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Increasing autism prevalence in metropolitan New Jersey

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Abstract

High baseline autism spectrum disorder prevalence estimates in New Jersey led to a follow-up surveillance. The objectives were to determine autism spectrum disorder prevalence in the year 2006 in New Jersey and to identify changes in the prevalence of autism spectrum disorder or in the characteristics of the children with autism spectrum disorder, between 2002 and 2006. The cohorts included 30,570 children, born in 1998 and 28,936 children, born in 1994, residing in Hudson, Union, and Ocean counties, New Jersey. Point prevalence estimates by sex, ethnicity, autism spectrum disorder subtype, and previous autism spectrum disorder diagnosis were determined. For 2006, a total of 533 children with autism spectrum disorder were identified, consistent with prevalence of 17.4 per 1000 (95% confidence interval = 15.9–18.9), indicating a significant increase in the autism spectrum disorder prevalence ($p < 0.001$), between 2002 (10.6 per 1000) and 2006. The rise in autism spectrum disorder was broad, affecting major demographic groups and subtypes. Boys with autism spectrum disorder outnumbered girls by nearly 5:1. Autism spectrum disorder prevalence was higher among White children than children of other ethnicities. Additional studies are needed to specify the influence of better awareness of autism spectrum disorder prevalence estimates and to identify possible autism spectrum disorder risk factors. More resources are necessary to address the needs of individuals affected by autism spectrum disorder.

Keywords

autism, autism spectrum disorder prevalence, developmental disabilities surveillance, epidemiology, New Jersey, population-based, public health monitoring

Introduction

Autism spectrum disorder (ASD) is a complex developmental disorder characterized by impairment in social and communication ability and restricted, anomalous, or repetitive behavior. ASD is evident before 3 years of age (Yeargin-Allsopp et al., 2003); variable in expression (Lord et al., 2006; Prior et al., 1998); more common in males (Newschaffer et al., 2007; Wing and Potter, 2002); and frequently accompanied by deficits in attention, cognition, and sensory-processing (Gillberg and Billstedt, 2000). Although there is a heritable dimension to ASD (Bailey et al., 1995; Folstein and Rutter, 1977; Lichtenstein et al., 2010; Weiss, 2009), neither genetic nor environmental factors have been successfully elucidated (Gilman et al., 2011; Hallmayer et al., 2011; Levy et al., 2011; Liu et al., 2010). The functional limitations of individuals with ASD and the life-long need for health, education, and support services (Honberg et al., 2009) underscore the public health significance of this disorder.

Not long ago, ASD was thought to affect one in 2000 children (Fombonne, 2009). Since 1990, the number of persons receiving services for autism has increased substantially (California Department of Developmental Services, 1999, 2003; Newschaffer et al., 2005), as have ASD estimates defined by epidemiologic studies (Baird et al., 2006; Chakrabarti and Fombonne, 2001; Hertz-Picciotto and

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Delwiche, 2009; Honda et al., 2005). However, significant controversy continues regarding whether the observed increases reflect true change in ASD risk, expansion of the definition, increased awareness, or other factors (Blaxill, 2004; Charman, 2002; Fombonne, 2009; Gernsbacher et al., 2005). Repeated, population-based surveillance in specific geographic areas, using birth year as a reference, may provide the best basis for inferring ASD prevalence and trends. Using such an approach, baseline ASD estimates from two cycles of monitoring by the Centers for Disease Control and Prevention (CDC)—Autism and Developmental Disabilities Monitoring (ADDM) Network, among 8-year-old children, born in 1992 and 1994 and residing in multiple US regions, averaged 6.7 per 1000 (range = 4.5–9.9) and 6.6 per 1000 (range = 3.3–10.6) in 2000 and 2002, respectively (CDC, 2007a, 2007b). However, ASD prevalence in New Jersey (9.9 and 10.6 per 1000), determined by the same method, was significantly higher ($p < 0.001$) than in all other ADDM states, in both years (CDC, 2007a, 2007b). For 2006, the ADDM Network (not including New Jersey) identified a marked increase in ASD prevalence to 9.0 per 1000 (range = 4.2–12.1), over the preceding 4 years (CDC, 2009).

