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Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000;

Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002; and

Evaluation of a Methodology for a Collaborative Multiple Source Surveillance Network for Autism Spectrum Disorders —Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002

DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION

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Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2000 Principal Investigators

Abstract

Problem/Condition: Data from a population-based, multisite surveillance network were used to determine the prevalence of children aged 8 years with autism spectrum disorder (ASD) in six areas of the United States and to describe the characteristics of these children.

Reporting Period: 2000.

Methods: Children aged 8 years were identified as having an ASD through screening and abstraction of evaluation records at multiple sources, with clinician review of abstracted records to determine case status. Children whose parent(s) or legal guardian(s) resided in one of the six surveillance areas during 2000 and whose records documented behaviors consistent with the American Psychiatric Association's criteria for diagnosing 1) autistic disorder, 2) pervasive developmental disorder-not otherwise specified, or 3) Asperger disorder were classified as having an ASD.

Results: For 2000, across six sites, a total of 1,252 children aged 8 years were identified as having an ASD. The overall prevalence of ASDs per 1,000 children aged 8 years ranged from 4.5 in West Virginia to 9.9 in New Jersey. With the exception of one surveillance site (Georgia), no statistically significant ($p<0.05$) differences were identified in the rate of ASDs between non-Hispanic black and non-Hispanic white children. The ratio of male-to-female prevalence varied (range: 2.8:1.0–5.5:1.0). The majority of children with ASDs received special education services and had a documented history of concerns regarding their development before age 3 years. The prevalence of children with a previously documented ASD classification varied across sites, but the median age of earliest documented ASD diagnosis was similar across sites (age 52–56 months). For three sites with sufficient data on intelligence quotient (IQ), cognitive impairment (i.e., IQ of ≤70) was reported for 40%–62% of children whose conditions were consistent with the case definition for ASD.

Interpretation: Findings from this first U.S. multisite collaborative study to monitor ASD prevalence demonstrated consistency across the majority of sites, with prevalence statistically significantly ($p<0.001$) higher in New Jersey. Average ASD prevalence across all six sites was 6.7 per 1,000 children aged 8 years. These results indicate that ASDs are more common than was believed previously.

Public Health Actions: Collecting data regarding prevalence of ASDs by associated characteristics (e.g., cognitive impairment, age of first documented concerns, and history of ASD diagnosis), race/ethnicity, and sex will provide important baseline standards that can be compared with follow-up surveillance data to track changes in ASD prevalence. Knowledge of these characteristics has implications for identification and intervention strategies and for medical and educational service planning for children with ASDs.

Introduction

Persons with an autism spectrum disorder (ASD)* have impairments in social, communicative, and behavior development that typically are present before age 3 years and that often are accompanied by abnormalities in cognitive functioning, learning, attention, and sensory processing (*1*). Autism was thought previously to be rare, but during the 1990s, the number of persons reported to be receiving services for ASDs increased substantially (*1–7*). This increase has elevated public concern regarding prevalence of conditions in the autism spectrum and underscores the need for systematic public health monitoring. The complex nature of these behaviorally defined disorders, together with the current lack of genetic or biologic markers for early and consistent identification, make epidemiologic investigation challenging (*8–10*).

* In this report, ASD is used to refer to autistic disorder; pervasive developmental disorder, not otherwise specified (PDD-NOS); and Asperger disorder. The terms ASD and autism are used interchangeably.

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Population-based studies conducted worldwide before 1985 indicated that prevalence of autism and related conditions was 0.4–0.5 per 1,000 children aged <18 years (*11–14*). The most recent studies using current *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) (*15*) and *International Classification of Diseases, Tenth Revision* (ICD-10) (*16*) criteria have identified ASD rates ranging from 2.0 to 12.0 per 1,000 children (*1,4,17–23*), with "best-estimate" rates of 2.0–6.0 per 1,000 children (*14,24–26*). Recent findings reflect the expansion of the definition of autism to encompass a spectrum of disorders that might include co-occurring mental retardation (MR) or cognitive impairment, and the findings have challenged previously accepted ideas concerning the population characteristics of persons with ASDs. For example, certain studies have identified male-to-female ratios twice the four-to-one male-to-female ratio often identified in older studies (*22*) and much lower rates of co-occurring MR (approximately 25%–50% rather than the typically cited 70%) (*21,26*).

Studies of ASD prevalence in the United States during the 1990s have identified rates of 2.0–7.0 per 1,000 children (*1–3, 5,7,18,27–29*), a greater-than-tenfold increase from rates of 0.1–0.4 per 1,000 children identified during the 1980s (*30–32*). Certain studies have used data from single-service provision systems (e.g., numbers of children classified as having autism for special education or public health disability services) (*2,3,5,7,27,29*). Tracking the number of persons identified for services is important to measure the intervention needs and costs of care for persons with an identified ASD. However, because the number of persons identified for services is dependant on multiple factors (e.g., changing eligibility criteria, increased awareness, and changes in service availability), aggregate data might underestimate prevalence and should be used with caution in examining population-based trends (*7,8,29,33*).

CDC-conducted surveys of parent reports of diagnosed autism in their children (*34*) indicated that 5.5–5.7 per 1,000 children aged 4–17 years received a diagnosis of autism during 2003–2004, corroborating recent best estimates of approximately six ASD cases per 1,000 children (*14,24–26*). In addition, CDC funds projects that track the number of children with ASDs, conducts studies to identify what factors might lead to a child having an ASD, and offers education and outreach materials for the early identification of autism and other developmental disabilities. Information regarding these projects is available at http://www.cdc.gov/autism. To improve understanding of prevalence, population characteristics, and the public health impact of these conditions, CDC also has conducted population-based surveillance projects, including a community-based investigation in Brick Township, New Jersey (*18*) and ongoing surveillance in the greater Atlanta metropolitan area (*1,35,36*).

In 2000, CDC organized the Autism and Developmental Disabilities Monitoring (ADDM) Network, a multisite, multiple-source, records-based surveillance program to collect data for determining prevalence of ASDs and other developmental disabilities (*9*). The ADDM Network, as with CDC's Atlanta population-based surveillance program, employs systematic screening of developmental evaluation records for behaviors associated with autism rather than depending on a previously documented diagnosis or classification of autism or a related disorder to identify children with ASDs (*1,9*). Because this methodology collects data from multiple health and service provision sources rather than from a single source, these data can be used to estimate a closer approximation of true population prevalence than would a single source of special education or clinical administrative data alone. CDC reports published previously regarding population-based prevalence of ASDs in two U.S. communities documented prevalences of 3.4 and 6.7 per 1,000 children aged 3–10 years (*1,18*). In the larger of these population studies conducted in Atlanta, the highest prevalence of ASDs was for children aged 8 years, which is consistent with observations of peak ASD prevalence among elementary-school–aged children (*26*). Therefore, to determine peak prevalence and evaluate trends, the ADDM Network uses an index age of 8 years. Specified procedures for case identification and reliability among clinician reviewers who verify case status provide confidence in this methodology (*9*).

This report presents findings for 2000 from the first six ADDM Network sites in the United States and establishes a baseline period prevalence for ASDs by race/ethnicity, sex, and multiple associated characteristics. Data from the ADDM Network will provide information regarding the clinical features of children with ASDs in select U.S. populations and make possible a comprehensive understanding of trends in rates of ASDs. Knowledge of these characteristics has implications for identification and intervention strategies and for medical and educational service planning for children with ASDs.

Methods

Study Sites and Population Characteristics

CDC and academic researchers at five universities (Table 1) working on behalf of their state health departments collaborated in identifying the occurrence of ASDs during 2000 in selected areas of Arizona (one county, including metropolitan Phoenix), Georgia (five counties in metropolitan Atlanta),

TABLE 1. Number and percentage of children aged 8 years,* by race/ethnicity and study site — Autism and Developmental Disabilities Monitoring (ADDM) Network, six sites, United States, 2000

Site	Arizona		Georgia		Maryland		New Jersey		South Carolina		West Virginia	
Site institution	University of Arizona		CDC		Johns Hopkins University		New Jersey Medical School – Newark		Medical University of South Carolina		Marshall University	
Study area	1 county, including metropolitan Phoenix		5 counties in metropolitan Atlanta		4 counties in Maryland plus Baltimore City		4 counties in New Jersey, including the city of Newark		23 counties (Coastal and PeeDee regions)		Statewide	
Race/Ethnicity	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
White, non-Hispanic	24,564	(54.2)	18,094	(41.5)	11,533	(53.6)	11,913	(40.0)	11,740	(47.9)	21,471	(93.1)
Black, non-Hispanic	2,041	(4.5)	19,232	(44.1)	8,507	(39.5)	7,860	(26.0)	11,607	(47.3)	814	(3.5)
Other†	18,718	(41.3)	6,267	(14.4)	1,492	(6.9)	9,941	(34.0)	1,188	(4.8)	780	(3.4)
Total	**45,322**		**43,593**		**21,532**		**29,714**		**24,535**		**23,065**	
Percentage receiving special education services	10.7%		9.9%		10.6%		12.1%		16.9%		16.0%	

* The total number of children aged 8 years in each study area was obtained from 2000 U.S. Census Bureau files; school districts that did not participate as ADDM data sources are excluded for three sites (Arizona, Maryland, and New Jersey).
† Includes those classified as Hispanic, American Indian/Alaska Native, Asian/Pacific Islander, or multiracial.

Maryland (four counties and Baltimore), New Jersey (four counties, including metropolitan Newark), South Carolina (23 counties in the Coastal and PeeDee regions), and West Virginia (statewide) (Table 1). The number of children aged 8 years residing in each site during 2000 ranged from 21,532 in Maryland to 45,322 in Arizona. The proportion of non-Hispanic white children was similar across the majority of sites (range: 40% [New Jersey]–54% [Arizona and Maryland]), with the exception of West Virginia, for which distribution was 93% (*37*). Greater variation was reported across sites in the distribution of non-Hispanic black children (range: 4% [West Virginia]–47% [South Carolina]). Breakdowns by sex were similar across sites, with roughly equal distribution of male and female children. Sites were chosen by CDC through a competitive objective review process on the basis of their ability to conduct ASD surveillance; sites were not selected to reflect a nationally representative sample. Each site satisfied local Institutional Review Board and other privacy and confidentiality requirements.

Surveillance Methods and Case Definition

The ADDM methodology was adapted from that used by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), an ongoing active population-based surveillance program that monitors the occurrence of developmental disabilities among children aged 8 years in the metropolitan Atlanta area (*1,9,18,35,36*). The ADDM Network implemented the basic MADDSP methodology using common data abstraction, case definition, clinician review, and quality assurance procedures (*9*).

Records of children born in 1992 who had at least one parent or legal guardian who resided in the surveillance area during 2000 were reviewed. Children were classified by clinician reviewers as having an ASD if they displayed behaviors from abstracted evaluations during 1992–2000 that were consistent with DSM-IV-TR criteria for diagnosing 1) autistic disorder; 2) pervasive developmental disorder, not otherwise specified (PDD-NOS), including atypical autism; or 3) Asperger disorder (*15*). Because the number and quality of ASD criteria specified by DSM-IV-TR are less stringent for diagnosis of PDD-NOS or Asperger disorder than for autistic disorder, an additional stricter requirement was added. A condition was classified as being consistent with an ASD case status if the criteria for PDD-NOS or Asperger were present to the extent that at least one of the autism-specific behaviors was of a sufficient quality or intensity to be highly indicative of an ASD. For example, in the case definition, the DSM-IV-TR social criterion of "limited social or emotional reciprocity" was defined as requiring a specific impairment (e.g., "rarely responds verbally or nonverbally to a social approach from others in a familiar setting"). The stricter requirement for PDD-NOS or Asperger disorder was used because case status was determined solely on the basis of information contained in evaluation records. The case definition focused on identifying the overall presence of an ASD rather than on attempting to identify specific subtypes of ASDs. Case determination was completed in two phases: case ascertainment and clinician review.

Case Ascertainment

Children suspected of having an ASD who satisfied the age, surveillance year, and residency requirements were identified through screening source files (*1,9*) at multiple settings, including education sources (i.e., public schools†) and health

† Educational sources consisted of public education systems in each surveillance area. Data were not obtained from private schools unless they were affiliated with one of the health sources or documentation was kept by the private schools.

sources (e.g., state health facilities, hospitals, clinics, diagnostic centers, and other clinical providers for children with developmental disabilities, particularly ASDs) for documented or suspected ASD classifications and for descriptions of behaviors associated with ASD diagnostic criteria. At educational sources, the evaluation records of children receiving special education services during either the 1999–2000 or the 2000–2001 school year were reviewed. Two sites (West Virginia during 1999–2000 and Maryland during 2000–2001) screened records from a single school year, and four sites (Arizona, Georgia, New Jersey, and South Carolina) screened records from both school years to identify additional cases. Demographic and exceptionality category for special education services, verbatim descriptions of behaviors associated with autism from evaluations, psychometric test results, developmental history, and evaluation summaries were abstracted from evaluation records for each child identified as possibly having an ASD. Screening and abstraction of information in evaluation records was conducted by abstractor staff who met initial and ongoing reliability standards (*9*). If information regarding a child was available from multiple sources, data were combined into a composite record. Each child was assigned a study classification number, and all information abstracted was protected by multiple confidentiality procedures.

Clinician Review

All abstracted evaluations from the case ascertainment phase were reviewed and scored by an ASD clinician reviewer (i.e., a qualified diagnostician with an advanced degree and/or certification in the assessment and diagnosis of children with developmental disabilities, especially ASDs). The clinician reviewer used a coding guide developed on the basis of DSM-IV-TR criteria (*15*) to determine if the child's condition was consistent with the ASD case definition. Any statement of an overall developmental concern or a delay in social skills, language, or symbolic play at age ≤3 years was scored, as were any indications of behavior regression or a plateau in skill development. Descriptions of associated features (e.g., odd responses to sensory stimuli) also were coded. A child was defined as having a previously documented case of an ASD if any evaluation contained a diagnosis of an ASD from a professional examiner qualified by education and training to evaluate the developmental status of children. Interrater reliability was established among ASD clinician reviewers to standards of 80%–85% agreement for individually scored items and 90% for agreement on overall case status. For ongoing interrater reliability checks, a random sample of records (10%) was scored independently by a second reviewer with acceptable (81%–100%) percentage agreements on final case definition.

Analytic Methods

For each child, race and ethnicity were determined from information contained in the source records or, if missing, from birth certificates. Period prevalence estimates were calculated using the denominator of the number of children aged 8 years in the surveillance area during 2000 according to U.S. Census Bureau estimates. Three sites (in Arizona, Maryland, and New Jersey) excluded nonparticipating school districts located in the study area from their population denominator, and cases identified from health sources in these districts were excluded from the numerator. Poisson approximation to the binomial distribution was used to calculate 95% confidence intervals (CIs) for prevalence rates (*38*). Prevalence results are reported per 1,000 children. Race-specific rates used the categories non-Hispanic white, non-Hispanic black, and other (which included persons who were Hispanic, Asian/Pacific Islander, and American Indian/Alaska Native). Chi-square analyses were used, and a p value of <0.05 was used for all tests of statistical significance.

To assess whether screening special-education files from a second school year might improve detection, two sites (Maryland and West Virginia) linked electronic records from the school year that were screened to an additional list of children receiving special education. This procedure was based on the assumption that the probability of identifying a child with a confirmed case of ASD from the school records screened would apply to those children who were identified through a second screening of education files. At each site, certain school and clinical records could not be located for screening, and the potential impact of these missing records on case ascertainment was assessed. For children who did have records to screen, a percentage case yield was calculated by the type of data source (i.e., education only, health only, or both education and health) and the presence of an ASD classification code (i.e., a diagnostic or special education eligibility code for ASD). To estimate the impact of missing records on final prevalence estimates, the percentage of case yield from the records identified was applied to the children for whom all or partial records were missing.

Results

Case Ascertainment

Across sites, the percentage of children with an ASD identified exclusively at educational sources ranged from 22% to 80%, and the percentage identified only at health sources ranged from 2% to 34%. Those identified at both educational and health sources ranged from 17% to 65% (Figure 1). The median number of evaluations abstracted for each child dif-

FIGURE 1. Percentage of children aged 8 years identified as having an autism spectrum disorder, by data source — Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000

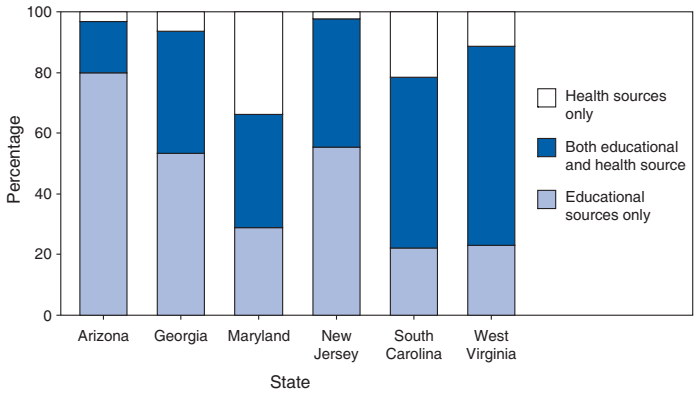
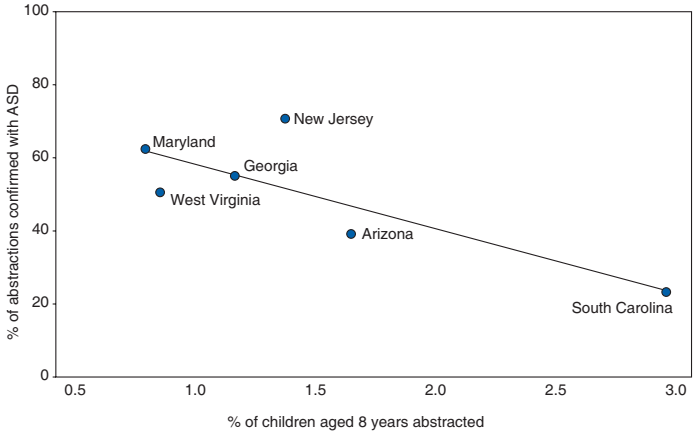


FIGURE 2. Percentage of children aged 8 years for whom records were abstracted and percentage of those abstracted classified as meeting the case definition* for autism spectrum disorder (ASD), by site — Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000



* Children born in 1992 who had at least one parent or legal guardian who resided in the surveillance area during 2000 were classified by clinician reviewers as having an ASD if they displayed behaviors from abstracted evaluations during 1992–2000 that were consistent with *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* criteria for diagnosing 1) autistic disorder; 2) pervasive developmental disorder, not otherwise specified, including atypical autism; or 3) Asperger disorder (*15*).

fered across sites, ranging from two (Georgia and Maryland) to eight (New Jersey) for those with an ASD and from one (Georgia, Maryland, and West Virginia) to five (New Jersey) for those without an ASD. The proportion of reviewed records abstracted to the population of children aged 8 years in each surveillance area ranged from 0.8% to 2.9%. With the exception of two sites (New Jersey and West Virginia), a strong inverse correlation was observed between the percentage of the total number of children abstracted and those classified as having an ASD (Figure 2). In New Jersey, the final case count was higher than expected on the basis of the population abstracted, whereas the reverse was true for West Virginia. Analyses were conducted for Maryland and West Virginia to evaluate possible missed cases attributable to screening a single year of special education data; the results of these analyses indicated that an estimated 17 cases would have been added for Maryland and an estimated 14 for West Virginia as a result of screening a second year of data. The estimated impact on prevalence of the files that could not be located for initial screening (i.e., the percentage of missed cases) varied (range: 3.4% [Georgia]–16.7% [Maryland]).

