

National Autism Prevalence Trends From United States Special Education Data

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ABSTRACT. *Objective.* Reports of large increases in autism prevalence have been a matter of great concern to clinicians, educators, and parents. This analysis uses a national data source to compare the prevalence of autism with that of other disabilities among successive birth cohorts of US school-aged children.

Design. Comparison of birth cohort curves constructed from administrative data.

Setting and Population. US children 6 to 17 years of age between 1992 and 2001.

Main Outcome Measures. A disability category classification of autism, mental retardation, speech and language impairment, traumatic brain injury, or other health impairment, as documented by state departments of education and reported to the Office of Special Education Programs, US Department of Education.

Results. Prevalences of disability category classifications for annual birth cohorts from 1975 to 1995 were calculated by using denominators from US Census Bureau estimates. For the autism classification, there were birth cohort differences, with prevalences increasing among successive (younger) cohorts. The increases were greatest for annual cohorts born from 1987 to 1992. For cohorts born after 1992, the prevalence increased with each successive year but the increases did not appear to be as great, although there were fewer data points available within cohorts. No concomitant decreases in categories of mental retardation or speech/language impairment were seen. Curves for other health impairments, the category including children with attention-deficit/hyperactivity disorder, also showed strong cohort differences.

Conclusions. Cohort curves suggest that autism prevalence has been increasing with time, as evidenced by higher prevalences among younger birth cohorts. The narrowing in vertical separation of the cohort curves in recent years may mark a slowing in the autism prevalence increase. *Pediatrics* 2005;115:e277–e282. URL: www.pediatrics.org/cgi/doi/10.1542/peds.2004-1958; *autism, prevalence, trends.*

ABBREVIATIONS. ASD, autism spectrum disorder; OSEP, Office of Special Education Programs; IDEA, Individuals with Disabilities Education Act; ADHD, attention-deficit/hyperactivity disorder.

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der; TBI, traumatic brain injury; MADDSP, Metropolitan Atlanta Developmental Disabilities Surveillance Program.

In recent years, concern has increased markedly about the magnitude and causes of the apparent increase in the prevalence of autism spectrum disorder (ASD) in the United States and other countries.¹ Administrative data, ie, information collected for the purposes of program management, as opposed to scientific research, from several states have been cited in scientific reports^{2,3} and media stories.^{4,5} Although there are challenges in interpreting trends in administrative data, this information at least indicates the real public health burden, in that it reflects the numbers of individuals receiving services in a given setting. A national source of administrative data on children with ASD is the United States Department of Education, Office of Special Education Programs (OSEP). OSEP maintains standardized compilations of state counts of children receiving free, appropriate, public education services, classified into 13 primary disability categories defined under the Individuals with Disabilities Education Act (IDEA). One of these categories is autism. This brief report uses OSEP administrative data to assess secular trends in ASD prevalence among US school-aged children and to compare these trends with those for selected other IDEA disability categories.

METHODS

Numerators for prevalence estimates were derived from annual reports issued by OSEP. The OSEP data are aggregations of counts supplied by state education departments, which conduct census counts of children in special education programs on December 1 of each year.^{6–15} Denominators were derived from US Census Bureau resident population estimations.^{16–24} Age-specific prevalences were calculated for 5 disability categories (autism, traumatic brain injuries [TBIs], mental retardation, speech/language impairment, and other health impairments) for ages 6 through 17 years in each of 10 years, 1992 through 2001. The year 1992 was the first year in which all states were mandated to provide counts for children in the autism and TBI categories.

Prevalence estimates were stratified according to birth cohort and displayed visually as a plot of prevalence (ordinate) versus age (abscissa). The ordinate uses a logarithmic scale, and the vertical distance between curves represents the percentage change, not the absolute difference, in prevalence estimates. For example, a 25% increase in prevalence at age 10 between a younger birth cohort and an older birth cohort would be evident as the same vertical distance regardless of the baseline prevalence for the older birth cohort. Also, to ensure visual comparability among graphs, ordinates are scaled as 2 log-units in length. Separation of the cohort curves (with younger cohorts having higher age-specific prevalence) indicates an increase in prevalence with time. It should be noted that the use of the logarithmic scale, while making differences comparable in percentage change terms, un-

derstates absolute differences. We also include a table displaying the prevalence estimates, percentage changes, and absolute differences with time for 3 of the 5 classifications for which we created graphs.

