DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

July 5, 2018

Aaron Siri
Sire and Glimstad, LLP
200 Park Avenue
Seventeenth Floor
New York, New York 10166
Via email: aaron@sirillp.com

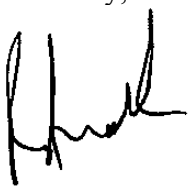
Dear Mr. Siri:

This letter is our final response to your Centers for Disease Control and Prevention and Agency for Toxic Substances and Disease Registry (CDC/ATSDR) Freedom of Information Act (FOIA) request of May 7, 2018, assigned #18-00687-FOIA, for "all drafts of the Morbidity and Mortality Weekly Report dated April 27, 2018, entitled 'Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014."

We located 385 pages of responsive records. After a careful review of these pages, no information was withheld from release.

If you need any further assistance or would like to discuss any aspect of the records provided please contact either our FOIA Requester Service Center at 770-488-6399 or our FOIA Public Liaison at 770-488-6277.

Sincerely,



Roger Andoh
CDC/ATSDR FOIA Officer
Office of the Chief Operating Officer
(770) 488-6399
Fax: (404) 235-1852

18-00687-FOIA

Prevalence of autism spectrum disorder among 8-year-old children — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Corresponding author: Jon Baio, EdS, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Jon Baio, EdS[1]

Lisa Wiggins, PhD[1]

Deborah L. Christensen, PhD[1]

Julie Daniels, PhD[2]

Zachary Warren, PhD[3]

Margaret Kurzius-Spencer, PhD[4]

Walter Zahorodny, PhD[5]

Cordelia Robinson Rosenberg, PhD[6]

Tiffany White, PhD[7]

Maureen Durkin, PhD[8]

Pamela Imm, MS[8]

Loizos Nikolaou, MPH[1,9]

Marshalyn Yeargin-Allsopp, MD[1]

Li-Ching Lee, PhD[10]

Rebecca Harrington, PhD[10]

Maya Lopez, MD[11]

Robert T. Fitzgerald, PhD[12]

Amy Hewitt, PhD[13]

Sydney Pettygrove, PhD[4]

John N. Constantino, MD[12]

Alison Vehorn, MS[3]

Josephine Shenouda, MS[5]

Jennifer Hall-Lande[13]

Kim Van Naarden Braun, PhD[1]

Nicole F. Dowling, PhD[1]

[1]*National Center on Birth Defects and Developmental Disabilities, CDC*

[2]*University of North Carolina, Chapel Hill*

[3]*Vanderbilt University Medical Center, Nashville, Tennessee*

[4]*University of Arizona, Tucson*

[5]*Rutgers University, Newark, New Jersey*

[6]*University of Colorado School of Medicine at the Anschutz Medical Campus*

[7]*Colorado Department of Public Health and Environment, Denver*

[8]*University of Wisconsin, Madison*

[9]*Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee*

[10]*Johns Hopkins University, Baltimore, Maryland*

[11]*University of Arkansas for Medical Sciences, Little Rock*

[12]*Washington University in St. Louis, Missouri*

[13]*University of Minnesota, Minneapolis*

Abstract

Problem/Condition: Autism spectrum disorder (ASD)

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of ASD among children aged eight years whose parents or guardians reside within multiple ADDM sites in the United States. ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder. This report provides updated ASD prevalence estimates for children aged eight years during the 2014 surveillance year, based on DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013 the American Psychiatric Association published the DSM-5, which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria may influence ADDM ASD prevalence estimates; therefore, many (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for

ASD consistent with the DSM-5 diagnostic criteria, which include the presence of an established DSM-IV-TR diagnosis of Autistic Disorder, PDD-NOS or Asperger Disorder. Results from a targeted comparison of these two case definitions are also reported.

Results: For the 2014 surveillance year, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (95% confidence interval: 16.4, 17.3) children aged eight years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged eight years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared to non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared to Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (IQ<=70), 25% were in the borderline range (IQ 71-85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by 36 months of age. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from CDC's ADDM Network, based on surveillance year 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among 8-year-olds in multiple communities in the United States. Because the ADDM 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 eight years in the United States. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by significant variation in ASD prevalence

when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar, but slightly lower estimate of ASD prevalence. The long-term impact of the revised diagnostic criteria remains in question, as the number of children aged eight years meeting DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis of Autistic Disorder, PDD-NOS or Asperger Disorder will decrease over time.

Public Health Action: The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates, and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged eight years in different communities throughout the United States, the need for enhanced public health strategies to deliver behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and non-genetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). The Centers for Disease Control and Prevention (CDC) began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2,3*). The first CDC study was based on an investigation in Brick Township, New Jersey (*2*), which identified similar characteristics but higher prevalence of ASD compared to other studies of that era. The second CDC study was conducted in metropolitan Atlanta, Georgia (*3*), which identified a lower prevalence of ASD compared to the Brick Township study but similar estimates compared to other prevalence studies of that era. 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 (*4,5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD may overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in the DSM-5 (*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a clearly defined surveillance case definition of ASD and using the same record-review methodology and behaviorally-defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged eight years in multiple US communities have risen from about one in 150 children in 2000-2002 to one in 68 in 2010-2012, more than doubling during this period (*6,7,8,9,10,11*). The observed increase in ASD prevalence substantiates a need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward Healthy People 2020 objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of about 4.5 male: 1 female with ASD from 2006 to 2012 (*9,10,11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000-2012

(range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006-2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9,10,11*). Although ASD prevalence estimates have historically been greater among white children compared to black children or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time due to larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared to the magnitude of increase in ASD prevalence among white children (*9*). Prior reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by about 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by about 50% in 2008, 2010 and 2012. ASD prevalence estimates from the ADDM Network have also varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). While ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change between 2002 and 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9,10*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (i.e., IQ <=70) has decreased gradually over time. During 2000-2002 nearly half of children with ASD had IQ scores in the range of intellectual disability (ID); during 2006-2008 this proportion was closer to 40%, and during 2010-2012 less than one third of children with ASD had IQ <=70. This trend was more pronounced for females as compared to males. The proportion of males with ASD and ID declined from approximately 40% during 2000-2008 to 30% during

2010-2012. The proportion of females with ASD and ID declined from about 60% during 2000-2002, to 45% during 2006-2008, and to 35% during 2010-2012.

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with the DSM-IV-TR diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including atypical autism); or Asperger Disorder. In the American Psychiatric Association's 2013 publication of its Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included several diagnostic subtypes, to Autism Spectrum Disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by severity levels. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Individuals diagnosed with ASD under DSM-5 must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors, and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input). According to the DSM-5 Workgroup on Neurodevelopmental Disorders, the need for new criteria for autism and related disorders was identified long before the Workgroup was convened in 2007 (*18*). Although the DSM-IV-TR criteria proved useful in identifying ASD in children aged five to eight years, they performed less well when used in the diagnosis of toddlers and preschool-aged children, adolescents, and young adults (*18*). Further, the DSM-IV-TR criteria were insufficient to accurately identify girls and women with autism and lacked the cultural sensitivity needed to identify cases in ethnic or racial minorities (*18*). The DSM-5 changes introduced a more focused diagnostic framework compared to that of DSM-IV-TR; however, DSM-5 states that any individual with a well-established DSM-IV-TR diagnosis of Autistic Disorder, Asperger Disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of Autism Spectrum Disorder. Previous studies suggest that

DSM-5 criteria for ASD may exclude some children who would have qualified for a DSM-IV-TR diagnosis but hadn't yet received one, particularly those who are very young and those without intellectual disability (*19,20,21,22,23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

The purpose of this report is to provide the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and to suggest targets for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include pediatric healthcare providers, school psychologists, educators, researchers, policymakers, and program administrators working to understand and address the needs of individuals with ASD and their families. These data can be used to help plan services, guide research into risk factors and effective interventions, and inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge which led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network. 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) (*24*). As feasible, the surveillance methods have remained consistent over time. Some minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the 8 ADDM Network surveillance 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 eight years because the baseline ASD prevalence study conducted by MADDSP suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals:1) to provide descriptive data on classification and functioning of the population of children with ASD; 2) to monitor the prevalence of ASD in different areas of the US; and 3) to understand the impact of ASD in US communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015 2018, during which time data are collected for children aged eight years during the 2014 and 2016 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. A total of six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee and Wisconsin) received permission to review education records in only some school districts within the overall geographic area covered for surveillance year 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total 8-year-old population. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites, 33% in Colorado and 26% in Wisconsin. In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and may request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged eight years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources is abstracted into a single composite record for each child.

In the second phase of surveillance, the abstracted composite evaluation files are de-identified and reviewed systematically by experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians) (*26*). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. Behavioral and diagnostic components of the DSM-IV-TR and DSM-5 ASD case definitions operationalized for ADDM

surveillance are outlined in Diagram 1. In practice, DSM-5 criteria automatically include children with a well-established DSM-IV-TR diagnosis of ASD, thus, the ADDM coding scheme similarly accommodated those with a previous DSM-IV-TR diagnosis in the DSM-5 case definition, regardless of whether documented symptoms independently met either the DSM-IV-TR or DSM-5 diagnostic criteria. The coding scheme allowed differentiation of children who met DSM-5 criteria on the basis of behavioral characteristics from those who met DSM-5 criteria solely through a previous DSM-IV-TR diagnosis.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase of ADDM, the accuracy of record review and abstraction is checked periodically. 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 (5). For the 2014 surveillance year, interrater agreement on case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined ($k = 0.77$), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined ($k = 0.84$). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*27*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged eight years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona, Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*28*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. Prevalence results are reported as the total number of children meeting the ASD case definition per 1,000 children aged eight 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 were obtained from an underlying Poisson distribution. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Pearson chi-square tests were also performed for testing 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 ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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 325,483 children aged eight years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged eight years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the total population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: 5; range: 3 [Arizona, Minnesota, Missouri, Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). Based on combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged eight years. Overall estimated prevalence of ASD was highest in New Jersey (29.3), Minnesota (24.0) and Maryland (20.0). Five sites reported prevalence estimates in the range of 13.1–14.1 per 1,000 (Arizona, Arkansas, Colorado, Missouri, Wisconsin), and three sites reported prevalence estimates ranging between 15.5–17.4 per 1,000 (Georgia, North Carolina, Tennessee).