In light of the high rates of ASD identified in New Jersey for 2000 and 2002 and the increases in ASD prevalence identified by the ADDM Network for 2006, the goals of this study were to provide updated estimates of ASD prevalence in the New Jersey Metropolitan Area (NJMA), using identical methods and procedures, for comparison of ASD prevalence, between 2002 and 2006.

Methods

Study region and population

ASD surveillance was conducted in Hudson, Essex, Union, and Ocean counties, New Jersey, a densely populated, urban–suburban, area of 2.4 million, within the largest US metropolis. The region includes three of the state's largest cities and over 75 communities, encompassing an ethnically diverse population (43% White, 25% Black, 26% Hispanic, and 6% others; United States. Bureau of the Census, 1991) and representing the widest range of socioeconomic strata. Surveillance was restricted to (8-year-old) children born in 1998, residing in the study region, in 2006. The study was approved by the New Jersey Medical School (NJMS) Institutional Review Board (IRB) and implemented with the cooperation of local school districts, developmental and behavioral health centers, as well as state education and health authorities. The cases were linked to New Jersey birth certificate data, to confirm additional demographic information.

Children with ASD were identified using the two-phase ADDM method of ASD ascertainment through (a) active, multiple-source screening and (2) independent case determination. The surveillance method has been described extensively elsewhere (CDC, 2007a, 2007b, 2009).

Case definitions

Autistic disorder (AD) was defined as a pattern of behaviors, as described in evaluation records by qualified professionals, consistent with the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; *DSM-IV-TR*) diagnostic criteria for AD, at any time, through age 8 years. Specifically, AD was defined as a case in which a child shows six or more features of autism, including two or more signs of social impairment and one or more signs each of communication and behavioral impairment, as well as documented developmental concern before the age of 3 years. ASD–not otherwise specified (ASD-NOS) was defined as a case in which the child met the *DSM-IV-TR* criteria for pervasive developmental disorders–not otherwise specified (PDD-NOS) or Asperger's disorder and also satisfied the study-specific requirement that at least one documented behavior be of such quality or intensity to be highly indicative of ASD. An evaluation record was an assessment conducted by a professional for determination of the need for special education services or to diagnose a developmental, behavioral, or neurological disorder. A qualified professional was defined as a medical, psychological, or other professional with specialized training in the observation of children with developmental disorders. Regression was documented by statements in professional evaluations indicating that the child lost previously acquired language or social skills. Children with an intelligence quotient (IQ) greater than 85, on a standard intelligence test, were defined to have average or above average cognitive ability. Children with an IQ between 71 and 85 were considered to have borderline cognitive impairment (BCI). Children with an IQ of 70 or below were classified as having cognitive impairment (CI).

Phase 1—case ascertainment

Records of children educated under any special education classification and/or receiving clinical evaluation or treatment under one or more of 80 *International Classification of Diseases*, 9th Revision (ICD-9) disorder codes were reviewed. Records of children with documented or suspected ASD diagnoses or with one or more description(s) of social impairment associated with autism were abstracted. The abstracted information included demographic and developmental data, clinical findings, including diagnoses, educational classification and placement information, verbatim descriptions of behavior and development, psychometric findings, service, and treatment data. The information from health and education sources was linked and organized as a composite, nonidentifiable, chronological case file per child.