RESULTS

Figure 1 displays the cohort curves for each selected disability category. Clear cohort differences are apparent for autism, ie, prevalence increases with successive (younger) birth cohorts. This effect is greatest for cohorts born between 1987 and 1992. For cohorts born after 1992, the rate of increase in prevalence for successive birth years does not appear to be as great as for the previous cohorts, although there are fewer data points available within cohorts. With respect to the age effect within cohorts, there is a fairly constant increase with age, which levels off only after 16 years of age. Because impairment associated with ASD is life-long, it is reasonable that no decline at older ages is observed. The finding that prevalence increases within birth cohorts through age 16 is notable, however. Experienced professionals can now diagnose autism reliably among children as young as age 2.²⁵ The later children with autism acquire the special education classification, presumably the later they are accessing the educational interventions most appropriate for them. It is possible that, for the most recent cohorts, with the greater

prevalence of classification at younger ages, the curves will level at older ages. This would accentuate the narrowing of the vertical distance between cohorts seen for the most recent birth years.

The TBI classification is of interest because it was introduced the same year as the autism classification. As suggested in Fig 1 and shown in Table 1, except for the first 2 years after introduction (the comparisons between the 1982 and 1984 cohorts for 10-year-old children and the 1986 and 1988 cohorts for 6-year-old children), the age-specific percentage increases in TBI prevalence for successive birth cohorts were smaller than those for autism. At each given age, the size of the percentage increase for younger cohorts diminishes with time, and the increases virtually vanish in the comparison of the calendar year 1999 and 2000 points for all cohorts (for example, the points at age 7 and 8 for the 1992 cohort or the points at age 15 and 16 for the 1984 cohort) (Fig 1). The increase seen consistently for all birth cohorts with the calendar year 2001 data points (for example, age 9 for the 1992 cohort or age 17 for the 1984 cohort) strongly suggests a period effect. No obvious cause for this single-year upsurge was documented in the state data notes included in the relevant year's OSEP reports¹²⁻¹⁴ or was anticipated in a report on a year 2000 survey of state special education program di-