Prevalence by Sex and Race/Ethnicity

Combining data from all 11 ADDM sites, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0 for all sites combined). ASD prevalence 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 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were

436 statistically significant in three sites (Arkansas, Missouri, Wisconsin), and the white-to-Hispanic
437 prevalence ratios were significant in seven sites. In nine sites the estimated prevalence of ASD was higher
438 among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was
439 significant in three of these nine sites. In New Jersey there was almost no difference in ASD prevalence
440 estimates among white, black and Hispanic children. Estimates for Asian/Pacific Islander children ranged
441 from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey), with notably wide CIs.

442 **Intellectual Ability**

443 Data on intellectual ability are reported only for nine sites (Arizona, Arkansas, Colorado,
444 Georgia, Maryland, Minnesota, New Jersey, North Carolina, Tennessee) having information available for
445 at least 70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North
446 Carolina]). The median age of children's most recent IQ tests, on which the following results are based,
447 was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual
448 ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or
449 race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714
450 children, 31% were classified in the range of intellectual disability (IQ $\leq$70), 25% were in the borderline
451 range (IQ = 71–85), and 44% had IQ >85. The proportion of children classified in the range of intellectual
452 disability ranged from 26.7% in Arizona to 39.4% in Tennessee.

453 Among children identified with ASD, the distribution by intellectual ability varied by sex, with
454 girls more likely than boys to have IQ $\leq$70, and boys more likely than girls to have IQ >85 (Figure 1). In
455 these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements
456 indicating intellectual disability compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4,
457 $p<0.01$), though among individual sites this proportion differed significantly in only one (Georgia, OR =
458 1.6, $p<0.05$). The proportion of children with ASD with borderline intellectual ability (IQ = 71-85) did
459 not differ by sex, whereas a significantly higher proportion of males (45%) compared to females (40%)
460 had IQ >85, i.e., average or above average intellectual ability (OR = 1.2, $p<0.05$).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of intellectual disability, compared with 35% of Hispanic children and 22% of white children. The proportion of blacks and whites with intellectual disability differed significantly in all nine sites and when combining their data (OR = 2.9, p<0.01). The proportion of Hispanics and whites with intellectual disability differed significantly when combining data from all nine sites (OR = 1.9, p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8, p = 0.09), North Carolina (OR = 1.8, p = 0.07) and Tennessee (OR = 2.1, p = 0.10). The proportion of children with borderline intellectual ability (IQ = 71-85) did not differ by race/ethnicity in any of these nine sites or when combining their data; however, when combining data from these nine sites the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR = 3.4, p<0.01) or Hispanic (36%, OR = 2.2, p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by 36 months of age (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV, DSM-5 or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR = 1.4, p<0.01). When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9, p=0.09) and 76% of Hispanic children (OR = 1.3, p<0.01); a significant difference was also found when comparing

the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5, $p<0.01$).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

Sites with access to education records collected information about the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from 40% in Wisconsin to 74% in North Carolina. Most other sites noted over half of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (43%) and New Jersey (48%). 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 nine years in many US states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of intellectual disability.

Sensitivity Analyses Evaluating Impact of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota

and Wisconsin), between 1% to 5% higher in five sites (Arkansas, Colorado, Missouri, New Jersey and North Carolina), about 8% higher in Maryland, and nearly 20% higher in Tennessee, where investigators did not obtain permission to review children's records in one of the fourteen school districts comprising the eleven-county surveillance area.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, about 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were requested for surveillance of five distinct conditions (autism, cerebral palsy, intellectual disability, hearing loss, vision impairment), about 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of DSM-IV-TR vs. DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged eight years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was about 4% higher based on the historical DSM-IV-TR case definition compared to the new DSM-5 case definition. In six of the 11 ADDM sites, DSM-5 case counts were within about 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-

539 IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%) and Colorado (14%). Kappa
540 statistics indicated strong agreement between DSM-IV-TR and DSM-5 case status among children
541 abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa
542 for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).
543 Stratified analysis of DSM-IV:DSM-5 ratios were very similar compared to the overall sample
544 (Table 9). DSM-5 estimates were about 3% lower than DSM-IV-TR counts for males, and about 6%
545 lower for females (kappa = 0.85 for both). Case counts were about 3% lower among white and black
546 children on DSM-5 compared to DSM-IV, 5% lower among Asian children, and 8% lower among
547 Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less
548 likely to meet DSM-5 than DSM-IV, whereas those evaluated by age 4 years were 6% less likely to meet
549 DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV.
550 Children with documentation of eligibility for autism special education services, as well as those with a
551 documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV.
552 Slightly over 3% of children whose earliest ASD diagnosis was Autistic Disorder met DSM-5 criteria but
553 not DSM-IV, compared to slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS
554 and 5% of those whose earliest diagnosis was Asperger Disorder. Children with no previous ASD
555 classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR.
556 Combining data from all 11 sites, children with IQ scores in the range of intellectual disability were 3%
557 less likely to meet DSM-5 criteria compared to DSM-IV-TR (kappa = 0.89), those with IQ scores in the
558 borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with
559 average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared to
560 DSM-IV-TR (kappa = 0.86).

561 **Discussion**

562 **Comparison to earlier ADDM surveillance years**

563 The overall ASD prevalence estimate of 16.8 per 1,000 children aged eight years in 2014 is
564 higher than previously reported estimates from the ADDM Network. An ASD case definition based on

565 DSM-IV-TR criteria was used during the entire period of ADDM surveillance from 2000 to 2014, as were
566 comparable study operations and procedures, although the geographic areas under surveillance have
567 varied over time. During this period ADDM ASD prevalence estimates increased from 6.7 to 16.8 per
568 1,000 children aged eight years, an increase of approximately 150%.

569 Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic
570 area, all six showed an increase in ASD prevalence estimates between 2012 and 2014, with a nearly 10%
571 prevalence increase in Georgia and Maryland, 19% in New Jersey, 23% in Missouri, 29% in Colorado
572 and 31% in Wisconsin. The ASD prevalence estimate from New Jersey continues to be one of the highest
573 reported by a population-based surveillance system. The two sites with the greatest relative increase in
574 prevalence are remarkable in that both gained access to children's education records in additional
575 geographic areas for 2014. Colorado was granted access to review children's education records in one
576 additional county for the 2014 surveillance year (representing nearly 20% of the population aged eight
577 years within the overall Colorado surveillance area), and Wisconsin was granted access to review
578 education records in parts of 2 of the 10 counties comprising their 2014 surveillance area. Although this
579 represented only 26% of the population aged eight years within the overall Wisconsin surveillance area,
580 2014 marked the first time Wisconsin has included education data sources. Comparisons to earlier
581 ADDM Network surveillance results should be interpreted cautiously due to changing composition of
582 sites and geographic coverage over time. For example, three ADDM Network sites completing both the
583 2012 and 2014 surveillance years (Arizona, Arkansas and North Carolina) covered a different geographic
584 area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in
585 collaboration with the ADDM Network.

586 Some characteristics of children with ASD were similar in 2014 compared to earlier surveillance
587 years. The median age of earliest known ASD diagnosis remained close to 53 months in prior surveillance
588 years and was 52 months in 2014. The proportion of children who received a comprehensive
589 developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006-2012. There
590 were a number of differences in the characteristics of the population of children with ASD in 2014, as

591 well. The male:female prevalence ratio decreased from 4.5:1 during 2002-2012 to 4:1 in 2014, driven by
592 a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease
593 in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002.
594 Among sites covering a population of at least 20,000 children aged eight years, New Jersey reported no
595 significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete
596 ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates
597 from combined ADDM sites have been about 20-30% higher among white children as compared to black
598 children. For surveillance year 2014 the difference was only 7%, the lowest difference ever observed for
599 the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among
600 Hispanic children in 2002 and 2006, and about 50% higher in 2008, 2010 and 2012, whereas for 2014 the
601 difference was only 22%. Data from a previously reported comparison of ADDM Network ASD
602 prevalence estimates from 2002, 2006 and 2008 (9) suggested greater increases in ASD prevalence
603 among black and Hispanic children compared to those among white children. Reductions in disparities in
604 ASD prevalence for black and Hispanic children may be due, in part, to more effective outreach directed
605 to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was
606 similar in 2012 and 2014 at about 30% of males and 35% of females. These proportions were markedly
607 lower than those reported in prior surveillance years.