Prevalence Estimates and Demographics

Across the six sites, the prevalence of ASDs ranged from 4.5 to 9.9 per 1,000 children aged 8 years (Table 2, Figure 3). Three sites had similar overall prevalence estimates: 6.3 per 1,000 population in South Carolina and 6.5 per 1,000 in Arizona and Georgia. The Maryland estimate (5.5 per 1,000 population) did not differ significantly from each of these three midrange estimates ($p = 0.223$, 0.112, and 0.105, respectively), whereas the West Virginia estimate (4.5 per 1,000 population) was significantly lower ($p = 0.001$, 0.006, and 0.001, respectively). However, when the impact of screening only 1 year of special education records for Maryland and West Virginia was taken into account, prevalence estimates for these sites increased to an estimated 6.3 per 1,000 population (CI = 5.3–7.4) for Maryland and 5.1 (CI = 4.2–6.1) for West Virginia. Estimated prevalence for New Jersey (9.9 per 1,000 population) was significantly higher ($p<0.001$) than those for all other sites.

Across sites, prevalence estimates exhibited heterogeneity by race/ethnicity. Within-site comparisons demonstrated a significant difference in ASD prevalence between non-Hispanic white and non-Hispanic black children only in Georgia, and only among males. Sex-specific ASD prevalence ranged from 6.6 to 14.8 for males and from 2.0 to 4.3 for females. The lowest male-to-female ratio was 2.8:1.0 (South Carolina and West Virginia); the highest was 5.5:1.0 (Georgia) (Table 2). Prevalence was based on period prevalence estimates of ASDs for children aged 8 years who resided in their respective surveillance areas during 2000. The proportion of children with ASDs who also were born in the surveillance areas was 67% in Arizona, 54% in Georgia, 77% in Maryland, 84% in New Jersey, 66% in South Carolina, and 81% in West Virginia.

Special Education Eligibility

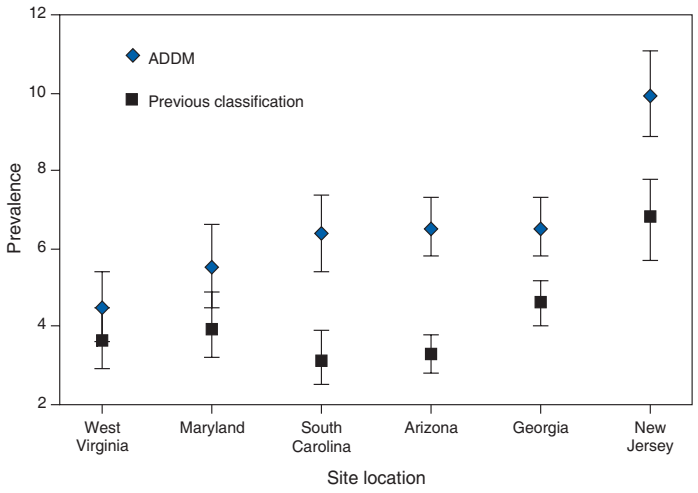
The estimated proportion of children aged 8 years with ASDs receiving special education services through public

TABLE 2. Estimated prevalence* of autism spectrum disorders (ASDs) among children aged 8 years, by race/ethnicity† — Autism and Developmental Disabilities Monitoring (ADDM) Network, six sites, United States, 2000

Site	No. children aged 8 yrs: Total in study area**	No. children aged 8 yrs: Total with ASDs	Prevalence: Overall§ Rate	Overall§ (95% CI††)	White, non–Hispanic Rate	White, non–Hispanic (95% CI)	Black, non–Hispanic Rate	Black, non–Hispanic (95% CI)	White-to-black ratio	Male Rate	Male (95% CI)	Female Rate	Female (95% CI)	Male-to-female ratio¶
Arizona	45,322	295	6.5	(5.8–7.3)	8.6	(7.5–9.8)	7.3	(4.4–12.2)	1.2	9.7	(8.5–11.1)	3.2	(2.5–4.0)	3.0
Georgia	43,593	285	6.5	(5.8–7.3)	7.9	(6.7–9.3)	5.3	(4.4–6.4)	1.5§§	11.0	(9.7–12.4)	2.0	(1.5–2.7)	5.5
Maryland	21,532	118	5.5¶¶	(4.6–6.6)	4.9	(3.8–6.4)	6.1	(4.7–8.0)	0.8	8.6	(7.1–10.6)	2.2	(1.5–3.3)	3.9
New Jersey	29,714	295	9.9	(8.9–11.1)	11.3	(9.5-13.3)	10.6	(8.5-13.1)	1.1	14.8	(13.0–16.8)	4.3	(3.3–5.5)	3.4
South Carolina	24,535	155	6.3	(5.4–7.4)	6.5	(5.2–8.2)	5.8	(4.5–7.3)	1.1	9.3	(7.8–11.2)	3.3	(2.4–4.5)	2.8
West Virginia	23,065	104	4.5¶¶	(3.6–5.4)	4.5	(3.7–5.5)			***	6.6	(5.2–8.2)	2.4	(1.6–3.5)	2.8

* Per 1,000 children aged 8 years in surveillance area.
† Because of limited sample sizes, only two racial/ethnic populations are presented.
§ All children are included in the total regardless of race/ethnicity. The total also includes children whose race is unknown.
¶ All male-to-female ratios differed significantly (p<0.0001) within sites.
** The total number of children aged 8 years in each ADDM surveillance area was obtained from 2000 U.S. Census Bureau files; surveillance areas exclude school districts that did not participate as data sources for three sites (Arizona, Maryland, and New Jersey).
†† Confidence interval.
§§ White-to-black prevalence ratios differed significantly (p<0.05) within sites only for Georgia.
¶¶ Adjusted ASD prevalence for Maryland and West Virginia also were calculated to account for having a single year of educational records screened for these two sites compared with 2 years of educational records for the other four sites. The adjusted rates per 1,000 children aged 8 years were 6.3 (95% CI = 5.3–7.4) for Maryland and 5.1 (95% CI = 4.2–6.1) for West Virginia.
*** Prevalence and white-to-black ratio not reported because of limited sample size.

FIGURE 3. Overall prevalence of autism spectrum disorders (ASDs) per 1,000 children aged 8 years and prevalence of children aged 8 years classified as meeting the case definition* for ASD and having a previous ASD classification — Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000



* Children born in 1992 who had at least one parent or legal guardian who resided in the surveillance area during 2000 were classified by clinician reviewers as having an ASD if they displayed behaviors from abstracted evaluations during 1992–2000 that were consistent with *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* criteria for diagnosing 1) autistic disorder; 2) pervasive developmental disorder, not otherwise specified, including atypical autism; or 3) Asperger disorder (*15*).

schools ranged from 70.3% in Maryland to 97.3% in Arizona (Table 3). Across sites, the proportion of children with ASDs receiving special education services with an autism eligibility classification ranged from 27% in South Carolina to 59% in Georgia.

Previously Documented Classification of ASDs

Children with a previously documented ASD classification included children who received special education services under an autism special education eligibility and those documented in the source records as having an ASD diagnosis. Prevalence estimates per 1,000 population derived for children with an ASD with a previous ASD classification were 3.1 in Arizona and South Carolina, 3.6 in West Virginia, 3.9 in Maryland, 4.6 in Georgia, and 6.8 in New Jersey. For all sites, ASD prevalence calculated on the basis of a child having received a previous classification of ASD was significantly (p<0.05) lower than prevalence estimated using the ADDM Network methodology, with the exception of West Virginia (Figure 3).

TABLE 3. Number and percentage of children aged 8 years with autism spectrum disorders (ASDs) receiving special education services and having autism eligibility* — Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000

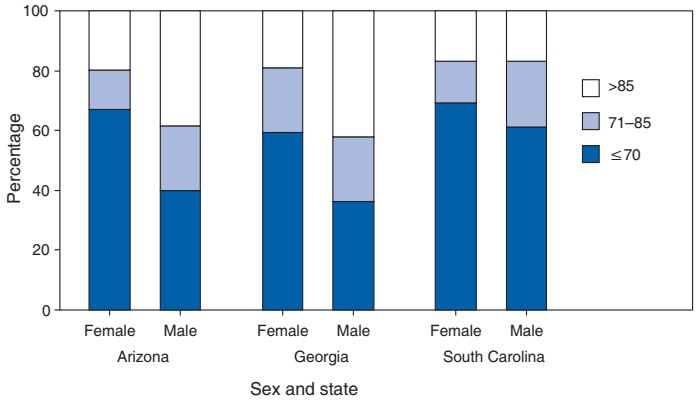
Site	Total no. with ASDs	Receiving special education services: No.	Receiving special education services: (%)	Receiving special education services with autism eligibility*: No.	Receiving special education services with autism eligibility*: (%)
Arizona	295	287	(97.3)	91	(31.7)
Georgia	285	261	(91.6)	155	(59.4)
Maryland	118	83	(70.3)	36	(48.6)
New Jersey	295	282	(95.6)	118	(41.8)
South Carolina	155	130	(83.9)	36	(27.7)
West Virginia	104	96	(92.3)	45	(46.9)

* The primary category under which a child was receiving special education services in the public schools.

Developmental Characteristics

Cognitive functioning as indicated by IQ findings is reported for the three sites in which >85% of children had psychometric test results: Arizona with 90%, Georgia with 94%, and South Carolina with 89%. Of the children with ASDs who had a cognitive or developmental IQ test result, the proportion of children with cognitive impairment (IQ of ≤70) was 46% (N = 123) in Arizona, 40% (N = 107) in Georgia, and 62% (N = 86) in South Carolina. The distribution of cognitive functioning in females was similar across sites. The proportion of males with cognitive impairment ranged from 36% in Georgia to 61% in South Carolina, and the proportion of males with average or above-average cognitive functioning (i.e., IQ of >85) ranged from 17% in South Carolina to 39% in Arizona (Figure 4).

FIGURE 4. Intelligence quotient (IQ) of children aged 8 years with an autism spectrum disorder for whom psychometric test data were available, by site and sex — Autism and Developmental Disabilities Monitoring Network, three sites, United States, 2000



The majority (69%–88%) of children with ASDs had documented developmental concerns before age 3 years. Across all sites, the most commonly documented early developmental concern was for language, followed by social concerns. Documented developmental concerns with imaginative play were least common across all sites (Table 4). The median age of earliest reported ASD diagnosis identified in the child's record was similar (range: 52–56 months) across sites (Table 5). The percentage of children with indications of regression (loss of previously acquired skills in social, communication, play, or motor areas) and plateau (lack of continued development without clear evidence of regression) in records ranged from 13% to 27% and 3% to 8%, respectively, across sites (Table 5). The median age of regression ranged from 23 to 26 months.

Discussion

Because ASDs are diagnosed on the basis of behavioral criteria, and clinicians might apply criteria differently to arrive at a diagnosis of autism and related subtypes, determining

TABLE 4. Number and percentage of children aged 8 years with autism spectrum disorder with developmental concerns* noted before age 3 years, by concern — Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000

Site	Total no. with ASDs	General concern		Social		Language		Imaginative play	
		No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	295	260	(88.1)	90	(30.5)	240	(81.4)	11	(3.7)
Georgia	285	218	(76.5)	91	(31.9)	190	(66.7)	38	(13.3)
Maryland	118	81	(68.6)	24	(20.3)	66	(55.9)	9	(7.6)
New Jersey	295	237	(80.3)	71	(24.1)	233	(79.0)	16	(5.4)
South Carolina	155	128	(82.6)	47	(30.3)	112	(72.3)	33	(21.3)
West Virginia	104	73	(70.2)	36	(34.6)	68	(65.4)	14	(13.5)

* For each child, all evaluation information was reviewed to categorize any concerns noted in developmental evaluations concerning the child's developmental status before age 3 years; any specified concerns regarding the development of social, language, or imaginative play before age 3 years also were documented.

TABLE 5. Median age at earliest diagnosis of autism spectrum disorder (ASD) and proportion and median age of children with a confirmed ASD at age 8 years with developmental regression or plateau noted in records — Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000

Site	Earliest documented diagnosis		Regression			Plateau		
	Median age (mos)	Range (mos)	Median age (mos)	Range (mos)	(%)	Median age (mos)	Range (mos)	(%)
Arizona	53	21–106	24	6–81	(12.5)	24	6–77	(7.8)
Georgia	56	17–103	24	1–91	(17.2)	24	6–72	(7.7)
Maryland	54	26–93	26	9–70	(20.3)	29	18–36	(6.8)
New Jersey	52	12–104	24	2–77	(23.7)	18	6–58	(6.4)
South Carolina	54	24–100	24	9–66	(19.4)	15	12–18	(2.6)
West Virginia	52	24–100	23	7–101	(26.9)	24	18–36	(4.8)

prevalence is challenging (*1,8,9*). The ADDM Network surveillance approach involved collecting detailed behavior data from multiple data sources regarding a substantial number of children with indications of a potential ASD. This methodology minimized reliance on a child's previously documented diagnoses or special education eligibility category to classify a child as having an ASD. Applying the ADDM Network approach in six areas of the United States generated ASD prevalence estimates for children aged 8 years ranging from 4.5 to 9.9 per 1,000 children aged 8 years. The estimate for West Virginia (4.5 per 1,000 children aged 8 years) was significantly lower, and the estimate for New Jersey (9.9 per 1,000 children aged 8 years) was significantly higher, than the midrange estimates. The average prevalence of 6.7 per 1,000 children aged 8 years identified in this report is consistent with the upper end of prevalence (5.8–6.7 per 1,000 children) from epidemiologic studies using active population screening and clinical case confirmation within the preceding 10 years (*18–21*). However, the significantly higher prevalence from New Jersey also was in line with a few studies indicating higher ASD rates (11.6 and 12.1 per 1,000 children aged 7–10 years) (*22,39*). The higher rate of ASDs in children aged 8 years in New Jersey indicates the importance of continuing to evaluate community variation and trends in prevalence in the United States.

ASD prevalence among children aged 8 years varied from 6.6 to 14.8 per 1,000 boys and from 2.0 to 4.3 per 1,000 girls. The male-to-female ratio (2.8:1.0–5.5:1.0) is consistent with previous literature indicating an average male-to-female ratio of 4.3:1.0 (*26*). Although a limited number of studies have reported race-specific ASD prevalence, the available data are inconsistent. Administrative data from California suggest a slightly higher prevalence in black than in white children (*40*), but a previous report from Georgia indicated a similar prevalence for black and white children (*1*). An analysis of claims data from Pennsylvania Medicaid recipients receiving services for autistic disorder demonstrated that being white was associated with receiving a first diagnosis at an earlier age (*41*), which might affect age-specific prevalence estimates and reflect access to diagnostic services. In this report, the confidence intervals for race-specific prevalence estimates overlapped considerably, with the exception of Georgia.

The proportion of children with ASDs who had cognitive impairment (IQ ≤70) ranged from 40% to 62% in the three sites for which IQ data were available. Children with ASDs in South Carolina, particularly males, were more likely to be classified with cooccurring cognitive impairment compared with children with ASDs in Arizona and Georgia. Females showed a similar distribution in level of cognitive impairment across these three sites, with the majority of females with ASDs also having cooccurring cognitive impairment. These proportions are below the 75% of children having cognitive impairment typically reported in earlier epidemiologic in which cases were identified solely on the basis of autistic disorder (*26*) but above estimates from studies conducted during the 1990s using active screening to identify all ASD cases (*20,22*). If these data are accurate, additional high-functioning children with ASDs might remain unidentified. Children with a very mild ASD might not be counted because inclusion in this system required that the child was evaluated for special educational or health-care needs. Variation exists in the proportion of children in the population identified for special education across study areas (Table 1); however, a clear pattern does not exist in which sites that identified more children for special education in the base population ultimately had a higher or lower prevalence of ASD.

Early identification and participation in intervention can improve the long term outcome for children with an ASD (*42*). The majority of children identified in these six sites received diagnostic evaluations that noted developmental concerns before age 3 years, primarily in the development of language skills; 11%–27% lost developmental skills at a young age (median age: 23–26 months); and 3%–8% demonstrated a plateau in development that was substantial enough to be reported in a developmental evaluation. The median age of the first documented ASD diagnosis was age 52–56 months. CDC has been working with caregiver and professional groups to improve the recognition of developmental concerns and to improve referral for further evaluation and intervention with the "Learn the Signs. Act Early." public awareness campaign (*43*).

As noted previously (*1*), the ability to access information from sources outside clinical sources typically utilized for public health surveillance sources is critical to the success of a records-based ASD monitoring effort. For example, a substantial proportion (range: 22%–80%, depending on site) of the children with a reported ASD would not have been identified without educational data. In addition, a proportion of those identified from a combination of educational and health data (range: 17%–65%, depending on site) also would have been missed if the information from educational sources had been unavailable. The added benefit of educational records in the monitoring system is derived primarily from the detailed behavior data in the evaluations contained in school records rather than the single label provided by a special education classification. As previous studies have indicated, reliance on special education classification alone to estimate population autism prevalence is problematic (*7,30,33*). In five of the six ADDM Network sites, less than half (as low as 27%) of the children with a confirmed ASD were served under an autism special education classification. Prevalence estimates derived from using a documented previous ASD classification as the

numerator ranged from 20% in West Virginia to 52% in South Carolina, lower than the estimates derived by using the ADDM Network monitoring approach (Figure 3).

One strength of the ADDM Network is its consistency of data collection and case determination across sites. The surveillance methodology uses standardized abstractor and clinician reviewer training, ongoing quality assurance monitoring, and similar standards to identify and confirm potential cases and to analyze data (*9,44*). Although the proportion of reviewed records abstracted in each surveillance area ranged from 0.8% to 2.9%, sites with a higher percentage of abstracted records actually had lower percentages of confirmed cases. This suggests that the standardized methods used for clinical review resulted in consistent application of the case definition across sites (Figure 2).

Although the intent of the ADDM Network sites was to use comparable methods, multiple sources of variability might be responsible for differences in prevalence across study sites. These include variation in state standards for evaluation and classification of children with ASDs, exclusion of certain sources (e.g., private schools), use of special education child count data from one rather than two school years, and inability to locate source files. Sites also varied in the percentage of records abstracted and in the quantity and quality of information available in some of the abstracted files. Because the ADDM methodology is records-based, the number and content of the records abstracted at any site could influence prevalence estimation. All ADDM sites included public schools and the major developmental disabilities evaluation and treatment centers serving their surveillance areas as sources of records. The effect of excluding private schools, charter schools, and smaller clinical providers on prevalence estimates is difficult to quantify but might have contributed to underestimation of prevalence, except for New Jersey, whose school system maintains records and evaluations for children receiving special education who attend nonpublic schools. Behavior descriptions contained in educational and health records might have overstated or understated autism symptoms; in addition, the information available probably was not complete enough to allow reviewers to determine whether a possible case was consistent with ASD criteria.