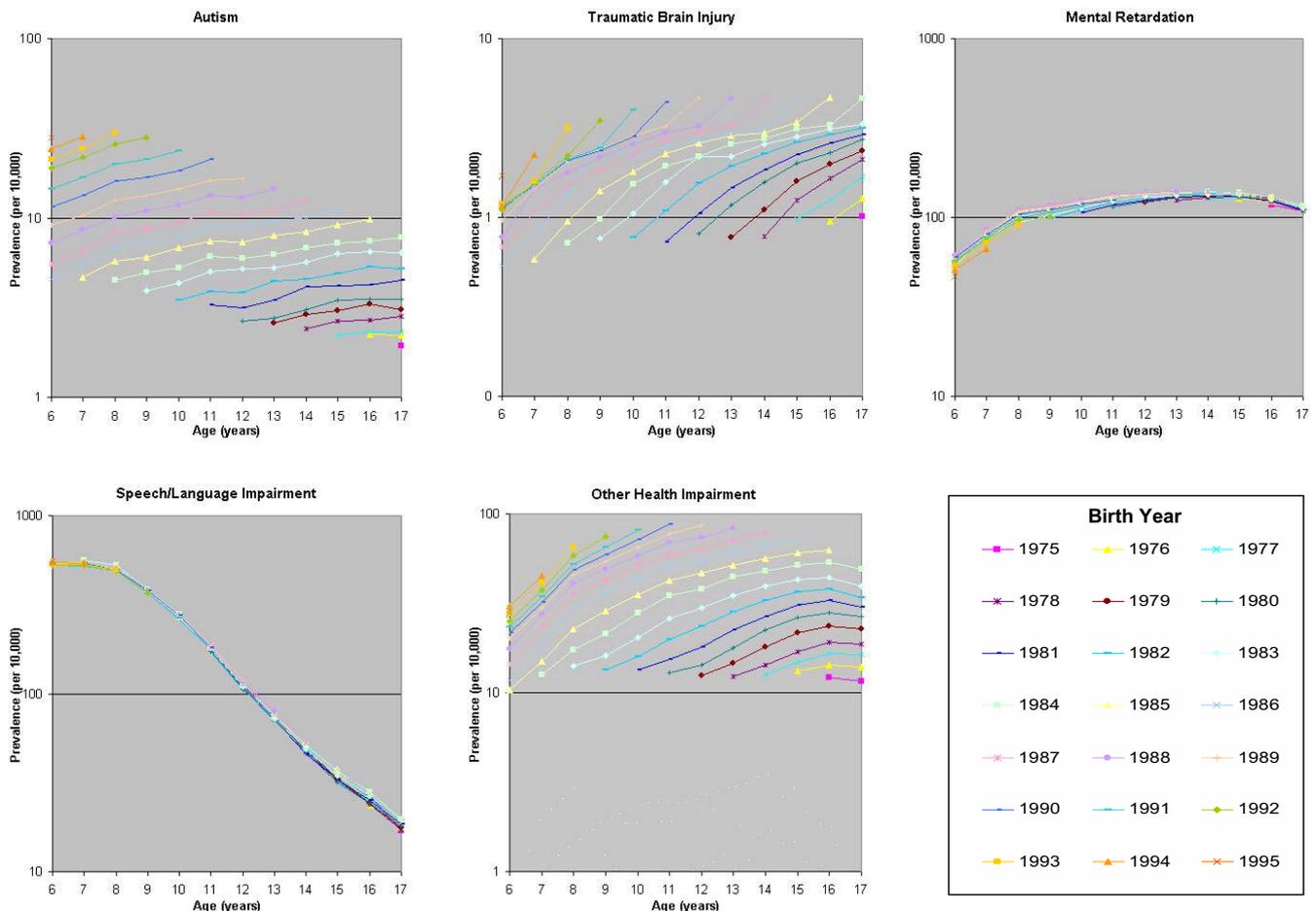


Fig 1. Prevalence (cases per 10 000 population) of select special education classifications among US children according to age and birth cohort.

TABLE 1. Prevalence Estimates for 3 Special Education Classifications and Percentage Changes From Previous-Year Cohorts, for Select Birth Cohorts and Years

Special Education Classification	Birth Cohort	10-Year-Olds			6-Year-Olds		
		Prevalence (Cases per 10 000 Population)	% Change	Absolute Difference (Cases per 10 000 Population)	Prevalence (Cases per 10 000 Population)	% Change	Absolute Difference (Cases per 10 000 Population)
Autism	1982	3.5					
	1984	5.3	51.4	1.8			
	1986	7.8	47.2	2.5	4.6		
	1988	11.8	51.3	4.0	7.2	36.1	2.6
	1990	18.3	55.1	6.5	11.5	59.7	4.3
	1992				19.1	66.1	7.6
	1994				24.1	26.2	5.0
Other health impairment	1982	15.9					
	1984	28.0	76.1	12.1			
	1986	43.4	35.5	15.4	11.7		
	1988	58.5	34.8	15.1	17.6	50.4	5.9
	1990	72.2	23.4	13.7	21.8	23.9	4.2
	1992				25.1	15.1	3.3
	1994				30.1	16.6	5.0
TBI	1982	0.8					
	1984	1.5	87.5	0.7			
	1986	2.1	40.0	0.6	0.5		
	1988	2.6	23.8	0.5	0.8	60.0	0.3
	1990	2.8	7.7	0.2	1.1	37.5	0.3
	1992				1.1	0.0	0
	1994				1.2	9.1	0.1

Numerators for prevalence estimates are from the OSEP, US Department of Education. Denominators are from US Census Bureau resident population estimations.

rectors regarding use of the TBI category.²⁶ The prevalence pattern according to age within birth cohorts, with higher prevalence at older ages, is as expected for this category, because TBI risks peak in the teenage years and TBI special education classifications, once received, are not likely to be changed.

