

US Department of Education Data on "Autism" Are Not Reliable for Tracking Autism Prevalence

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ABSTRACT. Many autism advocacy groups use the data collected by the US Department of Education (USDE) to show a rapidly increasing prevalence of autism. Closer examination of these data to follow each birth-year cohort reveals anomalies within the USDE data on autism. The USDE data show not only a rise in overall autism prevalence with time but also a significant and nearly linear rise in autism prevalence within a birth-year cohort as it ages, with significant numbers of new cases as late as 17 years of age. In addition, an unexpected reduction in the rise of autism prevalence occurs in most cohorts at 12 years of age, the age when most children would be entering middle school. These anomalies point to internal problems in the USDE data that make them unsuitable for tracking autism prevalence. *Pediatrics* 2005;116:e120–e124. URL: www.pediatrics.org/cgi/doi/10.1542/peds.2004-2341; *autism, prevalence, education*.

ABBREVIATIONS. USDE, United States Department of Education; IDEA, Individuals With Disabilities Education Act; DSM-IV, *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*; OAR, Oregon Administrative Rules.

The prevalence of autism and whether that prevalence is rising are 2 of the many controversies surrounding this disorder. Much of the controversy is attributable to the difficulty of finding good data. A number of studies have examined the prevalence of autism and related disorders^{1–6} in a number of different populations and periods. However, all of these studies are constrained by time and funding to examining either a relatively small population or relatively few points in time.

Many autism advocates have used data from the United States Department of Education (USDE) in their presentations to lawmakers⁷ and the public to show a dramatic and accelerating rise in the prevalence of autism in the United States. Because these data are being used to influence public policy, it is critically important to know if they can be used to reliably measure the prevalence of autism.

This study examined the autism data collected by the USDE by following individual birth-year cohorts

through time. It also examined the methods used to collect the USDE autism data and compared those with the methods used by medical practitioners to diagnose autism.

METHODS

Under the provisions of the Individuals With Disabilities Education Act (IDEA), the USDE Office of Special Education Programs collects data on children who qualify for special education assistance. This information is presented to Congress each year in an annual report that is available to the public. The number of children with a qualifying condition of autism has been collected and reported every year since 1992 (voluntary in 1992, mandatory 1993 to present).

USDE data provided the number of children in each single-year age group with the IDEA-qualifying condition of autism. This information was found in the Office of Special Education and Rehabilitation Services' 14th through 25th Annual Reports to Congress.⁸ These data are collected by the USDE from the education departments of each state (also from the District of Columbia, Puerto Rico, Guam, and other US possessions and territories), which in turn collect them from the individual school districts. The assessment criteria for autism (and the other IDEA-qualifying categories) are based on legislation passed by the individual state legislatures, as interpreted by the state education departments and local school districts.

Only data from 1993 and later were used, as autism was not reported separately until 1992 and mandatory reporting did not begin until 1993. The study was also restricted to ages 6 through 17 years because children who are younger than 6 and older than 17 are generally not required to attend school and seem to be underrepresented in the USDE data.

Population figures for each single-year age group were obtained from the US Census Bureau and were derived from the 1990 and 2000 decennial censuses. Populations of noncensus years were estimated by the US Census Bureau using their estimation algorithm. Information was extracted from the US Census Bureau's online database using the DataFerret search and retrieval program (www.dataferrett.census.gov).

Autism prevalence was calculated by dividing the number of children with autism of each age reported to the USDE by the total number of people in the United States of that age in that year. August census estimates were used for noncensus years.

Birth-year cohorts were developed by assigning children of each age to the birth year that corresponded to the middle of that age group (eg, all 6-year-olds in 2000 were assigned to the 1994 birth-year cohort).

χ^2 analysis was used to compare autism prevalence within a birth-year cohort from year to year as well as between birth-year cohorts at a specific age. The expected number of autistic children was calculated by taking the prevalence from the reference group and applying it to the population figure for the group being analyzed.