A limitation of using a records-based approach is that the amount and quality of information available varied across sites. Two sites (Maryland and West Virginia) screened special education files from one rather than two school years, which appears to account, in part, for the lower prevalence rates from these sites. After the impact of screening 1 year rather than 2 years of special education data was taken into account, prevalence estimates from Maryland and West Virginia (6.3 and 5.1 per 1,000 children aged 8 years, respectively) were similar to the majority of the other sites. One factor that affected all sites was the number of files not located at data sources during the case-ascertainment phase. Sensitivity analyses conducted by all sites to determine the effect of files that were not located indicated a possible prevalence underestimation of 3.4% to 16.7%, with the greatest impact in Maryland.

Among children whose case status was consistent with the ASD case definition, the median number of evaluations identified and abstracted for each child from birth to age 8 years ranged from two each in Georgia and Maryland to eight in New Jersey. Among children without ASDs, the median number of evaluations abstracted for each child ranged from one each in Georgia and Maryland to five in New Jersey. A qualitative review of each site's records indicates that in addition to New Jersey having the greatest number of evaluations per child, New Jersey evaluation records also contained more detailed information. In certain cases, the availability of information in records might have been affected by state law or by local school regulations. For example, New Jersey frequently employed multidisciplinary evaluations to confirm eligibility for special education, which might have resulted in more evaluations per child compared with sites for which a single evaluation was used to determine eligibility. Also, the substantial difference in the presence of cognitive functioning data on cases is a byproduct primarily of state policy regarding cognitive testing (e.g., in Arizona, Georgia, and South Carolina, all children with an autism exceptionality are required to have an IQ test, whereas no such requirement exists in New Jersey, Maryland, and West Virginia).

Another factor possibly contributing to variation in estimates is differential in- and out-migration in these six areas because prevalence estimates in this report are period prevalence estimated on the basis of residency in the study area during 2000. Although the reasons why families might have moved in or out of the study area could not be determined, the proportion of children with ASDs who were born in the study areas ranged from 54% in Georgia to 84% in New Jersey, indicating a potential for differential migration patterns in the sites. However, the high proportion of children with ASDs that were born in the New Jersey surveillance area compared with the other sites indicates that differential in-migration might not be a substantial contributor to New Jersey's higher prevalence of ASDs.

Etiologic differences also might contribute to across-site variation in prevalence. Conclusions about specific etiologic factors cannot be drawn from prevalence data alone and will need to be addressed through future studies. For example, following concern about high prevalence of ASD in Brick Township, New Jersey (*18*), an investigation was conducted to assess specific environmental exposures in that township, and no specific associations were identified between hazard

exposure from the municipal drinking water supply, town river, or landfill and ASD cases (*45*). In addition to better understanding of consistency and variance in ASD prevalence in different U.S. communities, specific studies are needed to investigate the complex genetic and environmental interactions likely at play in the development of heterogeneous conditions such as ASDs.

The initial findings presented in this report are derived from data collected by the first comprehensive U.S. monitoring network devoted to ASDs. Prevalence of ASDs in five of the six sites was consistent with the upper end of recent community and survey-based epidemiologic study estimates (*1,17,18,20,21,34,46*), and one site demonstrated a significantly higher ($p<0.001$) prevalence similar to two non-U.S. studies (*22,39*). These findings indicate that ASDs are more common than were once believed and are conditions of urgent public health concern. Since its inception, the ADDM Network has expanded to include additional sites that will continue to provide baseline ASD prevalence data and descriptive information regarding the ASD population in the United States. Ongoing surveillance to monitor trends in ASD prevalence and studies that include clinical validation of cases and noncases will be particularly useful for furthering the understanding of the prevalence of ASDs and of the characteristics of persons with ASDs.

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Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators

Abstract

Problem/Condition: Data from a population-based, multisite surveillance network were used to determine the prevalence of autism spectrum disorders (ASDs) among children aged 8 years in 14 areas of the United States and to describe the characteristics of these children.

Reporting Period: 2002.

Methods: Children aged 8 years were identified as having an ASD through screening and abstraction of evaluation records at health facilities for all 14 sites and through information from psychoeducational evaluations for special education services for 10 of the 14 sites. Case status was determined through clinician review of data abstracted from the records. Children whose parent(s) or legal guardian(s) resided in the respective areas in 2002 and whose records documented behaviors consistent with the *Diagnostic and Statistical Manual, Fourth Edition, Text Revision* (DSM-IV-TR) criteria for autistic disorder; pervasive developmental disorder, not otherwise specified; or Asperger disorder were classified as having ASDs.

Results: For 2002, of 407,578 children aged 8 years in the 14 surveillance areas, 2,685 (0.66%) were identified as having an ASD. ASD prevalence per 1,000 children aged 8 years ranged from 3.3 (Alabama) to 10.6 (New Jersey), with the majority of sites ranging from 5.2 to 7.6 (overall mean: 6.6 [i.e., one of every 152 children across all sites). ASD prevalence was significantly lower than all other sites in Alabama ($p<0.001$) and higher in New Jersey ($p<0.0001$). ASD prevalence varied by identification source, with higher average prevalence for ASDs in sites with access to health and education records (mean: 7.2) compared with sites with health records only (mean: 5.1). Five sites identified a higher prevalence of ASDs for non-Hispanic white children than for non-Hispanic black children. The ratio of males to females ranged from 3.4:1.0 in Maryland, South Carolina, and Wisconsin to 6.5:1.0 in Utah. The majority of children were receiving special education services at age 8 years and had a documented history of concerns regarding their development before age 3 years. However, the median age of earliest documented ASD diagnosis was much later (range: 49 months [Utah]–66 months [Alabama]). The proportion of children with characteristics consistent with the criteria for an ASD classification who had a previously documented ASD classification varied across sites. In the majority of sites, females with an ASD were more likely than males to have cognitive impairment. For the six sites for which prevalence data were available from both 2000 and 2002, ASD prevalence was stable in four sites and increased in two sites (17% in Georgia and 39% in West Virginia).

Interpretation: Results from the second report of a U.S. multisite collaboration to monitor ASD prevalence demonstrated consistency of prevalence in the majority of sites, with variation in two sites. Prevalence was stable in the majority of sites for which 2 years of data were available, but an increase in West Virginia and a trend toward an increase in Georgia indicate the need for ongoing monitoring of ASD prevalence.

Public Health Actions: These ASD prevalence data provide the most complete information on the prevalence of the ASDs in the United States to date. The data confirm that ASD prevalence is a continuing urgent public health concern affecting an approximate average of one child in every 150 and that efforts are needed to improve early identification of ASDs.

Introduction

Persons with autism spectrum disorder (ASDs)* have impairments in social, communicative, and behavior devel-

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* In this report, ASD is used to refer to autistic disorder; pervasive developmental disorder, not otherwise specified (PDD-NOS); and Asperger disorder. The terms ASD and autism are used interchangeably.

opment that typically are identified before age 3 years, often accompanied by abnormalities in cognitive functioning, learning, attention, and sensory processing (*1*). ASDs represent a spectrum of behaviorally defined conditions that are diagnosed through clinical observation of development. The complex nature of these behaviorally defined disorders, coupled with the current lack of genetic or biologic markers for early and consistent identification, make epidemiologic investigation challenging.

Although autism was defined previously primarily as autistic disorder and thought to be rare, autism is now considered one of multiple ASDs (*2,3*). During the 1990s, the number of persons reported to be receiving services for ASDs increased substantially (*4–9*). In California, the number of persons receiving services for autism increased approximately 300% during 1987–1998 and approximately 100% during 1998–2002 (*4,5*). After adjusting for changes in population size, prevalence for persons in the 1987–1994 birth cohorts receiving autism services in California increased from 0.6 to 1.5 per 1,000 population (*6*). In Minnesota, steady increases have been demonstrated in the prevalence of diagnosed autism among three birth cohorts (*7*); prevalence in children aged 8 years increased from 2.0 per 1,000 population in the 1997–1998 school year to 6.6 per 1,000 population in the 2001–2002 school year. Nationwide, the number of children receiving special education services for autism increased 500% from the 1991–1992 school year to the 1998–1999 school year (*8*). Data comparing the prevalence of autism with other disabilities for successive birth cohorts of school children indicated that among children aged 10 years, autism prevalence per 1,000 children increased from 0.5 in the 1984 birth cohort to 1.8 in the 1990 birth cohort; increases were greater in children aged 6 years, increasing from 0.5 in the 1986 birth cohort to 2.4 in the 1994 birth cohort (*9*).

Although more children are being identified with an ASD than in the past, receipt of educational or intervention services under an autism classification does not necessarily identify all persons with the behavioral profile indicative of an ASD and might not provide an accurate picture of total prevalence in the population (*1,10*). Studies that relied exclusively on single-source administrative data sets (e.g., clinic service records or annual reports of special education counts) are reportedly problematic (*9,11,12*). Single-source service data sets most likely underestimate prevalence and might not adequately capture population changes over time. Elevated public concern regarding the increase in reported ASD prevalence underscores the need for systematic public health monitoring (*11,13*).

In 2000, CDC organized the Autism and Developmental Disabilities Monitoring (ADDM) Network, a multisite, multiple-source, records-based surveillance program to collect data for determining prevalence of ASDs and other developmental disabilities (*13*). The ADDM Network conducts detailed screening and review of behavioral data from multiple educational and health facilities concerning children who have been evaluated for a range of developmental conditions and applies standard criteria for case identification, ascertainment, and case classification across multiple surveillance sites. Ongoing planning and cooperation among ADDM Network programs has been based on collaboration across multiple disciplines, organizations, and agencies.

The first study conducted by the ADDM Network reported results for 2000 from six sites in selected areas of Arizona, Georgia, Maryland, New Jersey, South Carolina, and West Virginia and established baseline period prevalence for ASDs by race/ethnicity and sex and described multiple associated characteristics (e.g., cognitive impairment) (*14*). In 2000, total ASD prevalence per 1,000 children aged 8 years in the six surveillance sites ranged from 4.5 in West Virginia to 9.9 in New Jersey (overall mean: 6.7). In 2002, to determine the prevalence of ASDs in additional areas of the United States, funding was provided to add eight sites in addition to the six studied previously. This report presents results for 2002 from the 14 sites studied, describes prevalence for ASDs overall and by race/ethnicity and sex and provides information concerning multiple associated characteristics. The additional data provided by the expanded ADDM Network will provide information regarding the prevalence and population characteristics in a large cohort of children in selected U.S. areas. Because six of these sites also collected data on ASD prevalence in 2000, changes in overall prevalence in these sites also are reported.

Methods

Study Sites and Population Characteristics

CDC and 13 project teams at state health departments or at universities working on behalf of their state health departments (Table 1) collaborated in monitoring reported occurrence of ASDs during 2002 in selected areas of Alabama (northern 32 counties), Arizona (one county, including metropolitan Phoenix), Arkansas (statewide), Colorado (two counties in metropolitan Denver), Georgia (five counties in metropolitan Atlanta), Maryland (five counties, including Baltimore City), Missouri (five counties in metropolitan St. Louis) New Jersey (four counties, including metropolitan Newark), North Carolina (eight central counties), Pennsylvania (Philadelphia County), South Carolina (23 counties in the Coastal and PeeDee regions), Utah (three counties in the Salt Lake

TABLE 1. Population characteristics for children aged 8 years, by site — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002

Site	Site institution	Surveillance area*	Total no. in area	White, non-Hispanic		Black, non-Hispanic		Hispanic		AI/AN†		A/PI§		Special education¶	
				No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Sites with access only to health records															
Alabama	University of Alabama – Birmingham	32 counties	35,472	24,552	(69.2)	9,442	(26.6)	1,046	(2.9)	178	(0.5)	254	(0.7)	5,407	(15.2)
Missouri	Washington University in St. Louis	5 counties in metropolitan St. Louis	28,049	19,043	(67.9)	7,817	(27.9)	548	(2.0)	80	(0.3)	561	(2.0)	3,569	(12.7)
Pennsylvania	University of Pennsylvania	Philadelphia County	21,061	5,795	(27.5)	11,388	(54.1)	2,956	(14.0)	59	(0.3)	863	(4.1)	1,586	(7.5)
Wisconsin	University of Wisconsin – Madison	10 counties in Southeastern Wisconsin, including Milwaukee	35,126	23,893	(68.0)	6,564	(18.7)	3,419	(9.7)	193	(0.5)	1,057	(3.0)	3,764	(10.7)
Sites with access to both education and health records															
Arizona	University of Arizona	1 county, including metropolitan Phoenix	45,113	25,252	(56.0)	2,377	(5.3)	15,348	(34.0)	966	(2.1)	1,169	(2.6)	6,289	(13.9)
Arkansas	University of Arkansas for Medical Sciences	Statewide	36,472	25,981	(71.2)	7,771	(21.3)	2,074	(5.7)	287	(0.8)	359	(1.0)	3,950	(10.8)
Colorado	Colorado Department of Public Health and Environment	2 counties in metropolitan Denver	11,020	7,516	(68.2)	933	(8.5)	2,026	(18.4)	67	(0.6)	478	(4.3)	1,258	(11.4)
Georgia	CDC	5 counties in metropolitan Atlanta	44,299	18,038	(40.7)	19,824	(44.8)	4,342	(9.8)	94	(0.2)	2,001	(4.5)	4,483	(10.1)
Maryland	Johns Hopkins University	5 counties in Maryland, including Baltimore City	29,722	17,100	(57.5)	10,865	(36.6)	735	(2.5)	82	(0.3)	940	(3.2)	2,968	(10.0)
New Jersey	New Jersey Medical School – Newark	4 counties, including metropolitan Newark	29,748	12,670	(42.6)	8,020	(27.0)	7,407	(24.9)	76	(0.3)	1,575	(5.3)	2,595	(13.0)
North Carolina	University of North Carolina at Chapel Hill	8 central counties	20,725	12,134	(58.5)	6,284	(30.3)	1,707	(8.2)	80	(0.4)	520	(2.5)	3,014	(14.5)
South Carolina	Medical University of South Carolina	23 counties in the coastal and Pee Dee regions	23,191	11,627	(50.1)	10,563	(45.5)	684	(2.95)	95	(0.4)	222	(1.0)	4,309	(18.5)
Utah	Utah Department of Health	3 counties around metropolitan Salt Lake City	26,108	21,201	(81.2)	363	(1.4)	3,447	(13.2)	190	(0.7)	907	(3.5)	3,404	(13.0)
West Virginia	Marshall University	Statewide	21,472	20,112	(93.7)	944	(4.4)	245	(1.1)	50	(0.2)	121	(0.6)	3,807	(17.7)

Source: Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics vintage 2004 postcensal population estimates (*13*).

* Surveillance area denominators exclude those school districts that did not allow access to records (Arizona and New Jersey).

† American Indian/Alaska Native.

§ Asian/Pacific Islander

¶ Each site provided the count of children in special education as reported by their local or state school districts.

City metropolitan area), West Virginia (statewide), and Wisconsin (10 counties in southeastern Wisconsin, including metropolitan Milwaukee). The Missouri site originally included three counties in Illinois that are considered part of metropolitan St. Louis, but data from these counties are not presented because the limited sources of data resulted in incomplete prevalence estimates. The number of children aged 8 years in the 14 surveillance sites ranged from 11,020 in Colorado to 45,113 in Arizona.

Distribution according to race or ethnicity among children aged 8 years varied across surveillance sites (*15*). The percentage of non-Hispanic white children ranged from 27.5% in Pennsylvania to 93.7% in West Virginia; the percentage of non-Hispanic black children ranged from 1.4% in Utah to 54.1% in Pennsylvania. The breakdown by sex was similar across sites, with approximately equal distribution of male and female children. Sites were selected through a competitive process that evaluated their ability to conduct ASD surveillance. They were not selected to reflect a nationally representative sample. The population of children studied (approximately 400,000) represented approximately 10% of the U.S. population aged 8 years in 2002. Each site met applicable local Institutional Review Board or other privacy and confidentiality requirements, or both. In three sites (Colorado, Utah, and West Virginia), ASDs were considered reportable conditions under state public health statute or administrative regulation.

Surveillance Methods and Case Definition

The methodology used by the ADDM Network was based on CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), an active, population-based surveillance program that monitors the occurrence of developmental disabilities among children aged 8 years in the metropolitan Atlanta area (*1,16,17*). The ADDM Network implemented the basic MADDSP methodology using a common case definition and standardized data abstraction, clinician review, and quality assurance procedures for the first year of surveillance in 2000 (*13,14*). For 2002, the case definition was modified to incorporate a brief screening, abstraction, and review of children's records if the child already had a documented ASD diagnosis or special education eligibility of autism.

Case Definition

Children born in 1994 who had at least one parent or legal guardian who resided in the study area during 2002 were classified by clinician reviewers as having an ASD if they either 1) had a documented previous classification of an ASD (i.e., the child had either an uncontradicted record of an autistic disorder or ASD diagnosis provided by a qualified examiner or documentation of qualification for special education services during 1994–2002 under an autism eligibility category) or 2) did not have a documented ASD classification but had an evaluation record from an educational or clinical source indicating unusual social behaviors consistent with an ASD. For children with a documented previous classification of an ASD, case status was confirmed on the basis of the existing ASD classification from the evaluation source records. For children without a documented ASD classification, data were abstracted on all pertinent ASD and developmental behaviors from education or health developmental evaluation to determine whether behaviors described in the child's evaluations by clinical reviewers were consistent with the criteria listed in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) (*2*) for autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder. Because the number and quality of criteria specified by DSM-IV-TR are lower for diagnosis of PDD-NOS or Asperger disorder than for autistic disorder, an additional stricter requirement was added that at least one of the autism-specific behaviors be of a sufficient quality or intensity to be highly indicative of an ASD (*14*). For example, in the case definition, the DSM-IV-TR social criterion of "limited social or emotional reciprocity" was defined as requiring a specific impairment (e.g., "rarely responds verbally or nonverbally to a social approach from others in a familiar setting"). The more stringent criterion for PDD-NOS or Asperger disorder was used because case status was determined solely on the basis of information contained in evaluation records. The case definition focused on identifying the overall presence of an ASD rather than on attempting to identify specific subtypes of ASDs. Case determination was completed in two phases: case ascertainment and clinician review.