608 **Comparison among ADDM 2014 sites**

609 Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely
610 among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the
611 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close
612 range, from 13.1 to 14.1 per 1,000 children, New Jersey's prevalence estimate of 29.4 per 1,000 children
613 was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota,
614 North Carolina) reported prevalence estimates that were significantly greater than those from any of the
615 five sites in the 13.1-14.1 per 1,000 range. It should be noted that two of the sites with prevalence
616 estimates of 20.0 per 1,000 or higher, Maryland and Minnesota, conducted surveillance among a total

617 population of less than 10,000 children aged eight years. Concentrating surveillance efforts in smaller
618 geographic areas, especially those in close proximity to diagnostic centers and those covering school
619 districts with advanced staff training and programs to support children with ASD, may yield higher
620 prevalence estimates compared to those from sites covering populations of more than 20,000 8-year-olds.
621 Those sites with limited or no access to education data sources (Colorado, Missouri, and Wisconsin) had
622 prevalence estimates near the lower range among all sites. In addition to variation among sites in reported
623 ASD prevalence, wide variation among sites is noted on the characteristics of children identified with
624 ASD, including the proportion of children who received a comprehensive developmental evaluation by
625 age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability.
626 Some of this variation might be attributable to regional differences in diagnostic practices and other
627 documentation of autism symptoms, although previous reports based on ADDM data have linked much of
628 the variation to other extrinsic factors such as regional and socioeconomic disparities in access to services
629 (*13*,*14*).

630 **Comparison between DSM-IV-TR and DSM-5 case definitions**

631 Agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably
632 close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype or level of
633 intellectual ability. Overall, ASD prevalence estimates based on the new DSM-5 case definition were very
634 similar in magnitude but slightly lower than those based on the historical DSM-IV-TR case definition.
635 Three of the 11 ADDM sites actually had slightly higher case counts using the DSM-5 framework
636 compared to the DSM-IV. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared to all
637 other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD
638 classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby
639 children with a documented DSM-IV-TR diagnosis of ASD automatically qualify as DSM-5 cases
640 regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have
641 influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases
642 would meet DSM-5 case criteria based solely on the presence of a documented DSM-IV-TR diagnosis.

643 This element of the DSM-5 case definition will carry less weight moving forward, as fewer children aged
644 eight years in health and education settings will have been diagnosed with ASD under the DSM-IV-TR
645 criteria. It is also possible that individuals who conduct developmental evaluations of children in health
646 and education settings will increasingly describe behavioral characteristics using language more
647 consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of
648 ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that
649 incorporates an existing DSM-IV-TR diagnosis reflect the actual patterns of diagnosis and services for
650 children in 2014, since children diagnosed under DSM-IV-TR did not lose their diagnosis when the
651 updated DSM-5 criteria were published. Using this approach, agreement in the application of the DSM-
652 IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex,
653 race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. In the coming years
654 prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and may
655 exclude some individuals who would have met DSM-IV-TR criteria for Autistic Disorder, PDD-NOS or
656 Asperger Disorder, while at the same time including individuals who do not meet those criteria but who
657 do meet the specific DSM-5 behavioral criteria.

658 **Comparison to national prevalence estimates**

659 The ADDM Network is the only ASD surveillance system in the United States providing robust
660 prevalence estimates for specific areas of the country, including those for subgroups defined by sex and
661 race/ethnicity, providing information about geographical variation that can be used to evaluate policies
662 and diagnostic practices that may affect ASD prevalence. It is also the only comprehensive surveillance
663 system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on
664 parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge
665 of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health,
666 The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH)
667 report estimates of ASD prevalence based on caregiver report of being told by a doctor or other healthcare
668 provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have

669 ASD. The most recent publication from NHIS showed that 27.6 per 1,000 children aged 3-17 years had
670 ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4,
671 respectively) (*29*). An estimate of 20.0 per 1,000 children aged 6-17 years was reported from the 2011-
672 2012 NSCH (*30*). The study samples for the two phone surveys are substantially smaller than the ADDM
673 Network; however, they were intended to be nationally representative, whereas the ADDM Network
674 surveillance areas were selected through a competitive process and, although large and diverse, were not
675 intended to be nationally representative. Geographic differences in ASD prevalence have been observed
676 in both the ADDM Network and national surveys, as have differences in ASD prevalence by age
677 (*6,7,8,9,10,11,29,30*). All three prevalence estimation systems are impacted by regional and policy-driven
678 differences in the availability and utilization of evaluation and diagnostic services for children with
679 developmental concerns. Phone surveys are likely more sensitive in identifying children who received a
680 preliminary or confirmed diagnosis of ASD but are not receiving services (for example, special education
681 services). The ADDM Network method based on analysis of information contained in existing health and
682 education records enables the collection of detailed, case-specific information reflecting children's
683 behavioral, developmental and functional characteristics, which are not available from the national phone
684 surveys. This detailed case level information may provide insight into temporal changes in the expression
685 of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic
686 criteria.

687 **Limitations**

688 The findings in this report are subject to a number of limitations. Foremost, ADDM Network sites
689 were not selected to represent the United States as a whole, nor were the geographic areas within each
690 ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is
691 monitored statewide). Although a combined estimate is reported for the Network as a whole to inform
692 stakeholders and interpret the findings from individual surveillance years in a more general context, data
693 reported by the ADDM Network should not be interpreted to represent a national estimate of the number
694 and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation -

among sites, between specific groups within sites, and across time - in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

When considering data on the characteristics of children with ASD, it is important to acknowledge limitations of information available in children's health and education records. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. It is possible that some children had earlier diagnoses that were not recorded in these records. Likewise, it is possible that some descriptions of historical diagnoses, i.e., those not made by the evaluating examiner, could be subject to recall error on the part of a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously due to myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted prior to age 6 years.

Because comparisons to the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3,6,7,8,9,10,11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to

offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

When the ADDM methodology was originally developed, estimating ASD prevalence among children aged eight years was determined to represent the peak prevalence, based on estimates for multiple ages in metropolitan Atlanta, GA in 1996 (*3*). Estimating prevalence among 8-year-olds requires quality data from both health and educational agencies and likely captures most children whose adaptive performance is impacted by ASD. However, because prevalence estimation takes considerable time and effort, reporting of estimates lags behind the surveillance year by 3-4 years. Thus, opportunities for policy or programmatic enhancements to impact key health indicators also lag. Focusing on younger cohorts may allow earlier assessment of systematic changes (e.g., policies, insurance, and programs) that impact younger children, rather than waiting until cohorts impacted by these changes reach eight years of age. Surveillance of ASD in older populations is also important, but may require different methodological approaches.

CDC's "Learn the Signs. Act Early." (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, healthcare professionals and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*31*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at 18 and 24 months of age. Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD are evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation may become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged four years (*33*), may

746 inform how policy initiatives such as screening recommendations and other social determinants of health
747 may impact the prevalence of ASD and characteristics of children with ASD, including the age at which
748 most children receive an ASD diagnosis.

749 **Conclusion**

750 The latest findings from the ADDM Network provide evidence that the prevalence of ASD has
751 increased compared to previously reported ADDM estimates, and continues to vary among certain
752 racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 (children
753 aged eight years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of
754 ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is
755 an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier;
756 to determine possible risk factors; and to address the growing behavioral, educational, residential and
757 occupational needs of this population.

758 Contrary to some predictions, the redefinition of ASD provided by the DSM-5 may have had a
759 relatively small impact on the overall ASD estimate provided by the ADDM Network. This may be due to
760 the carryover effect of including all DSM-IV-TR-diagnosed cases in the DSM-5 count. Over time, the
761 estimate may be influenced (downward) by a diminishing number of individuals who meet the DSM-5
762 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, and influenced (upward)
763 by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of
764 ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic
765 features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will
766 continue to evaluate these similarities and differences in much greater depth, and will examine at least
767 one more cohort of children aged eight years to expand this comparison. Over time, the ADDM Network
768 will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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Tables & Figures for MMWR Surveillance Summaries:
Prevalence of autism spectrum disorder among 8-year-old children — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

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, 2014

Site	Site Institution	Surveillance Area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	%	No.	%	No.	%	No.	%	No.	%
Arizona	Univ of Arizona	† Part of 1 county in metropolitan Phoenix	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	Univ of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Dept of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	Centers for Disease Control and Prevention	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins Univ	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	† Parts of 2 counties in Minneapolis-St. Paul	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	Univ of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	Univ of Wisconsin – Madison	10 counties in south-eastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All Sites Combined			**325,483**	167,048	(51.3)	72,751	(22.4)	67,181	(20.6)	16,596	(5.1)	1,907	(0.6)

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics (NCHS) Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder (ASD) per 1,000 children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014

Site	Total pop.	Total no. with ASD	Overall†		Sex				Male-to-Female prevalence ratio§
					Males		Females		
			Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	
Arizona	24,952	349	14.0	(12.6 - 15.5)	21.1	(18.7 - 23.8)	6.6	(5.3 - 8.2)	3.2
Arkansas	39,992	522	13.1	(12.0 - 14.2)	20.5	(18.6 - 22.5)	5.4	(4.5 - 6.5)	3.8
Colorado	41,128	572	13.9	(12.8 - 15.1)	21.8	(19.9 - 23.9)	5.5	(4.6 - 6.7)	3.9
Georgia	51,161	869	17.0	(15.9 - 18.2)	27.9	(25.9 - 30.0)	5.7	(4.8 - 6.7)	4.9
Maryland	9,955	199	20.0	(17.4 - 23.0)	32.7	(28.1 - 38.2)	7.2	(5.2 - 10.0)	4.5
Minnesota	9,767	234	24.0	(21.1 - 27.2)	39.0	(33.8 - 44.9)	8.5	(6.3 - 11.6)	4.6
Missouri	25,333	356	14.1	(12.7 - 15.6)	22.2	(19.8 - 25.0)	5.6	(4.4 - 7.0)	4.0
New Jersey	32,935	964	29.3	(27.5 - 31.2)	45.5	(42.4 - 48.9)	12.3	(10.7 - 14.1)	3.7
North Carolina	30,283	527	17.4	(16.0 - 19.0)	28.0	(25.5 - 30.8)	6.5	(5.3 - 7.9)	4.3
Tennessee	24,940	387	15.5	(14.0 - 17.1)	25.3	(22.6 - 28.2)	5.4	(4.2 - 6.9)	4.7
Wisconsin	35,037	494	14.1	(12.9 - 15.4)	21.4	(19.4 - 23.7)	6.4	(5.3 - 7.7)	3.4
All Sites Combined	325,483	5,473	16.8	(16.4 - 17.3)	26.6	(25.8 - 27.4)	6.6	(6.2 - 7.0)	4.0

Abbreviations: CI = confidence interval.