RESULTS

According to the USDE data, overall autism prevalence in children aged 6 to 17 years shows an exponential increase ($y = 3.2e^{0.19x}$; $r^2 = 0.999$) from 1993 to 2003 (Fig 1). When the data are segregated by birth year, every cohort born after 1980 shows a continu-

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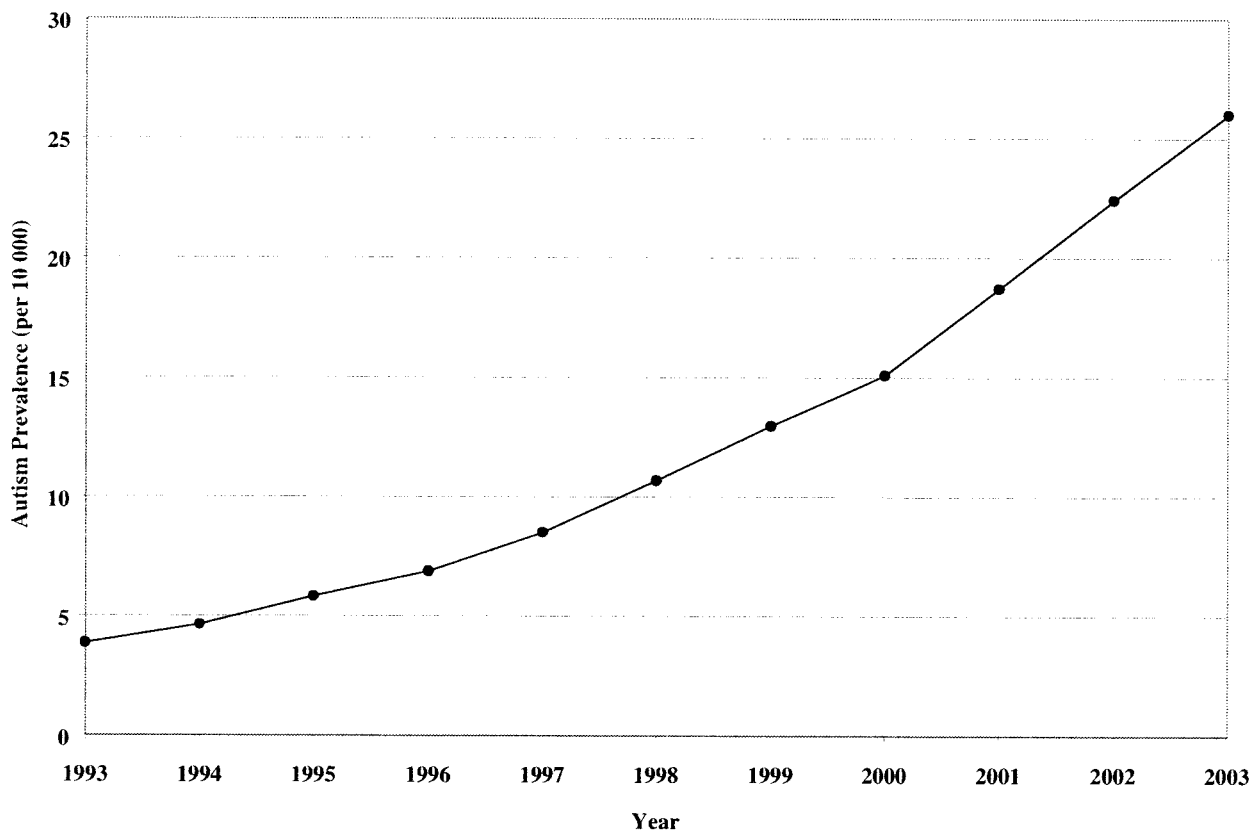


Fig 1. Autism prevalence in the United States among children 6 to 17 years of age (from USDE data).

ing rise in autism prevalence as the cohort ages (Fig 2). The rise in autism prevalence is surprisingly linear, with r^2 values >0.95 in all cohorts from 1984 onward. The rate of rise in autism prevalence also increases in later born cohorts: every cohort in this study had a higher rate of rise in autism prevalence than all earlier born cohorts.