It has been suggested that increased substitution of autism for mental retardation³ and/or language impairment²⁷ diagnoses might be accounting for some of the apparent increase in autism prevalence. If this substitution occurred with special education classifications, then increases in autism prevalence with subsequent birth cohorts would be accompanied by decreases in mental retardation and/or speech/language impairment prevalences. As shown in Fig 1, mental retardation prevalence shows no birth cohort effect; in other words, there is no suggestion that prevalence is decreasing (or increasing) among younger cohorts. The cohort curves overlap to reproduce faithfully the shape of a cross-sectional curve of prevalence according to age (curve not shown). Trends with age are as expected for mental retardation, with prevalence increasing steadily through age 8 and then leveling.

Similarly, the curves for speech/language impairment indicate no cohort differences. The patterns with respect to age are as expected. At young ages, speech/language impairment prevalence is many times higher than that of autism; however, prevalence decreases dramatically from age 7 to age 17 years. The decrease in the prevalence of speech and language impairment is likely a result of children losing this disability category classification, which is expected to occur to a greater extent for this category (ie, in cases of articulation disorders and dysfluency

that resolve with time), compared with the other categories.

The curves for other health impairments are notable for 2 reasons, ie, because this is the disability classification that typically includes children with attention-deficit/hyperactivity disorder (ADHD) and because there are strong cohort differences. Prevalence is higher for successive birth cohorts, with the greatest annual increases occurring between the 1980 and 1984 birth cohorts. Within cohorts, the prevalence of other health impairments increases sharply through 11 years of age, with the rate of increase gradually decreasing in successive years.

DISCUSSION

Cohort curves based on this national administrative data source suggest, not surprisingly, that ASD prevalence is increasing with time, as evidenced by higher prevalence among younger birth cohorts. The critical question of why ASD prevalence is increasing cannot be answered directly from these administrative data, but a few observations are potentially relevant. First, we note that the pattern of increasing prevalence in the past 15 years is not found in all disability categories, which suggests that the increasing prevalence of children with the autism classification is not the result of across-the-board increases in special education classification.

Because the autism classification was first introduced in 1992, some of the increase in prevalence should be attributable merely to local education agencies incorporating the new category into their special education classification practices. As mentioned, the TBI classification was introduced at the same time as the autism classification. Initial percent-

age increases observed for TBI were on the same order of magnitude as those for autism but these increases, which we can assume were largely introductory effects, had generally subsided by the mid-1990s (an exception being the increases in 2001, which likely represented a period effect, as noted above).

Prevalence trends for the mental retardation and speech/language categories have not increased over time. This is of particular interest because it has been speculated that children who in past years might have been classified in one or another of these categories are now being classified in the autism category and this “diagnostic shifting” could be responsible for prevalence increases. Because there was no indication of decreases in one or another of these categories concomitant with, and of similar magnitude to, increases in autism classification prevalence, these data do not support the hypothesis of diagnostic shifting.

Like autism, other health impairment classification prevalence has increased dramatically in successive birth cohorts during the past decade. In submitting count data to OSEP, several state departments of education commented that increases in other health impairment counts are being driven primarily by increasing numbers of children with ADHD.^{6–15} At least since 1991, when an OSEP policy memo was released clarifying the potential eligibility of children with ADHD under the other health impairment classification,²⁸ increasing numbers of children in this category have an ADHD diagnosis. Like ASD, ADHD is a complex, behavior-based diagnosis. The diagnoses underlying other special education classifications are not always straightforward, but in most instances they can be made on the basis of documented impairment in functional domains more easily measured than those of social interaction and attentiveness. This observation is, of course, not empirical evidence supporting the hypothesis that the increases in ADHD and ASD prevalences are attributable to changing patterns in diagnosis and classification, rather than changes in the real risk of the conditions. However, there is value in noting the similarities in the patterns of the curves for the autism and other health impairments categories and the contrast between these categories and the other categories. Whether the narrowing in vertical separation of the cohort curves, beginning for other health impairments with the 1987 birth cohort and for autism only with the most recent cohorts, marks the waning of increases in prevalence remains to be seen. Recent data have generally continued to suggest ASD prevalence growth,^{29,30} with one exception. Lingham et al³¹ used administrative data on autism cases identified in east London in the year 2000 to predict expected numbers of cases according to birth cohort, correcting for underascertainment among younger children with a statistical model. The data suggested prevalence leveling beginning with the 1993 birth cohort.