* Per 1,000 children aged 8 years.

† All children are included in the total regardless of race or ethnicity.

§ All sites identified significantly higher prevalence among males compared to females ($p<0.01$).

TABLE 3. Estimated prevalence* of autism spectrum disorder (ASD) per 1,000 children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014

Site	Race/ethnicity								Prevalence Ratio		
	White		Black		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			
Arizona	16.2	(14.1 - 18.6)	19.5	(13.3 - 28.6)	10.3	(8.5 - 12.5)	10.3	(5.5 - 19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6 - 15.5)	10.4	(8.3 - 12.9)	8.4	(6.2 - 11.3)	14.2	(8.1 - 25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5 - 16.7)	11.4	(8.0 - 16.2)	10.6	(9.0 - 12.5)	7.9	(4.8 - 12.9)	1.3	1.4†	1.1
Georgia	17.9	(16.0 - 20.2)	17.1	(15.4 - 18.9)	12.6	(10.6 - 15.0)	11.9	(8.9 - 16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0 - 23.8)	16.5	(12.7 - 21.4)	15.7	(9.1 - 27.0)	13.9	(7.5 - 25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8 - 29.8)	27.2	(21.7 - 34.2)	20.9	(14.7 - 29.7)	17.8	(12.3 - 25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4 - 16.0)	10.8	(8.6 - 13.6)	4.9	(2.2 - 10.9)	10.7	(5.8 - 20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4 - 33.3)	26.8	(23.3 - 30.9)	29.3	(26.2 - 32.9)	19.2	(13.9 - 26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5 - 20.9)	16.1	(13.5 - 19.2)	11.9	(9.3 - 15.2)	19.1	(13.7 - 26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3 - 18.2)	12.5	(9.7 - 16.0)	10.5	(7.6 - 14.7)	12.5	(6.7 - 23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6 - 17.0)	11.3	(8.9 - 14.2)	12.5	(10.0 - 15.6)	10.2	(6.1 - 16.9)	1.3†	1.2	0.9
All Sites Combined	17.2	(16.5 - 17.8)	16.0	(15.1 - 16.9)	14.0	(13.1 - 14.9)	13.5	(11.8 - 15.4)	1.1†	1.2§	1.1§

Abbreviations: CI = confidence interval

* Per 1,000 children aged 8 years.

† Prevalence ratio significant at p<0.05.

§ Prevalence ratio significant at p<0.01.

TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder (ASD) who received a comprehensive evaluation by a qualified professional before age 3 years, 4 years, or later – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Earliest age when child received a comprehensive evaluation						Mention of general delay	
	<=36mos		37-48mos		>48mos		<=36mos	
	No	%	No	%	No	%	No	%
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All Sites Combined	1737	(41.9)	790	(19.0)	1620	(39.1)	3525	(85.0)

*Includes children identified with ASD who were linked to an in-state birth certificate

TABLE 5. Median age (in months) of earliest known autism spectrum disorder (ASD) diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic Disorder			ASD/PDD			Asperger Disorder			Any Specified ASD Diagnosis		
	Median Age	No.	%	Median Age	No.	%	Median Age	No.	%	Median Age	No.	%
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All Sites Combined	46	1810	(47.7)	56	1746	(46.0)	67	238	(6.3)	52	3794	(69.3)

Abbreviation: PDD = pervasive developmental disorder - not otherwise specified.

TABLE 6. Number and percentage of children aged 8 years identified with autism spectrum disorder (ASD) for whom special education data were available, by primary special education eligibility category* – Autism and Developmental Disabilities Monitoring Network, 10 sites with access to education records, United States, 2014

	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	N. Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with Special Education records	311 (89.1)	455† (87.2)†	148§ (NR)¶	752 (86.5)	159 (79.9)	201 (85.9)	851 (88.3)	444 (84.3)	293† (75.7)†	167§ (NR)¶
Primary Exceptionality										
Autism (%)	65.3	65.1	43.2	57.8	66.0	65.2	47.7	74.3	68.9	39.5
Emotional Disturbance (%)	2.9	0.9	7.4	2.0	2.5	4.5	1.5	2.5	0.3	5.4
Specific Learning Disability (%)	6.8	3.1	14.2	4.0	11.9	1.0	8.0	2.7	0.7	2.4
Speech or Language Impairment (%)	5.5	10.3	10.1	2.4	3.8	5.0	13.6	3.6	10.9	19.2
Hearing or Visual Impairment (%)	0.0	0.2	0.0	0.1	0.0	1.0	0.6	0.5	0.0	0.6
Health, Physical or Other Disability (%)	6.8	13.2	15.5	3.6	8.8	14.4	19.3	10.6	5.5	15.0
Multiple Disabilities (%)	0.3	4.2	4.7	0.0	4.4	1.5	6.9	1.6	0.0	0.0
Intellectual Disability (%)	3.2	3.1	4.1	2.0	1.9	7.0	1.8	2.7	2.0	0.6
Developmental Delay / Preschool (%)	9.3	0.0	0.7	28.1	0.6	0.5	0.6	1.6	11.6	17.4

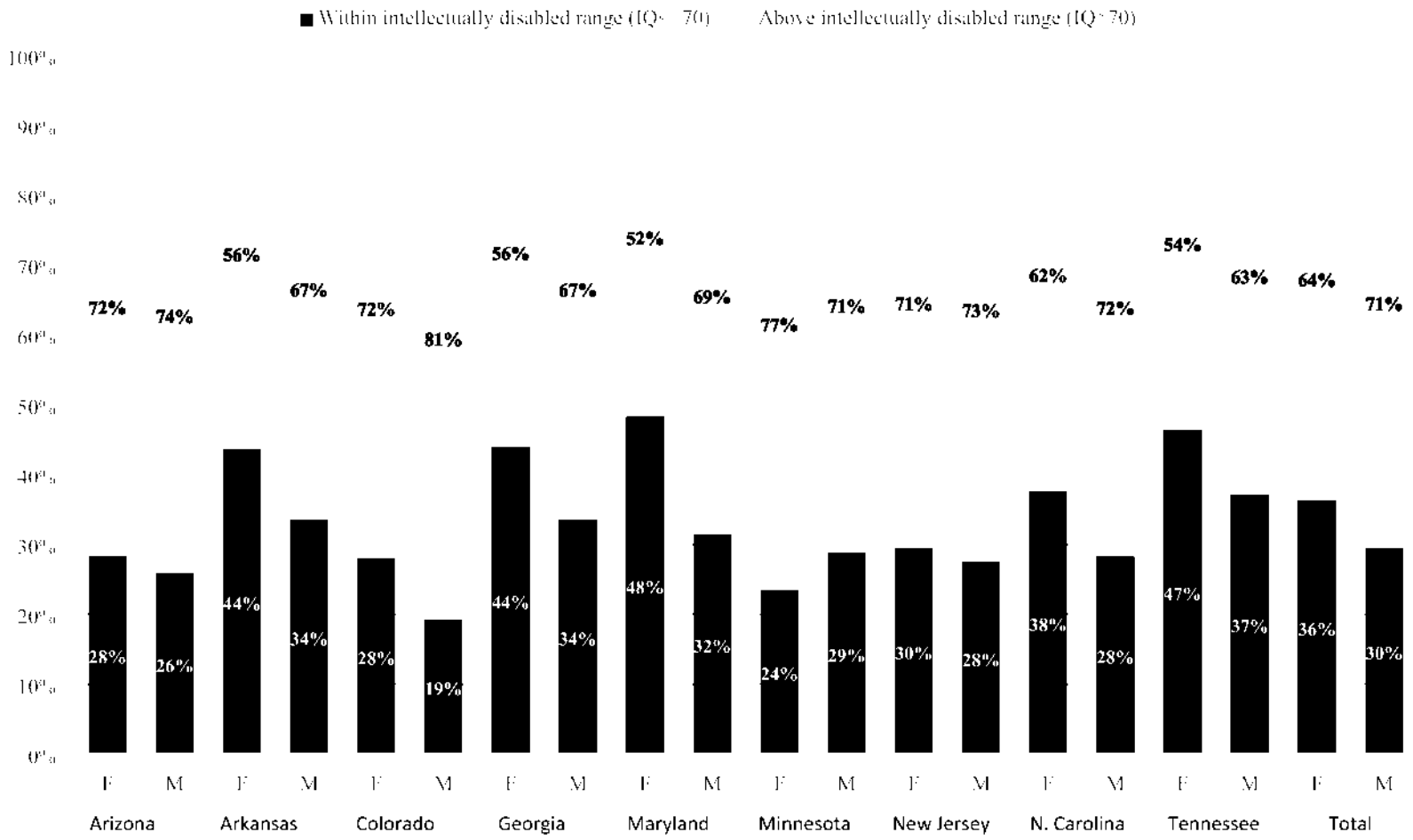
* Some state-specific categories were recoded or combined to match current U.S. Department of Education categories.

