

Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010



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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2010.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system in the United States that provides estimates of the prevalence of ASD and other characteristics among children aged 8 years whose parents or guardians live in 11 ADDM sites in the United States. ADDM surveillance is conducted in two phases. The first phase consists of screening and abstracting comprehensive evaluations performed by professional providers in the community. Multiple data sources for these evaluations include general pediatric health clinics and specialized programs for children with developmental disabilities. In addition, most ADDM Network sites also review and abstract records of children receiving special education services in public schools. The second phase involves review of all abstracted evaluations by trained clinicians to determine ASD surveillance case status. A child meets the surveillance case definition for ASD if a comprehensive evaluation of that child completed by a qualified professional describes behaviors consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for any of the following conditions: autistic disorder, pervasive developmental disorder—not otherwise specified (including atypical autism), or Asperger disorder. This report provides updated prevalence estimates for ASD from the 2010 surveillance year. In addition to prevalence estimates, characteristics of the population of children with ASD are described.

Results: For 2010, the overall prevalence of ASD among the ADDM sites was 14.7 per 1,000 (one in 68) children aged 8 years. Overall ASD prevalence estimates varied among sites from 5.7 to 21.9 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and racial/ethnic group. Approximately one in 42 boys and one in 189 girls living in the ADDM Network communities were identified as having ASD. Non-Hispanic white children were approximately 30% more likely to be identified with ASD than non-Hispanic black children and were almost 50% more likely to be identified with ASD than Hispanic children. Among the seven sites with sufficient data on intellectual ability, 31% of children with ASD were classified as having IQ scores in the range of intellectual disability (IQ ≤ 70), 23% in the borderline range (IQ = 71–85), and 46% in the average or above average range of intellectual ability (IQ > 85). The proportion of children classified in the range of intellectual disability differed by race/ethnicity. Approximately 48% of non-Hispanic black children with ASD were classified in the range of intellectual disability compared with 38% of Hispanic children and 25% of non-Hispanic white children. The median age of earliest known ASD diagnosis was 53 months and did not differ significantly by sex or race/ethnicity.

Interpretation: These findings from CDC's ADDM Network, which are based on 2010 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD in multiple communities in the United States. Because the ADDM Network sites do not provide a representative sample of the entire United States, the combined prevalence estimates presented in this report cannot be generalized to all children aged 8 years in the United States population. Consistent with previous reports from the ADDM Network, findings from the 2010 surveillance year were marked by significant variations in ASD prevalence by geographic area, sex, race/ethnicity, and level of intellectual ability. The extent to which this variation might be attributable to diagnostic practices, underrecognition of ASD symptoms in some racial/ethnic groups, socioeconomic disparities in access to services, and regional differences in clinical or school-based practices that might influence the findings in this report is unclear.

Public Health Action: ADDM Network investigators will continue to monitor the prevalence of ASD in select communities, with a focus on exploring changes within these communities that might affect both the observed prevalence of ASD and population-based characteristics of children identified with ASD. Although ASD is sometimes diagnosed by 2 years of age, the median age of the first ASD diagnosis remains older than

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age 4 years in the ADDM Network communities. Recommendations from the ADDM Network include enhancing strategies to address the need for 1) standardized, widely adopted measures to document ASD severity and functional limitations associated with ASD diagnosis; 2) improved recognition and documentation of symptoms of ASD, particularly among both boys and girls, children without intellectual disability, and children in all racial/ethnic groups; and 3) decreasing the age when children receive their first evaluation for and a diagnosis of ASD and are enrolled in community-based support systems.

Introduction

Autism spectrum disorder (ASD) is a lifelong developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction and restricted, repetitive patterns of behavior, interests, or activities (*1*). Initial signs and symptoms typically are apparent in the early developmental period; however, social deficits and behavioral patterns might not be recognized as symptoms of ASD until a child is unable to meet social, educational, occupational, or other important life stage demands. Functional limitations vary among persons with ASD and might develop over time.

The global prevalence of autism has increased twentyfold to thirtyfold since the earliest epidemiologic studies were conducted in the late 1960s and early 1970s. At that time, prevalence estimates from European studies were one in 2,500 children in the population (*2*), and by the 2000s prevalence estimates from large surveys were 1%–2% of all children (*3–5*). Although the underlying reasons for the apparent prevalence changes are difficult to study empirically, select studies suggest that much of the recent prevalence increase is likely attributable to extrinsic factors such as improved awareness and recognition and changes in diagnostic practice or service availability (*5,6*).

Reported increases in the number of children receiving services for ASD and reports of ASD prevalence estimates that are higher than expected have increased concern among members of the public, underscoring the need for systematic public health monitoring of ASD (*7*). In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD as well as other developmental disabilities in the United States. Tracking the prevalence of ASD poses unique challenges because of its complex nature, lack of diagnostic biomarkers, and changing diagnostic criteria.

The earliest reports from the ADDM Network provided estimates of ASD prevalence among children aged 8 years from six sites for the 2000 surveillance year (*8*) and from 14 sites for the 2002 surveillance year (*9*). Combined data from all sites in each respective surveillance year indicate that ASD prevalence estimates were similar for both years: 6.7 per 1,000 in 2000 (range among six sites: 4.5–9.9) and 6.6 per 1,000 in 2002 (range among 14 sites: 3.3–10.6), or approximately one in every 150 children aged 8 years. A subsequent ADDM

Network report provided data on ASD prevalence among children aged 8 years for 2004 (eight sites) and 2006 (11 sites) (*10*). When data from all sites were combined, overall ASD prevalence was 8.0 per 1,000 in 2004 (range among eight sites: 4.6–9.8) and 9.0 per 1,000 in 2006 (range among 11 sites: 4.2–12.1), or one in every 110 children aged 8 years in 2006. In 2012, the ADDM Network published data from 14 sites for the 2008 surveillance year, reporting a combined ASD prevalence of 11.3 per 1,000 children aged 8 years (range among 14 sites: 4.8–21.2), or one in 88 children (*11*). Comparison of the 2008 findings with those for previous surveillance years showed an increase in ASD prevalence of approximately 23% compared with the 2006 estimates and 78% compared with 2002. The largest increases from 2002 to 2008 were noted among Hispanic children, non-Hispanic black children, and children without co-occurring intellectual disability. This recent and rapid increase in ASD prevalence underscores the importance of continuing surveillance to monitor trends in the population and the need to continue expanding research into risk factors, etiology, and effective interventions.

Since the last ADDM Network report on ASD prevalence was published in 2012 (*11*), other studies conducted in the United States and Canada also suggest a continued upward trend in prevalence (*3–5,12*). This report from the ADDM Network provides updated ASD prevalence estimates for the 2010 surveillance year, representing 11 geographic areas in the United States. In addition to prevalence estimates, characteristics of the population of children with ASD are described.

The purpose of this report is to provide the latest available ASD prevalence estimates from the ADDM Network and to provide public health recommendations for continued monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audience for this report includes pediatric health-care providers, school psychologists, educators, researchers, policymakers, and program administrators working to understand and address the needs of persons with ASD and their families. These data can be used to help plan services, guide research into risk factors and effective interventions, and develop policies that promote improved outcomes in health care and education. To better understand autism, additional efforts are underway to perform focused analyses on factors that might influence changes over time in the identification of children with ASD and to identify potential risk factors that merit additional investigation.

Methods

Study Sites

The Children's Health Act (13) authorized CDC to create the ADDM Network in 2000. Since that time, CDC has funded grantees in 14 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, West Virginia, and Wisconsin). The ADDM Network uses multisite, multiple-source, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (14). The surveillance methods have remained as consistent as possible over time. Some minor changes have been introduced to improve efficiency and data quality. Although not all geographic areas have been covered in all years, these changes have been documented to facilitate evaluation of their impact.

The core surveillance activities in all ADDM Network sites focus on children aged 8 years because the baseline ASD prevalence study conducted by MADDSP demonstrated that this is the age of peak prevalence (14). ADDM has multiple goals: 1) to obtain as complete a count as possible of the number of children with ASD in multiple surveillance areas, 2) to report comparable population-based ASD prevalence estimates from different sites every 2 years and to evaluate how these estimates are changing over time, 3) to study whether autism is more common among some groups of children than among others, and 4) to provide descriptive data on the population of children with ASD.

Funding for ADDM Network sites participating in the 2010 surveillance year was awarded for a 4-year cycle covering 2010–2014, during which time data are being collected for the 2010 and 2012 surveillance years. Sites were selected through a competitive objective review process on the basis of their ability to conduct active, records-based surveillance of ASD; they were not selected to be a nationally representative sample. A total of 11 sites are included in the current report (Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah, and Wisconsin). Each ADDM site participating in the 2010 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act (HIPAA) of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (15).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or professional reporting of an existing ASD diagnosis or classification to determine ASD case status.

ADDM staff members conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves screening and abstracting records at multiple data sources in the community. In the second phase, all abstracted evaluations are compiled and reviewed by trained study personnel to determine ASD case status. Children's records are screened at multiple data sources; therefore, developmental assessments completed by a wide range of health and education providers are reviewed. Data sources are categorized as either 1) education source type, including evaluations to determine eligibility for special education services, or 2) health-care source type, including diagnostic and developmental assessments from psychologists, neurologists, developmental pediatricians, child psychiatrists, physical therapists, occupational therapists, and speech/language pathologists. Agreements to access records are made at the institutional level in the form of contracts, memoranda, or other formal agreements. All ADDM Network sites have agreements in place to access records at health-care sources; however, not all sites have permission to access education records. Two ADDM sites (Missouri and Wisconsin) have not been granted access to records at any education sources. Among the remaining sites, some receive permission from their state Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Therefore, three ADDM sites (Alabama, Colorado, and North Carolina) did not have access to education records from all school districts within the overall geographic area covered for surveillance year 2010. For the Alabama and Colorado ADDM sites, access to education records was limited to a small portion of the overall geographic area covered, representing about 10% of the resident population in the overall surveillance area covered by each site. Because access to educational records was not permitted in Alabama during surveillance years 2002–2008, obtaining access to these records for 2010 in five of the nine counties in the Alabama surveillance area enhanced the surveillance. In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM study and may request that their children's education records be excluded. Access to education records at the North Carolina ADDM site was permitted throughout most of the overall geographic area covered (in all but one school district), representing about 90% of the resident population in the North Carolina surveillance area.

