Analysis of Prevalence Trends of Autism Spectrum Disorder in Minnesota

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Background: Alarming increases in the prevalence of autism spectrum disorder have been reported recently in the United States and Europe.

Objectives: To quantify and characterize prevalence trends over time in autism spectrum disorder in Minnesota.

Methods: We conducted an age-period-birth cohort analysis of special educational disability data from the Minnesota Department of Children, Families & Learning from the 1981-1982 through the 2001-2002 school years.

Results: Prevalence rates of autism spectrum disorder rose substantially over time within single-age groups and increased from year to year within birth cohorts. Autism spectrum disorder prevalence among children aged 6 to 11 years increased from 3 per 10,000 in 1991-1992 to 52 per 10,000 in 2001-2002. All other special educational disability categories also increased during this period, except for mild mental handicap, which decreased slightly from 24 per 10,000 to 23 per 10,000. We found that federal and state administrative changes favoring identification of autism spectrum disorders corresponded in time with the increasing rates.

Conclusions: We observed dramatic increases in the prevalence of autism spectrum disorder as a primary special educational disability starting in the 1991-1992 school year, and the trends show no sign of abatement. We found no corresponding decrease in any special educational disability category to suggest diagnostic substitution as an explanation for the autism trends in Minnesota. We could not assess changes in actual disease incidence with these data, but federal and state administrative changes in policy and law favoring better identification and reporting of autism are likely contributing factors to the prevalence increases and may imply that autism spectrum disorder has been underdiagnosed in the past.


Autism spectrum disorder (ASD) comprises a heterogeneous group of phenotypes apparent in early childhood, usually by age 3 years, and characterized with varying severity by impairments in social functioning and reciprocation, deficits in speech and language, and unusual behavioral manifestations such as habitual repetitive movements and great distress from environmental changes. Associated comorbidities in some patients may include, but are not limited to, mental retardation, seizure disorders, chronic gastrointestinal disorders, and hyperactivity. Autism spectrum disorder is hypothesized to result from aberrant neurodevelopmental processes with complex genetic origins, but the causal pathways have not been elucidated. No biological test or profile exists for diagnosis. Rather, the disorder is characterized according to behavioral criteria as described by the Diagnostic and Statistical Manual of Mental Disorders, Revised Fourth Edition (DSM-IV-R) under the rubric of pervasive developmental disorder. A multitude of ASD screening and diagnostic tools are available, but unfortunately no single diagnostic instrument or method is universally accepted and used as the standard. No cure for the disorder exists, although some evidence suggests that early, intensive behavioral treatments may improve functioning.

See also pages 619 and 628

As evidenced by recent articles in the scientific and lay literature and by increased research funding allocations from the Centers for Disease Control and Prevention, Atlanta, Ga, and the National Institutes of Health, Bethesda, Md, awareness of and concern about ASD is growing rapidly. The crux of the issue is an alarming trend of increasing reporting of ASD. It is not established whether the increase in prevalence of ASD reflects a true rise in incidence or changes related to ascertainment, or both. The dilemma is far more than an academic conundrum. For in-
stance, well-publicized fears that the measles, mumps, and rubella vaccine is causally related to ASD onset, 34-36 despite a preponderance of evidence against such a relation. 37-46 have contributed to an erosion of confidence about the safety of immunizations among some parents in the United States and Great Britain and led to a corresponding drop in immunization coverage among children in both countries. 37,47-53

The magnitude of the apparent increase in ASD incidence is difficult to quantify, because there is a paucity of population-based ASD surveillance systems. 34-46

In Minnesota, as in most states in the United States, no incidence registry exists and the only consistent data source for monitoring ASD prevalence is through the school systems. The federal Individuals With Disabilities Education Act (IDEA) mandates reporting of data on any child receiving funded special educational services, whether in public or private school. 37-39 Each such child must be designated by the school system to one primary disability category. The categories, however, have changed over time, and so too, at least in Minnesota, have the efforts applied by the educational community to properly identify and serve children with ASD. The primary aim of this analysis is to quantify and characterize trends over time in ASD prevalence in Minnesota.