† Includes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 12% Tennessee)

§ Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 67% Colorado, 74% Wisconsin)

¶ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed)

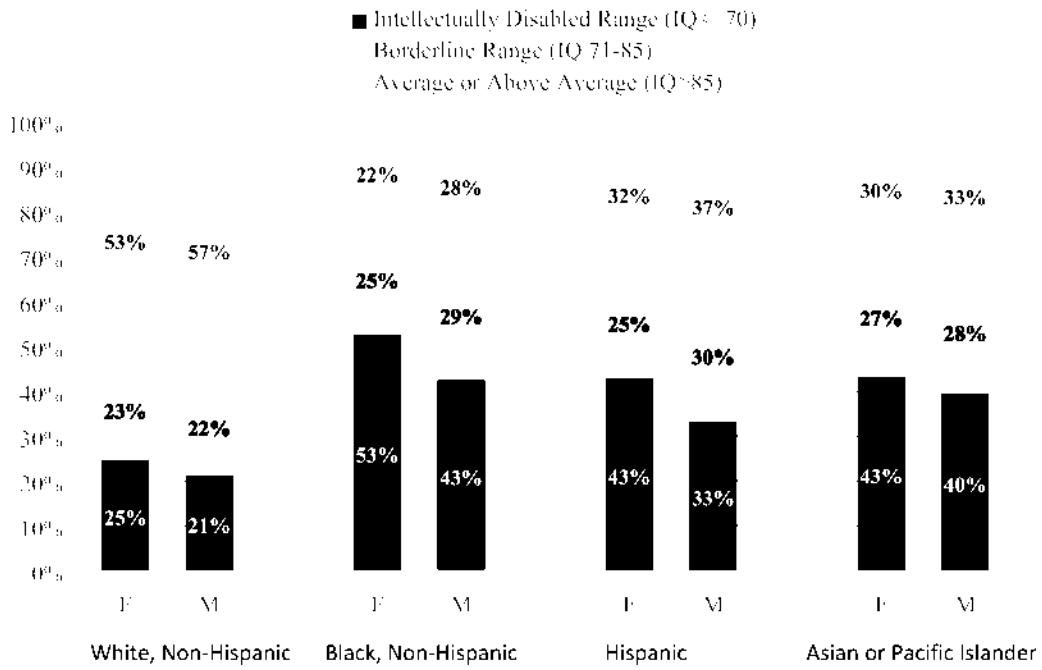
Figure 1. Most recent intelligence quotient score as of age 8 years among children with autism spectrum disorder for whom test data were available, by sex and site — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



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 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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



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.

TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — ADDM Network, 11 Sites, United States, 2014

Site	Site Institution	Surveillance Area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	%	No.	%	No.	%	No.	%	No.	%
Arizona	Univ of Arizona	† Part of 1 county in metropolitan Phoenix	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	Univ of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Dept of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	Centers for Disease Control and Prevention	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins Univ	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	† Parts of 2 counties in Minneapolis-St. Paul	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	Univ of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	Univ of Wisconsin – Madison	10 counties in south-eastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All Sites Combined			**263,775**	130,930	(49.6)	67,246	(25.5)	50,258	(19.1)	13,903	(5.3)	1,438	(0.5)

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics (NCHS) Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — ADDM Network, 11 Sites, United States, 2014

	Met DSM-IV or DSM-5	Met Both DSM-IV and DSM-5		Met DSM-IV Only		Met DSM-5 Only		DSM-IV vs. DSM-5	
ADDM Site	n	n	%	n	%	n	%	Ratio	Kappa
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All Sites Combined	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85

TABLE 9. Stratified comparison of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — ADDM Network, 11 Sites, United States, 2014

	Met DSM-IV or DSM-5	Met Both DSM-IV and DSM-5		Met DSM-IV Only		Met DSM-5 Only		DSM-IV vs. DSM-5	
Characteristic	**n**	**n**	**%**	**n**	**%**	**n**	**%**	**Ratio**	**Kappa**
Met ASD case definition under DSM-IV and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Sex									
Male	3978	3452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
Race/Ethnicity									
White, non-Hispanic	2486	2159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian / Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
Earliest comprehensive evaluation on record*									
<=36 months	1509	1372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37-48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1503	1195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Documented ASD Classification									
Autism special education eligibility	2270	2156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement†									
Earliest ASD diagnosis <=36 months	951	936	(98.4)	0	(0.0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis Autistic Disorder	1577	1526	(96.8)	0	(0.0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ASD-NOS	1564	1525	(97.5)	0	(0.0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger Disorder	221	210	(95.0)	0	(0.0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Most recent intelligence quotient score§									
Intellectual disability (IQ <=70)	1191	1089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71-85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1620	1391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

* Includes children identified with ASD who were linked to an in-state birth certificate

† A DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder automatically qualifies a child as meeting the DSM-5 surveillance case definition for ASD

§ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases

Diagram 1. ASD case determination criteria under DSM-IV-TR

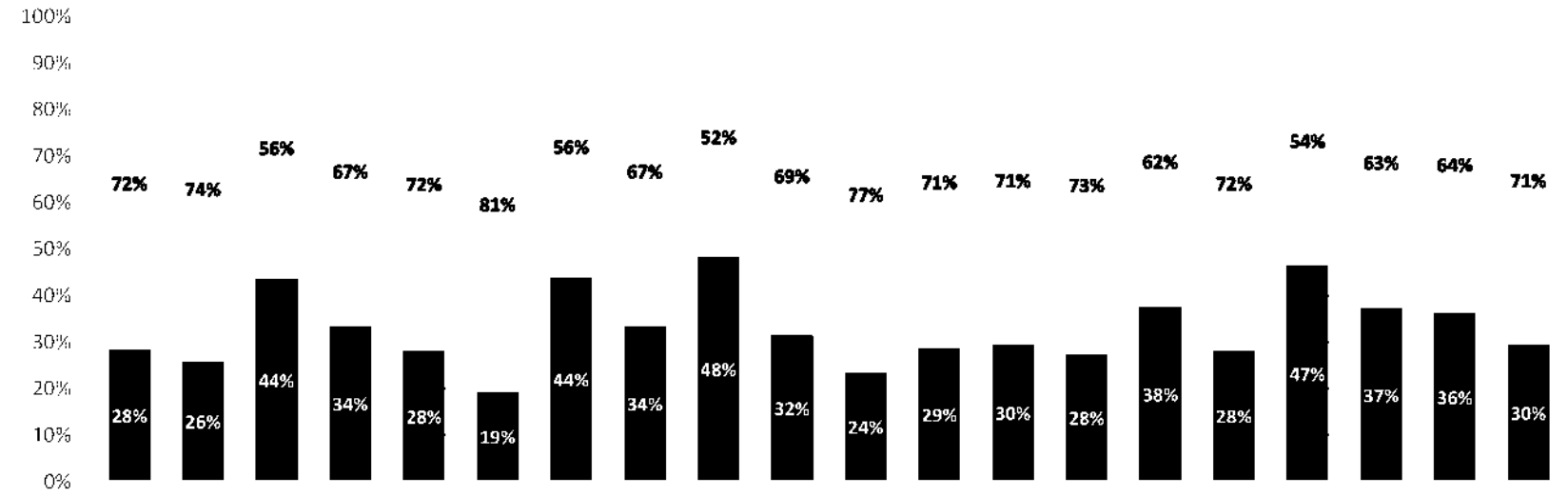
DSM-IV-TR Behavioral Criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted Behavior/Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental History	Child had identified delays or any concern with development in the following areas at or before the age of three years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism Discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR Case Determination	At least 6 behaviors coded with a minimum of 2 Social, 1 Communication, and 1 Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of three years OR At least 2 behaviors coded with a minimum of 1 Social and either 1 Communication and/or 1 Restricted Behavior/Interest; AND at least one Autism Discriminator coded

Diagram 2. ASD case determination criteria under DSM-5

DSM-5 Behavioral Criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD Diagnosis	A well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder - not otherwise specified (PDD-NOS)
DSM-5 Case Determination	All 3 behavioral criteria coded under part A, and at least 2 behavioral criteria coded under part B OR A DSM-IV diagnosis of autistic disorder, Asperger's disorder, or PDD-NOS

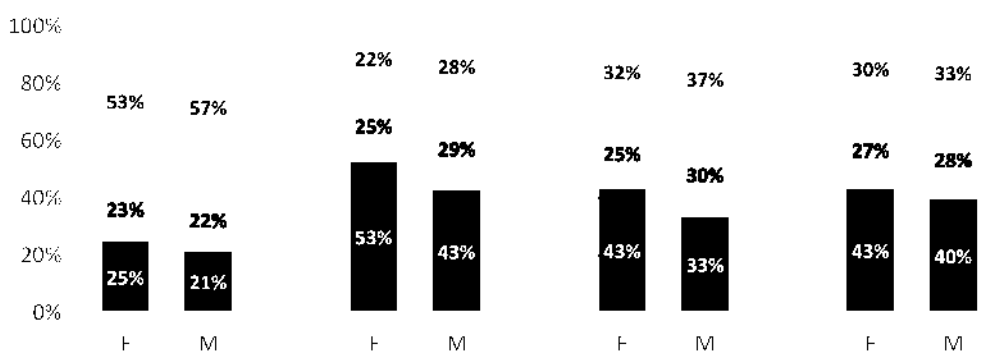
ADDM SY2014 8yo ASD MMWR

IQ by SEX by SITE



	Within intelle
Arizona	F
	M
Arkansas	F
	M
Colorado	F
	M
Georgia	F
	M
Maryland	F
	M
Minnesota	F
	M
New Jersey	F
	M
North Carolina	F
	M
Tennessee	F
	M
Total	F
	M