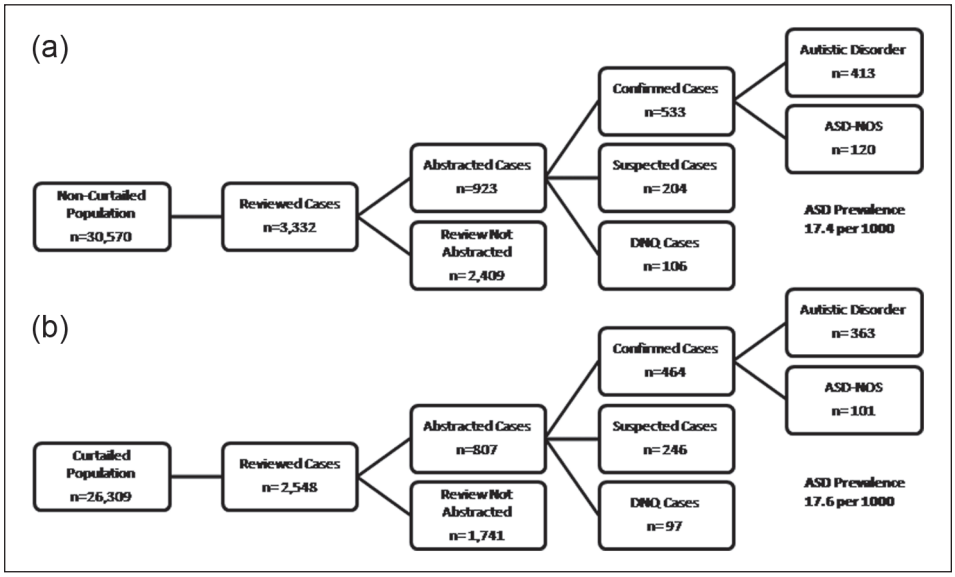

Figure 1. Study diagram. (a) Describes the 2006 study population, ASD was found to be 17.4 per 1000 children and (b) describes the curtailed population in 2006, which is used in comparison to data from SY2002, ASD prevalence was found to be slightly higher than 17.6 per 1000 children.
ASD: autism spectrum disorder; SY: study year.

Phase 2—clinician review and analysis

Subjects' case information was scored and analyzed by certified child development specialists (one developmental pediatrician, two psychologists, and one learning disabilities consultant), each with more than 10 years of professional experience and more than 5 years of expertise using the CDC-ADDM *DSM-IV-TR*–based Clinician Review coding procedures to determine ASD case status (Case, Suspected, Does Not Qualify (DNQ)) and ASD Type (AD, ASD-NOS). Children were identified as having documented ASD if they received a diagnosis of any ASD from a qualified professional. Prior to the analytic phase, expert reviewers established interrater reliability according to the CDC-ADDM standard of >95% agreement for ASD case definition and >80% agreement for other scored features. Ongoing interrater reliability testing was conducted on a random, blinded 10% sample of reviewed records. The percent agreement for final case definition was very good (range: 91%–100% (kappa range: 0.8–1.0)).

Analytic methods

The total population of 8-year-olds in the surveillance region was 31,069. Seventy-five of 78 school districts participated with the study, representing 30,570 children (98.2%) in the region, according to the National Center for Health Statistics (NCHS) vintage 2007 postcensal data. The prevalence estimates were calculated using the total number of 8-year-olds who resided in the 75 participating districts. NCHS datasets provided population counts by county, year of birth, sex, and ethnicity. Ethnicity-specific estimates were calculated for the categories: White non-Hispanic; Black non-Hispanic; Hispanic; and Others, which encompassed children of Asian and/or American Indian ancestry. Poisson's distribution was used to calculate 95% confidence intervals (CIs) for prevalence rates. For the purposes of comparing ASD prevalence between 2002 and 2006, an adjusted set representing only data from districts participating both years was established and analyzed (Figure 1). Chi-square tests were used to compare prevalence estimates and rate ratios, and percentage changes were used to compare changes between 2002 and 2006. A maximum value of $p < 0.05$ determined statistical significance. Because ASD prevalence is determined on the basis of information contained in evaluation records, multiple factors that could influence the estimate, including variability in access, the effects of migration, and missing or incomplete records, were assessed.

Results

Overall ASD prevalence study year 2006

In a population of 30,570 eight-year-olds, the clinical and educational records of 3332 children from 75 school districts were reviewed. Subsequently, records of 923 children (3% of the total 8-year-old population) met the conditions for abstraction and were analyzed, leading to the identification of 533 children with study-determined ASD, a prevalence of 17.4 per 1000 (Table 1). Two children with Rett's syndrome were identified but not included in the prevalence count. ASD prevalence was much higher among boys (28.3 per 1000) than girls (5.8 per 1000) and highest among

Table 1. Prevalence of ASD among children aged 8 years, 2002–2006 rate ratio, and percentage of prevalence change—NJAS, 2002 and 2006.