Within each education and health data source, ADDM sites identify records to review based on a child's year of birth and one or more 1) select eligibility classifications for special education or 2) *International Classification of Diseases, Ninth Revision* (ICD-9) billing codes for select childhood

disabilities or psychological conditions. Children's records are first screened to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the source files are screened for certain behavioral or diagnostic descriptions defined by ADDM as triggers for abstraction (e.g., child does not initiate interactions with others, prefers to play alone or engage in solitary activities, or has received a documented ASD diagnosis). If abstraction triggers are found, evaluation information from birth through the current surveillance year is abstracted into a single composite record for each child.

In the second phase of surveillance, the abstracted composite evaluation files are deidentified and reviewed systematically by clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* (16) criteria for ASD. A child meets the surveillance case definition for ASD if behaviors described in the composite record are consistent with the DSM-IV-TR diagnostic criteria for any of the following conditions as described in a comprehensive evaluation by a qualified professional at any time from birth through the end of the year when the child reaches age 8 years: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder.

The ADDM Network ASD case definition has been based on the DSM-IV-TR diagnostic criteria since the initial (2000) surveillance year. In 2013, the American Psychiatric Association published the fifth version of the DSM (DSM-5) (1). This edition consolidated the three distinct ASD conditions from the DSM-IV-TR (autistic disorder, PDD-NOS, and Asperger disorder) into one condition (autism spectrum disorder) that no longer has subtypes. Substantial revisions to the diagnostic criteria were incorporated into the DSM-5 as well. Because the new definition and criteria were not published until 2013, information in children's health and education records remained consistent with the DSM-IV-TR definition until that time; therefore, the ADDM Network ASD case definition for surveillance years 2010 and 2012 are based on the DSM-IV-TR. Beginning with the 2014 surveillance year, the ADDM methods will incorporate a case definition according to the newer standards but will continue to evaluate whether children meet the DSM-IV-TR diagnostic criteria to better understand ASD prevalence trends and provide a population-based perspective on the impact of the DSM-5 revisions.

Descriptive Characteristics

The diagnostic conclusions from each evaluation record also are summarized for each child, including notation of any ASD diagnosis by subtype, when available. Children

are considered to have a previously documented ASD classification if they 1) received a diagnosis of autistic disorder, PDD-NOS, Asperger disorder, or ASD that was documented in an abstracted evaluation or by an ICD-9 billing code at any time from birth through the year when they reached age 8 years or 2) had documentation of eligibility for special education services under an autism category.

Information on children's functional skills also is abstracted from source records, when available, including scores on tests of adaptive behavior and intellectual ability. Because no standardized, validated measures of functioning specific to autism have been widely adopted in clinical practice and because adaptive behavior rating scales are not consistently available in education records of children with ASD, scores of intellectual ability have remained the primary source of information on children's functional skills. Children are classified as having intellectual disability if they have an IQ score of ≤ 70 on their most recent test available in the record. Borderline intellectual ability is defined as having an IQ score of 71–85, and average or above average intellectual ability is defined as having an IQ score of >85 . In the absence of a specific IQ score, an examiner's statement based on a formal assessment of the child's intellectual ability, if available, is used to classify the child in one of these three levels. Data on intellectual ability are reported only for seven sites (Arkansas, Arizona, Georgia, Maryland, New Jersey, North Carolina, and Utah) having information available for at least 70% of children who met the ASD case definition.

For this report, data on the first comprehensive evaluation on record were restricted to children with ASD who were born in the state where the ADDM site is located, as confirmed by linkage to birth certificate records. Data were restricted in this manner to reduce error in the estimate that was introduced by children who were born out of state and migrated into the surveillance area between the time of birth and the year when they reached age 8 years.

Quality Assurance

All sites follow the same quality assurance standards established by the ADDM Network. In the first phase of ADDM, screening and abstraction of source records are checked periodically for accuracy. In the second phase, interrater reliability is monitored on an ongoing basis using a blinded, random 10% sample of abstracted records that are scored independently by two reviewers. For the 2010 surveillance year, interrater agreement on case status (confirmed ASD versus not ASD) was 90.7% when comparison samples from all sites were combined ($k = 0.80$). This exceeds the quality assurance standards established for the ADDM Network (17).

Analytic Methods

Results for all sites combined were based on pooled numerator and denominator data from all sites, in total and stratified by race/ethnicity, sex, and level of intellectual ability. Population denominators for calculating ASD prevalence estimates were obtained from CDC's bridged-race population estimates for the April 2010 decennial census (18). CDC provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2010 surveillance year were compiled from counts of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In one site (Arizona), only part of a county is covered by surveillance. Therefore, geographic boundaries were defined by the school districts included in the surveillance area. Counts of children living in outlying school districts were subtracted from the county-level census denominators using school enrollment data from the U.S. Department of Education's National Center for Education Statistics (19). Enrollment counts of students in third grade during the 2010–11 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled in a grade other than the customary grade for their age, in private schools, or in home schools. Because these differences varied by race and sex within the applicable counties, race- and sex-specific adjustments based on enrollment counts were applied to the CDC population estimates to derive school district-specific denominators for Arizona.

Each ADDM site attempted to obtain birth certificate data for all children meeting the ASD case definition through linkages conducted using state vital records. These data were only available for children born in the state where the ADDM site is located. The race/ethnicity of each child was determined from information contained in source records or, if not found in the source file, from the birth certificate data. Race- or ethnicity-specific prevalence estimates were calculated for five populations: non-Hispanic white, non-Hispanic black, Hispanic (regardless of race), Asian/Pacific Islander, and American Indian/Alaska Native. In this report, non-Hispanic white children are referred to as white, and non-Hispanic black children are referred to as black. Prevalence results are reported as the total number of children meeting the ASD case definition per 1,000 children aged 8 years in the population in each race/ethnicity group. ASD prevalence also was estimated separately for boys and girls, as well as within each level of intellectual ability. Overall prevalence estimates include all children identified with ASD regardless of sex, race/ethnicity, or level of intellectual ability and thus are not affected by the availability of data on these characteristics.

Statistical tests were selected and confidence intervals (CIs) for prevalence estimates were calculated under the assumption that the observed counts of children identified with ASD

are random variables drawn from an underlying Poisson distribution. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates within and across sites and between surveillance years. Pearson chi-square tests also were performed to test for significance in comparisons of proportions, and Mantel-Haenszel common odds ratio (OR) estimates were calculated to further describe these comparisons. To reduce the effect of outliers, distribution medians were typically presented, although one-way analysis of variance (ANOVA) was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p < 0.05$.

Evaluation Methods

Some education and health records were missing for certain children, including records that could not be located for review, those affected by the passive consent process unique to the Colorado site, and those for children receiving special education services in one school district for which the North Carolina site did not have permission to review and abstract education records. A sensitivity 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 closely associated with final case status: information source (health-care source only, education source only, or both source types) and the presence or absence of either an autism special education eligibility or an ICD-9-CM code for ASD, collectively forming six strata. 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 having ASD would have been similar to that of children for whom no records were missing. Within each stratum, the proportion of children with no missing records who were confirmed as having ASD was applied to the number of children with missing records to estimate the number of missed cases, and the estimates from all six strata were added to calculate the total for each site. This evaluation was conducted solely to investigate the potential impact of missing records on the presented estimates. The estimates presented in this report do not reflect this adjustment or any of the other assessments of the potential effects of the assumptions underlying our approach.

All ADDM sites identified records to review at most health-care sources by conducting record searches that were based on a common list of ICD-9 billing codes. Because several sites were conducting surveillance for other developmental disabilities in addition to ASD (i.e., one or more of the following: cerebral palsy, intellectual disability, hearing loss, and vision impairment), they reviewed records based on an expanded list of ICD-9 codes. The Colorado site also requested

code 781.3 (lack of coordination), which was identified in that community as a commonly used billing code for children with ASD. The proportion of children meeting the ASD surveillance case definition whose records were obtained solely on the basis of those additional codes was calculated to evaluate the potential impact on ASD prevalence.

Results

A total population of 363,749 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2010 surveillance year (Table 1). This number represented 9% of the total U.S. population of children aged 8 years in 2010 (18). A total of 60,130 records for 47,371 children were reviewed at health-care and education sources. Of these, the source records of 9,769 children met the criteria for abstraction, which was 20.6% of the total number of children whose source records were reviewed and 2.7% of the total population under surveillance (range: 1.4% [Alabama] to 4.2% [Utah]). Of the records reviewed by clinicians, 5,338 children met the ASD surveillance case definition. The number of evaluations abstracted for each child ultimately identified with ASD varied (median: 6; range: 4 [Arizona, Colorado, and Missouri] to 9 [Arkansas]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2010 surveillance year was 14.7 per 1,000 (one in 68) children aged 8 years, based on combined data from all 11 sites (range: 5.7 [Alabama] to 21.9 [New Jersey]) (Table 2). Overall estimated prevalence of ASD was highest in New Jersey (21.9), Utah (18.6), and North Carolina (17.3). Three sites reported prevalence estimates of 15–16 per 1,000 (Arizona, Arkansas, and Georgia), with a total of five sites with prevalence estimates of 14–17 per 1,000 (Arizona, Arkansas, Georgia, Maryland, and Missouri). Prevalence in two sites was 9–10 per 1,000 (Colorado and Wisconsin), and Alabama reported significantly lower ASD prevalence (5.7 per 1,000) than any other site. The four sites with limited or no access to children's education records (Alabama, Colorado, Missouri, and Wisconsin) reported the lowest prevalence estimates among all ADDM sites (Figure 1). In sites with access both to health-care and education sources throughout most or all of the surveillance area, the proportion of ASD cases identified exclusively from education sources ranged from 14% in Utah to 58% in Arizona.