IQ by SEX by RACE



	Intellectua
White, Non-Hispanic	F
	M
Black or African-American, Non-Hispanic	F
	M
Hispanic, regardless of Race	F
	M
Asian or Pacific Islander, Non-Hispanic	F
	M

ctually disabled	rctually disabled range (IQ>70)
28%	72%
26%	74%
44%	56%
34%	67%
28%	72%
19%	81%
44%	56%
34%	67%
48%	52%
32%	69%
24%	77%
29%	71%
30%	71%
28%	73%
38%	62%
28%	72%
47%	54%
37%	63%
36%	64%
30%	71%

ılly Disabled Rangerline Range (IQ 7	or Above Average (IQ>85)
25%	23%	53%
21%	22%	57%
53%	25%	22%
43%	29%	28%
43%	25%	32%
33%	30%	37%
43%	27%	30%
40%	28%	33%

Prevalence of autism spectrum disorder among 8-year-old children — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Corresponding author: Jon Baio, EdS, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Jon Baio, EdS[1]

Lisa Wiggins, PhD[1]

Deborah L. Christensen, PhD[1]

Julie Daniels, PhD[2]

Zachary Warren, PhD[3]

Margaret Kurzius-Spencer, PhD[4]

Walter Zahorodny, PhD[5]

Cordelia Robinson Rosenberg, PhD[6]

Tiffany White, PhD[7]

Maureen Durkin, PhD[8]

Pamela Imm, MS[8]

Loizos Nikolaou, MPH[1,9]

Marshalyn Yeargin-Allsopp, MD[1]

Li-Ching Lee, PhD[10]

Rebecca Harrington, PhD[10]

Maya Lopez, MD[11]

Robert T. Fitzgerald, PhD[12]

Amy Hewitt, PhD[13]

Sydney Pettygrove, PhD[4]

John N. Constantino, MD[12]

Alison Vehorn, MS[3]

Josephine Shenouda, MS[5]

Jennifer Hall-Lande[13]

Kim Van Naarden Braun, PhD[1]

Nicole F. Dowling, PhD[1]

[1]*National Center on Birth Defects and Developmental Disabilities, CDC*

[2]*University of North Carolina, Chapel Hill*

[3]*Vanderbilt University Medical Center, Nashville, Tennessee*

[4]*University of Arizona, Tucson*

[5]*Rutgers University, Newark, New Jersey*

[6]*University of Colorado School of Medicine at the Anschutz Medical Campus*

[7]*Colorado Department of Public Health and Environment, Denver*

[8]*University of Wisconsin, Madison*

[9]*Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee*

[10]*Johns Hopkins University, Baltimore, Maryland*

[11]*University of Arkansas for Medical Sciences, Little Rock*

[12]*Washington University in St. Louis, Missouri*

[13]*University of Minnesota, Minneapolis*

Abstract

Problem/Condition: Autism spectrum disorder (ASD)

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of ASD among children aged eight years whose parents or guardians reside within multiple ADDM sites in the United States. ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder. This report provides updated ASD prevalence estimates for children aged eight years during the 2014 surveillance year, based on DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013 the American Psychiatric Association published the DSM-5, which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria may influence ADDM ASD prevalence estimates; therefore, many (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for

ASD consistent with the DSM-5 diagnostic criteria, which include the presence of an established DSM-IV-TR diagnosis of Autistic Disorder, PDD-NOS or Asperger Disorder. Results from a targeted comparison of these two case definitions are also reported.

Results: For the 2014 surveillance year, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (95% confidence interval: 16.4, 17.3) children aged eight years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged eight years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared to non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared to Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (IQ<=70), 25% were in the borderline range (IQ 71-85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by 36 months of age. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from CDC's ADDM Network, based on surveillance year 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among 8-year-olds in multiple communities in the United States. Because the ADDM 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 eight years in the United States. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by significant variation in ASD prevalence

when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar, but slightly lower estimate of ASD prevalence. The long-term impact of the revised diagnostic criteria remains in question, as the number of children aged eight years meeting DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis of Autistic Disorder, PDD-NOS or Asperger Disorder will decrease over time.

Public Health Action: The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates, and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged eight years in different communities throughout the United States, the need for enhanced public health strategies to deliver behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and non-genetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). The Centers for Disease Control and Prevention (CDC) began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2,3*). The first CDC study was based on an investigation in Brick Township, New Jersey (*2*), which identified similar characteristics but higher prevalence of ASD compared to other studies of that era. The second CDC study was conducted in metropolitan Atlanta, Georgia (*3*), which identified a lower prevalence of ASD compared to the Brick Township study but similar estimates compared to other prevalence studies of that era. 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 (*4,5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD may overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in the DSM-5 (*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a clearly defined surveillance case definition of ASD and using the same record-review methodology and behaviorally-defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged eight years in multiple US communities have risen from about one in 150 children in 2000-2002 to one in 68 in 2010-2012, more than doubling during this period (*6,7,8,9,10,11*). The observed increase in ASD prevalence substantiates a need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward Healthy People 2020 objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of about 4.5 male: 1 female with ASD from 2006 to 2012 (*9,10,11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000-2012

(range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006-2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9,10,11*). Although ASD prevalence estimates have historically been greater among white children compared to black children or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time due to larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared to the magnitude of increase in ASD prevalence among white children (*9*). Prior reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by about 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by about 50% in 2008, 2010 and 2012. ASD prevalence estimates from the ADDM Network have also varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). While ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change between 2002 and 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9,10*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (i.e., IQ <=70) has decreased gradually over time. During 2000-2002 nearly half of children with ASD had IQ scores in the range of intellectual disability (ID); during 2006-2008 this proportion was closer to 40%, and during 2010-2012 less than one third of children with ASD had IQ <=70. This trend was more pronounced for females as compared to males. The proportion of males with ASD and ID declined from approximately 40% during 2000-2008 to 30% during 2010-2012.

The proportion of females with ASD and ID declined from about 60% during 2000-2002, to 45% during 2006-2008, and to 35% during 2010-2012.

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with the DSM-IV-TR diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including atypical autism); or Asperger Disorder. In the American Psychiatric Association's 2013 publication of its Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included several diagnostic subtypes, to Autism Spectrum Disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by severity levels. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Individuals diagnosed with ASD under DSM-5 must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors, and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input). According to the DSM-5 Workgroup on Neurodevelopmental Disorders, the need for new criteria for autism and related disorders was identified long before the Workgroup was convened in 2007 (*18*). Although the DSM-IV-TR criteria proved useful in identifying ASD in children aged five to eight years, they performed less well when used in the diagnosis of toddlers and preschool-aged children, adolescents, and young adults (*18*). Further, the DSM-IV-TR criteria were insufficient to accurately identify girls and women with autism and lacked the cultural sensitivity needed to identify cases in ethnic or racial minorities (*18*). The DSM-5 changes introduced a more focused diagnostic framework compared to that of DSM-IV-TR; however, DSM-5 states that any individual with a well-established DSM-IV-TR diagnosis of Autistic Disorder, Asperger Disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of Autism Spectrum Disorder. Previous studies suggest that

DSM-5 criteria for ASD may exclude some children who would have qualified for a DSM-IV-TR diagnosis but hadn't yet received one, particularly those who are very young and those without intellectual disability (*19,20,21,22,23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

The purpose of this report is to provide the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and to suggest targets for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include pediatric healthcare providers, school psychologists, educators, researchers, policymakers, and program administrators working to understand and address the needs of individuals with ASD and their families. These data can be used to help plan services, guide research into risk factors and effective interventions, and inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge which led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network. 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) (*24*). As feasible, the surveillance methods have remained consistent over time. Some minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the 8 ADDM Network surveillance 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 eight years because the baseline ASD prevalence study conducted by MADDSP suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals:1) to provide descriptive data on classification and functioning of the population of children with ASD; 2) to monitor the prevalence of ASD in different areas of the US; and 3) to understand the impact of ASD in US communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015 2018, during which time data are collected for children aged eight years during the 2014 and 2016 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. A total of six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee and Wisconsin) received permission to review education records in only some school districts within the overall geographic area covered for surveillance year 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total 8-year-old population. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites, 33% in Colorado and 26% in Wisconsin. In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and may request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged eight years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources is abstracted into a single composite record for each child.