Category	2006 population[a]		2006 prevalence rate (95% CI)[a]	2002 population[b]		2002 prevalence rate	2006 population[b]		2006 prevalence rate	2002–2006 rate ratio		% Change from 2002 to 2006
	Total no.	Total confirmed no.		Total No.	Total confirmed no.		Total no.	Total confirmed no.		Ratio	95% CI	
Overall												
Total	30,570	533	17.4 (16.0–19.0)	28936	312	10.8	26,309	464	17.6	1.65**	(1.42–1.90)	63
Sex												
Male	15,739	446	28.3 (25.8–31.1)	14953	254	17.0	13,533	388	28.7	1.71**	(1.46–2.00)	69
Female	14,831	87	5.87 (4.75–7.24)	13983	58	4.15	12,776	76	5.95	1.44*	(1.02–2.02)	43
Race/ethnicity												
White, non-Hispanic	13,599	278	20.4 (18.2–23.0)	12247	155	12.7	11,387	240	21.1	1.68**	(1.37–2.06)	66
Black, non-Hispanic	7719	116	15.0 (12.5–18.0)	7827	61	7.79	6569	97	14.8	1.91**	(1.38–2.63)	90
Hispanic	7609	112	14.7 (12.2–17.7)	7272	72	10.0	6876	103	15.1	1.51*	(1.12–2.05)	51
Asian	1573	22	14.0 (9.21–21.24)	1520	22	14.5	1414	20	14.1	1.03	(0.56–1.88)	2.9
Race/ethnicity and sex												
Male												
White, non-Hispanic	7011	242	34.5 (30.4–39.1)	6267	127	20.6	5855	202	34.5	1.73**	(1.38–2.16)	70
Black, Non-Hispanic	3694	91	23.0 (18.7–28.2)	4050	50	12.3	3383	75	22.2	1.81**	(1.26–2.60)	80
Hispanic	3882	91	23.4 (19.1–28.8)	3827	57	14.9	3496	83	23.7	1.61*	(1.14–2.26)	59
Asian	837	17	20.3 (12.6—32.7)	775	18	22.7	761	17	21.8	0.96	(0.49–1.88)	1.3
Female												
White, non-Hispanic	6588	36	5.46 (3.94–7.58)	5980	28	4.68	5532	33	6.01	1.28	(0.78–2.13)	27
Black, Non-Hispanic	3755	25	6.66 (4.50–9.85)	3777	11	2.91	3186	21	6.59	2.72*	(1.09–4.72)	126
Hispanic	3727	21	5.63 (3.67–8.64)	3445	15	4.35	3380	19	5.62	1.29	(0.66–2.55)	29
Asian	736	5	6.79 (2.83–16.3)	745	4	5.34	653	3	4.57	0.86	(0.19–3.84)	−14
ASD diagnosis/classification												
ASD diagnosis on record	30,570	367	12.01 (10.8–13.3)	28936	193	6.67	26,309	307	11.7	1.76**	(1.47–2.11)	75
Special education classification: autism	30,570	227	7.43 (6.52–8.46)	28936	130	4.49	26,309	195	7.41	1.66**	(1.32–2.07)	65
NJAS—definitions												
NJAS defined: autism type	30,570	413	13.51[c]	28936	227	7.84	26,309	363	13.8	1.77**	(1.50–2.09)	76
NJAS defined: ASD-NOS type	30,570	120	3.92[c]	28936	85	2.94	26,309	101	3.84	1.31	(0.98–1.75)	31
Regression	30,570	98	3.20[c]	28936	67	2.31	26,309	84	3.20	1.38*	(1.00–1.90)	38

ASD: autism spectrum disorder; NJAS: New Jersey Autism Study; ASD-NOS: autism spectrum disorder–not otherwise specified; CI: confidence interval; SY: study year.
ASD prevalence rate is given per 1000 children aged 8 years old. American Indian Race is not included due to very small number.
[a]Total 8-year-old population for SY2006 noncurtailed.
[b]Total 8-year-old population for SY2002 and SY2006 are curtailed to reflect a common study area between SY2002 and SY2006.
[c]CIs are not calculated.
*$p < 0.05$, **$p < 0.001$.