Prevalence by Sex and Race/Ethnicity

Combining data from all 11 ADDM sites, ASD prevalence was 23.7 per 1,000 (one in 42) boys and 5.3 per 1,000 (one

in 189) girls (prevalence ratio: 4.5 for all sites combined). The prevalence of ASD was significantly ($p < 0.01$) higher among boys than among girls in all 11 ADDM sites (Table 2), with male-to-female prevalence ratios ranging from 3.6 (Alabama and Colorado) to 5.1 (North Carolina). Estimated ASD prevalence also varied by race/ethnicity. When data from all sites were combined, the estimated prevalence among white children (15.8 per 1,000) was significantly greater than that among black (12.3 per 1,000) and Hispanic children (10.8 per 1,000). All 11 sites reported higher prevalence estimates among white children than among black or Hispanic children. The white-to-black prevalence ratios were statistically significant in five sites, and the white-to-Hispanic ratios were significant in eight sites. In seven sites, the estimated prevalence of ASD was higher among black children than Hispanic children. The black-to-Hispanic prevalence ratio was significant in four of these seven sites as well as when combining data from all 11 sites. Estimates for Asian/Pacific Islander children ranged from 3.0 per 1,000 (Alabama) to 21.0 per 1,000 (New Jersey), with notably wide CIs.

Intellectual Ability

Seven sites had accompanying data on intellectual ability for at least 70% of children who met the ASD case definition (range: 76% [New Jersey] to 96% [North Carolina]). Combining data from these seven sites, 3,604 (87%) of 4,140 children with ASD had accompanying data on intellectual ability. This proportion did not differ by sex or race/ethnicity in any of the seven sites or when combining data from all seven sites. Among these 3,604 children, 31% were classified in the range of intellectual disability ($IQ \leq 70$ or an examiner's statement of intellectual disability), 23% were in the borderline range ($IQ = 71-85$), and 46% had IQ scores of >85 or an examiner's statement of average or above average intellectual ability. The proportion of children classified in the range of intellectual disability ranged from 18% in Utah to 37% in Georgia. This proportion did not differ by sex in Arkansas (35%) or New Jersey (29%), whereas in two sites (Maryland and North Carolina) a significantly higher proportion of girls than boys were classified in the range of intellectual disability (Figure 2). When data from all seven sites were combined, 229 (36%) of 633 girls with ASD had IQ scores or examiners' statements indicating intellectual disability compared with 900 (30%) of 2,971 males ($OR = 1.3$, $p < 0.01$). Combining data from these seven sites, the prevalence of ASD with co-occurring intellectual disability was 4.7 per 1,000 children aged 8 years, whereas prevalence of ASD without co-occurring intellectual disability was 10.2 per 1,000. Among these seven sites, Utah had the lowest prevalence of ASD with co-occurring intellectual disability and the highest prevalence of ASD without intellectual disability (Figure 3).

All other sites reported prevalence of ASD with co-occurring intellectual disability ranging from 4.2 to 5.5 per 1,000 and prevalence of ASD without intellectual disability ranging from 8.7 to 11.9 per 1,000.

The proportion of children classified in the range of intellectual disability also differed by race/ethnicity. Approximately 48% of black children with ASD were classified in the range of intellectual disability, compared with 38% of Hispanic children and 25% of white children. These proportions differed significantly from each other when combining data from the seven sites; however, the difference in the proportion of blacks and whites with intellectual disability was not significant in Arizona (OR = 0.8, $p = 0.57$), and the difference in the proportion of Hispanics and whites with intellectual disability was not significant in Maryland (OR = 1.6, $p = 0.41$), North Carolina (OR = 1.7, $p = 0.09$), or Utah (OR = 1.5, $p = 0.18$). None of the individual sites reported a higher proportion of Hispanic than black children with ASD who had IQ scores of >70 , although a significant difference was found between these groups when the data from all sites were combined (OR = 1.5, $p < 0.01$). Combining data from these seven sites, the prevalence of ASD with co-occurring intellectual disability was 6.1 per 1,000 black children, 4.2 per 1,000 Hispanic children, and 4.1 per 1,000 white children (Figure 4). The male-to-female, white-to-black, and white-to-Hispanic prevalence ratios were all higher among children without intellectual disability than the corresponding ratios among children with ASD and co-occurring intellectual disability.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site ($n = 4,078$ of 5,338 confirmed cases), 44% had a comprehensive evaluation on record by 36 months of age (range: 33% [Utah] to 59% [North Carolina]) (Table 3). Approximately 36% of these 4,078 children did not have a comprehensive evaluation on record until after age 48 months; however, mention of developmental concerns by age 36 months was documented for almost 89% (range: 83% [New Jersey] to 94% [Alabama]).

The median age of the first evaluation was 44 months when combining data from all ADDM sites (range: 33 [North Carolina] to 45 [Arkansas and Utah]). The median age was slightly younger among white children (38 months) than black children (40 months), although a comparison of means (43 versus 44 months, respectively) showed no significant difference. The median age of first evaluation among Hispanic children was 43 months, and comparison of means indicated significant differences when comparing Hispanic children (mean = 46 months) both to white children (mean = 43, $p < 0.01$) and black children (mean = 44, $p < 0.05$). However,

these differences were less apparent when the data were stratified by site, and the same pattern was not observed in all sites. When stratified by site, the mean age of first evaluation was significantly higher among Hispanics than whites in only one site (Georgia). No sites observed significant differences in the mean age of first evaluation when comparing Hispanic to black children.

In all seven ADDM sites with information on intellectual ability available for at least 70% of children identified with ASD, the median age of first evaluation was younger among children classified in the range of intellectual disability than among children with $IQ > 70$. Approximately 56% of 874 children with intellectual disability had a comprehensive evaluation on record by 36 months of age (range among seven sites: 41% [Utah] to 73% [North Carolina]), compared with only 36% of children with $IQ > 70$. These proportions were significantly different in five of the seven sites.

Previously Documented ASD Classification

Approximately 80% of all children meeting the ASD surveillance case definition had either eligibility for autism special education services or a DSM-IV/ICD-9 diagnosis documented in their records (range among 11 sites: 65% [Colorado] to 90% [Utah and Wisconsin]) (Figure 5). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 77% of girls (OR = 1.3, $p < 0.01$). Among 5,280 children with ASD for whom data were available, nearly 82% of white children had a previously documented ASD classification, compared with 78% of black children (OR = 1.3, $p < 0.01$) and 75% of Hispanic children (OR = 1.5, $p < 0.01$); however, no significant difference was found when comparing the proportion of black children with a previous ASD classification to the proportion of Hispanic children. When stratified by site, Wisconsin was the only site with any significant differences by race/ethnicity in the proportion of children with a previously documented ASD classification (comparing proportion among white to that among Hispanic children, OR = 3.7, $p < 0.01$).

The median age of earliest known ASD diagnosis documented in children's records (Table 4) varied by diagnostic subtype (autistic disorder: 48 months; ASD/PDD: 50 months; Asperger disorder: 74 months). Within these subtypes, the median age of first known diagnosis did not differ by sex, nor did any difference exist in the proportion of boys and girls who initially received a diagnosis of autistic disorder (43%), ASD/PDD (46%), or Asperger disorder (11%). However, the median age of earliest known diagnosis and distribution of subtypes varied by site. The median age of first known diagnosis for all subtypes combined was 53 months, ranging

from 46 months in Missouri and North Carolina to 61 months in Arkansas, which also had the highest proportion of children with a diagnosis of Asperger disorder. Of the 3,822 children with a diagnostic subtype on record, 453 (11.9%) had different subtypes noted across multiple evaluations, suggesting instability in the initial subtype diagnosed for approximately one in eight children. Although these subtypes are no longer relevant under the new DSM-5 category autism spectrum disorder, they are included in this report because of their relevance during the applicable time period.

When stratified by race/ethnicity, the median age of first known diagnosis for all subtypes combined was the same among white and black children (52 months), and slightly older, but not statistically different, among Hispanic children (56 months). All three racial/ethnic groups had a similar proportion of children who initially received a diagnosis of ASD/PDD; however, the subtype of first known diagnosis was more likely to be autistic disorder among black children (51%) and Hispanic children (52%) than among white children (39%, $p < 0.01$). Conversely, the subtype of first known diagnosis was more likely to be Asperger disorder among white children (14%, $p < 0.01$) compared with black children (4%) and Hispanic children (5%). Because these proportions vary significantly by race/ethnicity, the median age of first known diagnosis for all subtypes combined should be interpreted with caution when stratifying in this manner.

Combining data from seven sites with information on intellectual ability available for at least 70% of children identified with ASD, children classified in the range of intellectual disability were more likely to receive an initial diagnosis of autistic disorder (63%) than ASD/PDD (36%) or Asperger disorder (1%). The median age of first known diagnosis for all subtypes combined was 44 months among children classified in the range of intellectual disability and 59 months among children with IQ > 70 , and a similar pattern was observed in all seven sites.

Special Education Eligibility

Sites with access to education records collected information about the eligibility categories under which special education services were received in public schools (Table 5). Among children with ASD who were receiving special education services in public schools during 2010, the proportion of children with a primary eligibility category of autism ranged from 30% in Colorado to 69% in Maryland. Because autism is a subcategory of physical disability in Colorado, the primary eligibility might have been documented as autism or physical disability, depending on the school district. All other sites reported nearly half or more children with a primary special

education eligibility category of autism. Other common special education eligibilities included health or physical disability, speech and language impairment, specific learning disability, and a general developmental delay category that is used until age 9 years in some sites. All sites reported $< 10\%$ of children with ASD receiving special education services under a primary eligibility category of intellectual disability.

In-migration

To reduce bias in comparisons that could be influenced by the migration of children into the surveillance area (i.e., in-migration) between the time of birth and the year of their eighth birthday, children with ASD were classified according to migration status. The proportion of children with ASD who were born within the state where the ADDM site is located as confirmed by linkage to a birth certificate record ranged from 67% (North Carolina) to 84% (Alabama). Of note, the two ADDM sites with the highest proportions of children born in the state (Alabama [84%] and New Jersey [83%]) reported the lowest and highest prevalence estimates for surveillance year 2010, respectively. Conversely, data are not available for out-migration.

