey** — a representative survey of more than 40,000 households in the U.S. This annual survey now asks only whether a child has ever been diagnosed. By adding the new question, we can use that survey to monitor the difference between children who have ever been diagnosed with autism and those who currently have a diagnosis.