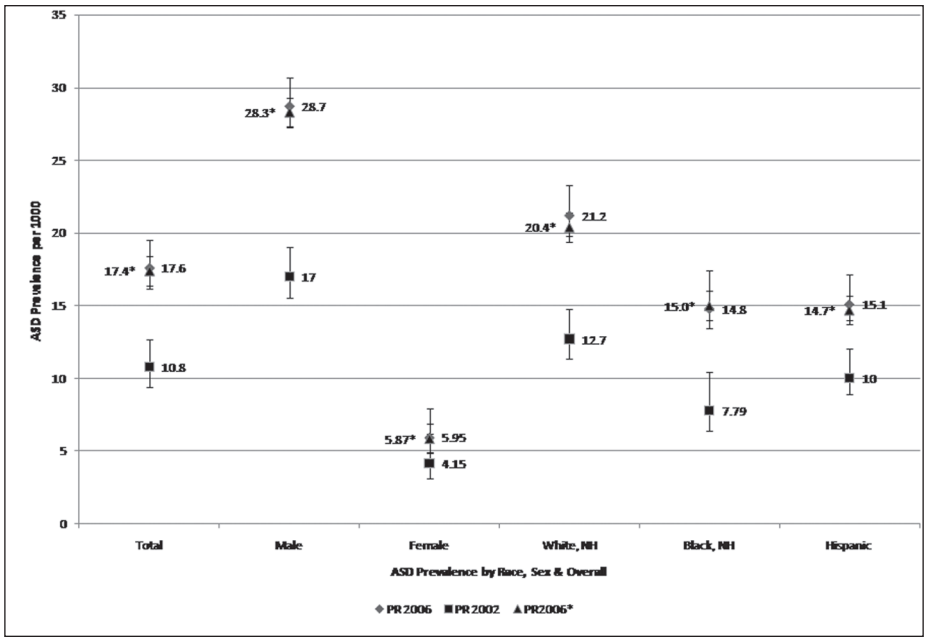

Figure 2. Comparison of ASD prevalence between SY2002 and SY2006.
ASD: autism spectrum disorder; SY: study year.

White non-Hispanic boys, ranging from 30.4 to 39.1 per 1000. A total of 413 (77%) children satisfied the full diagnostic criteria for AD, and 367 (69%) had a documented (previous) ASD diagnosis from a community provider. Agreement between previous ASD diagnosis and ASD case status by the surveillance method was 99%. Five hundred nine ASD children (95%) received special education service in 2006, and 224 (44%) were educated under an autism classification.

Comparison between New Jersey areas surveyed in 2002 and 2006

To reduce the possibility of changes in population affecting our prevalence estimates, we compared ASD prevalence across the 58 New Jersey communities that participated in both surveillance years. Between 2002 and 2006, ASD prevalence increased from 10.8 to 17.6 per 1000 ($p < 0.001$; Table 1; Figure 2). Higher ASD rates were evident across most demographic and functional categories. ASD prevalence among boys rose from 17.0 to 28.7 per 1000 ($p < 0.001$) and increased from 4.1 to 5.9 per 1000 among girls ($p < 0.05$). The ASD prevalence rates between girls and boys were significantly different in 2002 and 2006 ($p < 0.001$). However, though the 2002–2006 rate ratio change of 1.71 for boys was greater than the rate ratio change observed for girls (1.41), the overlapping 95% CIs between boys and girls indicate that the difference is not statistically significant (Table 1). Likewise, the ASD rates rose significantly among Black non-Hispanic, White non-Hispanic, and Hispanic children (90%, 66%, and 51%, respectively; Table 1; Figure 2). While the number of children satisfying the criteria for AD increased, the proportion of ASD children with regression was unchanged (Table 2). Rising ASD prevalence was also reflected in greater numbers of children diagnosed with ASD by a community professional (6.7–11.7 per 1000 ($p < 0.001$)) and children educated under an autism eligibility (4.5–7.4 per 1000 ($p < 0.001$); Table 1; Figure 3).

To assess possible influences on ASD prevalence, multiple factors representing case characteristics and data completeness were compared (Table 2). In-migration was stable during the period. Measures reflecting data quality, including the percentage of ASD children receiving special education services (98%–95%) and the proportion of children with evaluations from both clinical and educational sources (83%–86%), were uniformly high (Table 2), while the number of unavailable cases or cases with incomplete information was small across years (unpublished findings). The abstraction proportion, representing the percent of the total population whose records underwent review and analysis, increased significantly during the period, but a smaller proportion of analyzed cases satisfied the ASD case definition. The ages of earliest professional evaluation and earliest documented ASD diagnosis declined between 2002 and 2006 (Table 2).