The available data allowed for a general assessment of the proportion of children whose county of residence at birth was within the ADDM state but outside the 2010 surveillance area. This analysis excluded Arkansas, where the ADDM surveillance area is statewide, and Wisconsin, where data on birth residence were not reported. Among children identified with ASD who were born in state, the proportion whose residence at birth was outside the surveillance area ranged from 3% (Missouri and Arizona) to 17% (Maryland), indicating wide variation among sites in the proportion of children with ASD migrating into the surveillance area from some other area of the state between the time of birth and age 8 years.

Evaluation of Missing Records and Expanded ICD-9 Codes

An evaluation of missing records determined that for eight of the 11 sites in the study, missing records contributed to an underestimate of ASD prevalence of $\leq 1\%$, and for the remaining three sites, missing records contributed to a 10% underestimate in Utah and a 3% underestimate in Alabama and Maryland. Most sites reported very similar findings when comparing these estimates to those from surveillance year 2008; however, the underestimate attributable to missing records was much higher in Alabama (17%) and Maryland (16%) and slightly higher in Georgia (3%) and North Carolina (4%) in 2008 compared with 2010.

The impact on prevalence estimates of using an expanded list of ICD-9 codes varied from site to site. Colorado was the only site in which >1% of ASD surveillance cases were identified solely on the basis of the expanded code list. In several sites, use of an expanded list of ICD-9 codes contributed to partial identification of <10% of cases. Additional cases identified by those sites that specifically requested ICD-9 codes for surveillance of cerebral palsy ranged from 5% to 9%: Alabama (7.2%), Georgia (8.4%), Missouri (6.7%), and Wisconsin (5.5%). In Colorado, billing code 781.3 (lack of coordination) was added, and 8.9% additional cases were identified. (Code 781.3 is also one of the additional codes requested for cerebral palsy surveillance.)

Discussion

Prevalence estimates presented in this report varied widely among the ADDM Network sites, particularly by sex and by race/ethnicity. Although not the primary focus of this report, comparisons between the 2010 estimate and those from previous surveillance years indicated that ASD prevalence estimates from the ADDM Network continue to increase, with a growing proportion of children with ASD who have average or above average intellectual ability.

Variation in ASD Prevalence by Site, Sex, and Race/Ethnicity

Consistent with previous reports from the ADDM Network, findings from the 2010 surveillance year were marked by significant variation in ASD prevalence when stratified by geographic area, sex, race/ethnicity, and level of intellectual ability. Whereas the prevalence of ASD in the overall ADDM Network was one in 68 children, ASD prevalence estimates varied widely among the 11 ADDM Network communities, ranging from one in 175 children in Alabama to approximately one in 45 children in New Jersey. ASD prevalence also was 4–5 times higher among boys than girls, with a prevalence of one in 42 boys compared with one in 189 girls in these communities.

White children were approximately 30% more likely to be identified with ASD than black children and were almost 50% more likely to be identified with ASD than Hispanic children. When stratified by site, the white-to-black prevalence ratios were significant in five sites, and the white-to-Hispanic ratios were significant in eight sites. Black children were approximately 10% more likely to be identified with ASD than Hispanic children. The black-to-Hispanic prevalence ratio was significant in four sites as well as when combining data from all 11 sites; however, four sites reported a slightly higher prevalence among Hispanic children than black children; therefore, the

black-to-Hispanic prevalence ratio did not maintain the same direction among all sites.

Although stratifying the findings by intellectual ability reveals no clear patterns to explain the variation among sites in overall ASD prevalence estimates, comparisons among sites indicate that the range of estimates was greater for prevalence of ASD without co-occurring intellectual disability than for the prevalence of ASD with co-occurring intellectual disability. Additional study is needed. Similarly, although stratifying by intellectual ability and sex might not explain a great deal of the variation among sites in overall ASD prevalence estimates, the stratification underscores the substantial prevalence difference between boys and girls. Whereas 36% of girls with ASD were classified with intellectual disability compared with 30% of boys, the number of boys with ASD and intellectual disability was in itself greater than the number of girls with ASD overall.

Stratifying by sex and race/ethnicity, the male-to-female, white-to-black, and white-to-Hispanic prevalence ratios were all higher among children without intellectual disability than the corresponding ratios among children classified in the range of intellectual disability. The much higher prevalence of ASD without co-occurring intellectual disability among white children appears to explain much of the variation in ASD prevalence estimates between different racial/ethnic groups. Among white children, the prevalence of ASD without intellectual disability was nearly double the prevalence among either black children or Hispanic children (OR = 1.8, $p < 0.01$ for both comparisons). Conversely, the prevalence of ASD with co-occurring intellectual disability was similar among white children and Hispanic children but significantly higher among black children than among both of these groups. This suggests that in these seven sites, the significant white-to-black and white-to-Hispanic prevalence ratios were primarily driven by higher prevalence of ASD without intellectual disability among white children, and the significant black-to-Hispanic prevalence ratio was primarily driven by higher prevalence of ASD with co-occurring intellectual disability among black children.

No data are available to support possible etiologic implications for these differences, including the sex difference (20). Some of this variation might be attributable to diagnostic practices and other documentation of autism symptoms, although much of the variation has been linked to other extrinsic factors such as regional and socioeconomic disparities in access to services (21–24). Despite anecdotal reports that caregivers of children with ASD might be more likely to migrate toward larger metropolitan areas in expectation of greater access to quality services, ADDM Network data have not revealed any scientific evidence associating in-migration with higher prevalence estimates. The birth certificate linkage provides useful information about children with ASD who

were born in the state and lived within a given surveillance area during 2010; however, the data are nonetheless limited in that the level of out-migration is unknown. Thus, whether, or the extent to which, sites such as Alabama and New Jersey (which seem to have similar levels of in-migration of children with ASD) might have different numbers and percentages of children with ASD who were born within the surveillance area but subsequently moved out of the area before age 8 and were thus not identified by the ADDM site as meeting the ASD case definition cannot be discerned.

Consistent with results from previous ADDM Network surveillance years, sites with access both to health-care and education sources throughout most or all of the surveillance area reported higher prevalence estimates than sites relying primarily on data from health-care sources (Figure 1). Access to children's education records provides valuable information regarding the intellectual ability of children with ASD and the special education eligibility categories under which these children are served. Because socioeconomic variables can influence a child's access to diagnostic and treatment services, the evaluation both of health-care and education records provides an opportunity to identify service delivery patterns. Analyses of these patterns are a focus of further investigation and might affect policy and funding decisions surrounding the early identification and treatment of ASD. Although access to education records is considered an enhancement to ADDM surveillance and continues to provide evidence of more complete case ascertainment overall, prevalence by race/ethnicity still varies widely within and among these sites. Rigorous analytic designs using data from previous ADDM Network surveillance years have shown evidence that having access to education records might attenuate some of the racial/ethnic differences observed in prevalence estimates among ADDM sites (25).

In addition to variation in ASD prevalence, some characteristics of children with ASD varied by race/ethnicity, sex, and geographic area. As described previously, a positive association was found between ASD with co-occurring intellectual disability, initial diagnosis under the autistic disorder subtype, and younger age at ASD diagnosis. A positive association was also found between ASD without co-occurring intellectual disability, initial diagnosis under the Asperger disorder subtype, and older age at ASD diagnosis. Previous studies based on ADDM Network data have shown that children with co-occurring intellectual disability and initial diagnosis under the autistic disorder subtype have greater ASD symptoms and younger age at initial ASD diagnosis (26). It might follow that these associations would be similar by sex and race/ethnicity. However, although girls are more likely than boys to be classified in the range of intellectual disability, the median age of first known diagnosis did not differ by sex, nor was any

difference found in the distribution of subtypes when stratified by sex. Furthermore, black children and Hispanic children were more likely to be classified in the range of intellectual disability, more likely to have an initial diagnosis of autistic disorder, and less likely to have an initial diagnosis of Asperger disorder than white children. However, the median age of first known diagnosis for all subtypes combined was exactly the same among white children and black children and somewhat older among Hispanic children, with no significant differences between the mean ages for these three groups. The extent that this variation, or lack of variation when it would otherwise be expected, can be attributed to clinical practices such as choice of testing instruments or underrecognition of ASD symptoms in some racial/ethnic groups, cultural differences influencing the decision to seek services, or socioeconomic disparities in access to services is uncertain.

Variation in ASD Prevalence Over Time

The overall ASD prevalence estimate for the ADDM 2010 surveillance year exceeds that of all previous surveillance years, with the highest total number of children identified with ASD. The 2010 prevalence estimate for New Jersey was the highest ever reported for a single site in the ADDM Network. For the ADDM Network overall, the 2010 ASD prevalence estimate of 14.7 per 1,000 (95% CI = 14.3–15.1), or one in 68 children aged 8 years, was 29% higher than the preceding estimate of 11.3 per 1,000 (95% CI = 11.0–11.7), or one in 88 children aged 8 years in 2008. Additional comparisons between the 2010 estimate and those from previous surveillance years show a 64% increase from 2006 (9.0 per 1,000; one in 110) and a 123% increase from 2002 (6.6 per 1,000; one in 150). These comparisons are based on the total number of children identified with ASD and the total denominator of children aged 8 years as published for each surveillance year. They do not control for changes in geographic ascertainment areas among sites across surveillance years. Three ADDM sites reporting data for 2008 are not included in this report because they either did not participate in the 2010 ADDM surveillance year or were unable to provide the complete data needed to calculate the statistics for this report. Among sites that have participated in previous surveillance years, some similarities to earlier reports were observed, including the highest prevalence estimates coming from New Jersey and Utah and the lower estimates from Alabama. Additional analyses are underway to evaluate the detailed trends in ASD prevalence among ADDM sites during 2000–2010, controlling for factors that have changed in these communities over that decade such as the geographic area covered, the number and racial/ethnic distribution of children living in these communities, sociodemographic population characteristics, and other factors

that might influence the prevalence and characteristics of children with ASD in the population.

