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How Many Kids Have Autism?



By CARL BIALIK

Several skeptical Numbers Guy readers have suggested I look into an alarming claim: that one in 166 U.S. children has autism.

That stat has received a lot of attention recently in [advocacy materials](#), television [ads](#) and newspapers, including reports in the [Dallas Morning News](#), the [Chicago Tribune](#) and the [Savannah Morning News](#).

Join a Discussion



How important is it to accurately count the number of children with autism? Does the one-in-166 number seem too high, or too low, or accurate? Do you generally believe statistics on the number of people suffering from conditions? Do such numbers affect your opinions? [Join a discussion with Carl Bialik.](#)

Autism experts told me that research broadly supports the estimate -- with two major caveats. Those caveats help explain why the stat, while alarming, doesn't support related claims by some advocates: that autism cases have been mushrooming with "epidemic speed," and that more than one million Americans have autism.

First, the stat comes from figures [published](#) by the Centers for Disease Control and Prevention, based on a review of several studies that came up with estimates. But the CDC was careful to point out that the studies produced a wide range of results. Indeed, the headline-grabbing number focuses on the worst-case scenario: The CDC said the number of children with autism was somewhere between one in 500 and one in 166.

Second, the numbers take into account a relatively modern definition of autism that includes a full range of disorders. The changing definition of autism has played a major role in influencing statistics.

The cause of autism isn't completely understood; a combination of genetic and environmental factors is believed to play a part, [according to the CDC](#). Autism can usually be diagnosed before the age of three, [according to the National Institutes of Health](#). Different from mental retardation, autistic disorders (as they are now defined) are characterized by impairment in communication and other social interaction. Mental retardation, characterized in part by a low intelligence-test score, can coincide with autism, but some people with autism have above-

average IQs.

Those with "high-functioning autism" or with Asperger's Disorder -- distinguished by less-severe symptoms that may not become apparent until later in life -- are likely to have an easier time of adapting to mainstream society, and therefore their conditions can be more difficult to diagnose. Other people with more severe cases of autism may require special education throughout school years and may have difficulty living independently as adults.

The broad definition used to arrive at the one-in-166 figure, which includes milder forms like Asperger's syndrome, was published by the American Psychiatric Association in 1994 in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, known as the DSM-IV -- the primary handbook for diagnosing mental disorders.

Eric Fombonne, an autism expert at Montreal's McGill University, told me that while about a dozen studies around the world have found autism prevalence rates that would be in line with the one-in-166 estimate, that same research found that the majority of those people had a mild form of the condition.

The high profile of the one-in-166 number has been driven by increased public-awareness campaigns about autism from the government and advocacy groups. In 2004, the CDC, the Department of Health and Human Services, the American Academy of Pediatrics and other groups issued an alert ([Autism A.L.A.R.M.](#)) to doctors citing the 1-in-166 stat and advising on how to screen for cases. Since then, the CDC has reaffirmed the number in an online [fact sheet](#) (where it cited the broad range of estimates) and in a May [report](#) in its Morbidity and Mortality Weekly Report -- the latter was based on parents' self-reporting of their doctors' diagnoses. Meanwhile, an even more recent U.K. study [published](#) over the summer in the Lancet found a rate of children with autism of between one in 110 and one in 70.

The CDC has increased research spending on autism by 80% since 2002, to \$15.1 million this year. (Autism groups say the government is still spending too little on research and support for parents and adults with autism.)

A nonprofit autism-advocacy group called Autism Speaks put the one-in-166 stat front and center in a media [campaign](#) distributed by the nonprofit Ad Council. The organization has grown quickly since launching last year, and is distributing \$15 million in research funds this year, spokeswoman Susan Arons told me. "We're using what is a very well-known, well-accepted number," she said. "We don't want to be alarmists; we want to be accurate."

The nonprofit Autism Society of America, one of the oldest and largest autism groups, has seen its budget grow steadily in recent years, to about \$20 million this year, President Lee Grossman told me. He attributed the increased donations to greater public awareness.

"The one in 166 has been the biggest boon to awareness we've had," said Marguerite Colston, director of communications for the Autism Society. "Those kinds of numbers stop people in their tracks, as they should."

More Numbers

Equally galvanizing but more questionable are claims by some advocates, including the Autism Society, that autism prevalence has grown rapidly. An Autism Society [Web page](#) said autism is "the fastest-growing developmental disability," and said the number of people with autism increased 172% in the 1990s while population rose 13%.

Trend figures for autism are difficult to pin down. Most of the scientific studies looking at the size of the autistic population have been completed relatively recently, and don't have historical comparisons, a point made in a 2001 [paper](#) by Dr. Fombonne questioning the existence of an autism epidemic.