Discussion

Just as recent epidemiologic studies have converged at a 1% estimated level of ASD prevalence (Baird et al., 2006; CDC, 2009; Fombonne, 2009; Honda et al., 2005), this study

Table 2. Comparison of study methodology and characteristics between SY2002 and SY2006.

New Jersey Autism Study—characteristics									
Category	SY2002				SY2006				% Change from 2002 to 2006
	Median	SD	Range	N	Median	SD	Range	N	
Data collection									
Curtailed 8-year-old population	28,936				26,309				−9
Total reviewed cases in each SY from the total population (n, %)	2335, 8.1%				2548, 9.7%				20
Total abstracted cases from total population (n, %)	419, 1.4%				807, 3.1%				113
Number of confirmed cases in each study year from total abstracted cases	312, 74.3%				464, 57%				−22.6
Study methodology									
Percentage of children with both educational and health information reviewed	259, 83.0%				398, 85.8%				3.37
Percentage of children receiving autism test	55, 17.6%				99, 21.3%				21.0 confirmed cases only
Average number of evaluations per child	7	4.78	1–36	419	7	5.04	1–41	807	0
ASD—age									
Age of ASD diagnosis noted in child record (months)	52.50	20.53	15–101	210	48.00	22.02	9–102	305	−8.57
Earliest age of evaluation (months)	43.50	18.84	3–105	312	39.00	19.34	1–99	464	−10.34
Developmental concerns									
Category	SY2002				SY2006				% Change from 2002 to 2006
Developmental concerns before age of 3 (n, %)	279, 89.4%				416, 89.6%				0.21
Regression (n, %)	67, 21.5%				84, 19.6%				−15.3
IQ ≤ 70	76, 24.3%				108, 23.3%				−4.11
Special education									
Autistic classification (n, %)	133, 42.5%				206, 44.3%				4.33
Total confirmed cases receiving special education (n, %)	306, 98%				440, 95%				−3
NJ Pk thru 12 receiving special education (%)	16.1%				16.6%				2.6
New Jersey birth certificate linkage									
Confirmed cases born in NJ (n, %)	262, 84%				379, 82%				−2.4

ASD: autism spectrum disorder; SY: study year; SD: standard deviation.
NJ Pk thru 12, refers to school years, pre-Kindergarten thru 12th grade.

suggests that ASD prevalence may be closer to 2%, in some US regions. Using a comprehensive, population-based method, we determined that 1 in 57 eight-year-olds in the NJMA, in 2006, had an ASD. While this estimate is higher than the rates from other US areas using the same case-finding method (CDC, 2009), higher than the rates derived from nationally representative health survey data for the same period (Kogan et al., 2009), and higher than baseline ASD prevalence in the same region 4 years earlier (CDC, 2009), the overall ASD prevalence of 17.4 per 1000 is in the range of recent ASD estimates from Cambridgeshire, United Kingdom (Baron-Cohen et al., 2009), and Goyang, South Korea (Kim et al., 2011). Higher ASD prevalence in New Jersey in comparison to other US regions, across surveillance cycles, may be a function of more detailed information in New Jersey records, leading to more complete ASD ascertainment. However, additional effects from as-yet-unknown demographic and/or environmental factors cannot be ruled out. Consistent with multiple studies (CDC, 2009; Parner et al., 2008; Posserud et al., 2006), nearly five times as many boys than girls were affected, representing an absolute level of male ASD prevalence (1 in 35) that is startling, if not unprecedented (Kim et al., 2011), and underscoring the need for further research into the sex-based differences in autism. In our population, ASD prevalence also varied by ethnicity, with White non-Hispanic children showing the highest levels of ASD, consistent with some epidemiologic studies (CDC, 2007a, 2007b; Kogan et al., 2009) and contrary to others (Fombonne, 2001; Hillman et al., 2000; Yeargin-Allsopp et al., 2003). The observed differences in ethnic distribution