Over the last decade, the most notable change in characteristics of children identified with ASD through the ADDM Network is the growing number who have average or above average intellectual ability. This proportion has increased consistently over time from 32% in 2002, to 38% in 2006, to 46% in 2010, or almost half of children identified with ASD. Concurrently, the proportion of children with ASD and co-occurring intellectual disability has steadily decreased from 47% in 2002, to 41% in 2006, to 31% in 2010. This shift in distribution of intellectual ability among children identified with ASD during 2002–2010 indicates that a large proportion of the observed ASD prevalence increase can be attributed to children with average or above average intellectual ability (IQ >85). Several studies have shown similar patterns of increases in ASD prevalence among persons without intellectual disability (27), although which factors are driving this change is unclear.

Although intellectual ability is one characteristic of the population of children with ASD that has changed notably during 2000–2010, other characteristics have not varied over time (when combining data from all ADDM Network sites). The male-to-female prevalence ratio has remained relatively constant between 4:1 and 5:1, although this ratio varies more widely among individual sites. The median age of earliest known ASD diagnosis also has remained fairly constant at roughly 4.5 years, and since 2006 the distribution of diagnosed subtypes (autistic disorder, ASD/PDD, or Asperger disorder) has not changed in substantially. Prevalence ratios among different racial/ethnic groups continue to show significantly higher prevalence estimates for white children in many individual sites and collectively among all sites. The white-to-black and white-to-Hispanic prevalence ratios observed for surveillance year 2010 are very similar to those from the 2008 surveillance year. Finally, results from various program evaluation analyses, such as those evaluating the impact of missing records, did not appear to affect comparisons to previous ADDM Network findings. For example, the impact of missing records on prevalence estimates was estimated to be slightly less than that for previous surveillance years in the ADDM Network overall; however, the improved ability to locate children's records in 2010 affected findings for two individual sites rather substantially; underestimates due to missing records decreased by approximately ten percentage points for both Alabama and Maryland. It is uncertain to what extent, if any, this improved ability to locate children's records in Alabama and Maryland was directly linked to increased ASD prevalence estimates for those two sites compared with previous surveillance years.

Comparison of findings from the ADDM Network 2010 surveillance year with results from the CDC 2011–2012 National Survey of Children's Health (NSCH) on parent-reported ASD prevalence (5) revealed some similarities. Collectively, these two studies used three complementary data sources: health (ADDM), education (ADDM), and parent-report (NSCH). The report based on NSCH data estimated ASD prevalence of 2.0% among children aged 6–17 years in 2011–2012. Like the ADDM Network, NSCH also found a large increase in ASD prevalence compared with its previous estimate, which was based on 2007 data. The NSCH attributed this increase to children who received diagnoses at an older age, with a greater proportion judged as having mild (less severe) ASD according to parent report. Although not synonymous with ASD without co-occurring intellectual impairment, the increased number of children with milder ASD diagnosed at an older age in the NSCH study parallels the increasing percentage of children with normal intellectual ability and ASD identified in the ADDM Network.

Limitations

The findings in this report are subject to at least five limitations. First, although data in this report were obtained through the largest ongoing investigation of ASD prevalence in the United States, the surveillance sites were not selected to be representative of the entire United States, nor were they selected to be representative of the states in which they are located. Limitations regarding population size and racial/ethnic distribution among sites were considered when interpreting results. However, differences by sex and race/ethnicity reported in the overall findings might be confounded by site, and these patterns might not be universal among all sites.

Second, population denominators used for this report were based on the 2010 decennial census. Decennial population counts are considered to be more accurate than postcensal estimates, which are modeled for years following a decennial census and for intercensal estimates, which are modeled for years in between the two most recent decennial census counts (28). ADDM reports from nondecennial surveillance years such as 2002, 2006, and 2008 are likely influenced by greater error in the population denominators used for those previous surveillance years, which were based on postcensal estimates. For this reason and others described previously, comparisons with previous ADDM findings should be interpreted with caution. The method of adjusting census counts using school enrollment data, as described in the analytic methods section of this report, introduces another source of denominator error specific to the Arizona ADDM site.

Third, three of the nine sites with access to review children's education records did not receive permission to do so in all individual school districts within the site's overall surveillance area. In North Carolina, the impact of this could be addressed in the evaluation of missing records, and because the school districts participating in this study comprised the vast majority (>90%) of the overall population covered by the North Carolina ADDM site, prevalence estimates for North Carolina were similar whether including or excluding the geographic area encompassed by the nonparticipating school district. In Colorado, the participating school districts comprised a relatively small portion (<10%) of the overall population covered by the Colorado ADDM site. Consistent with the results from Colorado as reported for the 2008 surveillance year (11), prevalence estimates for the geographic area encompassed by the participating school districts were higher than for the overall surveillance area. In Alabama, where the participating school districts also comprised a relatively small portion (about 10%) of the overall population covered, prevalence estimates for the geographic areas encompassed by participating school districts were similar to those from the remainder of the overall surveillance area. For all three of these sites, the extent to which these comparisons reflect completeness of case ascertainment or geographic differences such as regional and socioeconomic disparities in access to services is uncertain. Study of this topic in much greater depth is planned.

Fourth, all results describing intellectual ability were restricted to sites that had these data for at least 70% of children with ASD, with the proportion ranging from 76% to 96%. Therefore, findings that address intellectual ability might not be generalizable to all ADDM sites or, among the seven sites reporting data on intellectual ability, to those children with ASD for whom these data were not available.

Finally, throughout this report, race and ethnicity are presented in very broad terms and should not be interpreted as generalizable to all persons within those categories. For example, children were categorized as Hispanic regardless of their racial group or geographic origin, which might differ among ADDM sites. Likewise, other attributes such as socioeconomic status might differ widely among children categorized in any single category of race/ethnicity.

Future Study Directions

ADDM Network investigators are compiling and analyzing data to evaluate trends in ASD prevalence throughout 2000 to 2010. This evaluation includes a study design that accounts for changes in the geographic areas covered by surveillance, the size and racial/ethnic distribution of underlying populations,

access to education records, community factors that might influence prevalence estimates, and characteristics of the population of children with ASD. Other topics of interest focus on socioeconomic indicators as well as perinatal risk factors such as timing of conception, weight gain during pregnancy, parental age, and interpregnancy interval. ADDM investigators have published several reports on these topics in recent years, and several more are in progress.

Beginning with the 2010 surveillance year, surveillance of ASD among children aged 4 years (the Early ADDM Network) began in several ADDM Network sites in addition to the core surveillance of ASD among children aged 8 years. These sites are collecting data for the second Early ADDM Network cohort, children aged 4 years in 2012. It is expected that surveillance of ASD among children aged 4 and 8 years will continue throughout the next ADDM Network funding cycle.

As described previously, the American Psychiatric Association published the DSM-5 in 2013 (1). The update included substantial revisions to the definition and diagnostic criteria for autism. The effect of those revisions is uncertain, including how they might affect certain persons or groups who might be more or less likely to meet the new diagnostic criteria. Although the ASD case definitions for this report were based solely on the DSM-IV-TR diagnostic criteria, which were the most current and gold-standard criteria during the 2010 surveillance period, in future years, ADDM Network surveillance will offer the opportunity to apply ASD surveillance case definitions based on both the DSM-IV-TR and DSM-5 diagnostic criteria. Thus, the ADDM Network is uniquely poised to evaluate the effect of this change. Data from the ADDM Network will make an important contribution to understanding how the new DSM-5 diagnostic criteria affect the prevalence and characteristics of children with ASD in defined populations.

A common finding throughout this report and previous ADDM reports is the apparent differences in prevalence and other characteristics among children with ASD when stratifying by race/ethnicity and socioeconomic indicators. Although etiologic implications might exist in these differences, no mechanism has yet to account for them. CDC is collaborating with partners to work with communities to reduce discrepancies in ASD identification and services. Most recently, CDC partnered with communities in Atlanta, Georgia; Baltimore, Maryland; and St. Louis, Missouri, to host community engagement events with key stakeholders to identify barriers to and opportunities for improvements in early identification and access to services for all children with ASD.

Early identification of young children with ASD can lead to earlier entry into intervention programs that support improved developmental outcomes. The practice of early screening and identification is encouraged for health-care professionals and

monitored by the nation's *Healthy People 2020* objectives. The American Academy of Pediatrics recommends developmental screening of all children at age 9, 18, and 24 or 30 months, and programs such as CDC's *Learn the Signs. Act Early.* campaign encourage greater attention to children's language and social development. Data from the ADDM Network will continue to be used to monitor progress toward the *Healthy People 2020* objective of increasing the proportion of children with ASD having a first evaluation by 36 months.

Conclusion

These findings from CDC's ADDM Network of 11 sites provide updated population-based estimates of the prevalence of ASD in multiple U.S. communities. The overall prevalence of ASD was 14.7 per 1,000 children aged 8 years who lived in these 11 sites during 2010. Significant differences in the prevalence and characteristics of children with ASD were noted in comparisons stratified by geographic area, sex, race/ethnicity, and other characteristics. Although ASD can be diagnosed by the time a child reaches age 2 years, the median age of first ASD diagnosis remains older than age 4 years in the ADDM Network communities. Although several factors associated with the prevalence, characteristics, and timing of ASD diagnosis were examined in this report, one of the primary challenges in interpreting ASD prevalence data are the lack of a standardized, widely accepted indicator of severity. The new DSM-5 definition of ASD includes recording procedures for specifying the presence of accompanying intellectual impairment and the severity of ASD; however, without easily accessible, validated tools to assess symptom severity, practitioners might find it challenging to adopt these requirements in a standard way.