METHODS

DATA SOURCES

As required by the IDEA, the Minnesota Department of Children, Families & Learning (CFL) collects data annually from each school district on all children who receive special educational services that are provided by or paid for by the state, whether in private or public school. These data document the number of persons aged birth to 21 years who are served in any disability category on December 1 of every year. We received annual data by year of age and disability category from CFL for the academic years 1981-1982 through 2001-2002, in addition to the total number of children in the state’s school systems each year. The data file did not include individual-level information such as name, sex, race, or any unique identifiers, nor did it include age-specific counts of the total number of children enrolled in Minnesota schools. We therefore calculated age- and birth year–specific prevalence rates of ASD across school years using US Census Bureau annual population estimates for the denominator and CFL data for the numerator.

ASD AS A SPECIAL EDUCATIONAL DISABILITY CATEGORY

An IDEA disability designation is the category through which a child is found to be eligible for special educational services and through which districts receive federal monetary support. It serves as an administrative tool rather than a standardized clinical diagnosis. The ASD disability category is intended to include children who are identified as having autism, pervasive developmental disorder not otherwise specified, Asperger syndrome, Rett syndrome, or childhood disintegrative disorder, and whose primary special educational needs are judged to be best served under this disability category. The latter distinction is important, because if a child has more than 1 disability—for instance, autism with mild mental handicap or autism with speech and language deficiency—that child may be included in a mental retardation or speech and language disability category and thus not counted as autistic in CFL or IDEA statistics. Secondary disability categories are sometimes recorded by individual school districts, but they are not routinely reported in CFL or IDEA statistics. Although not mandated by federal requirements until 1991 (as discussed in the “Comment” section), CFL has collected data on autism since 1981.

Children, including preschoolers, who are identified through several means as potentially needing special educational services are evaluated by the school system or its designate. A multidisciplinary team is assembled to determine the services needed to best address the educational needs of the child and develop a formal individual education plan (IEP); this process includes evaluation to assign the child to an appropriate primary disability category. The services available to the child are individually determined and differ somewhat depending on the needs and the primary disability category assigned. Preschoolers who are assessed as having an educational disability are usually (but not always) placed in the developmental delay category (or early childhood special educational category before 1998), rather than a more specific disability category. Early childhood special educational and developmental delay categories may only be used until the child reaches age 6 years, when he or she must be moved to a specific primary disability category (such as ASD). In Minnesota, an autism specialist is required to be part of the IEP team for any child who is known to have or suspected of having a disorder that falls within the autism spectrum. The team often includes special educational teachers, therapists, educational psychologists, and one or both of the child’s parents. Notably, a clinical diagnosis of autism by a physician or neuropsychologist is not required for the IEP team to place a child in the ASD disability category, nor does a professional diagnosis of autism mandate inclusion of the child in the ASD category. The IEP team’s determination of ASD as the primary disability category includes evaluation of the child according to specific behavioral indicators that are consistent with the DSM-IV-R criteria. The CFL recommends that the evaluation include the Autism Diagnostic Observation Schedule, 36 but it is not required.

RESULTS

PREVALENCE DATA OVER TIME

Figure 1 shows the number of children in the ASD category statewide from the 1981-1982 through 2001-2002 school years. Little variation in the number of reported children with ASD occurred from 1981 to 1990. In contrast, ASD numbers rose from 251 children in the 1991-1992 school year to 4094 children in the 2001-2002 school year, a 16-fold increase. This difference represents the change in the “burden,” so to speak, that the school system encountered over time in serving children classified as having ASD. From the 1991-1992 through 2001-2002 school years, the number of children in all special educational disability categories combined rose 50%, from 82255 to 123835, while the total enrollment in the state's school system increased only 6%.

The annual prevalence of ASD per 10 000 persons aged 21 years or younger is illustrated in Figure 2. Two prevalence lines are shown depending on the source population (denominator) used in the calculations. The top line shows the prevalence rates using the annual number of children enrolled by the state’s school system. The ASD prevalence rate rose from 3 per 10 000 enrolled children in 1991-1092 to 44 per 10 000 enrolled children in 2001-2002. These ASD prevalence rates based on school enroll-
ment, however, are biased because they include in the enumeration (numerator) persons with ASD younger than 6 years or older than 18 years who are required by law to be served by the school system if they qualify for special education with a designated disability, but who would not be enrolled in the school system if they had no educational disability. The bottom line in Figure 2 shows annual ASD prevalence rates considering all children presumably “at risk” for ASD by using US Census Bureau population estimates of persons aged 21 years and younger. The prevalence rates in this comparison show a pattern similar to that of the top line but at a lower magnitude:

ASD prevalence rose from 2 per 10000 children in 1991-1992 to 27 per 10000 children in 2001-2002, a nearly 14-fold increase. All of our further calculations use the age-specific US Census Bureau estimates for denominator data.