Case Ascertainment

Children suspected of having an ASD who satisfied the age, surveillance year, and residency requirements were identified through screening evaluation records (e.g., assessments to determine the need for special education services or the presence of a developmental disorder). Records were screened at multiple educational or health sources (including state health facilities, hospitals, clinics, diagnostic centers, and other clinical providers), or at both for documented or suspected ASD classifications and for descriptions of behaviors associated with an ASD diagnosis. All sites screened files from health sources that maintained evaluation records for children with developmental disabilities, particularly ASDs. The files that were screened were identified by having a diagnostic or billing *International Classification of Diseases, Ninth Revision* (ICD-9)

(*18*) code for child neurodevelopmental disorders (e.g., speech and language disorders). All sites were either state health departments or acted as their heath department representative to collect or receive information used for protecting public health (*19*). On the basis of site-specific collaboration with their state and local departments of education, 10 sites (Arizona, Arkansas, Colorado, Georgia, Maryland, New Jersey, North Carolina, South Carolina, Utah, and West Virginia) (Table 1) also screened the special education evaluation records retained by schools of children receiving special education services during the 2001–2002 or 2002–2003 school years (or both years). One site (Pennsylvania) screened a limited subset of children's special education records after parental authorization to review the records.

For children with a previously documented classification of an ASD, limited abstraction and review of evaluation records was conducted. This limited (or "streamlined") review based on data obtained from MADDSP ASD surveillance indicated that 98% of children aged 3–10 years with a previous ASD diagnosis and 99% of children with previous autism eligibility for special education services satisfied the surveillance criteria for having an ASD (*1*). The streamlined abstraction included demographic and school service data, psychometric test results, developmental history, and evaluation summaries but excluded verbatim descriptions of behaviors associated with autism; this review was employed by 12 of the 14 sites (all except South Carolina and West Virginia). On the basis of local diagnostic practices (*3*), each site chose one of the three following scenarios to qualify a record for limited abstraction: 1) a record that documented a previous diagnosis of an ASD (i.e., autistic disorder, PDD-NOS, or Asperger disorder) as indicated by a corresponding ICD-9 (*19*) code or a written diagnosis; 2) a record that documented a previous diagnosis of "autistic disorder" as indicated by a corresponding ICD-9 code or a written diagnosis; or 3) a record that documented that the child had been previously served in a special education program under an autism eligibility category. All other records that were not consistent with the criteria for streamlined abstraction were fully abstracted, including an abstraction of verbatim descriptions of behaviors predetermined to be associated with an ASD. For all abstracted records, information from multiple sources was combined into one composite summary for each child.

Clinician Review

The clinician review process has been described previously and consists of systematic classification of behaviors and case status by qualified reviewers (*1,13*). Before clinician review, interrater reliability was established among reviewers according to standards, and only clinicians that met reliability standards were permitted to assign case status. Continuing interrater reliability checks were conducted on a random sample of 15% of fully abstracted records. These were scored independently by a second reviewer. For all sites, the percent of agreement for final case definition was acceptable (79%–100%; Kappa = 0.55–1.00) (*3*).

For records that underwent limited abstraction because of a previously documented ASD classification, children were considered to meet the ASD case definition on the basis of the previously documented diagnosis unless 1) conflicting information was noted in the record, 2) the reviewer needed additional information, or 3) the record indicated that an ASD had been ruled out as a diagnosis. In those circumstances, a full abstraction was performed, and the case was reviewed again by the clinician reviewer. Data abstracted were reviewed and scored by an ASD clinician reviewer according to a coding guide on the basis of DSM-IV-TR criteria (*2*). Any statement of general developmental concerns or delays in the areas of social skills, language, or symbolic play at age ≤3 years was scored, as were indications of behavioral regression or a plateau in skill development. Descriptions of associated features (e.g., odd responses to sensory stimuli, or abnormalities in eating, drinking, or sleeping) also were coded.

Analytic Methods

The race/ethnicity of each child was determined from information contained in the source records or, if not located in the source file, from birth certificates (if available). Period prevalence estimates were calculated using as the denominator the number of children aged 8 years residing in the surveillance area according to the National Center for Health Statistics (NCHS) vintage 2004 postcensal population estimates for July 1, 2002 (*15*). NCHS datasets provide estimated population counts by county, single year of age, race, Hispanic origin, and sex. Poisson approximation to the binomial distribution was used to calculate 95% confidence intervals (CIs) for prevalence (*20*). Race- or ethnicity-specific rates used five categories: non-Hispanic white, non-Hispanic black, Hispanic, Asian/Pacific Islander, and American Indian/Alaska Native. Prevalence results are reported per 1,000 children aged 8 years. Chi-square tests were used to compare prevalence estimates within and across sites within the 2002 surveillance year, and rate ratios were used to compare prevalence changes within each site from the years 2000 and 2002 (*21,22*). A maximum p value of <0.05 was used for all tests of statistical significance.

The majority of sites considered the same broad criteria of eligible children (i.e., ICD-9 codes and categories of educational exceptionality). However, seven sites (Alabama, Arkansas, Georgia, North Carolina, South Carolina, Utah, and

Wisconsin) reviewed records for additional ICD codes because they also were conducting surveillance for other developmental disabilities or because they added locally used codes that might have identified additional cases of ASDs. To facilitate an evaluation of the potential effect on ASD prevalence of reviewing health records for children with ICD-9 codes requested by certain sites, the number of children who were identified solely on the basis of those additional codes were identified (*3*).

Two sites (Arizona and New Jersey) had a few school districts in their entire surveillance area that did not participate. Because school records were critical to case ascertainment and those districts represented clearly defined geographic boundaries, final geographic study areas were finalized by removing these school districts from the surveillance area. Children who resided in nonparticipating school districts were subtracted from the denominator and, if a case was ascertained at a health source, it also was not included in the site's numerator. Because the NCHS postcensal population estimates were available only at the county level (*15*), enrollment data from nonparticipating school districts were used to curtail denominators. School enrollment data were obtained from the U.S. Department of Education's National Center for Education Statistics (*23*). Enrollment counts of students in third grade during the 2002–03 school year were noted to differ from NCHS postcensal population estimates (*15*), which was attributed primarily to children being enrolled out of the customary grade for their age, in private schools, or home-schooled. Because these differences varied by race and sex within the applicable counties, enrollment counts were adjusted by compiling data for all districts within each county, stratifying by race and sex, and comparing to NCHS postcensal counts. This provided an adjustment factor for each race-sex stratum on the basis of its variance from the corresponding NCHS estimate for that county. The appropriate adjustment factor was then applied to the stratified enrollment counts for each nonparticipating district, and the adjusted counts were subtracted from the NCHS postcensal estimates used for each county's denominator.

At each site, certain education and health records could not be located for review, and at three sites (Colorado, Maryland, and North Carolina), certain schools in the area elected not to participate. These schools did not represent clearly defined geographic boundaries, so they could not be excluded from the final surveillance area as was the case when entire districts did not participate. Therefore, an analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for screening were first stratified by two factors highly associated with final case status: information source (education only, health only, or both types of sources) and the presence or absence of either an ASD ICD-9 code or autism special education eligibility. The potential number of cases missed because of missing records was estimated under the assumption that within each of these six strata, the proportion of children with missing records who would ultimately be confirmed as ASD cases would have been similar to that of children with no missing records.

Results

Total Prevalence Estimates

In 2002, across the 14 sites, total prevalence of ASDs in children aged 8 years ranged from 3.3 (95% confidence interval [CI] = 2.7–3.9) to 10.6 (CI = 9.5–11.9) per 1,000 children (Table 2). The overall mean prevalence was 6.6 (CI = 6.3–6.8) per 1,000 children. Of the 14 sites, 12 were clustered in a tighter range (5.2–7.6 per 1,000 children), and these rates did not differ from each other significantly. However, Alabama's rate (3.3 per 1,000 population) was significantly ($p<0.001$) lower than all other sites' rates, and New Jersey's rate (10.6 per 1,000 population) was significantly ($p<0.0001$) higher than all other sites' rates.

Sources of Case Ascertainment and Effects on Prevalence

Sites varied in the proportion of children aged 8 years whose records were abstracted in their population, ranging from 0.7% in Wisconsin to 2.2% in Colorado, with the majority of sites ranging from 1.0% to 1.8%. ASD prevalence was correlated with the type of data source ($p<0.05$) (Figure 1). The weighted average ASD prevalence for sites that relied solely on health records to identify ASD cases was significantly lower (5.1 per 1,000 children aged 8 years; CI = 4.7–5.5) than that of sites that relied on both education and health records (7.2; CI = 6.9–7.5) ($p<0.0001$). Three of the four sites that had limited or no access to special education records (Alabama, Pennsylvania, and Wisconsin) had the lowest three estimates of ASD prevalence (Table 2). Pennsylvania obtained authorization from only 15% of parents with children aged 8 years who were receiving special education services to review their special education records. The review of this sample yielded 17 additional cases. Thus, 85% of potential records were not reviewed, and the number of potential cases from these records is unknown. The prevalence of ASDs in one site (Missouri) without access to special education records was higher than in six of the sites that had full access to both health and education records. No statistically significant variability in ASD prevalence was observed between nine of the 10 sites (range: 5.9–7.6) with access to both school and health records (Table 2).

TABLE 2. Estimated prevalence* of autism spectrum disorders (ASDs) among children aged 8 years, by site and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002

Site	Total no. in study area	Total no. with ASDs	Prevalence									
			Overall†		White, non-Hispanic		Black, non-Hispanic		Hispanic		AI/AN§		A/PI¶	
			Rate	(95% CI**)	Rate	(95% CI)	Rate	(95% CI)	Rate	(95% CI)	Rate	(95% CI)	Rate	(95% CI)
Sites with access only to health records														
Alabama	35,472	116	3.3	(2.7–3.9)††	3.3	(2.6–4.1)	3.4	(2.4–4.8)	1.9	(0.5–7.7)	—§§		—	
Missouri¶¶	28,049	205	7.3	(6.4–8.4)	7.7	(6.5–9.0)***	4.7	(3.4–6.5)***	1.8	(0.3–13.0)	—		7.1	(2.7–19.0)
Pennsylvania	21,061	111	5.3	(4.4–6.4)	7.6	(5.7–10.2)***†††	4.2	(3.2–5.6)***	4.7	(2.8–8.0)†††	—		1.2	(0.2–8.2)
Wisconsin	35,126	181	5.2	(4.5–6.0)	5.9	(5.0–6.9)***†††	3.7	(2.5–5.5)***	0.3	(0.0–2.1)†††	5.2	(0.7–36.8)	3.8	(1.4–10.1)
Sites with access to both education and health records														
Arizona	45,113	280	6.2	(5.5–7.0)	7.7	(6.7–8.9)†††	6.3	(3.8–10.5)	3.4	(2.6– 4.5)†††	3.1	(1.0–9.6)	2.6	(0.8–8.0)
Arkansas	36,472	251	6.9	(6.1–7.8)	7.4	(6.5–8.6)	5.8	(4.3–7.8)	2.9	(1.3– 6.4)	3.5	(0.5–24.7)	—	
Colorado	11,020	65	5.9	(4.6–7.5)	6.4	(4.8–8.5)†††	6.4	(2.9–14.3)	2.0	(0.7–5.3)†††	14.9	(2.1–106.0)	6.3	(2.0–19.6)
Georgia	44,299	337	7.6	(6.8–8.5)	8.9	(7.7–10.4)***†††	6.8	(5.7– 8.0)***	4.6	(3.0–7.1)†††	—		5.0	(2.7–9.3)
Maryland	29,722	199	6.7	(5.8–7.7)	7.0	(5.8–8.3)	6.2	(4.9–7.8)	1.4	(0.2–9.7)	—		3.2	(1.0–9.9)
New Jersey	29,748	316	10.6	(9.5–11.9)††	12.5	(10.7–14.6)***	7.7	(6.0–9.9)***	9.7	(7.7–12.3)	—		14.0	(9.2–21.2)
North Carolina	20,725	135	6.5	(5.5–7.7)	6.4	(5.2–8.0)	7.2	(5.4–9.6)	4.10	(2.0– 8.6)	12.5	(1.8–88.7)	1.9	(0.3–13.7)
South Carolina	23,191	140	6.0	(5.1–7.1)	6.0	(4.8–7.6)	5.5	(4.2–7.1)	4.4	(1.4–13.6)	—		4.5	(0.6–32.0)
Utah	26,108	196	7.5	(6.5–8.6)	8.0	(6.9–9.3)††	5.5	(1.4–22.0)	4.4	(2.6– 7.2)†††	—		2.2	(0.6–8.8)
West Virginia	21,472	153	7.1	(6.1–8.4)	6.8	(5.7–8.0)	6.4	(2.9–14.2)	—		—		—	

Source: Population data were obtained from CDC's National Center for Health Statistics vintage 2004 postcensal population estimates (*13*).

* Per 1,000 children aged 8 years.

† All children are included in the total regardless of race or ethnicity. The total also includes children for whom race/ethnicity was unknown. Because of limited sample sizes, results for Asians/Pacific Islanders and for AI/ANs are not presented. Because of the lack of an appropriate denominator, data for multiracial children and those of other races/ethnicities are not presented.

§ American Indian/Alaska Native.

¶ Asian/Pacific Islander.

** Confidence interval.

†† Alabama and New Jersey prevalence are each significantly different from all other sites ($p<0.001$ and $p<0.0001$, respectively).

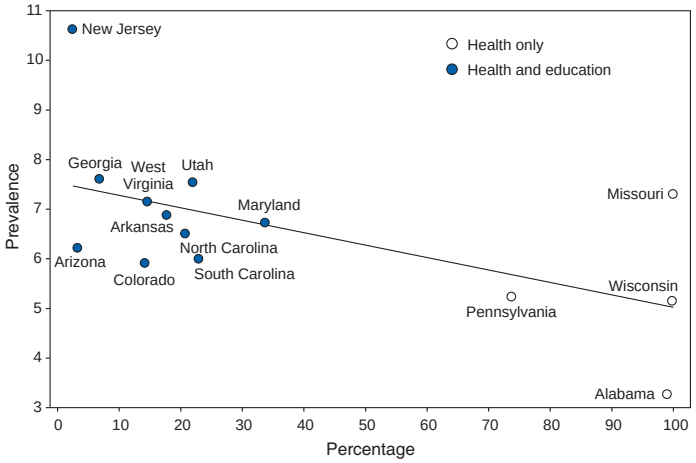
§§ No children were identified in this racial/ethnic population.

¶¶ Only Missouri data are presented from the Missouri/Illinois site as a result of limited numbers in Illinois.

*** Black-white prevalence ratio significantly different within site ($p<0.05$).

††† White-Hispanic prevalence ratio significantly different within site ($p<0.05$).

FIGURE 1. Prevalence* and percentage† of autism spectrum disorders (ASDs) among children aged 8 years, by type of data source — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002



* Per 1,000 children aged 8 years ($R^2 = 0.334$, $p = 0.03$).

† Of children with ASDs identified by health sources only.

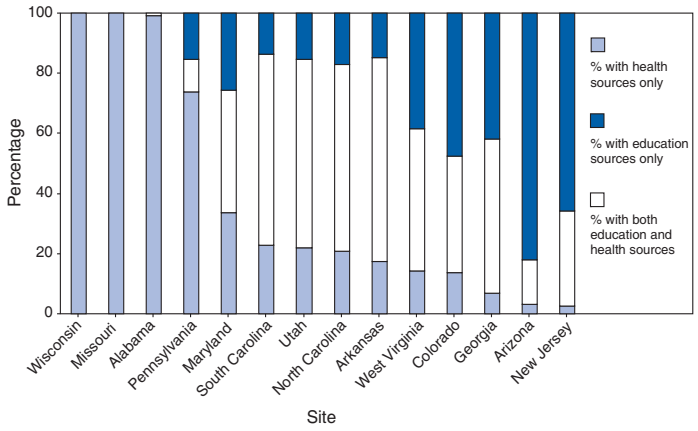
Only the estimated prevalence in New Jersey (10.6 per 1,000 population) was significantly different ($p<0.0001$).

The percentage of ASD cases identified exclusively from school sources varied from zero in sites without access to special education records to nearly 85% in Arizona (Figure 2). Similarly, the percentage identified only at health sources ranged from <10% in Arizona, Georgia, and New Jersey to 100% in the sites without access to school records.

Prevalence by Race or Ethnicity and Sex

For multiple sites, ASD prevalence also varied to a certain extent by race and ethnicity (Table 2). In 10 sites, prevalence was higher among non-Hispanic white children than among non-Hispanic black children, but this difference was statistically significant ($p<0.05$) for only five sites (Georgia, Missouri, New Jersey, Pennsylvania, and Wisconsin). In all sites with prevalence estimates for Hispanic children, prevalence was lower for Hispanic than for non-Hispanic white children; this difference was statistically significant ($p<0.05$) for six sites

FIGURE 2. Percentages of children aged 8 years with autism spectrum disorders, by data source — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002



(Arizona, Colorado, Georgia, Pennsylvania, Utah, and Wisconsin). Prevalence estimates were lower for Hispanic children than for non-Hispanic black children, except for New Jersey, where prevalence was higher among Hispanic children (9.7 per 1,000 population; CI = 7.7–12.3) than among non-Hispanic black children (7.7 per 1,000 population; CI = 6.0–9.9) (Table 2). Overall, population and case numbers were too limited and CIs too wide to provide reliable prevalence estimates for Asians/Pacific Islanders or American Indians/Alaska Natives (Table 2).

A consistent finding in all sites was significantly higher ($p<0.0001$) prevalence of ASDs among males than among females (Table 3). Prevalence among males ranged from 5.0 per 1,000 population (CI = 4.1–6.2) in Alabama to 16.8 (CI = 14.9–19.0) per 1,000 population in New Jersey. Female prevalence ranged from 1.4 per 1,000 population (CI = 0.9–2.1) in Alabama to 4.0 per 1,000 population (CI = 3.1–5.2) in New Jersey. When male-to-female prevalence was compared, observed sex ratios ranged from 3.4:1.0 in Maryland, South Carolina, and Wisconsin to 6.5:1.0 in Utah.

Special Education Eligibility

For the 10 sites that had full access to school records, the percentage of children with ASDs receiving special education services through public schools was determined. This percentage was >60% in all 10 sites and >80% in eight sites (Table 4). The percentage of children with ASDs that received special education services with an autism special education eligibility ranged from 31% in Colorado to 74% in Maryland (Table 4).

TABLE 3. Estimated prevalence* of autism spectrum disorders (ASDs) among children aged 8 years, by site and sex — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002

Site	Prevalence				Male-to-female ratio§
	Males		Females		
	Rate	(95% CI†)	Rate	(95% CI)	
Sites with access only to health records					
Alabama	5.0	(4.1–6.2)	1.4	(0.9–2.1)	3.6:1
Missouri	11.3	(9.7–13.2)	3.1	(2.3–4.3)	3.6:1
Pennsylvania	8.7	(7.1–10.6)	1.8	(1.2–2.9)	4.8:1
Wisconsin	7.9	(6.7–9.3)	2.3	(1.7–3.1)	3.4:1
Sites with access to both health and education records					
Arizona	10.1	(8.8–11.4)	2.2	(1.7–2.9)	4.6:1
Arkansas	10.7	(9.3–12.3)	2.9	(2.2–3.8)	3.7:1
Colorado	9.9	(7.6–12.9)	1.7	(0.9–3.2)	5.8:1
Georgia	12.4	(11.0–13.9)	2.6	(2.3–3.4)	4.8:1
Maryland	10.2	(8.7–11.9)	3.0	(2.3–4.1)	3.4:1
New Jersey	16.8	(14.9–19.0)	4.0	(3.1–5.2)	4.2:1
North Carolina	10.6	(8.9–12.8)	2.1	(1.4–3.2)	5.0:1
South Carolina	9.2	(7.6–11.1)	2.7	(1.9–3.9)	3.41
Utah	12.7	(11.0–14.8)	2.0	(1.3–2.9)	6.5:1
West Virginia	11.0	(9.2–13.12)	3.0	(2.1–4.2)	3.7:1

Source: Population data were obtained from CDC's National Center for Health Statistics vintage 2004 postcensal population estimates (*13*).
* Per 1,000 children aged 8 years.
† Confidence intervals.
§ All male-to-female ratios rounded to one decimal place; all male-to-female ratios significantly different within sites ($p<0.0001$).