The data presented here, although derived from the only available source for national prevalence es-

timates, do have several limitations. Numerators are incomplete because some US school-aged children with ASD and/or the other conditions considered here do not acquire special education classifications and/or are educated outside of public school. Because educational classifications are intended only to match individuals with the most appropriate service delivery approach available, administrative data are more susceptible to diagnosis/classification bias than are data from research studies incorporating rigorous case definitions and case-confirmation criteria. IDEA does provide a standard definition for each disability category, but individual states develop their own eligibility criteria. The IDEA definition for autism is general enough to encompass all ASDs, but state eligibility criteria and the way in which they are implemented can limit, for example, the extent to which higher-functioning children on the autism spectrum receive autism special education classifications.

Since 1997, federal law has allowed state and local education agencies to extend use of the less-specific disability category “developmental delay” to children as old as age 9 at their discretion (it was limited previously to children ≤ 5 years of age). Children in the cohort born in 1991 were the first to have turned 6 years of age after this change went into effect. It is possible that increasing proportions of children in younger cohorts who would have been classified previously as having autism as they transitioned out of preschool special education retain developmental delay classifications. This could explain the observed narrowing of the distance between autism cohort curves beginning with the 1992 cohort and could mean that, contrary to what was conjectured earlier about an increasing prevalence of autism classification at younger ages leading to a flattening of the trend at older ages, there may actually be more children receiving autism classifications at older ages. In this case, the newest cohort curves, between which the distance appeared to be decreasing, may actually separate more at older ages.

One final classification issue to consider is that children with multiple impairments still receive only 1 special education classification. There could be variations with time in the single category to which children with autism and another impairment are assigned. IDEA includes an explicit category called “multiple disabilities,” which is intended for children whose combination of impairments creates educational needs that cannot be met in programs designed for 1 impairment alone. Examination of the data for this category showed no strong overall cohort effect (data not shown); however, there could be cohort effects in the extent to which the subgroup of children with autism are assigned to this category.

Finally, because estimates displayed here are for prevalence rather than incidence, the patterns seen are potentially a function of both incidence and duration. In these data, duration represents the period of time during which children retain their classification in a particular disability category. Some children who lose a classification retain the underlying dis-

ability, although such children no longer contribute to the observed prevalence of their original classification. This is likely a far less frequent occurrence for autism, mental retardation, and other health impairments, compared with speech/language impairment.

Most of the limitations discussed decrease the utility of the special education data for generating accurate estimates of absolute condition frequencies. Data from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) indicated that, although 91% of the 6- to 10-year-old children with identified autism in 1996 received special education services, only 48% of those who received special education services had autism as a primary special education classification (K. Van Naarden-Braun, personal communication, August 2004). At the same time, virtually all of the age-eligible children with a special education classification of autism met the case-definition criteria for autism in the MADDSP.²⁹ This indicates that, in general, autism prevalence estimates based on special education data alone will be underestimates.

The drastic increase in the prevalence of the autism classification presents a major challenge to the nation's special education service systems and is one that has already triggered responses from federal, state, and local agencies.³² These trends also present an epidemiologic challenge, by raising the question of how much of this increase can be attributed to real changes in risk, as opposed to changes in diagnostic and classification practices. An alliance of 16 sites, some working with the cooperation of their state's education departments, has been funded by the Centers for Disease Control and Prevention to develop public health surveillance approaches for ASD and other developmental disabilities.³³ These approaches are being modeled largely on the MADDSP experience. It is hoped that this effort will establish a stronger national information base with which ASD prevalence trends can be monitored and other important epidemiologic questions about ASD can be addressed.

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