In the second phase of surveillance, the abstracted composite evaluation files are de-identified and reviewed systematically by experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians) (*26*). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. Behavioral and diagnostic components of the DSM-IV-TR and DSM-5 ASD case definitions operationalized for ADDM

surveillance are outlined in Diagram 1. In practice, DSM-5 criteria automatically include children with a well-established DSM-IV-TR diagnosis of ASD, thus, the ADDM coding scheme similarly accommodated those with a previous DSM-IV-TR diagnosis in the DSM-5 case definition, regardless of whether documented symptoms independently met either the DSM-IV-TR or DSM-5 diagnostic criteria. The coding scheme allowed differentiation of children who met DSM-5 criteria on the basis of behavioral characteristics from those who met DSM-5 criteria solely through a previous DSM-IV-TR diagnosis.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase of ADDM, the accuracy of record review and abstraction is checked periodically. 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 (*5*). For the 2014 surveillance year, interrater agreement on case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined ($k = 0.77$), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined ($k = 0.84$). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*27*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged eight years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona, Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*28*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. Prevalence results are reported as the total number of children meeting the ASD case definition per 1,000 children aged eight 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 were obtained from an underlying Poisson distribution. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Pearson chi-square tests were also performed for testing 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 ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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 325,483 children aged eight years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged eight years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the total population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: 5; range: 3 [Arizona, Minnesota, Missouri, Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). Based on combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged eight years. Overall estimated prevalence of ASD was highest in New Jersey (29.3), Minnesota (24.0) and Maryland (20.0). Five sites reported prevalence estimates in the range of 13.1–14.1 per 1,000 (Arizona, Arkansas, Colorado, Missouri, Wisconsin), and three sites reported prevalence estimates ranging between 15.5–17.4 per 1,000 (Georgia, North Carolina, Tennessee).

Prevalence by Sex and Race/Ethnicity

Combining data from all 11 ADDM sites, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0 for all sites combined). ASD prevalence 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 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically

436 significant in three sites (Arkansas, Missouri, Wisconsin), and the white-to-Hispanic prevalence ratios
437 were significant in seven sites. In nine sites the estimated prevalence of ASD was higher among black
438 children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in
439 three of these nine sites. In New Jersey there was almost no difference in ASD prevalence estimates
440 among white, black and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9
441 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey), with notably wide CIs.

442 **Intellectual Ability**

443 Data on intellectual ability are reported only for nine sites (Arizona, Arkansas, Colorado, Georgia,
444 Maryland, Minnesota, New Jersey, North Carolina, Tennessee) having information available for at least
445 70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]).
446 The median age of children's most recent IQ tests, on which the following results are based, was 73
447 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability
448 for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in
449 any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were
450 classified in the range of intellectual disability (IQ $\leq$70), 25% were in the borderline range (IQ = 71–85),
451 and 44% had IQ >85. The proportion of children classified in the range of intellectual disability ranged
452 from 26.7% in Arizona to 39.4% in Tennessee.

453 Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls
454 more likely than boys to have IQ $\leq$70, and boys more likely than girls to have IQ >85 (Figure 1). In these
455 nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements
456 indicating intellectual disability compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4,
457 $p<0.01$), though among individual sites this proportion differed significantly in only one (Georgia, OR =
458 1.6, $p<0.05$). The proportion of children with ASD with borderline intellectual ability (IQ = 71-85) did
459 not differ by sex, whereas a significantly higher proportion of males (45%) compared to females (40%)
460 had IQ >85, i.e., average or above average intellectual ability (OR = 1.2, $p<0.05$).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of intellectual disability, compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with intellectual disability differed significantly in all nine sites and when combining their data (OR = 2.9, p<0.01). The proportion of Hispanics and whites with intellectual disability differed significantly when combining data from all nine sites (OR = 1.9, p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8, p = 0.09), North Carolina (OR = 1.8, p = 0.07) and Tennessee (OR = 2.1, p = 0.10). The proportion of children with borderline intellectual ability (IQ = 71-85) did not differ by race/ethnicity in any of these nine sites or when combining their data; however, when combining data from these nine sites the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR = 3.4, p<0.01) or Hispanic (36%, OR = 2.2, p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by 36 months of age (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV, DSM-5 or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR = 1.4, p<0.01). When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9, p=0.09) and 76% of Hispanic children (OR = 1.3, p<0.01); a significant difference was also found when comparing

the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5, $p<0.01$).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

Sites with access to education records collected information about the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from 40% in Wisconsin to 74% in North Carolina. Most other sites noted over half of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (43%) and New Jersey (48%). 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 nine years in many US states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of intellectual disability.

Sensitivity Analyses Evaluating Impact of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota

and Wisconsin), between 1% to 5% higher in five sites (Arkansas, Colorado, Missouri, New Jersey and North Carolina), about 8% higher in Maryland, and nearly 20% higher in Tennessee, where investigators did not obtain permission to review children's records in one of the fourteen school districts comprising the eleven-county surveillance area.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, about 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were requested for surveillance of five distinct conditions (autism, cerebral palsy, intellectual disability, hearing loss, vision impairment), about 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of DSM-IV-TR vs. DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged eight years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was about 4% higher based on the historical DSM-IV-TR case definition compared to the new DSM-5 case definition. In six of the 11 ADDM sites, DSM-5 case counts were within about 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%) and Colorado (14%). Kappa statistics indicated

539 strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of
540 the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined:
541 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

542 Stratified analysis of DSM-IV:DSM-5 ratios were very similar compared to the overall sample (Table
543 9). DSM-5 estimates were about 3% lower than DSM-IV-TR counts for males, and about 6% lower for
544 females (kappa = 0.85 for both). Case counts were about 3% lower among white and black children on
545 DSM-5 compared to DSM-IV, 5% lower among Asian children, and 8% lower among Hispanic children.
546 Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5
547 than DSM-IV, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those
548 initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV. Children with
549 documentation of eligibility for autism special education services, as well as those with a documented
550 diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV. Slightly over 3%
551 of children whose earliest ASD diagnosis was Autistic Disorder met DSM-5 criteria but not DSM-IV,
552 compared to slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of
553 those whose earliest diagnosis was Asperger Disorder. Children with no previous ASD classification
554 (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all
555 11 sites, children with IQ scores in the range of intellectual disability were 3% less likely to meet DSM-5
556 criteria compared to DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6%
557 less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average
558 intellectual ability were 4% less likely to meet DSM-5 criteria compared to DSM-IV-TR (kappa = 0.86).

559 **Discussion**

560 **Comparison to earlier ADDM surveillance years**

561 The overall ASD prevalence estimate of 16.8 per 1,000 children aged eight years in 2014 is higher
562 than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-
563 TR criteria was used during the entire period of ADDM surveillance from 2000 to 2014, as were
564 comparable study operations and procedures, although the geographic areas under surveillance have

565 varied over time. During this period ADDM ASD prevalence estimates increased from 6.7 to 16.8 per
566 1,000 children aged eight years, an increase of approximately 150%.

567 Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area,
568 all six showed an increase in ASD prevalence estimates between 2012 and 2014, with a nearly 10%
569 prevalence increase in Georgia and Maryland, 19% in New Jersey, 23% in Missouri, 29% in Colorado
570 and 31% in Wisconsin. The ASD prevalence estimate from New Jersey continues to be one of the highest
571 reported by a population-based surveillance system. The two sites with the greatest relative increase in
572 prevalence are remarkable in that both gained access to children's education records in additional
573 geographic areas for 2014. Colorado was granted access to review children's education records in one
574 additional county for the 2014 surveillance year (representing nearly 20% of the population aged eight
575 years within the overall Colorado surveillance area), and Wisconsin was granted access to review
576 education records in parts of 2 of the 10 counties comprising their 2014 surveillance area. Although this
577 represented only 26% of the population aged eight years within the overall Wisconsin surveillance area,
578 2014 marked the first time Wisconsin has included education data sources. Comparisons to earlier
579 ADDM Network surveillance results should be interpreted cautiously due to changing composition of
580 sites and geographic coverage over time. For example, three ADDM Network sites completing both the
581 2012 and 2014 surveillance years (Arizona, Arkansas and North Carolina) covered a different geographic
582 area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in
583 collaboration with the ADDM Network.

584 Some characteristics of children with ASD were similar in 2014 compared to earlier surveillance
585 years. The median age of earliest known ASD diagnosis remained close to 53 months in prior surveillance
586 years and was 52 months in 2014. The proportion of children who received a comprehensive
587 developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006-2012. There
588 were a number of differences in the characteristics of the population of children with ASD in 2014, as
589 well. The male:female prevalence ratio decreased from 4.5:1 during 2002-2012 to 4:1 in 2014, driven by
590 a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease

591 in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002.
592 Among sites covering a population of at least 20,000 children aged eight years, New Jersey reported no
593 significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete
594 ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates
595 from combined ADDM sites have been about 20-30% higher among white children as compared to black
596 children. For surveillance year 2014 the difference was only 7%, the lowest difference ever observed for
597 the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among
598 Hispanic children in 2002 and 2006, and about 50% higher in 2008, 2010 and 2012, whereas for 2014 the
599 difference was only 22%. Data from a previously reported comparison of ADDM Network ASD
600 prevalence estimates from 2002, 2006 and 2008 (*9*) suggested greater increases in ASD prevalence
601 among black and Hispanic children compared to those among white children. Reductions in disparities in
602 ASD prevalence for black and Hispanic children may be due, in part, to more effective outreach directed
603 to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was
604 similar in 2012 and 2014 at about 30% of males and 35% of females. These proportions were markedly
605 lower than those reported in prior surveillance years.

606 **Comparison among ADDM 2014 sites**

607 Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among
608 ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11
609 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close
610 range, from 13.1 to 14.1 per 1,000 children, New Jersey's prevalence estimate of 29.4 per 1,000 children
611 was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota,
612 North Carolina) reported prevalence estimates that were significantly greater than those from any of the
613 five sites in the 13.1-14.1 per 1,000 range. It should be noted that two of the sites with prevalence
614 estimates of 20.0 per 1,000 or higher, Maryland and Minnesota, conducted surveillance among a total
615 population of less than 10,000 children aged eight years. Concentrating surveillance efforts in smaller
616 geographic areas, especially those in close proximity to diagnostic centers and those covering school

617 districts with advanced staff training and programs to support children with ASD, may yield higher
618 prevalence estimates compared to those from sites covering populations of more than 20,000 8-year-olds.
619 Those sites with limited or no access to education data sources (Colorado, Missouri, and Wisconsin) had
620 prevalence estimates near the lower range among all sites. In addition to variation among sites in reported
621 ASD prevalence, wide variation among sites is noted on the characteristics of children identified with
622 ASD, including the proportion of children who received a comprehensive developmental evaluation by
623 age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability.
624 Some of this variation might be attributable to regional differences in diagnostic practices and other
625 documentation of autism symptoms, although previous reports based on ADDM data have linked much of
626 the variation to other extrinsic factors such as regional and socioeconomic disparities in access to services
627 (*13*,*14*).