TABLE 4. Number and percentage of children aged 8 years with autism spectrum disorders (ASDs) receiving special education services and with autism eligibility, by site — Autism and Developmental Disabilities Monitoring Network, United States, 2002

Site*	Total no. with ASDs	Receiving special education services		Receiving special education services with autism eligibility†	
		No.	(%)	No.	(%)
Arizona	280	271	(96.8)	107	(39.5)
Arkansas	251	206	(82.1)	120	(58.3)
Colorado	65	59	(90.8)	18	(30.5)
Georgia	337	309	(91.7)	211	(68.3)
Maryland	199	122	(61.3)	90	(73.8)
New Jersey	316	309	(97.8)	131	(42.4)
North Carolina	135	121	(89.6)	68	(56.2)
South Carolina	140	102	(72.9)	48	(47.1)
Utah	196	166	(84.7)	82	(49.4)
West Virginia	153	134	(87.6)	63	(47.0)

* With access to both education and health records.
† Primary special education eligibility category only.

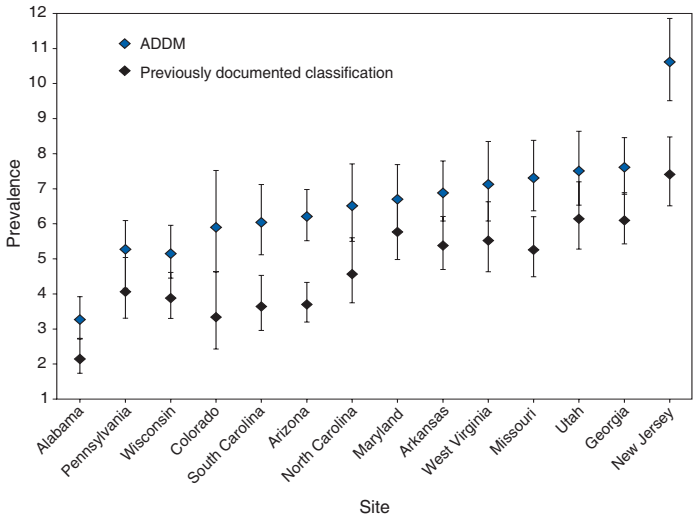
Previously Documented Classification of ASD

Children with a previously documented ASD classification included those who received special education services under an autism special education exceptionality category or those with a diagnosis of ASD documented in their health or education records, or both. In all sites, the prevalence estimated on the basis of having a previous diagnosis of an ASD was lower than that estimated on the basis of the ADDM Network Surveillance methodology (Figure 3).

Cognitive Functioning

Data regarding cognitive functioning are reported for seven sites in which ≥80% of children had psychometric test results. The proportion of children in these sites with ASDs who also had cognitive impairment (defined as having intelligence quotient [IQ] scores of ≤70) ranged from 33.1% in Utah to 58.5% in South Carolina (average: 44.6%) (Figure 4). In six sites (Arizona, Arkansas, Colorado, Georgia, South Carolina, and Utah), females were more likely than males to have cognitive impairment (Figure 4), and in four sites (Arizona, Arkansas, South Carolina, and Utah), females were significantly ($p<0.05$) more likely than males to have cognitive impairment. Differences between females and males were not statistically significant in Colorado, Georgia, or North Carolina. Only in South Carolina did more than half of males with ASDs have IQ scores of ≤70, and only in North Carolina did fewer than half of females with ASDs have IQ scores of ≤70. North Carolina was also the only site that had a higher proportion of males than females with IQ scores of ≤70. Across all sites, females were more likely than males (58.2% and 41.8%, respectively) ($p<0.001$) to have IQ scores in the range of cognitive impairment.

FIGURE 3. Overall prevalence* of autism spectrum disorders (ASDs) among children aged 8 years and prevalence of ASDs among children with a previously documented ASD classification,† by source type and order of ASD prevalence — Autism and Developmental Disabilities Monitoring (ADDM) Network, 14 sites, United States, 2002



*Per 1,000 population.
†Children were classified as having a previously documented ASD classification if they had 1) received a diagnosis of autistic disorder, pervasive developmental disorder (PDD)-not otherwise specified, Asperger syndrome, PDD, or ASD by a qualified professional that was documented in an evaluation record or 2) had special education services under an autism eligibility category.

Developmental Characteristics

In all sites, more than half (range: 51.0%–91.4%) of children meeting surveillance criteria for ASDs by age 8 years had documented developmental concerns before age 3 years (Table 5). The most commonly documented early developmental concern was for language skills, followed by social concerns. Documented developmental concerns with imaginative play were least common. The median age of earliest reported ASD diagnosis identified in a child's record ranged from 49 months in Utah to 66 months in Alabama (Table 6). The percentage of children with a documented indication of regression (i.e., loss of previously acquired skills in social, communication, play, or motor areas) ranged from 13.8% in Colorado to 31.6% in Utah, and the median age of regression ranged from 18 months in New Jersey, North Carolina, Utah, and Wisconsin to 33 months in Pennsylvania (Table 6). The percentage with indications of plateau (i.e., lack of continued development without clear evidence of regression) ranged from 2.4% in Arkansas to 12.8% in Utah.

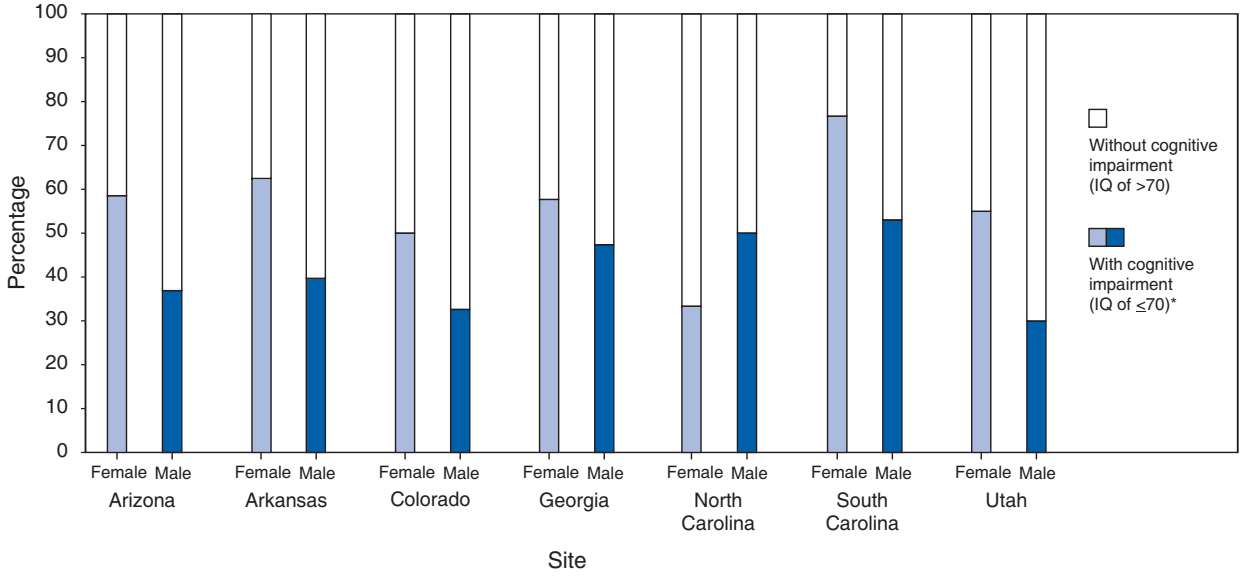
Comparison Between 2000 and 2002 Prevalence Estimates

Six sites had determined ASD prevalence previously using the ADDM Network methodology in 2000. Rate ratios were calculated to compare changes in prevalence during 2000–2002. ASD prevalence was stable for four sites (Arizona, Maryland, New Jersey, and South Carolina) and increased 17% in Georgia ($p = 0.06$) and 39% in West Virginia ($p<0.01$) (Table 7).

Methodological Results

New Jersey had the most evaluations available for review per child identified as having an ASD, with the median number of evaluations abstracted for each child ranging from two in Maryland to eight in New Jersey among children with ASDs,

FIGURE 4. Percentages of children aged 8 years with and without cognitive impairment, by intelligence quotient (IQ) score, site, and sex — Autism and Developmental Disabilities Monitoring Network, 14 sites,* United States, 2002



* Includes only sites with cognitive functioning data for >80% of cases.

TABLE 5. Percentage of children with autism spectrum disorders for whom developmental concerns were noted before age 3 years and median age at which concerns were noted — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002

Site	General concern		Social		Language		Imaginative play	
	%	Median age (mos)	%	Median age (mos)	%	Median age (mos)	%	Median age (mos)
Sites with access only to health records								
Alabama	91.4	≤24	33.6	≤36	85.3	≤24	14.7	≤36
Missouri	75.1	≤24	22.9	≤24	67.8	≤24	10.7	≤24
Pennsylvania	77.5	≤24	23.4	≤36	63.1	≤24	15.3	≤36
Wisconsin	86.2	≤24	37.0	≤24	77.3	≤24	16.0	≤24
Sites with access to both education and health records								
Arizona	82.5	≤24	31.8	≤36	75.4	≤24	4.3	≤36
Arkansas	84.9	≤24	28.7	≤36	77.7	≤24	6.0	≤36
Colorado	73.8	≤36	35.4	≤36	60.0	≤36	27.7	≤36
Georgia	79.5	≤24	24.9	≤36	70.3	≤24	8.6	≤36
Maryland	62.3	≤24	20.6	≤36	51.3	≤24	9.5	≤36
New Jersey	89.6	≤24	43.4	≤36	83.2	≤24	25.6	≤36
North Carolina	80.0	≤24	29.6	≤36	69.6	≤24	15.6	≤36
South Carolina	87.1	≤36	32.9	≤36	77.1	≤36	10.7	≤36
Utah	88.8	≤24	51.5	≤24	77.0	≤24	21.9	≤36
West Virginia	51.0	≤36	16.3	≤36	42.5	≤36	10.5	≤36

and from one in Maryland to five in New Jersey among children without ASDs. Of the seven sites requesting additional ICD-9 codes while conducting surveillance for other disabilities, three sites (Alabama, Arkansas, and Utah) did not identify any additional cases, two sites (Georgia and North Carolina) identified <1% of their ASD cases exclusively on the basis of the additional codes, and Colorado and Wisconsin identified 1.5% and 3.3% respectively of their ASD cases exclusively from the additional codes. On the basis of these findings, sites that used only the core ICD-9 codes for ASD case finding might have increased their case yield by 0–3%, if additional codes were requested.

TABLE 6. Median age at earliest diagnosis with autism spectrum disorder (ASD) and proportion and median age of children with a confirmed ASD at age 8 years and for whom developmental regression or plateau was noted in records — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002

Site	Age of earliest documented ASD diagnosis in record		Regression*		Plateau†	
	Median age (mos)	Range (mos)	(%)	Median age (mos)	(%)	Median age (mos)
Sites with access only to health records						
Alabama	66	10–101	25.0%	24	4.3%	14
Missouri	56	20–106	17.6%	24	4.4%	18
Pennsylvania	58	24–94	18.0%	33	3.6%	18
Wisconsin	54	11–104	25.4%	18	7.7%	15
Sites with access to both education and health records						
Arizona	63	20–101	18.6%	24	6.4%	21
Arkansas	59	21–106	17.1%	22	2.4%	18
Colorado	62	12–100	13.8%	24	7.7%	24
Georgia	58	23–103	17.5%	24	3.9%	22
Maryland	60	21–105	14.1%	24	4.5%	24
New Jersey	53	15–101	21.8%	18	11.4%	18
North Carolina	53	21–99	19.3%	18	3.7%	18
South Carolina	64	22–103	19.3%	20	3.6%	18
Utah	49	18–102	31.6%	18	12.8%	18
West Virginia	54	20–106	15.7%	24	0	0

* Includes any mention of a loss of skills that the child previously had in social, communication, play, or motor areas at any age in a child's evaluation records.
† Includes any mention of a leveling off of skills (i.e., lack of continued development but no clear loss of skills) in social, communication, play, or motor areas at any age in a child's evaluation records.

TABLE 7. Prevalence* of autism spectrum disorders (ASDs) — Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000 and 2002

Site	Total ASD prevalence				2000-to-2002 rate ratio		Prevalence change 2000–2002
	2000		2002				
	Rate	(95% CI†)	Rate	(95% CI)	Rate	(95% CI)	
Arizona	6.5	(5.8–7.3)	6.2	(5.5–7.0)	1.0	(0.8–1.1)	-0.3
Georgia	6.5	(5.8–7.3)	7.6	(6.8–8.5)	1.2	(1.0–1.4)§	+1.1§
Maryland	6.3	(5.6–7.4)¶	6.7	(5.8–7.7)	1.1	(0.9–1.3)	+0.4
New Jersey	9.9	(8.9–11.3)	10.6	(9.5–11.9)	1.1	(0.9–1.3)	+0.7
South Carolina	6.3	(5.4–7.4)	6.0	(5.1–7.1)	1.0	(0.8–1.2)	-0.3
West Virginia	5.1	(4.2–6.1)¶	7.1	(6.1–8.4)	1.4	(1.1–1.8)**	+2.0**

* Per 1,000 children aged 8 years.
† Confidence interval.
§ Not statistically significant at p=0.06.
¶ ASD prevalence reported for Maryland and West Virginia are the adjusted rates calculated to account for having a single year of education records that were screened for these two sites compared with 2 years of education records for the other four sites.
** Statistically significant at p<0.01.

Discussion

The ADDM Network surveillance method applies a standardized case definition to detailed behavioral data collected from health and education records of children evaluated for various developmental concerns. In the 14 areas studied in 2002, ASD prevalence estimates for children aged 8 years ranged from 3.3 per 1,000 population in Alabama to 10.6 per 1,000 population in New Jersey. The other 12 sites had a more restricted range (5.2–7.6 per 1,000 children aged 8 years identified with an ASD). The average prevalence estimate of 6.6 per 1,000 population (CI = 6.3–6.8) for all sites and 7.2 per 1,000 population (CI = 6.9–7.5) from sites with access to education information were consistent with the upper end of the prevalence (5.8–6.7 per 1,000 population) from recent epidemiologic studies using active population screening and clinical case confirmation in children (*1,14,24–35*). The higher rate identified in New Jersey was consistent with rates of 11.6 and 12.1 per 1,000 population recorded in two other recent

studies (*36,37*) indicating that approximately 1% of children were identified with an ASD. The lower rate of ASDs in children aged 8 years in Alabama and the higher rate in New Jersey, compared with the other 12 sites, indicates the importance of continued evaluation of cross-site variation and trends in prevalence in the United States.

ASD Prevalence by Race/Ethnicity and Sex

The majority of sites had sufficient populations to evaluate differences in ASD prevalence for non-Hispanic white and non-Hispanic black children. A trend was noted for non-Hispanic white children to have slightly higher prevalence estimates than non-Hispanic black children. This difference was statistically significant in three of the four sites for which access to health records only was possible (Missouri, Pennsylvania, and Wisconsin), but in only two of the 10 sites (Georgia and New Jersey) for which access to health and education records existed. In sites for which access to both health and education records existed, a statistically significant overall difference was noted by race, with more non-Hispanic white children (average: 7.7 per 1,000 population) than non-Hispanic black children (average: 6.5 per 1,000 population) identified as having an ASD. With the exception of New Jersey, prevalence for Hispanic children was lower than for non-Hispanic white or non-Hispanic black children. For American Indian/Alaska Native or Asian/Pacific Islander children, great variability was noted in prevalence of ASDs across sites, with small case and population numbers in each population contributing to highly imprecise site estimates. Differences in the racial or ethnic distribution of ASDs for populations other than non-Hispanic white and non-Hispanic black children should be interpreted with caution. Although racial differences are often reported not to be significant in children with ASDs (*38*), few studies have been based on large, diverse populations (*1*). These data indicate that ASD prevalence might vary by race/ethnicity; however, reasons for the differences need further investigation. Sociodemographic factors might influence both who gets evaluated for developmental concerns and how those concerns and behaviors are documented (*39*). Further analysis is needed of the sociodemographic features of the children identified with ASDs and identification patterns in evaluation records.

All sites identified more males than females with an ASD, with sex-specific ASD prevalence for males ranging from 5.0 in Alabama to 16.8 in New Jersey, and for females from 1.4 in Alabama to 4.0 in New Jersey. Male-to-female ratios ranged from 3.4:1 in Maryland, South Carolina, and Wisconsin to 6.5:1 in Utah. These ratios were similar to results reported previously (*38,40–44*). The average ASD prevalence across the 10 sites with access to both health and education sources indicated that ASD prevalence was 11.5 per 1,000 population for males and 2.7 per 1,000 population for females, resulting in a 4.3:1 ratio. Investigation is warranted concerning the possibility of differential identification and documentation of ASD symptoms within and across sites for males and females. Overall, these data confirm that ASDs affect males more than females in all areas, and variation in this phenomenon is not wide. The data also highlight the importance of considering sex differences in etiologic investigations of ASDs.

Cognitive Functioning

Epidemiologic studies of ASDs commonly include estimates of intellectual functioning, often reporting the proportion of all ASD cases with mental retardation and occasionally investigating differences according to diagnostic subtype. Other population-based studies have reported sex differences in intellectual functioning among children with ASDs, with certain indication of the male-to-female ASD prevalence ratio as decreasing with greater levels of impairment in intellectual functioning (*1,38*). The current ADDM Network findings indicate that females aged 8 years with ASDs were significantly more likely than males to score in the range of cognitive impairment on their most recent psychometric test. In the seven sites (Arizona, Arkansas, Colorado, Georgia, North Carolina, South Carolina, and Utah) with sufficient intellectual functioning data available, only one (South Carolina) reported more than half of the males with ASD with scores in the cognitively impaired range, and only North Carolina reported fewer than half of the females with ASDs with scores in the cognitively impaired range. In addition, North Carolina was the only site to have a higher proportion of males with cognitive impairment than females; however, the number of females represented by this comparison was low in North Carolina. Four of the remaining sites (Arizona, Arkansas, South Carolina, and Utah) had a significantly higher proportion of females with cognitive impairment compared with males ($p<0.05$). Overall, more than half of females (58%) and less than half of males (42%) had scores in the cognitively impaired range.