Recommendations from the ADDM Network include enhancing strategies to address the need for 1) standardized, widely adopted measures to document ASD severity and functional limitations associated with ASD diagnosis; 2) improved recognition and documentation of symptoms of ASD, particularly among children without intellectual disability and children in all sex and racial/ethnic strata; and 3) decreasing the age when children are first evaluated for ASD, first receive an ASD diagnosis, and are first enrolled in community-based supports. Additional information is available at <http://www.cdc.gov/autism>.

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Surveillance Summaries

TABLE 1. Number* and percentage of children aged 8 years, by race/ethnicity and site — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian/Pacific Islander		American Indian/Alaska Native	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Alabama	University of Alabama at Birmingham	9 counties in northeast and central Alabama	21,833	12,970	(59.4)	6,752	(30.9)	1,661	(7.6)	334	(1.5)	116	(0.5)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix [†]	33,768	16,239	(48.1)	1,958	(5.8)	13,739	(40.7)	1,082	(3.2)	750	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	38,956	26,335	(67.6)	7,516	(19.3)	4,087	(10.5)	693	(1.8)	325	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties including metropolitan Denver	38,806	21,598	(55.7)	2,402	(6.2)	12,697	(32.7)	1,898	(4.9)	211	(0.5)
Georgia	CDC	5 counties including metropolitan Atlanta	48,529	15,875	(32.7)	20,772	(42.8)	8,601	(17.7)	3,165	(6.5)	116	(0.2)
Maryland	Johns Hopkins University	6 counties in suburban Baltimore	27,605	17,713	(64.2)	6,209	(22.5)	1,842	(6.7)	1,763	(6.4)	78	(0.3)
Missouri	Washington University in St. Louis	5 counties including metropolitan St. Louis	25,367	17,058	(67.2)	6,436	(25.4)	973	(3.8)	825	(3.3)	75	(0.3)
New Jersey	Rutgers New Jersey Medical School	4 counties including metropolitan Newark	31,723	13,724	(43.3)	7,336	(23.1)	8,937	(28.2)	1,668	(5.3)	58	(0.2)
North Carolina	The University of North Carolina at Chapel Hill	11 counties in central North Carolina	37,783	20,376	(53.9)	9,604	(25.4)	5,968	(15.8)	1,713	(4.5)	122	(0.3)
Utah	University of Utah	3 counties in northern Utah	23,756	17,347	(73.0)	555	(2.3)	4,697	(19.8)	997	(4.2)	160	(0.7)
Wisconsin	University of Wisconsin—Madison	10 counties in southeastern Wisconsin	35,623	21,898	(61.5)	6,460	(18.1)	5,721	(16.1)	1,377	(3.9)	167	(0.5)
Total	—	—	363,749	201,133	(55.3)	76,000	(20.9)	68,923	(18.9)	15,515	(4.3)	2,178	(0.6)

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's April 1, 2010, bridged-race population estimates.

[†] Denominator excludes school districts that were not included in the surveillance area, calculated from National Center on Education Statistics enrollment counts of third graders during the 2010–2011 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010

Site	Total	Total no. with ASD	Sex						Male-to-female prevalence ratio [§]
			Total [†]		Male		Female		
			Prevalence	(95% CI)	Prevalence	(95% CI)	Prevalence	(95% CI)	
Alabama	21,833	125	5.7	(4.8–6.8)	8.8	(7.3–10.8)	2.4	(1.7–3.6)	3.6
Arizona	33,768	530	15.7	(14.4–17.1)	25.1	(22.9–27.6)	6.0	(4.9–7.3)	4.2
Arkansas	38,956	605	15.5	(14.3–16.8)	24.9	(22.8–27.2)	5.8	(4.9–7.0)	4.3
Colorado	38,806	384	9.9	(9.0–10.9)	15.3	(13.6–17.1)	4.2	(3.4–5.3)	3.6
Georgia	48,529	754	15.5	(14.5–16.7)	25.4	(23.5–27.5)	5.5	(4.6–6.5)	4.6
Maryland	27,605	458	16.6	(15.1–18.2)	27.0	(24.4–29.9)	5.6	(4.5–7.1)	4.8
Missouri	25,367	359	14.2	(12.8–15.7)	23.1	(20.6–25.9)	5.0	(3.9–6.3)	4.7
New Jersey	31,723	696	21.9	(20.4–23.6)	36.0	(33.1–39.0)	7.5	(6.2–9.0)	4.8
North Carolina	37,783	655	17.3	(16.1–18.7)	28.7	(26.4–31.2)	5.6	(4.6–6.8)	5.1
Utah	23,756	442	18.6	(16.9–20.4)	29.2	(26.3–32.4)	7.4	(6.0–9.1)	4.0
Wisconsin	35,623	330	9.3	(8.3–10.3)	15.3	(13.6–17.2)	3.1	(2.4–4.0)	5.0
Total	363,749	5,338	14.7	(14.3–15.1)	23.7	(23.0–24.4)	5.3	(5.0–5.7)	4.5

See footnotes on page 16.

TABLE 2. (Continued) Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010

Site	Race/Ethnicity								Prevalence ratio		
	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian/Pacific Islander		White to black	White to Hispanic	Black to Hispanic
	Prevalence	(95% CI)	Prevalence	(95% CI)	Prevalence	(95% CI)	Prevalence	(95% CI)			
Alabama	6.2	(5.0–7.8)	5.3	(3.8–7.4)	1.2	(0.3–4.8)	3.0	(0.4–21.3)	1.2	5.2 [†]	4.4 [†]
Arizona	18.8	(16.8–21.1)	16.3	(11.6–23.1)	10.6	(9.0–12.5)	19.4	(12.7–29.8)	1.2	1.8**	1.5 [†]
Arkansas	17.6	(16.1–19.3)	11.0	(8.9–13.7)	9.1	(6.6–12.5)	11.5	(5.8–23.1)	1.6**	1.9**	1.2
Colorado	11.3	(10.0–12.9)	9.2	(6.0–13.9)	6.1	(4.9–7.7)	7.4	(4.4–12.5)	1.2	1.8**	1.5
Georgia	18.2	(16.2–20.4)	14.0	(12.5–15.7)	10.7	(8.7–13.1)	12.3	(9.0–16.9)	1.3**	1.7**	1.3 [†]
Maryland	16.8	(15.0–18.8)	15.5	(12.7–18.9)	9.8	(6.2–15.5)	11.9	(7.8–18.3)	1.1	1.7 [†]	1.6
Missouri	13.7	(12.1–15.6)	8.4	(6.4–11.0)	12.3	(7.0–21.7)	8.5	(4.0–17.8)	1.6**	1.1	0.7
New Jersey	22.7	(20.3–25.3)	17.9	(15.0–21.2)	21.4	(18.5–24.6)	21.0	(15.1–29.2)	1.3 [†]	1.1	0.8
North Carolina	18.9	(17.1–20.9)	15.7	(13.4–18.4)	9.7	(7.5–12.6)	18.7	(13.2–26.4)	1.2	1.9**	1.6**
Utah	19.1	(17.1–21.3)	9.0	(3.7–21.6)	16.6	(13.3–20.7)	5.0	(2.1–12.0)	2.1	1.1	0.5
Wisconsin	10.5	(9.2–11.9)	4.6	(3.2–6.6)	5.6	(4.0–7.9)	5.8	(2.9–11.6)	2.3**	1.9**	0.8
Total	15.8	(15.2–16.3)	12.3	(11.5–13.1)	10.8	(10.0–11.6)	12.3	(10.7–14.2)	1.3**	1.5**	1.1[†]

Abbreviation: CI = confidence interval.

* Per 1,000 children aged 8 years.

† Children for whom race/ethnicity was unknown are included in these prevalence estimates.

§ All sites identified significantly higher prevalence among boys than girls ($p < 0.01$).[†] Prevalence ratio significant at $p < 0.05$.** Prevalence ratio significant at $p < 0.01$.**TABLE 3. Number and percentage of children aged 8 years* with autism spectrum disorder who received their first comprehensive evaluation by a qualified professional at age ≤ 36 months, 37–48 months, or > 48 months and those with a mention of a developmental concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010**

Site	Youngest age when child received comprehensive evaluation						Mention of developmental concern by age 36 mos	
	≤ 36 mos		37–48 mos		> 48 mos		No.	(%)
	No.	(%)	No.	(%)	No.	(%)		
Alabama	56	(53)	21	(20)	28	(27)	99	(94)
Arizona	147	(36)	87	(21)	178	(43)	364	(88)
Arkansas	161	(35)	103	(22)	200	(43)	416	(90)
Colorado	119	(41)	51	(18)	120	(41)	252	(87)
Georgia	242	(45)	110	(20)	192	(35)	488	(90)
Maryland	163	(45)	59	(16)	138	(38)	319	(89)
Missouri	160	(54)	50	(17)	84	(29)	266	(91)
New Jersey	235	(41)	134	(23)	207	(36)	480	(83)
North Carolina	259	(59)	61	(14)	118	(27)	395	(90)
Utah	108	(33)	84	(26)	137	(42)	289	(88)
Wisconsin	136	(51)	48	(18)	82	(31)	245	(92)
Total	1,786	(44)	808	(20)	1,484	(36)	3,613	(89)

* Of 5,338 children identified with autism spectrum disorder, 4,078 were linked to an in-state birth certificate.

TABLE 4. Median age when autism spectrum disorder was first diagnosed, by subtype of autism spectrum disorder — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010

Site	ASD subtype											
	Autistic disorder			ASD/PDD			Asperger disorder			Any ASD subtype		
	Median age (mos)	No.	(%)	Median age (mos)	No.	(%)	Median age (mos)	No.	(%)	Median age (mos)	No.	(%)
Alabama	51	32	(35)	53	51	(55)	73	9	(10)	55	92	(74)
Arizona	58	224	(72)	55	66	(21)	79	20	(7)	59	310	(59)
Arkansas	55	220	(53)	63	128	(31)	75	71	(17)	61	419	(69)
Colorado	51	151	(65)	60	55	(24)	84	27	(12)	60	233	(61)
Georgia	45	261	(51)	49	208	(40)	72	48	(9)	49	517	(69)
Maryland	50	114	(31)	55	213	(59)	74	37	(10)	56	364	(80)
Missouri	59	57	(19)	39	223	(73)	75	25	(8)	46	305	(85)
New Jersey	40	126	(24)	45	326	(63)	79	69	(13)	48	521	(75)
North Carolina	37	235	(56)	51	152	(37)	76	30	(7)	46	417	(64)
Utah	50	128	(36)	52	173	(49)	68	54	(15)	53	355	(80)
Wisconsin	41	108	(37)	51	154	(53)	73	27	(9)	50	289	(88)
Total	48	1656	(43)	50	1749	(46)	74	417	(11)	53	3,822	(72)

Abbreviations: ASD = autism spectrum disorder; PDD = pervasive developmental disorder—not otherwise specified.