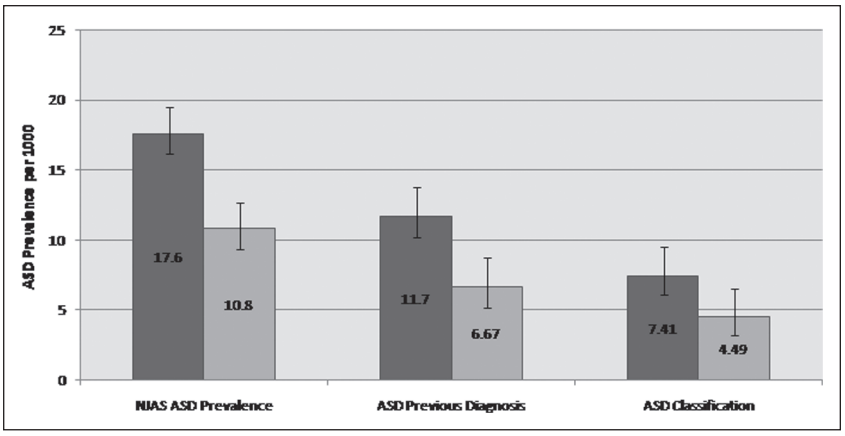

Figure 3. ASD prevalence rate in SY2002 and SY2006 by method of identification.
ASD: autism spectrum disorder; SY: study year.

of ASD may reflect variations in genetic susceptibility, environmental risk, ascertainment, or combinations of these factors. Regardless, further consideration of demographic influences on ASD prevalence is indicated, especially to understand disparities in ASD identification and diagnosis (Durkin et al., 2010; Levy et al., 2011; Mandell et al., 2009; Thomas et al., 2011). Following on stable baseline ASD estimates for 2000 and 2002, the upward shift in ASD prevalence in 2006 was unexpected. However, the increase was substantial and affected children across demographic groups, similar in magnitude (63%) to the increases in autism special education classification (65%) and community-diagnosed ASD in our region (75%), and consistent with the average increase in ASD prevalence (57%), reported by the US ADDM Network sites, between 2002 and 2006. In the absence of a significant change in definition, policy, or service availability relevant to ASD, it is difficult to understand why all indicators of autism prevalence would have escalated 50%–75% during the period.

A number of factors may have influenced our estimates. For example, enhanced awareness and improved diagnosis of ASD could have contributed to the observed changes. Comparing the 2002 and 2006 ASD case characteristics, we observed a reduction in the median age of ASD diagnosis and an increased number of children with previously diagnosed ASD, two gauges of (community) awareness that might have influenced the determination of ASD prevalence. However, the shift in age of earliest ASD diagnosis was relatively modest (4.5 months), while the proportion of previously diagnosed ASD children was unchanged over the period, indicating that these specific factors may not have exerted a substantial influence on our prevalence estimation. Alternatively, improving awareness of ASD might have been expressed through enhanced recognition of ASD in children from minority groups or among children with higher cognitive functioning. While we did identify increased numbers of Black and Hispanic children with ASD, as well as more ASD children with borderline IQ and average or above average IQ, in 2006, significant increases in diagnosed and study-defined ASD were also evident among White children and children with CI, suggesting a broadly based escalation of ASD, rather than an increase reflecting improved case-finding in specific populations. Another possibility is that the ascertainment method was overinclusive and/or prone to inflation over time due to increasing identification of borderline or atypical ASD cases. Regarding the first point, a recent validation study (Avchen et al., 2011) found that the (CDC-ADDM) ascertainment method is conservative, with high specificity and low sensitivity and, therefore, more likely to underestimate ASD prevalence than to overstate it. Furthermore, contrary to expectation, comparing 2002 and 2006 estimates, we found significant increase in the proportion of children satisfying the criteria for AD but not in children identified with ASD-NOS. Interestingly, 70%–75% of 8-year-old ASD children, across all surveillance cycles, satisfied the strict diagnostic criteria for AD, in keeping with the subtype distribution described by some studies (Bertrand et al., 2001; CDC, 2007a, 2007b, 2009) and at variance with others (Chakrabarti and Fombonne, 2001; Fombonne, 2003). Since the ADDM surveillance method analyzes detailed, subject-specific, information across multiple evaluations, it is very likely to have a more robust array of information and to confirm AD more frequently than studies that define ASD subtype by one or two evaluative contacts.