Some groups (including the Autism Society) publish trend figures based on data collected from the Department of Education, which compiles counts of students with various disabilities as part of the [Individuals with Disabilities Education Act](#). But changes in the way data are classified and handled have made that database an unreliable source for determining trends.

Until 1993, autism was lumped into other categories, such as mental retardation or emotional disturbance. Even after schools were asked to report autism separately, they labored initially under a narrower definition that preceded the DSM-IV. It took schools years to report more fully and catch more cases, Alexa Posny, director of special education programs at the Department of Education, told me. That made comparisons with figures before 2000 difficult. "We're better at diagnosing and catching the students much earlier" now, Ms. Posny said.

There has been a doubling since 2000 in the number of students aged six to 21 that schools identified as having autism, to 166,000 in 2004 from 80,000 in 2000. (Again, these figures use a broad definition of autism.) Several experts I spoke with told me they believed the increase has more to do with better record keeping and diagnosis than an increase in the number of autistic children.

Steven Goodman, associate professor of oncology, pediatrics, epidemiology and biostatistics at the Johns Hopkins Schools of Medicine and Public Health, told me in an email, "There have been a number of excellent papers that concluded that the definitions of autism are wholly to blame for the alleged increase in incidence; others have concluded they are partly to blame, and that some component of the increase is real. What is almost certainly not true is that this rate represents a 10- or 20- or whatever-fold increase in autism rates since the 1980s, which many quite vocal activist folks have claimed and vigorously promoted."

Ms. Colston agreed that some of the growth the Autism Society cites can be attributed to improved diagnostics and reporting. "Diagnostics have improved so much," she said. But she added that other evidence, including reports from her group's members and from overtaxed state agencies, suggests a very real increase in incidence. "That's what we believe, and what we see," Ms. Colston said.

The national media has also, at times, promoted the concept of an autism epidemic. Responding to some of these claims, Morton Ann Gernsbacher, professor of psychology at the University of Wisconsin, co-authored a [paper](#) last year in *Current Directions in Psychological Science* titled, "Three Reasons Not to Believe in an Autism Epidemic." One of her reasons stemmed from a close examination of data from California used to show a 273% increase from 1987 to 1998. Prof. Gernsbacher showed how broader diagnostic criteria "will result in a dramatic increase in diagnosed cases." For example, among a sample of students diagnosed with autism before the broader DSM-IV definition was published in 1994, 61% were identified as having intellectual impairments. But only 27% of a more recent group of children categorized as autistic had such impairments.

As for the Department of Education data, the paper pointed out that other reporting categories showed huge growth immediately after they were introduced, as schools got on firm footing with new definitions. The number of students reported as having traumatic brain injuries soared more than 50-fold in the decade after it was introduced as its own category in 1991. Counts for

children with "developmental delay," meanwhile, rose more than seven-fold in the three years after that category was introduced in 1997.

Counting Everyone

The Autism Society also states that one to 1.5 million Americans have autism, a number derived by applying the CDC range of prevalence among children to an estimate of the general U.S. population of 300 million (and then applying some major rounding). [Other advocacy groups](#) cite a prevalence of 1.7 million, which based on the most recent decennial census's estimate of 280 million Americans.

But the available studies are all based on children. "We really do not have a sense of how many adults would have been diagnosed with current-day criteria when those adults were children," the University of Wisconsin's Prof. Gernsbacher said.

Ms. Colston said of the Autism Society's estimate for total U.S. population: "It's not a hard, fast, scientific number." She added that generally, there is a need for more study -- and funding -- for adult autism. "It's the area of awareness that really needs to take off, and that includes statistics, as there aren't enough statistics on it," she said.

The bottom line: Stripped of spin and taken in context, the one-in-166 estimate does appear to be sound, if overly simplified.

Marshalyn Yeargin-Allsopp, a medical epidemiologist with the CDC in Atlanta, said autism studies can be particularly complex -- hence the CDC's reported range. But she understands the desire to reduce the research into a convenient number. "The general public, they want one number. All this information, across studies, areas, populations, they want to distill into one number," she said. "My response is: It depends upon the methods used. There's not just one number out there."

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Thanks to everyone who posted to the most recent [forum](#) about my [column](#) on the accuracy of polls before this month's elections. I'll be reading, and responding to, your comments about autism numbers in a [new forum](#) this week. And please remember to use your full name with posts. (If you have a comment or suggestion unrelated to this week's column, please email me directly at numbersguy@wsj.com.)

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