TABLE 5. Number and percentage of children aged 8 years identified with autism spectrum disorder with available special education records, by primary special education eligibility category* — Autism and Developmental Disabilities Monitoring Network, eight sites,† United States, 2010

Primary special education eligibility category	Arizona	Arkansas	Colorado	Georgia	Maryland	New Jersey	North Carolina	Utah
Autism (%)	60	60	30	64	69	54	66	48
Emotional disturbance (%)	6	2	3	2	3	1	2	3
Specific learning disability (%)	7	3	13	2	6	6	10	7
Speech or language impairment (%)	9	16	10	2	6	11	3	15
Hearing or visual impairment (%)	0	0	0	0	0	0	0	0
Health or physical disability [§] (%)	6	10	20	5	9	18	9	9
Multiple disabilities (%)	1	3	18	0	4	8	2	2
Intellectual disability (%)	9	6	8	4	1	3	4	3
Developmental delay /preschool (%)	1	0	0	22	2	0	4	13
Total no. of ASD cases	530	605	56[¶]	754	458	696	628[¶]	442
Total no. (%) of ASD cases with special education records	486 (92)	496 (82)	40 (71)	643 (85)	381 (83)	650 (93)	543 (87)	357 (81)

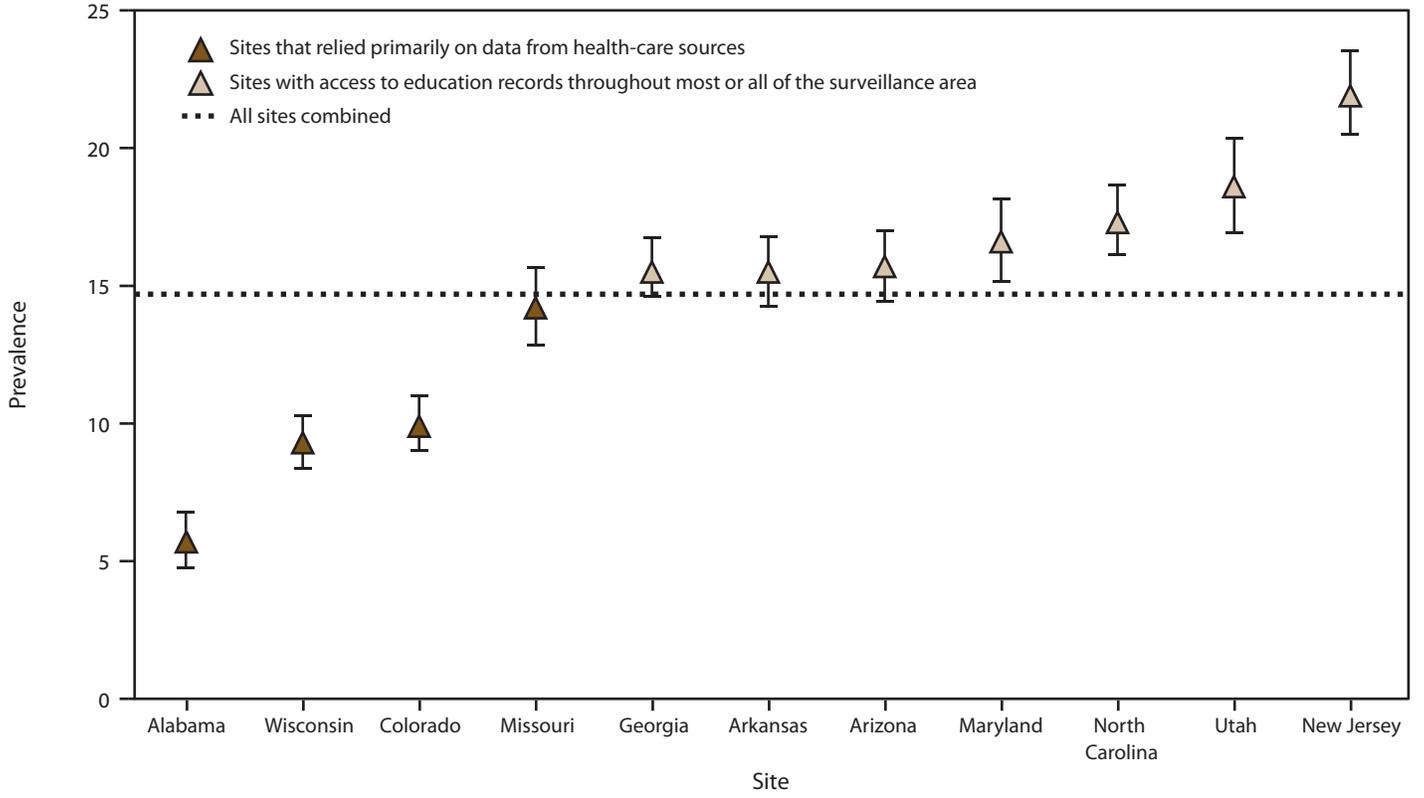
* Some state-specific categories were recoded or combined to match current U.S. Department of Education categories.

† Sites with available special education records.

§ In 2010, autism was a subcategory of physical disability in Colorado. The primary eligibility might have been documented as either autism or physical disability depending on the school district.

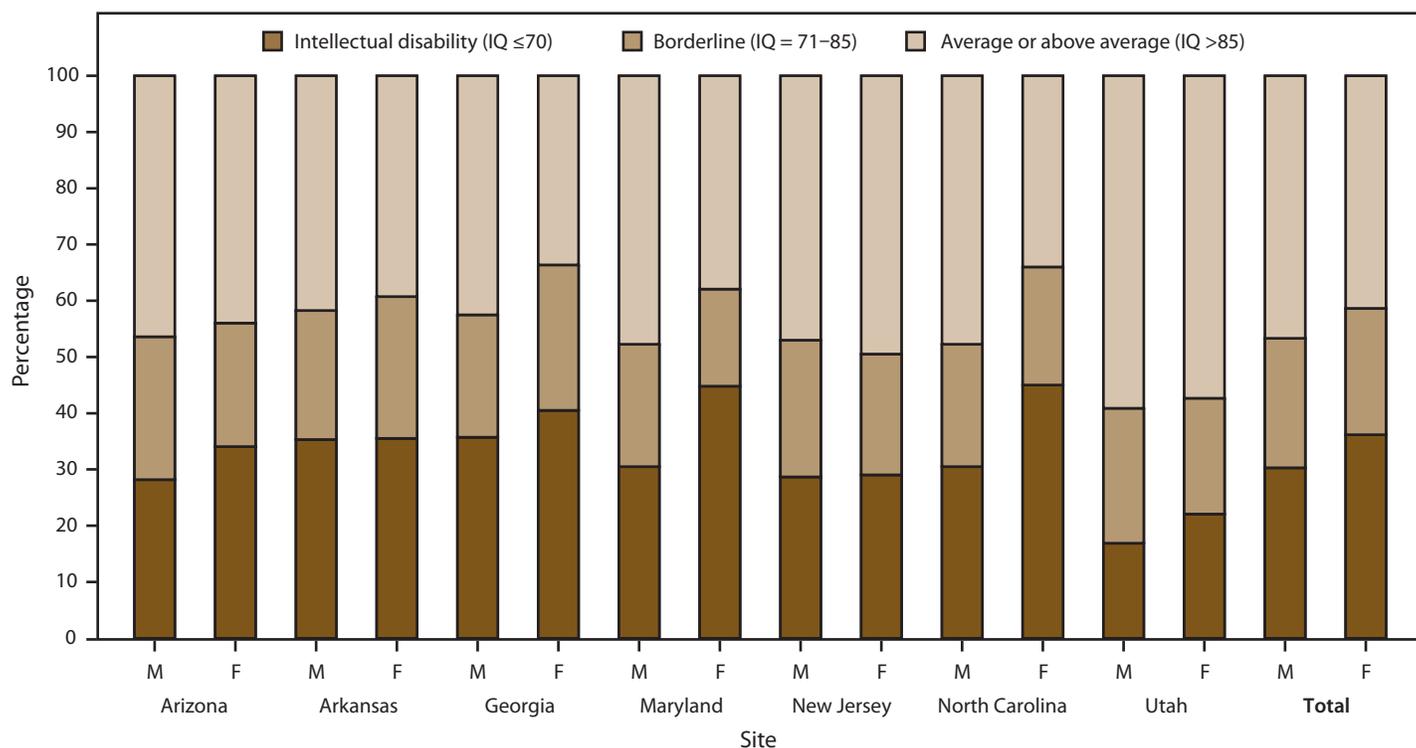
¶ Excludes children living in school districts where the surveillance site did not obtain permission to access educational records.

FIGURE 1. Estimated prevalence* of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010



* Per 1,000 children aged 8 years.