Although the ADDM Network methodology does not provide diagnostic subclassification of all children identified with ASDs, the current findings are consistent with other epidemiologic studies showing a higher proportion of males diagnosed with Asperger disorder and PDD-NOS, and a lower proportion of children with these diagnostic subtypes scoring in the range of cognitive impairment (*1,39–44*).

Developmental Characteristics

Children with a previously documented ASD classification included those who had received special education services under an autism special education eligibility and those with a clear diagnosis of ASD documented in the education or health source records, or both. Across the sites for which education information was accessible, the proportion of children identified with ASDs receiving special education services with an autism eligibility ranged from 31% in Colorado to 74% in Maryland. The prevalence estimates derived for children aged 8 years with ASDs who had a previously documented ASD classification ranged from 2.2 per 1,000 population in Alabama to 7.4 per 1,000 population in New Jersey. For all sites, the prevalence calculated from having a previous classification of ASD was lower than the ADDM Network prevalence of having an ASD. These results indicate that if an ASD is identified on the basis only of a documented diagnosis or eligibility for autism on record, prevalence would have been underestimated by as much as 30%.

An experienced clinician using standardized methods can reliably diagnose autism in children as young as age 2 years (*45*). Across the ADDM Network sites, the majority of children aged 8 years had diagnostic evaluations indicating general developmental concerns before age 3 years. Concerns in language development were generally noted at younger ages than concerns in social or imaginative play. However, age at first documented ASD diagnosis in the reviewed records varied greatly, from 10 months in the areas studied in Alabama to as late as 8 years, 10 months in the areas studied in Arkansas, Missouri, and West Virginia. These data confirm an earlier report (*46*) that a significant lag exists between early concerns and actual identification of an ASD as reported in records in multiple areas of the country, contributing to potentially significant delays in intervention. Given the benefit of early intervention (*47*), identification of an ASD at earlier ages in the United States is essential to ensure that children receive optimal early intervention services. CDC has been working with caregiver and professional groups to improve the early recognition of developmental concerns and to improve referral for further evaluation and intervention with the "Learn the Signs. Act Early." public awareness campaign (*48*).

Children with an ASD can experience a loss of developmental skills or a plateau in development, or both. Across all ADDM Network sites, 2%–13% of children had a plateau in development that was significant enough to be reported in a developmental evaluation. In addition, 14%–32% of the children were noted to have lost developmental skills at young ages, usually before age 2 years. The majority of ADDM Network sites reported developmental regression below the proportion reported from another study (*49*) that suggested that 25%–33% of children with an ASD are reported to experience a loss of developmental skills by the second year of life. However, the distinction between a loss of skills and a plateau in skills has not been made in previous studies. Reliance on existing records might not adequately ascertain this feature because certain providers might not evaluate or document the potential for developmental regression. Therefore, these results should be considered a minimal estimate of plateau and regression among ASD cases.

Changes in ASD Prevalence During 2000–2002

Six sites (in Arizona, Georgia, Maryland, New Jersey, South Carolina, and West Virginia) had previously determined the prevalence of ASD using the ADDM Network methodology in the year 2000 (*14*). Prevalence was stable for four of these sites (Arizona, Maryland, New Jersey, and South Carolina). In one site (West Virginia), ASD prevalence was significantly higher ($p<0.01$) in 2002 than in 2000, and the prevalence in Georgia appeared to be increasing, but the change was not statistically significant ($p<0.06$). New Jersey's ASD prevalence was higher than all other sites in both years, but it did not increase significantly from 2000 to 2002 (among children born in 1992 and 1994, respectively). Whether the disproportionate increase in the West Virginia ASD prevalence was attributable to a true increase in the prevalence of the condition in that state compared with that in the other five areas or was an artifact of the record-review methodology is difficult to determine. Because case status is confirmed by descriptions in records, greater detail in records for the 2002 study year would potentially provide more data that would be needed to confirm cases in this surveillance year than in 2000. An informal, qualitative assessment of differences in the quality and quantity of information contained in evaluation records across sites indicated that the quality and amount of information contained in West Virginia's evaluation records improved over time. However, other factors relating to differential prevalence cannot be ruled out. Future ADDM Network surveillance years will add a rating of the quality of information contained in the records to help evaluate the role that changing quality of records might play in determining prevalence. Further analysis of prevalence in sites with multiple prevalence estimates will be reported in future site-specific analyses and reports.

Strengths, Limitations, and Factors Influencing Prevalence Estimates

A strength of the ADDM Network is the consistency in data collection and case determination methods across sites and surveillance years. The ADDM Network surveillance

methodology requires standardized training of abstractors and clinician reviewers, ongoing monitoring for quality assurance, and standardization of methods to identify and confirm potential cases and conduct data analysis. The level of detail in the abstracted records from multiple sources, coupled with careful, standardized clinician reviews, improves upon previous estimates based solely on administrative records or single-source surveillance. With the addition of access to both health and education evaluation sources in all sites, the prevalence estimates from this methodology might more closely approximate true prevalence.

Although the ADDM Network method has strengths, certain limitations exist. Direct reevaluation of each child to determine case status is not part of a records-based approach to surveillance, thereby minimizing the burden on children and their families. Children identified with an ASD have had case status validated through record review and concordance between having a previous classification of an ASD and being identified as having an ASD is high. However, case identification has not been validated independently against a standard diagnostic reevaluation of each child. A validation study that includes independent examination of children is currently underway at the Georgia site.

Multiple factors can contribute to the quality of data and, ultimately, to prevalence estimates (*14,50*). Variability in prevalence among sites is likely attributable to differences in access to records at all sources, evaluation practices, and the resulting level of detail in records. The majority of ADDM Network sites included as sources of records public schools and major developmental disabilities evaluation and treatment centers serving their respective surveillance areas. The majority of sites did not include private schools, charter schools, and clinical providers or service centers with small numbers of clients (*3*). The resulting effect on prevalence estimates was difficult to quantify, but might have contributed in some manner to underestimation of prevalence. With the exception of New Jersey's higher prevalence, prevalence estimates were consistent across nine of the 10 sites with access to education evaluations. Prevalence was much more variable among the sites with access only to health evaluations, ranging from 3.3 per 1,000 population in Alabama to 7.3 per 1,000 population in Missouri. Although evaluations at education sources were not reviewed in Missouri, evaluation records were reviewed at regional developmental assessment and intervention centers within the Missouri Department of Mental Health. These sources might have served as a source of detailed ASD case information unique to that site and could have contributed to the Missouri site having the highest ASD prevalence among the sites that did not review education records. For sites with access to education information, a substantial proportion of persons with ASDs (15%–82%) would not have been identified without education data. In addition, a proportion of those cases identified from a combination of education and health data (range: 15%–68% of cases) also might have been missed if the information from education sources was unavailable. Thus, access to information from both health and education sources appears essential for obtaining accurate prevalence and to the success of records-based ASD monitoring in the United States. This emphasizes both the importance of including schools in surveillance activities and of public schools in the evaluation and treatment of children with disabilities.

Sources of evaluations by public service agencies doubtlessly provide information on children representing the broad sociodemographic spectrum because all children who show educational impairments are entitled to an evaluation and to a free, appropriate education (*50*). Because the ADDM Network method screens records of children evaluated or qualified for special education for features of ASDs, regardless of eligibility, this method should eliminate the bias of identifying children with ASD that have additional access to private healthcare sources for evaluation and treatment of developmental concerns. However, further evaluation of potential variability in the quality of information required to confirm ASD case status is needed because there could be systematic variation in information on children's developmental features by type of source or by sociodemographic characteristics of children.

A crucial aspect of a records-based surveillance system is being able to actually locate the evaluation record that contains the diagnostic and behavioral information to confirm case status. Sensitivity analyses conducted by all sites determined that files that were eligible for review but not located contributed to an underestimate in prevalence from 0.4% to 20%. Because of unfound files, prevalence might have been underestimated by <5% in eight sites (Alabama, Arizona, Arkansas, Colorado, Georgia, New Jersey, North Carolina, and Wisconsin), by 6%–8% in three sites (Missouri, Utah, and West Virginia), by up to 15% in two sites (Maryland and Pennsylvania), and as high as 20% in South Carolina. The number of the records abstracted at each ADDM Network site could have influenced prevalence estimation (*3*). A larger pool of children in special education or with evaluations for clinical services could increase the probability of identifying cases; however, sites that abstracted a higher proportion of records per population did not have correspondingly higher prevalence estimates. For example, New Jersey had the highest prevalence, but it did not have a significantly greater proportion of the population identified for special education or a

greater proportion of records screened and abstracted than other sites.

The majority of sites considered the same broad criteria of eligible children (on the basis of ICD-9 codes and categories of educational exceptionality). However, six sites reviewed records for additional ICD codes because they were also conducting surveillance for other developmental disabilities, or because they added locally used codes. Those extra codes might have identified a few more cases of ASDs, but given the initial breadth of the review criteria, the effect of this activity was likely minimal.

A common explanation for increases in ASDs over time has been that changes have occurred in the level of community and professional awareness about the symptoms of ASD and the application of an ASD diagnosis to a wider range of symptomology (*10,38,44,51*). Because the ADDM Network screens children who have been evaluated for special education or diagnostic services for multiple reasons, the primary way in which increased awareness could account for differences in prevalence across sites, or over time in the same site, is if either differences occurred in who is evaluated for developmental concerns or changes occurred in how the social and other ASD behaviors were documented in the evaluation records. However, across the ADDM Network sites with access to both education and health records, no clear relation existed among sites that identified more students in their populations for special education and the prevalence of ASDs. Using ADDM Network methods in areas in which more children were classified as eligible to receive special education for any reason did not result in identification of more children with an ASD. However, children with an ASD who have not been evaluated or qualified for services documented by the health or education sources might still exist, and this could have underestimated prevalence. For children with evaluation records, the quality of the information in the records might have been a factor. A qualitative review of West Virginia's records during 2000–2002 indicated that more behavioral descriptions existed to confirm case status for the later study year. Also, New Jersey had more evaluations per child and a qualitative review of information indicated more detailed behavioral descriptions. However, if higher prevalence in New Jersey was caused by better symptom documentation in evaluation records, that would suggest that prevalence in other sites might have been underestimated, which would indicate that ASDs could be more common then previously thought. For the 2006 surveillance year, ADDM Network surveillance has included a rating to classify the quality of information in the records.

Another factor possibly contributing to variation in prevalence among sites was differential migration in and out of the surveillance area. The prevalence estimates provided in this report are period prevalence based on residency in the study area during 2002. The effects of migration patterns could not be evaluated, but the proportion of children with ASDs who were born in the study areas ranged from 28% in Colorado to 57% in Arizona and Georgia and 85% in Alabama, indicating potentially significant variation in migration patterns across sites. For Colorado, 29% of children identified as having ASDs were born in a neighboring county to the study area counties, indicating potential differential migration around metropolitan Denver based on having a child with a developmental disability.

Conclusion

This report has described multiple sources of variability that might be responsible for differences in observed prevalence across study sites. Although certain sources of variability were not easily quantifiable, the inclusion or exclusion of education data was one known source of variability that appeared to have a direct effect on prevalence estimates. Other known and unknown sources of error most likely contributed to an underestimate of ASD prevalence and have been examined elsewhere (*3*). Despite these limitations, the ADDM Network has provided a comprehensive, population-based monitoring program for ASDs in the United States. Implementation of the ADDM Network requires ongoing collaboration with data sources at each site for access to records. The standardized protocol yielded prevalence estimates that were stable across multiple sites in the country in which access to both education and health records was possible. Although the initial start-up of each site took multiple years, future reports of ASD prevalence should be more timely. In the majority of sites for which 2 years of surveillance data were available, prevalence remained stable; however, a trend existed toward increased prevalence in Georgia and a significant ($p<0.01$) increase was observed in West Virginia. As the protocol is implemented using the same methods in future years, the ADDM Network will continue to monitor temporal trends in ASD prevalence in specific areas of the United States. Prevalence estimates also will be used to plan policy and educational and intervention services for persons with ASDs. Continuing to monitor the prevalence of ASDs in the United States is important, and more in-depth analyses of case identification by source type, quality of information, and sociodemographic factors should be conducted to improve understanding of these disorders. ADDM Network data provide a solid baseline prevalence with which future estimates can be compared. They also confirm that ASDs are more common then previously thought and are conditions of urgent public health concern.

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Evaluation of a Methodology for a Collaborative Multiple Source Surveillance Network for Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002

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Abstract

Problem: Autism spectrum disorders (ASDs) encompass a spectrum of conditions, including autistic disorder; pervasive developmental disorders, not otherwise specified (PDD-NOS); and Asperger disorder. Impairments associated with ASDs can range from mild to severe. In 2000, in response to increasing public heath concern regarding ASDs, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network. The primary objective of this ongoing surveillance system is to track the prevalence and characteristics of ASDs in the United States. ADDM data are useful to understand the prevalence of ASDs and have implications for improved identification, health and education service planning, and intervention for children with ASDs. Because complete, valid, timely, and representative prevalence estimates are essential to inform public health responses to ASDs, evaluating the effectiveness and efficiency of the ADDM methodology is needed to determine how well these methods meet the network's objective.

Reporting Period: 2002.

Description of System: The ADDM Network is a multiple-source, population-based, active system for monitoring ASDs and other developmental disabilities. In 2002, data were collected from 14 collaborative sites. This report describes an evaluation conducted using guidelines established by CDC for evaluating public health surveillance systems and is based on examination of the following characteristics of the ADDM Network surveillance system: simplicity, flexibility, data quality, acceptability, representativeness, sensitivity, predictive value positive (PVP), timeliness, stability, data confidentiality and security, and sources of variability.

Results and Interpretation: Using multiple sources for case ascertainment strengthens the system's representativeness, sensitivity, and flexibility, and the clinician review process aims to bolster PVP. Sensitivity and PVP are difficult to measure, but the ADDM methodology provides the best possible estimate currently available of prevalence of ASDs without conducting complete population screening and diagnostic clinical case confirmation. Although the system is dependent on the quality and availability of information in evaluation records, extensive quality control and data cleaning protocols and missing records assessments ensure the most accurate reflection of the

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records reviewed. Maintaining timeliness remains a challenge with this complex methodology, and continuous effort is needed to improve timeliness and simplicity without sacrificing data quality. The most difficult influences to assess are the effects of changes in diagnostic and treatment practices, service provision, and community awareness. Information sharing through education and outreach with site-specific stakeholders is the best mechanism for understanding the current climate in the community with respect to changes in service provision and public policy related to ASDs, which can affect prevalence estimates.

Public Health Actions: These evaluation results and descriptions can be used to help interpret the ADDM Network 2002 surveillance year data and can serve as a model for other public health surveillance systems, especially those designed to monitor the prevalence of complex disorders.

Introduction

Autism spectrum disorders (ASDs) encompass a spectrum of conditions, including autistic disorder; pervasive developmental disorders not otherwise specified (PDD-NOS); and Asperger disorder. Impairments associated with ASDs can range from mild to severe. ASDs are of increasing public health concern because the number of children receiving services for these conditions is growing. Despite the need to understand ASDs better, few data are available concerning the prevalence, characteristics, and trends of these conditions. In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to track the prevalence and characteristics of ASDs in the United States. The ADDM network is a multiple-source, active, population-based surveillance system that reviews developmental records at educational and health sources and employs a standardized case algorithm to identify ASD cases. ADDM data are useful to understand the prevalence of ASDs and can promote improved identification, health and education service planning, and intervention for children with ASDs.

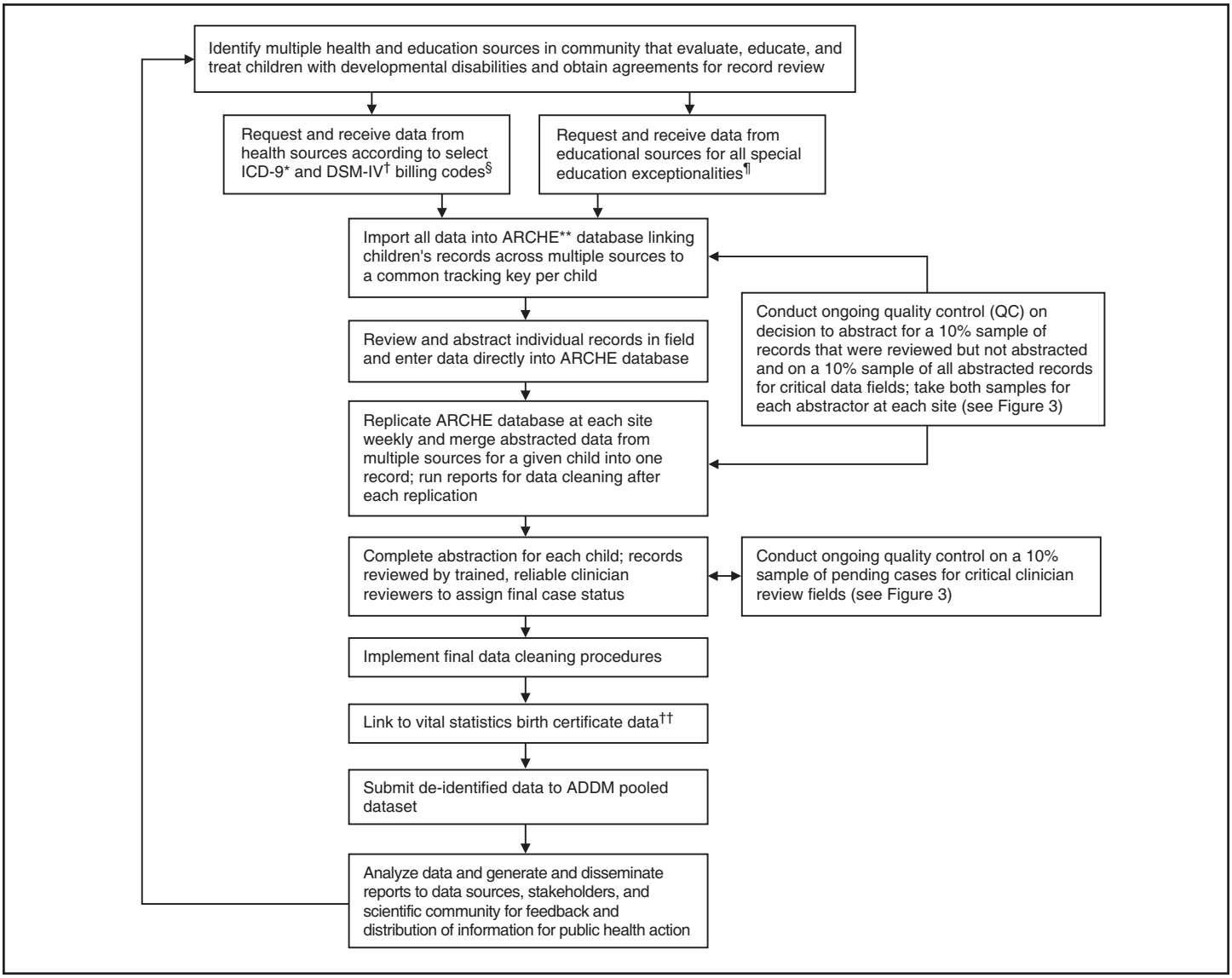
Complete, valid, timely, and representative prevalence estimates are essential to inform public health responses to ASDs. Evaluation of the effectiveness and efficiency of the ADDM methodology, described in detail elsewhere (*1*), is necessary to understand how well the methods meet the network's objective. This report examines the ADDM Network methodology employed by 14 collaborative sites that collected data for the 2002 surveillance year and evaluates the validity and completeness of prevalence estimates and the effect of sources of variability on intersite prevalence differences. This evaluation was conducted using guidelines established by CDC for evaluating public health surveillance systems and includes examination of the following characteristics of the ADDM Network surveillance system, including simplicity, flexibility, data quality, acceptability, representativeness, predictive value positive, sensitivity, timeliness, stability, data confidentiality and security, and sources of variability (*2*).