The autism prevalence from year to year (Table 1) shows a statistically significant increase within birth-year cohorts as they age. This continues to 16 years of age in most cohorts, with half (5 of 10) of the cohorts also showing a significant increase in autism prevalence between ages 16 and 17 years. Later born cohorts have a higher initial prevalence of autism in addition to a faster rate of rise.

A regular exception to the rising prevalence of autism is the interval between ages 11 and 12 years. Most birth-year cohorts showed either no significant change in autism prevalence (7 of 10) or a small decrease in prevalence (1 of 10) during this interval. Even in the cohorts that had a rise in autism prevalence between ages 11 and 12 years, the rise during this period was less than half the rate of rise for the preceding or (if available) the following age interval (Table 2).

DISCUSSION

The USDE data on autism seem to indicate that there has been an exponential rise in autism prevalence between 1993 and 2003. They also suggest that there are as many children who are newly catego-

rized as autistic at 15 years of age as there are at 8 years of age. These data also seem to show a consistent break in the rise of autism prevalence between ages 11 and 12 years, with 1 cohort (1988) showing a statistically significant decrease in autism prevalence in this interval. Instead of showing a rise in autism prevalence at the age when most children move from elementary school to the more challenging and less structured environment of middle school, the USDE data show the opposite. All of these point to problems within the USDE data.

Autism, as defined in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV), is a developmental disorder that is usually first observed between birth and 3 years of age. Although it is often diagnosed later, the impairments must be present by age 3 years to make the diagnosis of autism.⁹ Four recent studies examined age of first diagnosis of autism and suggested that the majority of diagnoses are made before the age of 8 years.

A study of records from British general practitioners found that the mean age at first diagnosis was 6.25 years (SD: 4.52 years).¹⁰ A study of 2 cohorts (born 1974–1983 and 1984–1993) in Iceland showed an even younger age at first diagnosis: 3.6 years and 4.0 years, respectively (ranges: 1.7–17 and 2.2–13.8 years, respectively).¹ A study of Medicaid-eligible children in Philadelphia, Pennsylvania, had a mean age at first diagnosis of 7.4 years (SD: 3.1 years).¹¹