**AGE-PERIOD-BIRTH COHORT EVALUATION**

We focus now on selected age-specific prevalence rate changes over time given in the Table, limited to children of elementary school age. The Table gives selected results of an age-period-birth cohort analysis and illustrates several related trends. First, it is evident that ASD prevalence has increased dramatically in successive birth cohorts. The ASD prevalence rate among 6-year-old children rose from 13 per 10000 in 1995-1996 to 35 per 10000 in 1999-2000. Among 8-year-old children, rates increased from 20 per 10000 in 1997-1998 to 66 per 10000 in 2001-2002. Second, the change in ASD prevalence within birth cohorts is observable. For instance, children born in 1991 had a prevalence rate of 21 per 10000 in 1997, when they were aged 6 years. The rates increased for this birth cohort each year as it aged. In 2001, when the 1991 birth cohort was 10 years of age, the prevalence rate was 52 per 10000. A period effect, although evident from the Table, is better illustrated in Figure 3. The dotted lines represent the ASD prevalence rates by age for every other year from the 1991-1992 school year through the 2001-2002 school year. The rates increase for each age during each successive period. In the earlier periods, the pattern of rates by age is fairly consistent, with little variation in rates (note the fairly flat line). In the later years, the pattern shows a marked bubble effect, resulting from a much higher ASD prevalence.
among the younger children entering elementary school. The black lines in the figure represent the prevalence among the cohort of children born in the denoted year as they age over time.

TRENDS IN ASD AND OTHER SPECIAL EDUCATIONAL CATEGORIES

The prevalence rates of children aged 6 through 11 years who were classified as having ASD, along with other major special educational disability categories, are shown on a log scale in Figure 4. Autism spectrum disorder and “other health impairment” (which includes attention-deficit/hyperactivity disorder) show dramatic increases during the 11 years. All of the other categories also show increases from 1991-1992 to 2001-2002, except for severe mental handicap. Severe mental handicap decreased during this period, from 24 per 10,000 to 23 per 10,000, while ASD increased from 3 per 10,000 to 52 per 10,000.

COMMENT

This analysis of administrative data from the educational system of Minnesota illustrates the dramatic increase in the prevalence of ASD during the past decade. The prevalence rates rose substantially over time within single-age groups and increased from year to year within birth cohorts. The pattern of increase within birth cohorts is incongruent with expectations of a nonfatal chronic disease diagnosed early in life. With complete, early case ascertainment and a stable population, the rate of disease would theoretically be constant as the birth cohort ages. That is, given a stable population, the prevalence among second graders in 1992 should be roughly equivalent to that among sixth graders in 1996. We observed this type of pattern in the earlier years of the study (Figure 3) but not in recent years. Rather, the pattern now shows the prevalence increasing in each successive birth cohort, and the trend shows no current signs of abatement.

Our findings must be considered in the context of several limitations. Diagnostic procedures used for determining special educational disability, including ASD, are not standardized across districts in the state, nor have they been uniform over time. We had no personal identifying information on these students and were unable to confirm the appropriateness of the ASD designation. As such, we could...
not validate the diagnosis or assess the effect of phenotype changes, such as the proportion of the increase that is attributable to Asperger syndrome or pervasive developmental disorder not otherwise specified. We also could not quantify how many children in Minnesota meet ASD diagnostic criteria but are not included in these statistics, or the number of children with an ASD designation who do not meet formal DSM-IV-R criteria for ASD.