Simplicity

The simplicity of a public health surveillance system refers to both its structure and ease of operation. The simplicity of an autism surveillance system is limited by the variability of ASD signs and symptoms and methods of diagnosis (*3,4*). Impairments associated with ASDs can range from mild to severe. More subtle features at the less severe end of the spectrum can remain undiagnosed as they are found in children with better communication skills and average to above-average intellectual functioning. Severity also can change as the child ages or in response to effective intervention. No observable physical attribute or clinical test can define case status, nor can cases be identified at a single point in time or type of data source. A diagnosis of an ASD is made on the basis of a constellation of behavioral symptoms rather than on biologic markers; therefore, surveillance case ascertainment requires standardized interpretation of behavioral evaluations from records at both education and health facilities. A broad range of diagnoses over multiple years must be reviewed to ensure complete case finding because children rarely receive a specific diagnosis of an ASD before age 2–3 years, with a more stable diagnosis by age 8 years (*5–7*). The ADDM Network common methodology (Figure 1) uses a record-based surveillance system dependent on access to education, health, and service agencies (e.g., public schools, state health clinics and diagnostic centers, hospitals, and other providers for children with developmental disabilities [DDs]) to identify cases and ensure unduplicated case counting. The process for case ascertainment occurs in two phases: 1) identification of potential cases through record screening and abstraction and 2) review of abstracted information by an ASD clinician reviewer to determine whether behaviors described in the child's evaluations are consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) (*8*) criteria for autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder (*1,9*).

Accurate collection and review of detailed evaluation information from multiple data sources is time consuming, and the

FIGURE 1. Surveillance methodology flowchart — Autism and Developmental Disabilities Monitoring (ADDM) Network



* *International Classification of Diseases, Ninth Revision.*
† *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision.*
§ ADDM sites conducting surveillance of mental retardation (MR), cerebral palsy (CP), hearing loss, and vision impairment request codes specific to these disorders in addition to those for ascertainment of autism spectrum disorders (ASDs).
¶ To improve timeliness, North Carolina did not review special education records of children with a speech and language impairment (SLI) exceptionality. A sample of these children indicated that this decision had a minimal effect on North Carolina prevalence. Georgia did not review special education records of children with a SLI, behavior disorder (BD) or learning disorder (LD) exceptionality. Georgia reviewed all records at the Psychological Services Department affiliated with the State Department of Special Education. The records of all children with a comprehensive psychological evaluation in special education are located at the psychological services department capturing children with BD and LD exceptionalities. A sample of children in SLI showed that this decision had a minimal effect on Georgia prevalence.
** Alliance for Research in Child Health Epidemiology.
†† All sites conducting surveillance for CP are conducting linkage of cases with vital statistics death certificates. If feasible, sites conducting ASD and MR surveillance also conducted this death certificate linkage. For sites that completed this linkage, no ASD cases were identified.

lack of electronic records at the majority of data sources requires additional tasks (e.g., coordination with agencies, travel, record abstraction, and data entry). Time-tracking data collected systematically by all abstractors in Arizona indicated that abstractors spent an average of 55 hours to review or abstract, or both, 100 records. Survey data from six sites indicated that a single clinician review required an average of 20 minutes under the streamlined protocol (see Predictive Value Positive) and 47 minutes under the routine protocol. Quality assurance procedures implemented throughout data collection add time, effort,

and complexity to the overall system. However, a detailed, labor-intensive approach might be the only way to produce accurate prevalence estimates for this complex behavior disorder.

Flexibility

The flexibility of a public health surveillance system refers to its ability to accommodate changes in information needs or operating conditions with little additional time, personnel, or allocated funds. The flexibility of the ADDM Network methodology allows the system to add new data sources, collect additional data elements, and incorporate the evolving science of developmental disabilities (e.g., new case definitions). The ADDM methodology can adapt to changes in data elements and case definitions between surveillance years; however, retrospective changes would be limited to data already collected. ADDM Network methods rely on, and are limited by, the availability and quality of data in evaluation records and access to those records. ADDM Network surveillance activities have been expanded to monitor other developmental disabilities, including hearing loss, vision impairment, mental retardation and cerebral palsy simultaneously. ADDM Network data also can be linked to external datasets (e.g., state birth certificate files, birth defects surveillance and newborn screening data, and complementary instruments to track children's medication prescriptions).

Data Quality

Data quality refers to the completeness and validity of a surveillance system. The amount and quality of information available from the record of an existing evaluation varies within and across ADDM Network sites and is difficult to quantify. Variability in state and local regulations, regional practices for evaluating children, and the number of providers visited can affect the number and types of evaluations available. For example, in certain states, a single record is sufficient to obtain autism eligibility for special education, but other states (e.g., New Jersey) often use multiple multidisciplinary evaluations. A qualitative comparison indicates that both the amount and quality of relevant information in records in New Jersey were greater than those at other sites. Case ascertainment is influenced by the rate of referral of children for developmental evaluation and by the sensitivity of the evaluation in detecting and recording signs and symptoms of ASDs. The ADDM Network methodology maximizes data quality by evaluating the completeness of record review, maintaining reliability in data collection and coding, and cleaning the data fields. Although these measures are taken to ensure the accuracy of data capture, the validity of the conclusions is dependent on the data in the evaluation records reviewed by project staff.

Evaluating the Completeness of Record Review

Eligible records identified by data sources but not located or available for access (e.g., located at a nonparticipating school) were classified as missing. The nature of missing records might have been systematic across multiple data sources within each ADDM site, but missing records probably were nonsystematic within an individual data source. A sensitivity analysis was conducted to evaluate the effect of missing records on prevalence (see Sensitivity).

Maintaining Reliability in Data Collection and Coding Methods

The reliability of data collection and coding was measured against standards to ensure effective initial training, identify ongoing training needs, and adhere to the prescribed methodology. These efforts support the reliability of ADDM data by quantifying potential error caused by inconsistent data collection and coding procedures. Initial and ongoing quality control reliability methods follow a set protocol (Figures 2 and 3).

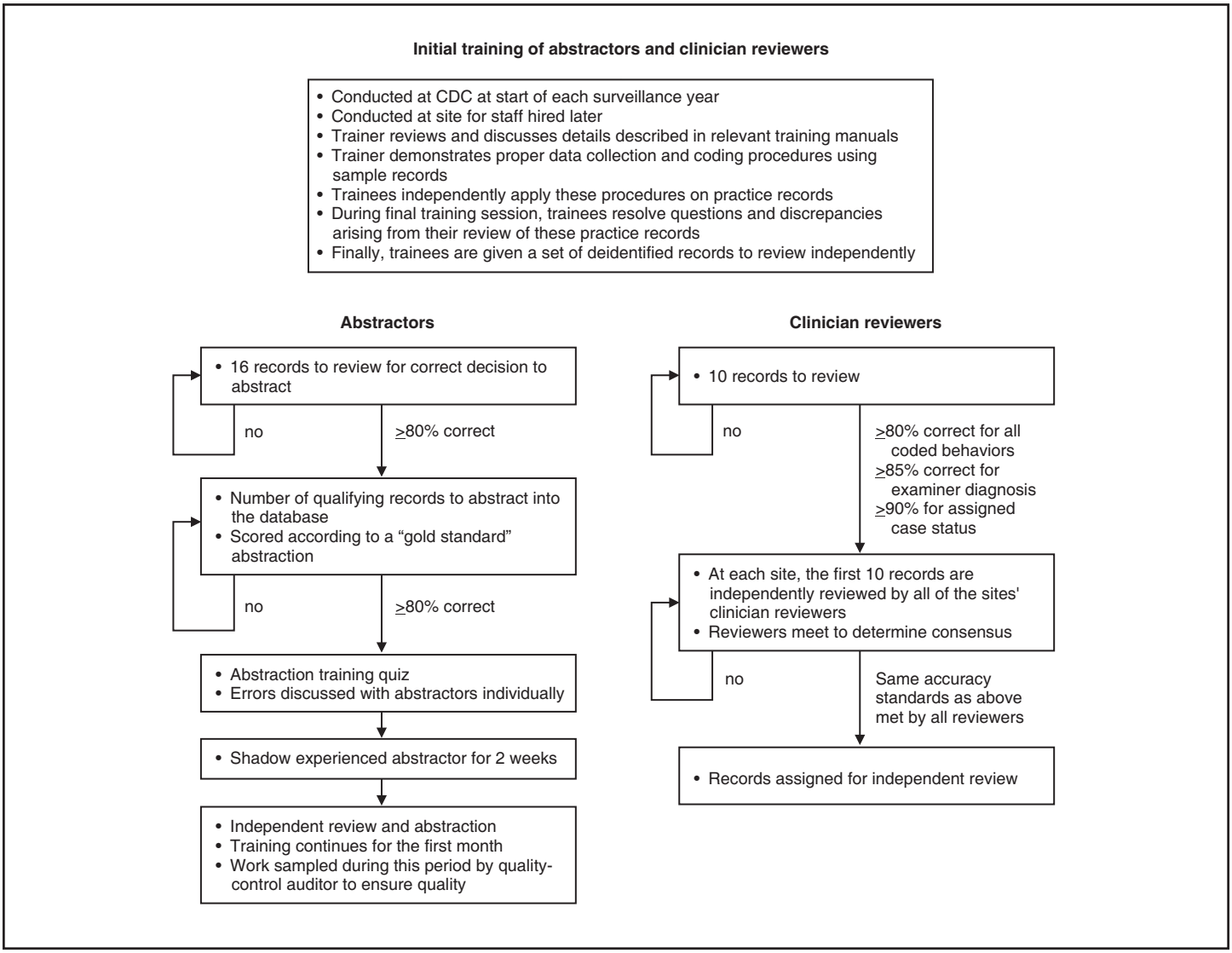
Cleaning Data Fields

The ADDM Network implements regular, extensive, and systematic data cleaning to identify inconsistencies in reviewed and abstracted data and resolve conflicts that arise. Missing race and ethnicity information was obtained through linkage with state vital birth records.

Acceptability

The acceptability of a surveillance system is demonstrated by the willingness of persons and organizations to participate in surveillance system activities. The project's overall success was dependent on acceptance of the ADDM Network by health and education sources of each site, as these sources were needed to identify cases of ASDs. Voluntary agreements (e.g., memoranda of understanding or contracts) were established between ADDM Network sites and health and education sources that authorized site personnel to review and collect information from health or education records (Table 1). ASDs were reportable conditions at three sites (Colorado, Utah, and West Virginia), giving these sites public health authority to review and collect data from health-care facilities with no separate agreements required. At six sites (Arkansas, Maryland, North Carolina, South Carolina, Utah, and West Virginia), all targeted health sources participated. At eight sites (Alabama, Arizona, Colorado, Georgia, Missouri, New Jersey, Pennsylvania, and Wisconsin), at least one targeted health facility did not participate. The project's acceptability was lower among education sources; four sites were unable to gain access to edu-

FIGURE 2. Flowchart for quality control for initial reliability — Autism and Developmental Disabilities Monitoring Network

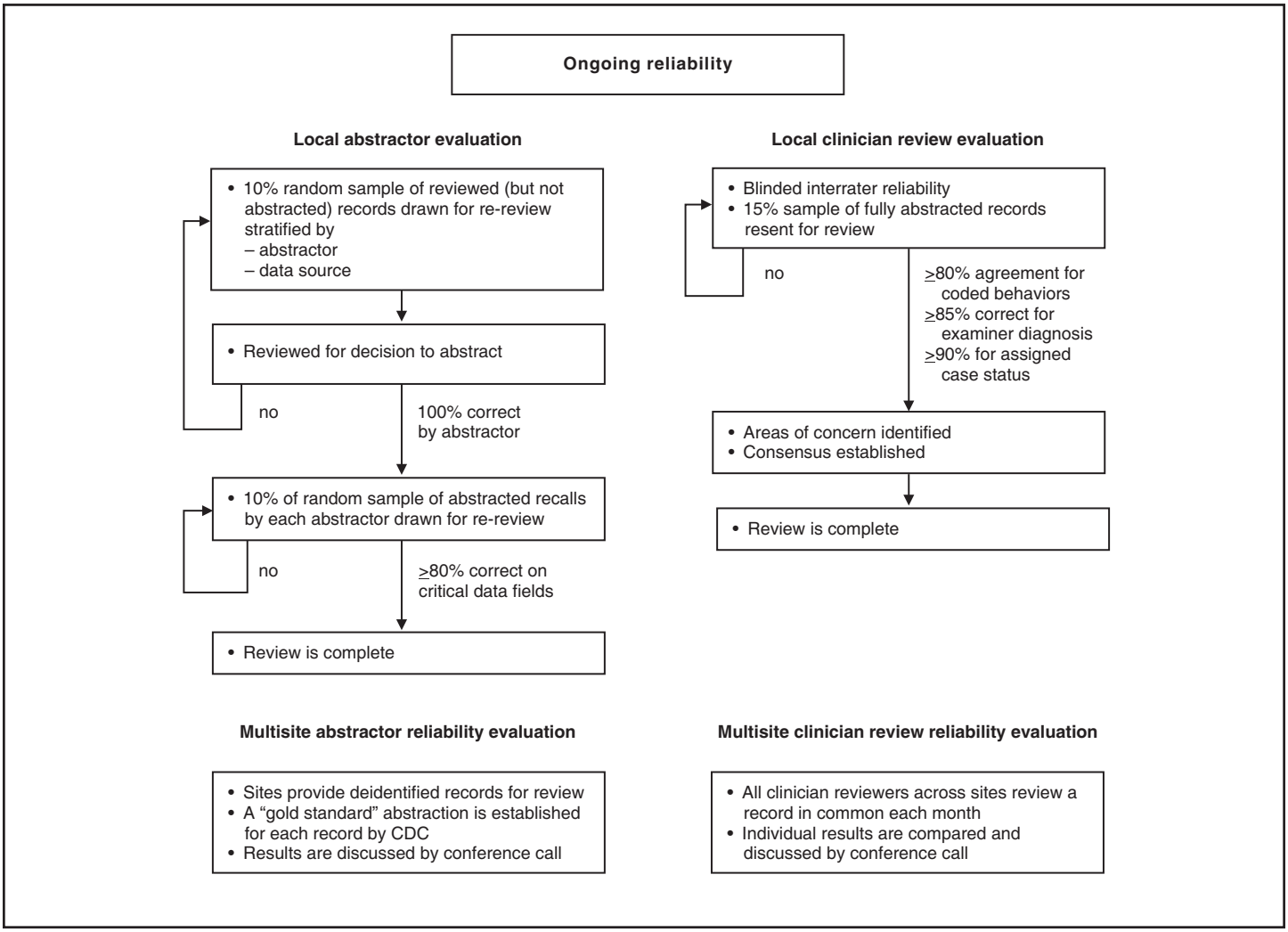


cation facilities or had minimal access (Alabama, Missouri, Pennsylvania, and Wisconsin). At six sites (Arizona, Arkansas, Colorado, Maryland, New Jersey, and North Carolina), certain schools or entire districts in their surveillance area elected not to participate. In four sites (Georgia, South Carolina, Utah, and West Virginia), school participation was complete. Lack of participation by education sources caused four sites (Arizona, Colorado, New Jersey, and North Carolina) to redefine their surveillance areas after data collection had started. Project coordinators were surveyed to determine their perception of the factors that influenced acceptability by health and education sources. The most common factors reported were privacy and confidentiality concerns of the sources, including the Health Insurance Portability and Accountability Act (HIPAA), time or resources required from the sources, and the Family Education Rights and Privacy Act (FERPA). Project staff distributed literature to parents and stakeholders at multiple forums and attended conferences to increase reporting of developmental concerns to providers, understanding of the importance of population-based surveillance of ASDs, and awareness of ASD among parents and community members.

Representativeness

Correct interpretation of surveillance data requires evaluation of the representativeness and accuracy of the surveillance system in describing the occurrence of ASDs in the population. The ADDM Network 2002 surveillance year included 14 sites that accounted collectively for 10.1% of the U.S. population aged 8 years. Because participating sites were selected through a competitive federal award process and not specifically to be representative of the entire U.S. population, ADDM

FIGURE 3. Flowchart for quality control for ongoing reliability — Autism and Developmental Disabilities Monitoring Network



Network results cannot be used as a basis for estimating the national prevalence of ASDs. Two national surveys designed as random samples of the U.S. noninstitutionalized population estimated prevalence of ASDs from parental reports of autism diagnosis among children aged 6–8 years to be 7.5 and 7.6 cases per 1,000 population, respectively (*10*). Although generated using a different methodology, these estimates were similar to ADDM estimates, thereby providing external validation.

The denominator is another determinant of representativeness. The 2002 surveillance year sites used data from the National Center for Health Statistics (NCHS) vintage 2004 postcensal bridged-race population estimates for July 1, 2002, to obtain counts by sex and race and ethnicity of the number of children aged 8 years (*11*). NCHS bridged postcensal population estimates are produced by the U.S. Census Bureau immediately after a decennial census. However, trends noted between two decennial censuses can vary substantially from trends forecast in the postcensal estimates (*12*). For this reason, annual postcensal estimates are updated after the subsequent decennial census, and intercensal estimates are produced. Once the 2010 census has been completed and intercensal estimates are published for 2002 and beyond, the ADDM Network will recalculate previously reported prevalence estimates to evaluate the effect of any postcensal and intercensal differences within and across sites. Using postcensal estimates rather than intercensal estimates results has been demonstrated to overestimate the prevalence of a disorder; the extent might vary by race/ethnicity (*13,14*). The effect of postcensal and intercensal differences might not be significant for the 2002 surveillance year but will become important as the ADDM Network collects data in subsequent surveillance years and trends are examined. No better alternative has been developed for calculating prevalence for all ADDM Network sites than NCHS data.