To ensure the comparability of ASD estimates over time, we maintained CDC-ADDM ascertainment methods, case definitions, and analytic procedures, including quality assurance operations, across the surveillance cycles. The total population of 8-year-olds decreased in three of four surveillance counties between 2002 and 2006, but our access to multiple high-quality health and education records was consistently high, resulting in maximum levels of exposure to potential cases. Though the study was not

designed to evaluate the effects of migration patterns on ASD, the base population of the NJMA is stable and the in-migration level is low. In 2002 and 2006, 84% and 82% of ASD cases, respectively, matched to New Jersey birth certificates, suggesting that in-migration did not have a significant influence on the overall prevalence estimate or on changing prevalence, over time. To reduce the possibility of error in calculating change in prevalence, we only compared districts that participated with ASD surveillance, both years. Our analyses of data quality showed high levels of completeness and no significant difference on most indicators, between the two cycles (unpublished findings). While the number of records reviewed on behalf of ASD surveillance did not vary significantly over cycles, the number of abstracted cases increased from 419 in 2002 to 807 in 2006, representing a significant increase in the proportion (1.4%–3.1%) that underwent expert analysis. It is difficult to determine the extent to which the change in abstraction proportion affected the 2006 prevalence estimate. In previous cycles of ASD surveillance by the ADDM Network, the abstraction proportion ranged between 1% and 3% without systematic effect on ASD prevalence (CDC, 2007a, 2007b). On the other hand, it stands to reason that high levels of ASD awareness and higher levels of ASD diagnosis will serve to an enlarged scope of ascertainment and may affect the prevalence estimate.

Overall, this study shows a high and increasing number of children in the NJMA affected by ASD. Some of the increase may be a function of improved awareness and diagnosis. However, the possibility of an increase in ASD prevalence, due to changing risk, cannot be ruled out. Ongoing ASD surveillance using the same epidemiologic method by the entire ADDM Network and New Jersey is essential to monitor possible, future, changes in the expression or prevalence of autism and to allow the comparisons that will clarify ASD risk and ascertainment factors. Even in regions like New Jersey, where the population has good to excellent access to clinical specialists and where children are served by a universal, well-funded, public education system, a significant minority of children with ASD are not diagnosed (with ASD) before age 8. This gap in identification has been consistent across time and US surveillance sites and points to the fact that administrative or registry-based estimates of ASD prevalence that are based only on already-diagnosed children will underestimate the actual number of individuals with ASD.

This study has a number of strengths, deriving from the design and the large, diverse, nature of the population. Consistent implementation of an active, multiple-source ascertainment strategy, in a well-specified region, provides the most accurate ASD prevalence estimates and the best opportunity to evaluate changes in prevalence. The detailed case-specific information derived from multiple sources allows for identification of ASD in children without a previous diagnosis, thereby ensuring the most complete ASD estimates. Linkage of highly detailed case-specific data with birth certificate, census files, and other sets permits additional analyses that may lead to the identification of ASD risk factors and to appreciation of disparities in service to ASD children.

Some limitations of the study should be pointed out. Only children identified for special education or for clinical (developmental) services came under the purview of our surveillance. Some children with Asperger's syndrome or high-functioning ASD are educated in general education settings and did not come to the attention of their school district or our study, thereby leading to underestimate ASD prevalence. Also, since the surveillance method is able to analyze a large amount of detailed information across multiple professionals contained in evaluation records, while an approach based on direct clinical assessment is limited to defining ASD type from observations by one professional at a single point in time, our method may overestimate the prevalence of AD, relative to atypical ASD.

Regardless of whether one acknowledges an increased ASD prevalence, all the epidemiologic and administrative studies confirm that ASD is now among the most common, severe, developmental disorders. It is too soon to know at what point ASD prevalence will plateau. As more children with ASD are identified, more resources will be required to assist the affected individuals and their families. Additional research is needed to assess the factors bearing on increasing ASD prevalence and to identify the etiological factors of this key disorder. The multiple-source, active, case-finding method can be especially effective for monitoring behaviorally defined disorders like ASD and may be fruitfully extended to other developmental, learning, and/or psychiatric disorders.

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Declaration of conflicting interest

The authors report no conflicts of interest. The findings and conclusions in this report are those of the authors and do not necessarily represent the position of the New Jersey Governor's Council for Biomedical Research and Treatment of Autism or the CDC.

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