One study of a single health district in Northern

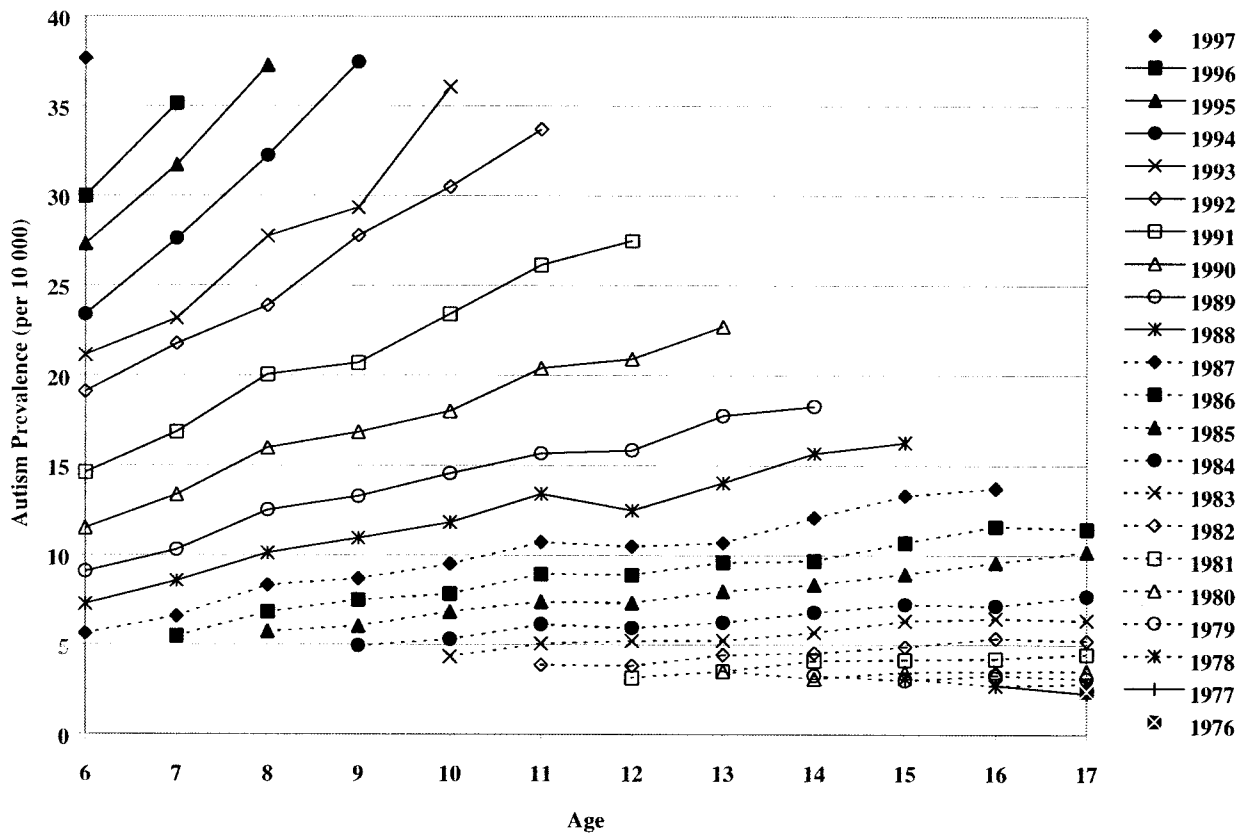


Fig 2. Autism prevalence in each birth-year cohort according to age (from USDE data).

England looked specifically at the difference in timing of medical diagnosis and educational assessment (statement of special educational needs). They found that, for children in mainstream schools, the mean age at diagnosis was 6.5 years (range: 2–12 years) and the mean age of receiving a statement of special educational needs was 5.6 years, indicating that the

educational assessment of autism generally preceded the medical diagnosis.¹²

The interval between ages 11 and 12 years is the time when most children make the transition from elementary school to middle school. Although it might be expected that moving from the structured academic and social environment of elementary

TABLE 1. Autism Prevalence in Each Birth-Year Cohort According to Age (From USDE Data)

Birth-Year Cohort	Age, y											
	6	7	8	9	10	11	12	13	14	15	16	17
1997	37.6*											
1996	30.0*	35.1†										
1995	27.3*	31.7†	37.3†									
1994	23.4*	27.6†	32.2†	37.4†								
1993	21.1*	23.2†	27.7†	29.3†	36.1†							
1992	19.1*	21.8†	23.9†	27.8†	30.5†	33.7†						
1991	14.6*	16.9†	20.1†	20.7†	23.4†	26.2†	27.5†					
1990	11.5*	13.4†	16.0†	16.8†	18.0†	20.4†	20.9†	22.7†				
1989	9.1*	10.3†	12.5†	13.3†	14.5†	15.6†	15.8†	17.8†	18.3†			
1988	7.3*	8.6†	10.1†	10.9†	11.8†	13.4†	12.5†	14.0†	15.7†	16.2†		
1987	5.6*	6.6†	8.3†	8.7†	9.5†	10.7†	10.5†	10.7†	12.1†	13.3†	13.7†	
1986		5.5*	6.8†	7.5†	7.8†	8.9†	8.9†	9.6†	9.7†	10.7†	11.6†	11.5†
1985			5.7*	6.0†	6.8†	7.7†	7.3†	8.0†	8.4†	8.9†	9.6†	10.2†
1984				4.9*	5.3†	6.1†	5.9†	6.2†	6.8†	7.2†	7.2†	7.7†
1983					4.3*	5.1†	5.2†	5.2†	5.7†	6.3†	6.5†	6.4†
1982						3.9*	3.8†	4.4†	4.5†	4.9†	5.4†	5.2†
1981							3.2*	3.5†	4.1†	4.2†	4.2†	4.5†
1980								3.5*	3.1†	3.5†	3.5†	3.5†
1979									3.3*	3.0†	3.3†	3.1†
1978										3.1*	2.7†	2.8†
1977											2.7*	2.3†
1976												2.4*

* There were no previous-year data for comparison.

