Autism: An Epidemic?

A closer look at the statistics suggests something more than a simple rise in incidence BY SCOTT O. LILIENFELD AND HAL ARKOWITZ

IF THE FIGURE of "one in 166" has a familiar ring, perhaps that's because you recently heard it on a television commercial or read it in a magazine. According to widely publicized estimates, one in 66 is now the proportion of children who suffer from autism. This proportion is astonishingly high compared with the figure of one in 2,500 that autism researchers had accepted for decades. Across a mere 10-year period—1993 to 2003—statistics from the U.S. Department of Education revealed a 657 percent increase in the nationwide rates of autism.

Not surprisingly, these bewildering increases have led many researchers and educators to refer to an autism "epidemic." Representative Dan Burton of Indiana declared in 2002 that "we have an epidemic on our hands." But what's really going on?

Before we explore this question, a bit of background is in order. Autism is a severe disorder that first appears in infancy. Individuals with autism are characterized by problems in language, social bonding and imagination. All suffer from serious communication deficits, and some are mute. They do not establish close relationships with others, preferring to remain in their own mental worlds. They engage in highly stereotyped and repetitive activities, exhibiting a marked aversion to change. About two thirds of autistic individuals are mentally retarded. For reasons that are unknown, most are male.

The causes of autism remain enigmatic, although studies of twins suggest that genetic factors play a prominent role. Still, genetic influences cannot readily account for such a rapid and astronomical rise in a disorder's prevalence over a matter of just a few years.



As a consequence, investigators have turned to environmental factors for potential explanations. The causal agents proposed include antibiotics, viruses, allergies, enhanced opportunities for parents with mild autistic traits to meet and mate, and, in one recent study conducted by Cornell University researchers, elevated rates of television viewing by infants. Few of these explanations have been investigated systematically, and all remain speculative.

Problem Shots?

Yet one environmental culprit has received the lion's share of attention: vaccines. At first blush, vaccines would seem to make a plausible candidate for the source of the epidemic. The debilitating symptoms of autism typically become apparent shortly after age two, not long after infants have received vaccinations for a host of diseases. Indeed, many parents claim that their children developed autism shortly after receiving vaccinations, either following a vaccine series for mumps, measles and rubella (German measles)—the socalled MMR vaccine—or following vaccines containing thimerosal, a preservative containing mercury.

Much of the hype surrounding a vaccine-autism link was fueled by a widely covered investigation of 12 children published in 1998 by British gastroenterologist Andrew Wakefield and his colleagues. The study revealed that autism symptoms emerged shortly after the children received the MMR vaccine. (Ten of the 13 authors have since published a retraction of the article's conclusions.) Public interest in the vaccine-autism link was further stoked by the provocatively entitled book Evidence of Harm (St. Martin's Press, 2005), by investigative journalist David Kirby, which was featured in an extended segment on NBC's Meet the Press.

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several large American, European and Japanese studies demonstrate that although the rate of MMR vaccinations has remained constant or declined, the rate of autism diagnoses has soared. In addition, after the Danish government stopped administering thimerosalbearing vaccines, the rates of autism continued to rise. These studies and others, summarized by the Institute of Medicine, suggest there is little evidence that vaccines cause autism. It is possible that vaccines trigger autism in a small subset of children, but if so that subset has yet to be identified.

Changing Criteria

Making matters more confusing, ample reason exists to question the very existence of the autism epidemic. Vaccines may be what scientists call an "explanation in search of a phenomenon." As University of Wisconsin-Madison psychologists Morton Gernsbacher and H. Hill Goldsmith and University of Montreal researcher Michelle Dawson observed in a 2005 review, there is an often overlooked alternative explanation for the epidemic: changes in diagnostic practices. Over time, the criteria for a diagnosis of autism have loosened, resulting in the labeling of substantially more mildly afflicted individuals as autistic.

Indeed, the 1980 version of the American Psychiatric Association's diagnostic manual (known as DSM-III) required individuals to meet six of six criteria for an autism diagnosis. In contrast, the 1994 version (known as DSM-IV), which is currently in use, requires individuals to meet any eight of 16 criteria. Moreover, DSM-III contained only two diagnoses relevant to autism, namely, autism itself and Asperger's syndrome, which most researchers regard as a high-functioning variant of autism. In contrast, DSM-IV contains five such diagnoses, including several additional mild variants of autism.

Legal changes may also be playing a significant role. As Gernsbacher and his colleagues noted, an amended version of the Individuals with Disabilities Education Act (IDEA), passed by Congress in 1991, required school districts to provide precise counts of children with disabilities. IDEA resulted in sharp surges in the reported numbers of children with autism. Nevertheless, these numbers are not based on careful diagnoses of autism or on representative samples of the population. As a consequence, researchers who rely on "administrative-based estimates," which come from government data submitted by schools, will arrive at misleading conclusions about autism's prevalence. They must instead rely on "population-based estimates," which are developed from statistically reliable and representative surveys of autism's occurrence in the general population. Further contributing to the reported increase may be the "Rain Man Effect," the public's increased familiarity with the features of autism following the 1988 Academy Award-winning film starring Dustin Hoffman and Tom Cruise.

Numbers Analyzed

Two recent studies buttress assertions that the autism epidemic may be more illusory than real. First, in 2005 psychiatrist Suniti Chakrabarti of the Child Development Center in Stafford, England, and psychiatrist Eric Fombonne of the University of Montreal conducted an investigation that used rigorous population-based estimates to track the prevalence of autism diagnoses from 1992 to 1998 in a sample of more than 10,000 children in the same area of England. They found no support for a change in prevalence, suggesting that when researchers maintain the same criteria for autism, the rates of diagnosis do not change over time.

Second, a 2006 article by University of Wisconsin–Madison psychologist Paul Shattuck cited "diagnostic substitution": as the rates of the autism diagnosis increased from 1994 to 2003, the rates of diagnoses of mental retardation and learning disabilities decreased. This finding raises the possibility that the overall "pool" of children with autisticlike features has remained constant but that the specific diagnoses within this pool have swapped places.

It is still too early exclude the possibility that autism's prevalence is growing, but if so it is unlikely that it is growing at anywhere near the rate that many have suggested. As Cornell University astronomer Carl Sagan reminded us, extraordinary claims require extraordinary evidence. The claim of an enormous epidemic of autism diagnoses is indeed extraordinary. Yet the evidence in support of this claim leaves much to be desired. M

SCOTT O. LILIENFELD and HAL ARKOWITZ serve on the board of advisers for *Scientific American Mind*. They welcome reader suggestions for column topics: editors@sciammind.com

(Further Reading)

- Separating Fact from Fiction in the Etiology and Treatment of Autism: A Scientific Review of the Evidence. J. D. Herbert, I. R. Sharp and B. A. Gaudiano in Scientific Review of Mental Health Practice, Vol. 1, No. 1, pages 25-45; Spring-Summer 2002.
- Immunization Safety Review: Vaccines and Autism. Immunization Safety Review Committee. Board of Health Promotion and Disease Prevention, Institute of Medicine. National Academy Press, 2004.
- Three Reasons Not to Believe in an Autism Epidemic. M. A. Gernsbacher, M. Dawson and H. H. Goldsmith in Current Directions in Psychological Science, Vol. 14, pages 55– 58; 2005.