This data source, unfortunately, also cannot be used to answer the important question of why ASD prevalence is rising. Prevalence is a function of disease incidence, disease ascertainment, disease duration, and population dynamics. Because ASD is a nonfatal condition beginning in early childhood, changes in disease duration theoretically cannot affect these trends. In addition, population changes in Minnesota were modest during the study period and are unlikely to account for much of the observed increase. Two other potentially influential factors should be considered. Autism spectrum disorder incidence, as some suspect, may be on the rise.26-33 One could speculate that the changing exposure profile of one or more environmental factors is causing interactive effects among a small pool of genetically susceptible children, resulting in higher ASD incidence rates.61 We are not able to assess that hypothesis in this data set. Current evidence supports genetic susceptibility as an important etiologic factor in ASD, with a complex interaction of multiple genes.7 Although evolutionary genetic processes cannot explain the sudden increases in ASD prevalence, the role of assortative mating of individuals with an attenuated phenotype (such as Asperger syndrome) has been hypothesized as a causal factor in the popular press62 but has yet to be studied scientifically.

Croen et al32 recently analyzed data from California and concluded that diagnostic substitution, from mental retardation to autism, may be an important factor in the apparent increase in ASD incidence in that state. Our data are not congruent with that hypothesis, at least in Minnesota. We found a very slight decrease in the prevalence rates of severe mental handicap and a very slight increase in the prevalence rates of mild to moderate mental handicap. The decrease in severe mental handicap was not sufficient to explain even a small proportion of the autism increase, and no other special educational category showed decreasing prevalence from the 1991-1992 through 2001-2002 school years.

Another plausible contributing factor to the trend could be recent changes in administrative policies leading to improved case identification and ascertainment. The federal government, through the US Department of Education,63 first implemented the Education of the Handicapped Act and the Elementary and Secondary Education Act in 1976. The former included 9 categories of educationally related handicaps and the latter included 6 such categories, but ASD was not included in either. In 1978, the laws were made consistent with each other, and multihandicap and deaf or blindness categories were added but not ASD. In 1990, the IDEA supplanted the Education of the Handicapped Act and the Elementary and Secondary Education Act. The following year, in 1991, ASD was added as a specific reporting category in the IDEA, and all states were required to report the number of children with a designated primary disability of ASD who were receiving special educational services. Inclusion of ASD in the IDEA funding and reporting mechanism coincides with the beginning of the upward trend in ASD prevalence observed in Minnesota. In Minnesota, CFL began implementing in 1992 a policy requiring an autism specialist to be included on any IEP team of a child suspected of having an ASD. Then, in 1994, the US government consolidated all federal funding sources for special education into the IDEA, thus becoming the sole funding source for ASD educational services. A grant from CFL in 1997 established a network of regional technical assistance and training projects in Minnesota with the goal of building the capacity of staff, districts, and regions to provide services for young children with ASDs. The focus was on outreach and dissemination of information. Although statistics are not kept by the state on the frequency of use of the Autism Diagnostic Observation Schedule in special educational evaluations, in the past 3 years alone CFL has formally trained 260 educational staff to use the instrument. Therefore, during the 1990s and continuing today, there is a growing emphasis on identification of and services for children with ASD.59 If these efforts represent a major improvement in ascertainment—and our data are consistent with such a conclusion—it appears there has been a substantial underestimate of ASD in the past. Because the IDEA mandates reporting of only the primary disability identified by the IEP team, children with ASD as a “secondary” disability are not included in the statewide statistics. If parents and IEP teams are more likely now than before to classify children with multiple educational disabilities that include an ASD in the ASD primary category, that too may explain some of the observed increase. We cannot quantify the extent to which the changing administrative laws and efforts related to special educational services for children with ASD contribute to the observed pattern of increasing disease prevalence. We can surmise, however, that these phenomena are important contributing factors.

There is great controversy surrounding autism, including whether autism incidence is actually on the rise, rather than a result of changes in awareness, diagnostic criteria, and case ascertainment. Few studies have carefully quantified the increase in prevalence rates. To our knowledge, no studies have provided a trend analysis using the age-period-birth cohort approach. This study provides such an analysis, quantitatively illustrating the dramatic changes that are occurring across and within birth cohorts and over time. Furthermore, this study provides evidence that, at least in Minnesota, diagnostic substitution does not largely explain the increasing trends, as was recently reported from data in California. Rather, we provide a succinct chronology of federal and state administrative policies that coincide in time with the increase in prevalence, suggesting that autism may have been previously underdiagnosed.