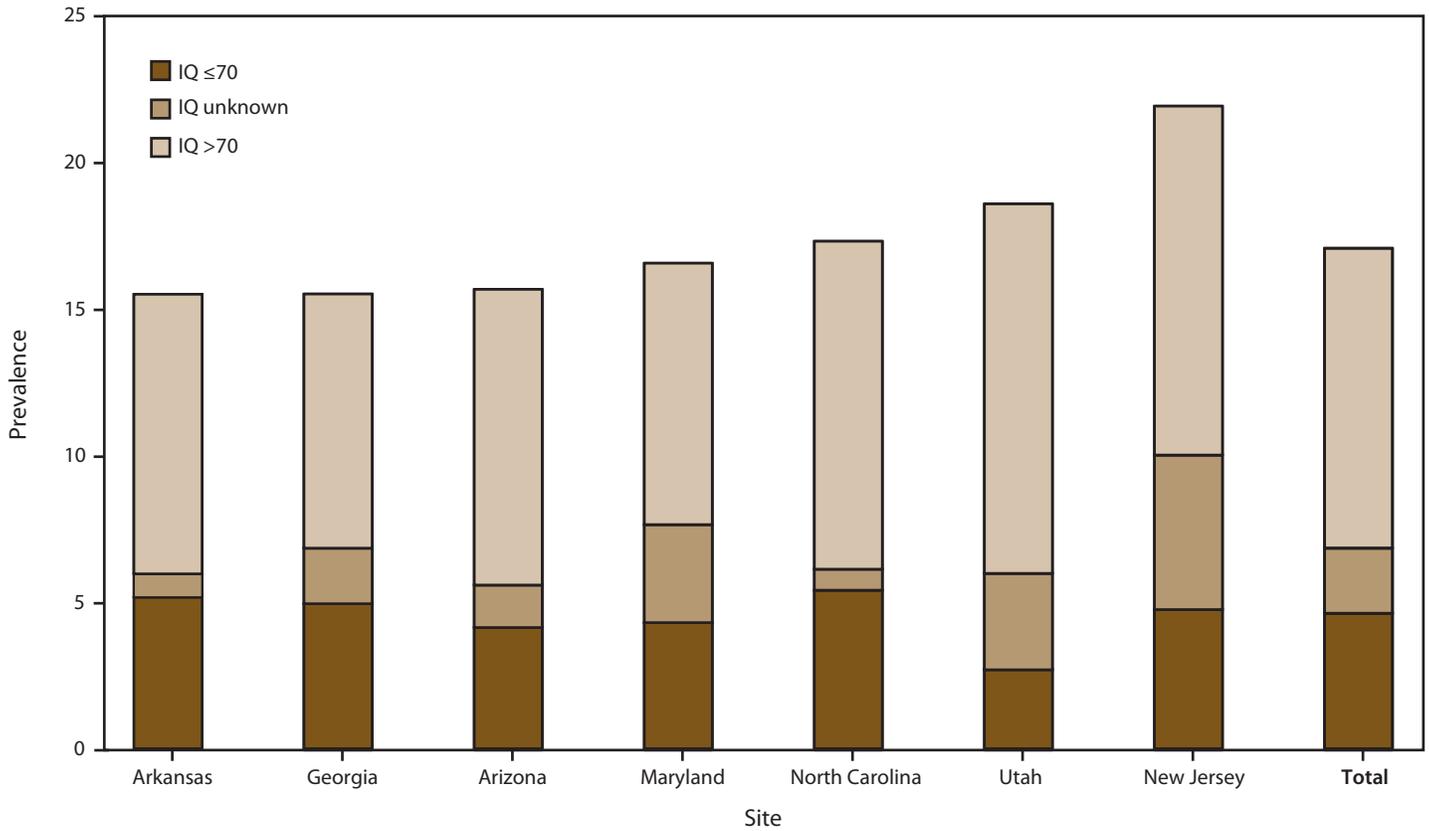
FIGURE 2. Most recent intelligence quotient score as of age 8 years among children with autism spectrum disorder for whom test data were available, by sex and site — Autism and Developmental Disabilities Monitoring Network, seven sites,* United States, 2010



Abbreviations: ASD = autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes sites that had intellectual ability data available for ≥70% of children who met the ASD case definition.

FIGURE 3. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by most recent intelligence quotient score and by site — Autism and Developmental Disabilities Monitoring Network, seven sites,† United States, 2010

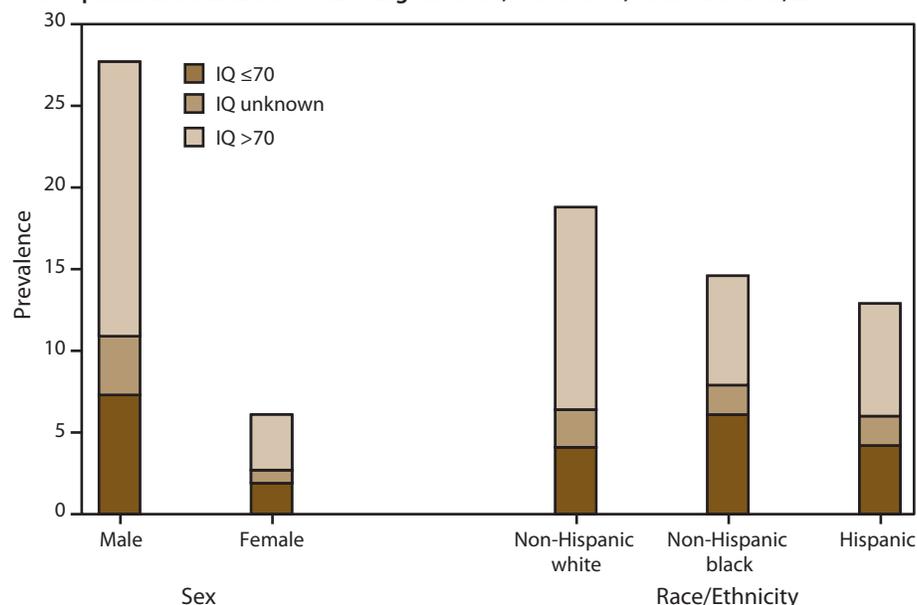


Abbreviations: ASD = autism spectrum disorder; IQ = intelligence quotient.

* Per 1,000 children aged 8 years.

† Includes sites that had intellectual ability data available for ≥70% of children who met the ASD case definition.

FIGURE 4. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by most recent intelligence quotient score and by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, seven sites,† United States, 2010

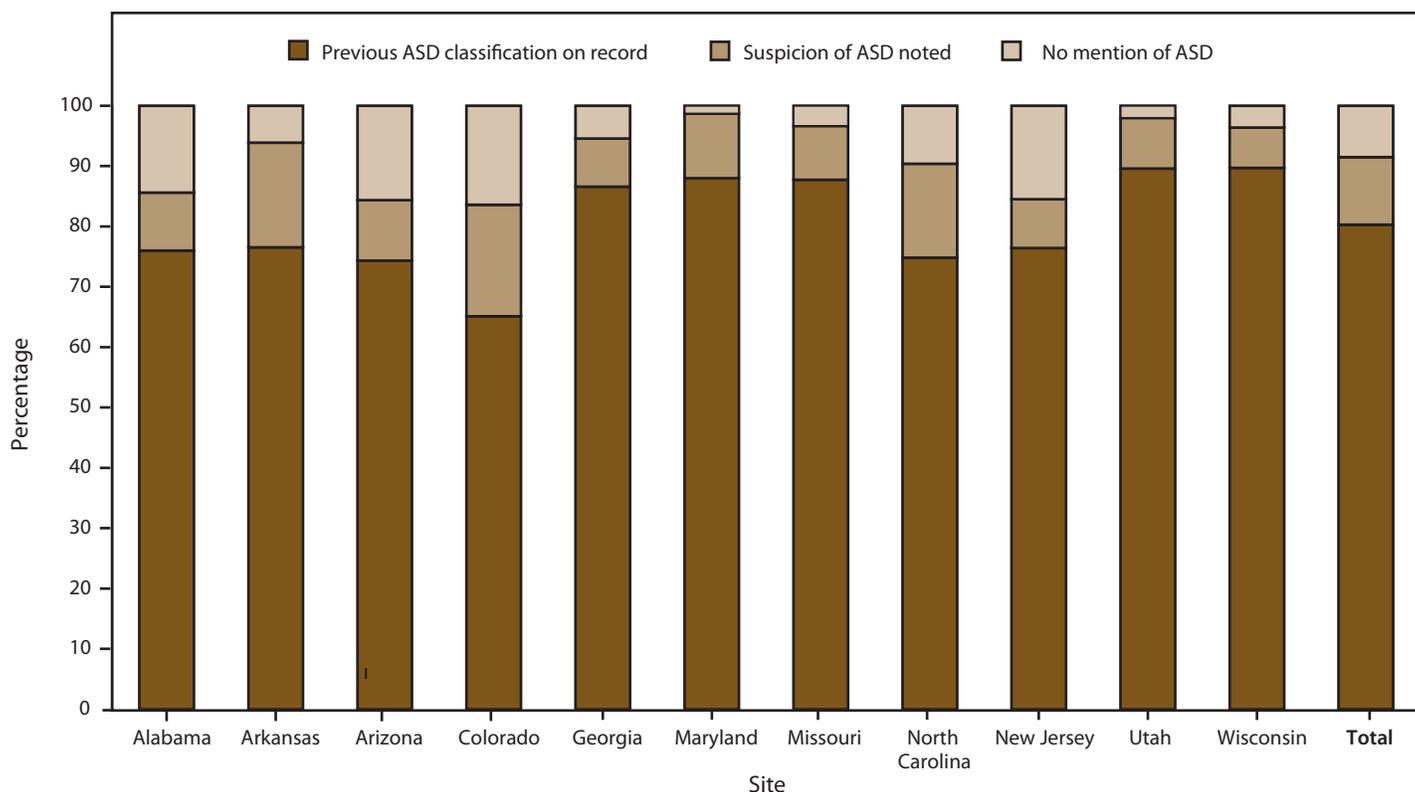


Abbreviation: IQ = intelligence quotient.

* Per 1,000 children aged 8 years.

† Includes sites that had intellectual ability data available for ≥70% of children who met the ASD case definition.

FIGURE 5. Percentage of children with autism spectrum disorder at age 8 years who had previous autism spectrum disorder classification on record, suspicion of the disorder noted, or no mention of the disorder, by site — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010



Abbreviation: ASD = autism spectrum disorder.

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