† Statistically significant ($P < .05$) change from the previous year.

TABLE 2. Percentage Change in Autism Prevalence Within Selected Cohorts (From USDE Data) Focusing on the Vicinity of the 11- to 12-Year Age Interval

Birth-Year Cohort	Age Interval, y				
	9–10	10–11	11–12	12–13	13–14
1990	7.0	13.2	2.5	8.6	NA
1989	9.7	7.7	1.1	12.2	2.9
1988	8.1	13.5	−6.9	12.3	11.8
1987	9.4	12.9	−2.3	2.0	13.2
1986	4.7	14.2	−0.6	7.8	1.0
1985	13.4	8.2	−0.9	8.7	4.7
1984	7.2	15.7	−3.2	5.3	8.9
1983	N/A	16.7	3.1	0.5	8.4

NA indicates not available.

school to the more self-directed environment of middle school would “unmask” milder cases of autism, the USDE data show just the opposite. Most (5 of 6) of the cohorts that have complete data for the period surrounding this transition show a greater rise in autism prevalence for the 2 years before middle school than in the 2 years after the transition to middle school.

The USDE data suggest that the prevalence of autism is rising, but is this attributable to an actual increase in prevalence or to a broader definition of autism and greater public awareness? A number of studies have suggested that the diagnosis of autism, even by medical practitioners, has experienced significant drift over time.^{1,4,5} A review by Wing and Potter¹³ provides an excellent overview of this problem. A recent study of autism incidence between 1976 and 1997 concluded that the timing of the increase in autism diagnoses suggests that it was attributable to increased awareness and changes in diagnostic criteria.¹⁴

Despite the specific diagnostic criteria provided by the DSM-IV, the diagnosis of autism is completely subjective. There are no objective findings, radiologic studies, or laboratory tests that are diagnostic for autism. Even the presence of disorders such as fragile X^{15,16} or tuberous sclerosis,^{17,18} which are often associated with autism, are not diagnostic of autism, because only a fraction of patients with these conditions have autism.

Finally, at least 2 studies have suggested that autistic traits are not a discrete feature seen only in the presence of autism but rather are a continuum. As such, a certain degree of “autistic” behaviors are expected in many “typical” individuals.^{19,20} This further complicates the diagnosis of autism, because there is no distinct “cutoff” point between typical and autistic. There are indications that the increasing awareness of autism in the medical and educational communities may have led to a gradual shift in diagnosis to include less disabled individuals who would not previously have been described as autistic¹³ or would have received a different diagnosis.⁵

Although the diagnosis of autism seems to have changed with time, the guidelines for educational assessment of autism also vary from state to state. With only 10 qualifying disabilities under IDEA,²¹ the assessment criteria used by the states are understandably broad. As, perhaps, an extreme example of

this, compare a section of the diagnostic criteria for autism from the DSM-IV with the corresponding section of the assessment criteria used in the state of Oregon (from the Oregon Administrative Rules [OAR]):

DSM-IV:

“(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (eg, by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity”¹⁰

OAR:

“(ii) Impairments in social interaction”²²

The criteria found in the OAR are obviously much broader and more general than those in the DSM-IV. The choice of Oregon for this comparison was not random: Oregon has consistently had the highest prevalence of autism in the USDE data of any state (2 to 3 times the national prevalence) since autism was first reported as a separate disability.

As has been shown, the USDE data on autism are at odds with studies of autism prevalence, largely because the criteria used by the school districts (the source of the USDE data) to categorize children as autistic are neither rigorous nor consistent. They are inconsistent over time, as are the medical criteria, and are inconsistent from region to region. The USDE data are not reliable for tracking the prevalence of autism, and they in fact never were meant to fill this need.

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