

## BEHAVIOR &amp; SOCIETY

## The Real Reasons Autism Rates Are Up in the U.S.

A hard look at whether the rise comes from more awareness, better diagnosis—or something else

By Jessica Wright, Spectrum on March 3, 2017



*Credit: Bee Johnson Spectrum*

The prevalence of autism in the United States has risen steadily since researchers first began tracking it in 2000. The rise in the rate has sparked fears of an autism ‘epidemic.’ But experts say the bulk of the increase stems from a growing awareness of autism and changes to the condition’s diagnostic criteria.

Here’s how researchers track autism’s prevalence and explain its apparent rise.

### **How do clinicians diagnose autism?**

There is no blood test, brain scan or any other objective test that can diagnose autism

—although researchers are actively trying to develop such tests. Clinicians rely on observations of a person’s behavior to diagnose the condition.

In the U.S., the criteria for diagnosing autism are laid out in the “Diagnostic and Statistical Manual of Mental Disorders” (DSM). The criteria are problems with social communication and interactions, and restricted interests or repetitive behaviors. Both of these ‘core’ features must be present in early development.

### **What is the prevalence of autism in the U.S.?**

The Centers for Disease Control and Prevention (CDC) estimates that 1 in 68 children in the U.S. have autism. The prevalence is 1 in 42 for boys and 1 in 189 for girls. These rates yield a gender ratio of about five boys for every girl.

### **How does the CDC arrive at this number?**

CDC researchers collect health and school records for 8-year-old children who live in select U.S. counties. These researchers are part of the Autism and Developmental Disabilities Monitoring Network, which the CDC set up in 2000 to estimate autism prevalence.

Every two years, trained clinicians scan the records for signs of autism features, such as social problems or repetitive behaviors. They focus on 8-year-olds because most children are enrolled in school and have had routine health assessments by that age<sup>2</sup>. They then decide whether each child meets the criteria for autism, even if the child does not have a diagnosis, and extrapolate the results to all children in the state.

The most recent prevalence estimates are based on data from 11 network sites in 11 states. The CDC plans to focus on 10 of these sites for future assessment. At six of the sites, clinicians plan to survey the records of children at both 4 and 8 years of age.

### **How has autism prevalence changed over time?**

The latest estimate of autism prevalence—1 in 68—is up 30 percent from the 1 in 88 rate reported in 2008, and more than double the 1 in 150 rate in 2000. In fact, the trend has been steeply upward since the early 1990s, not only in the U.S. but globally, says Maureen Durkin, who heads the network site in Wisconsin.

### **How accurate is the CDC's approach?**

The strength of the approach is that it takes a snapshot of all children who live in a certain area, not just those who have a diagnosis, according to Eric Fombonne, professor of psychiatry at Oregon Health and Science University in Portland. But, he notes, relying on school and medical records is not as accurate as assessing a child in person.

The approach also misses children who have no school or medical records, including some who are home-schooled or live in isolated regions. And children within the monitored areas may not be representative of all children in a state.

One indication that the method is imperfect is the fact that autism rates vary dramatically between states. The prevalence in Colorado, for instance, is 1 in 93 children, whereas in New Jersey it is 1 in 41. It is unlikely that the rates naturally vary that much between states, Fombonne says. Instead, the difference probably reflects varying levels of autism awareness and of services offered in those states.

### **Has our definition of autism changed over the years?**

How people think about and diagnose autism has changed substantially since the diagnosis was first introduced nearly 75 years ago. In 1943, Leo Kanner first coined the term 'infantile autism' to describe children who seemed socially isolated and withdrawn.

In 1966, researchers estimated that about 1 in 2,500 children had autism, according to criteria derived from Kanner's description. This and other early estimates of prevalence probably focused on children at the severe end of the spectrum and missed those with subtler features.

Autism didn't make its debut in the DSM until 1980. In 1987, a new edition expanded the criteria by allowing a diagnosis even if symptoms became apparent after 30 months of age. To garner a diagnosis, a child needed to meet 8 of 16 criteria, rather than all 6 of the previous items. These changes may have caused the condition's prevalence to tick above 1 in 1,400.

Then, in 1991, the U.S. Department of Education ruled that a diagnosis of autism qualifies a child for special education services. Before this time, many children with autism may instead have been listed as having intellectual disability. The change may have encouraged families to get a diagnosis of autism for their child. The number of children who have both a diagnosis of autism and intellectual disability has also risen steadily over the years.

In 1994, the fourth edition of the DSM broadened the definition of autism even further, by including Asperger syndrome on the milder end of the spectrum. The current version, the DSM-5, was released in 2013, and collapsed autism, Asperger syndrome and pervasive developmental disorder-not otherwise specified into a single diagnosis.

The most recent CDC estimate of autism prevalence is based on the fourth edition of the DSM. Future estimates will be based on DSM-5 criteria—which may lower autism rates.

### **Has the rising awareness of autism contributed to the prevalence?**

Increased awareness of autism has undoubtedly contributed to its rise in prevalence, Durkin says.

Until the 1980s, many people with autism were institutionalized, rendering them effectively invisible. Studies show that parents who are aware of autism's presentation—by living near someone with the condition, for example—are more likely to seek a diagnosis for their children than parents with no knowledge of the condition. Living close to urban centers and having access to good medical care also boost the likelihood of diagnosis.

Greater awareness of autism is also likely to boost CDC estimates by increasing the chances that autism traits, such as lack of eye contact, show up in school and medical records, says Fombonne.

Policy changes may have also played a role. In 2006, the American Academy of Pediatrics recommended screening all children for autism during routine pediatrician visits at 18 and 24 months of age. This move may have led to diagnoses for children who would otherwise have slipped under the radar.

### **Are there other factors that have influenced prevalence?**

Many individuals diagnosed with autism may, in the past, have been misdiagnosed with other conditions, such as intellectual disability: As diagnoses of autism have risen, those of intellectual disability have decreased.

What's more, a diagnosis of autism gives children greater access to specialized services and special education than do diagnoses of other conditions. This benefit makes clinicians more likely to diagnose a child with autism, even those who are on the borderline of the clinical criteria.

Prior versions of the DSM did not allow for children to be diagnosed with both autism and attention deficit hyperactivity disorder. The DSM-5 allows multiple diagnoses, and most children with developmental delay are routinely screened for autism.

Autism prevalence has traditionally been highest in white children in the U.S, but this is starting to change. African-American and Hispanic children have lower rates of diagnosis because of a lack of access to services. Widespread screening has improved detection of autism in these groups, and raised overall prevalence.

### **Is there no real increase in autism rates, then?**

Awareness and changing criteria probably account for the bulk of the rise in prevalence, but biological factors might also contribute, says Durkin. For example, having older parents, particularly an older father, may boost the risk of autism. Children born prematurely also are at increased risk of autism, and more premature infants survive now than ever before.

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