TABLE 1. Characteristics of participating data sources and record review process, by site — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002

Characteristic	No. participating data sources	No. records requested	No. children for whom records were requested	No. records abstracted	No. children for whom records were abstracted	No. children reviewed for ASDs*
Sites with access to health records						
Alabama†	24	2,769	2,147	866	584	318
Missouri-Illinois§	23	3,972	3,149	672	434	403
Pennsylvania¶	124	1,049	796	330	252	252
Wisconsin†	18	4,404	3,897	716	558	239
Sites with access to health and education records						
Arizona§	36	4,437	4,185	555	475	475
Arkansas**††	293	7,547	5,908	1,632	1,137	525
Colorado§	24	2,721	2,387	518	415	415
Georgia§§	43	5,747	3,784	2,042	1,245	687
Maryland¶¶	9	4,747	4,013	421	311	311
New Jersey§	62	2,758	2,415	519	431	428
North Carolina**	32	3,980	3,518	810	602	369
South Carolina**	70	4,280	3,601	863	679	293
Utah**	31	5,941	4,549	1,010	566	409
West Virginia	60	4,383	4,093	295	200	200

* Autism spectrum disorders.
† Monitored ASDs and cerebral palsy.
§ Represents records and children identified as a part of original surveillance area of Arizona, Colorado, Missouri-Illinois, and New Jersey. When limited to children in the final surveillance area, the number of children abstracted for ASDs were 474 in Arizona, 239 in Colorado, 363 in Missouri, and 425 in New Jersey.
¶ Pennsylvania had access to a limited number of school records through a parental consent pilot study.
** Monitored ASDs and mental retardation.
†† Large number of individual school districts.
§§ Monitored ASDs, mental retardation, cerebral palsy, hearing loss, and vision impairment.
¶¶ School districts were large and few in number.

Predictive Value Positive

Predictive value positive (PVP) is the probability that a child whose condition is consistent with the surveillance case definition actually has the disease or condition under surveillance. A clinical diagnosis of an ASD requires intensive in-person examination of a child and often interview with the primary caregivers. Clinical confirmation of all cases identified using ADDM Network methods is resource prohibitive. The ADDM Network multiple-source, active record review methodology provides a feasible approach to population-based monitoring of ASDs. However, the ADDM methodology relies on past diagnoses, special education eligibilities, and behaviors described in children's health or education records to classify a child as having an ASD. The lack of a "gold standard" in-person standardized clinical assessment to validate these methods introduces the possibility of false-positive cases.

The validity of the ADDM Network methodology for determining case status is under assessment in a study by the Georgia ADDM Network site using clinical examinations to calculate the proportion of false-positives among confirmed ASD cases using ADDM Network methods. In 2002, the University of Miami was funded as an ADDM Network grantee to validate its ASD surveillance methods. Results from this validation project indicate that the concordance between a previously documented ASD diagnosis and the ADDM Network record review case status (97%) was greater than that of a screening with the Social Communication Questionnaire (87% at a cut-off test score of 13 points) (Marygrace Yale Kaiser, University of Miami, unpublished communication, 2006). Although not compared directly to the results of a clinical examination, these data lend support to reasonable PVP of the ADDM case-status determination.

Across the 14 ADDM Network sites for the 2002 surveillance year, 57%–86% of children classified by the ADDM Network methodology as having confirmed cases of ASDs had a previous ASD diagnosis or special education classification of autism. Past assessments of ADDM Network methodology, together with another report of 93% (*15*), support the assumption that PVP for this subgroup of cases is high. A study noting a relatively high (36%) false-positive rate of diagnoses reported in education records in the United Kingdom examined a limited sample (n = 33) and was difficult to compare with the ADDM Network system (*16*). Conversely, across sites, 14%–43% of children confirmed in the ADDM Network system as having an ASD had not received an ASD

classification previously. Suspicion of an ASD was noted for 6%–19% of these children, leaving 7%–31% with no previous mention in the records of an ASD. ADDM Network methods were designed to identify children with noted behaviors consistent with ASDs but who lacked a formal diagnosis; however, this group might have had the greatest potential for false-positive classification.

One final issue affecting the sensitivity and specificity of the ADDM Network methodology for the 2002 surveillance year is the implementation of a streamlined abstraction and review protocol for children with a previous ASD diagnosis. In an earlier evaluation of these methods, 97% of children aged 8 years who were identified with a previous ASD classification ultimately were confirmed by surveillance clinician reviewers as having ASDs (CDC, unpublished data, 1996). To improve timeliness, 12 of the 14 sites adopted a streamlined abstraction and review protocol for such children. The criteria used in determining which records qualified for streamlining varied by site, and the percentage of cases ascertained using the streamlined protocol ranged from 19% in Colorado to 68% in Georgia (see Sensitivity). Because streamlined abstraction involves limited data collection of behavioral descriptions beyond those required to determine case status, the 2002 ADDM Network sites were unable to evaluate the proportion of persons whose cases would not have been confirmed on the basis of a full review of the behavioral descriptions in the children's records. However, data from the four sites that implemented full abstraction and review for the 2000 surveillance year and streamlined abstraction and review for the 2002 surveillance year indicated that the potential effect of false-positives attributable to the streamlined protocol might have been minimal (weighted average: 6%).

PVP has been improved by selectively screening high-risk segments of the population, including children receiving special education services in public schools or children with select *International Classification of Diseases, Ninth Edition* (ICD-9) and DSM-IV-TR billing codes related to developmental disabilities in health sources, or both (*8,17*).

Sensitivity

Prevalence of ASDs Detected by ADDM Network Methods

The completeness of case ascertainment depends on the sensitivity of the methodology to ascertain children with ASDs in the population. To assess potential underascertainment, quantitative or qualitative examinations (or both) were performed to identify the effects of the number of home school and private school children with ASDs; nonparticipating or unidentified data sources; abstractor error; missing records; sites requesting additional ICD-9 and DSM-IV-TR codes; and differing streamlining criteria.

Private school or home school children whose conditions were consistent with the case definition might have been missed because site agreements with public schools did not include access to information on children in nonpublic schools. Data from a random weighted sample of U.S. children aged 4–17 years from the National Survey of Children's Health (NSCH) reported that 14.2% of children whose parents reported them as having a past diagnosis of autism were attending private schools, and 1.8% were home schooled (CDC, unpublished data, 2006). Although such children were not identified systematically by ADDM Network methods through review of public education records, a subgroup might have been identified through one or more health facilities at a given ADDM Network site.

Efforts were made to identify all sources that had evaluated children for ASDs. The project continually tracked new examiners and facilities identified from children's evaluation histories to ensure that all potential data sources were pursued. However, certain health and education facilities declined to participate or were not identified by project staff (See Acceptability). Using statistical capture-recapture techniques to estimate the effect of this issue on prevalence was considered, but the assumption of independence would have been violated, thereby invalidating that method. Therefore, a quantitative assessment could not be made of the extent to which missing sources affected surveillance estimates.

Results from ongoing quality control activities were used to evaluate the accuracy of the decision made by abstractors to review the record and final case determination assigned by clinician reviewers at each site. The range of percentage of concordance regarding the decision to abstract between the quality-control auditor and abstractor at each site ranged from 87% in Georgia to 100% in North Carolina and West Virginia. For clinician review, the percentage of concordance on final case definition ranged from 79% in Utah to 100% in New Jersey (Table 2). Although quality control results for certain sites were below the established threshold, records for all abstractors and clinician reviewers that fell below the threshold were resampled until the thresholds were met. In addition, the secondary clinician review process provided assurance that the primary clinician review results are an underestimate of true agreement on final case status. The clinician review process also serves to strengthen PVP as discordance on final case status can result in over- or underascertainment.

To evaluate the effect of missing records on prevalence, all children initially identified for screening from participating sources at each site were classified into three groups: 1) all

TABLE 2. Measurable evaluation characteristics, by site — Autism and Developmental Disabilities Monitoring Network,* 14 sites, United States, 2002

Site	Ongoing abstractor quality control: % concordance on decision to abstract	Ongoing clinician reviewer quality control: % concordance on final case definition	Missing records: Estimated % prevalence effect	Additional requested ICD-9 codes†: Estimated % prevalence effect	Streamlined records§: Estimated % prevalence effect
Sites with access to health records					
Alabama	92%	91%	-1.8%	0–+4.3%	-3.4%
Missouri	97%	89%	-8.1%	**	-3.9%
Pennsylvania¶	92%	92%	-14.7%	**	-9.9%
Wisconsin	98%	86%	-0.4%	+3.3–+5.0%	-2.8%
Sites with access to both health and education records					
Arizona	99%	86%	-1.4%	**	-0.7%
Arkansas	††	92%	-3.9%	0	-3.6%
Colorado	99%	88%	-1.4%	+1.5–+4.6%	-4.6%
Georgia	87%	93%	-4.3%	+0.9–+4.7%	-3.6%
Maryland	94%	94%	-14.8%	**	-9.0%
New Jersey	††	100%	-4.9%	**	0%
North Carolina§§	100%	91%	-4.8%	+0.7%	-5.9%
South Carolina	99%	81%	-20.2%	**	-4.3%
Utah	††	79%	-7.8%	0–+0.5%	-0.6%
West Virginia	100%	86%	-6.1%	**	-2.0%

* Estimates of the effect of each evaluation characteristic cannot be summed to calculate an adjusted prevalence estimate because the measures are not mutually exclusive, other evaluation characteristics effecting prevalence were not quantifiable, and a significant overlap between the characteristics presented might exist. All abstractors and clinician reviewers had to meet initial reliability standards before beginning record review; therefore, initial quality control was completed at all sites.

† The lower bound of the range represents the effect of children who were identified exclusively from data sources with additional *International Classification of Diseases, Ninth Edition* (ICD-9) codes, and the upper bound represents the effect of children with more than one data source for which one data source had exclusively the additional ICD-9 code(s) and another source had an ICD-9 code on the common list. Whether the record from the data source with the additional ICD-9 code list would have provided information to contribute to case confirmation is unclear.

§ Least conservative streamlining criteria were applied to all children abstracted at each site.

¶ Pennsylvania had access to a limited number of school records through a parental consent pilot study.

** Evaluation of this characteristic was not applicable to a given site because the site did not request additional ICD-9 codes.

†† Site did not conduct specific evaluation according to joint methods.

§§ North Carolina identified one child (0.7%) uniquely from data sources with additional ICD-9 codes and no children with more than one data source for which one data source exclusively had the additional ICD-9 code(s) and another source had a common list ICD-9 code. Therefore, a range is not presented.

requested records located, 2) certain requested records not located, and 3) no requested records located. The children were further subdivided into six strata by type of data source (education only, health only, or both) and specificity of ASD screening criterion (presence of an ASD-specific ICD-9 or DSM-IV-TR code or school eligibility, compared with all other school eligibility, ICD-9, and DSM-IV-TR codes). Data were analyzed assuming that within each type of source or ASD-specific stratum, children with missing records would have had the same likelihood of being identified as a confirmed ASD case child, had their records been located, as children for whom all records were available for review. These analyses indicated that the possible effect of missing records on prevalence underestimation ranged from 0.4% in Wisconsin to 20% in South Carolina (Table 2).

A standard basic list of ICD-9 and DSM-IV-TR codes was reviewed for the 2002 surveillance year. However, sites that also conducted surveillance for mental retardation (Arkansas, Georgia, North Carolina, South Carolina, and Utah); cerebral palsy (Alabama, Georgia, and Wisconsin); and both hearing loss and vision impairment (Georgia) requested additional ICD-9 codes. One site (Colorado) also requested codes identified as important because of specific coding practices in the area. The proportion of additional cases identified from these additional ICD-9 codes, assuming all records with these unique codes would contribute to case status, ranged from 0% in Arkansas to 5.0% in Wisconsin (Table 2). This suggests that the additional codes would not have increased prevalence estimates substantially.

The criteria used for determining which children qualified for streamlining varied by site. Seven sites (Arizona, Arkansas, Georgia, Maryland, Missouri, New Jersey, and Pennsylvania) elected to streamline children with a primary school eligibility category of autism or a broad-spectrum ASD diagnosis, whereas Utah based streamlining on autism eligibility but a more restrictive diagnosis of autistic disorder. Four sites

(Alabama, Colorado, North Carolina, and Wisconsin) streamlined records only for children with an autistic disorder diagnosis. West Virginia and South Carolina did not implement the streamlined protocol for the 2002 surveillance year. To facilitate comparability between site prevalence estimates, given this potential variability in ascertainment from using different criteria for streamlining, the least conservative streamlining criteria were applied to all children abstracted at each site. The effect on prevalence ranged from 0 in New Jersey to 9.9% in Pennsylvania (Table 2).

Ability of ADDM Network Methods to Monitor Changes in Prevalence

The use of consistent methods for case identification across surveillance years enhances the ability of the ADDM Network methods to detect changes in ASD prevalence over time. However, a true increase in ASD population prevalence might be difficult to distinguish from an increase attributable to increases in provider awareness of ASDs, changes in service provision regulations or diagnostic and treatment patterns, or differences in the breadth and depth of behavioral information in evaluation records. For example, between the 2000 and 2002 surveillance years, the prevalence of ASDs in West Virginia increased 39%. A qualitative assessment of behavioral descriptions contained in their site's evaluations indicated that improvements were made in the quality and amount of information in evaluation records during this period which might have contributed to the increase. Beginning with the 2006 surveillance year, the ADDM Network will begin rating the quality of information in records to facilitate quantitative evaluation of changes in the quality of information contained in records and their effect on prevalence over time. Because ADDM Network prevalence estimates do not rely solely on a documented ASD diagnosis from a single source, they are less likely to be affected by trends in specific usage of ASD diagnoses as long as children with social, communication, and behavioral symptoms continue to be evaluated by health or education sources for treatment or services, or both.

Although ADDM Network methods are subject to these challenges, recent studies have demonstrated that aggregate administrative data (e.g., autism eligibility data from the U.S. Department of Education) are not optimal for measuring period prevalence or monitoring changes over time. The ADDM Network's multiple-source methodology produces prevalence estimates with greater robustness to minimize classification bias than alternative available ASD prevalence measures (*18–20*).

Timeliness

The timeliness of the surveillance system is the speed of progression from identifying data sources to releasing results. The ADDM Network population-based surveillance system can be resource and time intensive, particularly at its inception at a new site, as evidenced by the multitude of data sources required for participation, high volume of records for review, and abstraction and clinician review and time estimates previously reported for each step in the process (Table 1). Each site must first identify potential sources for identification of potential cases, obtain access to health and education records, hire and train staff, and ensure that reliability thresholds for abstractors and clinician reviewers are met. Although the ADDM sites participating in the 2002 surveillance year represent multiple grant cycles, the estimated time required for this surveillance year, from start of funding to reporting of results, was approximately 3–4 years. Once the surveillance system has been instituted at a site, these limitations to timeliness are greatly reduced for future surveillance years.

As ADDM Network surveillance methods have evolved, the time required to make data available has decreased. Multiple surveillance years can now be conducted concurrently, and clinician review has been restructured to increase efficiency. In addition, case yield is evaluated from specific ICD-9 and DSM-IV-TR codes to determine whether certain codes could be omitted, thereby reducing the number of records to review without decreasing prevalence estimates substantially. Data management methods also have improved, reducing the time from data collection to reporting of the results.

Stability

Stability is the reliability and availability of a surveillance system consistently over time. Stability of the ADDM Network system is promoted by the continuing technical support and coordination provided by CDC, which maintains consistency in methodology across sites. Computer and network support provided by CDC minimizes time lost through computer or other technical problems. Continuation of the ADDM Network has been assured through a new 4-year grant cycle for 2006–2010, and data collection for the 2004 and 2006 surveillance years are underway. Nevertheless, because ADDM Network methods rely on administrative data, changes in maintenance of records and classification and assessment of children with ASDs over time might affect ADDM Network stability.

Data Confidentiality and Security

Although not a formal attribute of the guidelines for evaluating public health surveillance systems, data confidentiality and security must be assured. The ADDM Network employs strict guidelines to maintain the highest level of data security and confidentiality. All staff members receive intensive training concerning confidentiality policies and sign nondisclosure agreements. The network employs enhanced protection of computer files and maintains information technology security procedures for the data collection instrument to ensure that the data remain secure and confidential, including Power On passwords, Windows 2000/XP/NT passwords, MS Access Workgroup Security, and MS Access Encryption. All backups of the ARCHE database are encrypted. Once the surveillance year is completed, deidentified data are submitted to the pooled dataset. Proposals to use the aggregate, deidentified data are reviewed by the principal investigators of the ADDM Network.

Sources of Variability Across ADDM Network Sites

The ADDM Network is a multiple-site, collaborative network using a common methodology. An important goal of the network is to make meaningful comparisons of prevalence across sites. Therefore, this evaluation assessed not only how well the population prevalence of ASDs is measured within each site but also how variations in the implementation of the common methodology affected comparison of prevalence across ADDM Network sites. Data collected previously using ADDM Network methods indicated the importance of education records in monitoring the prevalence of children with developmental disabilities (*9,21,22*). The primary difference between ADDM Network sites for the 2002 surveillance year was the ability to access education records as 4 sites had very limited or no access to education sources. The average prevalence for sites with access to both health and education sources was significantly higher ($p<0.0001$) than that of sites with access to health sources only (*9*).

All ADDM Network sites implemented a common methodology to obtain ASD prevalence. Variability across sites in specific aspects of the common protocol were introduced through attempts to improve timeliness and conduct surveillance of additional developmental disabilities, in addition to the uncontrollable variability in facility evaluation practices. Certain sources of variability are measurable for evaluation (Table 2). These sources of variability are not mutually exclusive and, therefore, cannot be summed to represent an adjusted range of potential prevalence estimates across ADDM Network sites. Moreover, these estimates are not a comprehensive list of all sources of overascertainment and underascertainment because multiple influences that might have had an effect on prevalence (e.g., quality of information in records or proportion of children who were not evaluated at any participating data source) were not quantifiable. Although evaluation results indicate variability across sites in the implementation of the common methodology, site-specific prevalence estimates are regarded as complete, valid, and accurate, and the results offer a reasonable method for comparing intersite prevalence characteristics.

The approach to streamlined abstraction and the review of additional ICD-9 billing codes varied slightly by site, as did the degree of missing records. Although consistency strengthens a common methodology, diagnostic and billing practices differed by data source within each site, and slight modifications to enhance the ability of a site to capture the true prevalence of ASD were expected. Although the quality of abstraction and clinician review inevitably will vary within and across sites, strict quality control protocols implemented by each site enabled them to monitor the variability in quality control and resolve problems quickly.

Conclusion

The ADDM Network is the only, active, ongoing, multiple-source surveillance system for tracking prevalence of ASDs and other developmental disabilities in the United States. Using multiple sources for case ascertainment strengthens the system's representativeness, sensitivity, and flexibility, and the clinician review process aims to bolster PVP. Although sensitivity and PVP are difficult to measure, ADDM methods provide the best estimate of the population prevalence of ASDs short of conducting complete population screening and diagnostic clinical case confirmation. Although the system depends on the quality and availability of information in evaluation records, extensive quality control and data cleaning protocols and assessment of missing records ensure the most accurate reflection of the records reviewed. Maintaining timeliness remains a challenge with this complex methodology; however, possibilities for streamlining to improve timeliness and simplicity without sacrificing data quality continue to be investigated. The effects of changes in diagnostic and treatment practices, service provision, and community awareness are the most difficult influences to assess.

Information sharing through education and outreach with site-specific stakeholders is the best mechanism for understanding the current climate in the community with respect to changes in service provision and public policy related to ASDs, which can affect prevalence estimates. This evaluation can be used to help interpret surveillance results and serve as a model for other systems, especially those that monitor the prevalence of complex disorders.

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