628 **Comparison between DSM-IV-TR and DSM-5 case definitions**

629 Agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close,
630 overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype or level of intellectual
631 ability. Overall, ASD prevalence estimates based on the new DSM-5 case definition were very similar in
632 magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the
633 11 ADDM sites actually had slightly higher case counts using the DSM-5 framework compared to the
634 DSM-IV. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared to all other sites, was
635 also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This
636 suggests that the diagnostic component of the DSM-5 case definition, whereby children with a
637 documented DSM-IV-TR diagnosis of ASD automatically qualify as DSM-5 cases regardless of social
638 interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5
639 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5
640 case criteria based solely on the presence of a documented DSM-IV-TR diagnosis. This element of the
641 DSM-5 case definition will carry less weight moving forward, as fewer children aged eight years in health
642 and education settings will have been diagnosed with ASD under the DSM-IV-TR criteria. It is also

643 possible that individuals who conduct developmental evaluations of children in health and education
644 settings will increasingly describe behavioral characteristics using language more consistent with DSM-5
645 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case
646 definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing DSM-
647 IV-TR diagnosis reflect the actual patterns of diagnosis and services for children in 2014, since children
648 diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were
649 published. Using this approach, agreement in the application of the DSM-IV-TR and DSM-5 case
650 definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR
651 diagnostic subtype, or level of intellectual ability. In the coming years prevalence estimates will align
652 more closely with the specific DSM-5 behavioral criteria, and may exclude some individuals who would
653 have met DSM-IV-TR criteria for Autistic Disorder, PDD-NOS or Asperger Disorder, while at the same
654 time including individuals who do not meet those criteria but who do meet the specific DSM-5 behavioral
655 criteria.

656 **Comparison to national prevalence estimates**

657 The ADDM Network is the only ASD surveillance system in the United States providing robust
658 prevalence estimates for specific areas of the country, including those for subgroups defined by sex and
659 race/ethnicity, providing information about geographical variation that can be used to evaluate policies
660 and diagnostic practices that may affect ASD prevalence. It is also the only comprehensive surveillance
661 system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on
662 parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge
663 of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health,
664 The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH)
665 report estimates of ASD prevalence based on caregiver report of being told by a doctor or other healthcare
666 provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have
667 ASD. The most recent publication from NHIS showed that 27.6 per 1,000 children aged 3-17 years had
668 ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4,

669 respectively) (*29*). An estimate of 20.0 per 1,000 children aged 6-17 years was reported from the 2011-
670 2012 NSCH (*30*). The study samples for the two phone surveys are substantially smaller than the ADDM
671 Network; however, they were intended to be nationally representative, whereas the ADDM Network
672 surveillance areas were selected through a competitive process and, although large and diverse, were not
673 intended to be nationally representative. Geographic differences in ASD prevalence have been observed
674 in both the ADDM Network and national surveys, as have differences in ASD prevalence by age
675 (*6,7,8,9,10,11,29,30*). All three prevalence estimation systems are impacted by regional and policy-driven
676 differences in the availability and utilization of evaluation and diagnostic services for children with
677 developmental concerns. Phone surveys are likely more sensitive in identifying children who received a
678 preliminary or confirmed diagnosis of ASD but are not receiving services (for example, special education
679 services). The ADDM Network method based on analysis of information contained in existing health and
680 education records enables the collection of detailed, case-specific information reflecting children's
681 behavioral, developmental and functional characteristics, which are not available from the national phone
682 surveys. This detailed case level information may provide insight into temporal changes in the expression
683 of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic
684 criteria.

685 **Limitations**

686 The findings in this report are subject to a number of limitations. Foremost, ADDM Network sites
687 were not selected to represent the United States as a whole, nor were the geographic areas within each
688 ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is
689 monitored statewide). Although a combined estimate is reported for the Network as a whole to inform
690 stakeholders and interpret the findings from individual surveillance years in a more general context, data
691 reported by the ADDM Network should not be interpreted to represent a national estimate of the number
692 and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation -
693 among sites, between specific groups within sites, and across time - in the number and characteristics of
694 children identified with ASD, and to use these findings to inform public health strategies aimed at

removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

When considering data on the characteristics of children with ASD, it is important to acknowledge limitations of information available in children's health and education records. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. It is possible that some children had earlier diagnoses that were not recorded in these records. Likewise, it is possible that some descriptions of historical diagnoses, i.e., those not made by the evaluating examiner, could be subject to recall error on the part of a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously due to myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted prior to age 6 years.

Because comparisons to the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3,6,7,8,9,10,11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

When the ADDM methodology was originally developed, estimating ASD prevalence among children aged eight years was determined to represent the peak prevalence, based on estimates for multiple ages in metropolitan Atlanta, GA in 1996 (*3*). Estimating prevalence among 8-year-olds requires quality data from both health and educational agencies and likely captures most children whose adaptive performance is impacted by ASD. However, because prevalence estimation takes considerable time and effort, reporting of estimates lags behind the surveillance year by 3-4 years. Thus, opportunities for policy or programmatic enhancements to impact key health indicators also lag. Focusing on younger cohorts may allow earlier assessment of systematic changes (e.g., policies, insurance, and programs) that impact younger children, rather than waiting until cohorts impacted by these changes reach eight years of age. Surveillance of ASD in older populations is also important, but may require different methodological approaches.

CDC's "Learn the Signs. Act Early." (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, healthcare professionals and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*31*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at 18 and 24 months of age (*32*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD are evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation may become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged four years (*33*), may inform how policy initiatives such as screening recommendations and other social determinants of health

may impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD has increased compared to previously reported ADDM estimates, and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 (children aged eight years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing behavioral, educational, residential and occupational needs of this population.

Contrary to some predictions, the redefinition of ASD provided by the DSM-5 may have had a relatively small impact on the overall ASD estimate provided by the ADDM Network. This may be due to the carryover effect of including all DSM-IV-TR-diagnosed cases in the DSM-5 count. Over time, the estimate may be influenced (downward) by a diminishing number of individuals who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged eight years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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Tables & Figures for MMWR Surveillance Summaries:
Prevalence of autism spectrum disorder among 8-year-old children — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

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, 2014

Site	Site Institution	Surveillance Area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	%	No.	%	No.	%	No.	%	No.	%
Arizona	Univ of Arizona	† Part of 1 county in metropolitan Phoenix	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	Univ of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Dept of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	Centers for Disease Control and Prevention	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins Univ	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	† Parts of 2 counties in Minneapolis-St. Paul	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	Univ of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	Univ of Wisconsin – Madison	10 counties in south-eastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All Sites Combined			**325,483**	167,048	(51.3)	72,751	(22.4)	67,181	(20.6)	16,596	(5.1)	1,907	(0.6)

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics (NCHS) Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.
† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder (ASD) per 1,000 children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014

Site	Total pop.	Total no. with ASD	Overall†		Sex				Male-to-Female prevalence ratio§
					Males		Females		
			Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	
Arizona	24,952	349	14.0	(12.6 - 15.5)	21.1	(18.7 - 23.8)	6.6	(5.3 - 8.2)	3.2
Arkansas	39,992	522	13.1	(12.0 - 14.2)	20.5	(18.6 - 22.5)	5.4	(4.5 - 6.5)	3.8
Colorado	41,128	572	13.9	(12.8 - 15.1)	21.8	(19.9 - 23.9)	5.5	(4.6 - 6.7)	3.9
Georgia	51,161	869	17.0	(15.9 - 18.2)	27.9	(25.9 - 30.0)	5.7	(4.8 - 6.7)	4.9
Maryland	9,955	199	20.0	(17.4 - 23.0)	32.7	(28.1 - 38.2)	7.2	(5.2 - 10.0)	4.5
Minnesota	9,767	234	24.0	(21.1 - 27.2)	39.0	(33.8 - 44.9)	8.5	(6.3 - 11.6)	4.6
Missouri	25,333	356	14.1	(12.7 - 15.6)	22.2	(19.8 - 25.0)	5.6	(4.4 - 7.0)	4.0
New Jersey	32,935	964	29.3	(27.5 - 31.2)	45.5	(42.4 - 48.9)	12.3	(10.7 - 14.1)	3.7
North Carolina	30,283	527	17.4	(16.0 - 19.0)	28.0	(25.5 - 30.8)	6.5	(5.3 - 7.9)	4.3
Tennessee	24,940	387	15.5	(14.0 - 17.1)	25.3	(22.6 - 28.2)	5.4	(4.2 - 6.9)	4.7
Wisconsin	35,037	494	14.1	(12.9 - 15.4)	21.4	(19.4 - 23.7)	6.4	(5.3 - 7.7)	3.4
All Sites Combined	325,483	5,473	16.8	(16.4 - 17.3)	26.6	(25.8 - 27.4)	6.6	(6.2 - 7.0)	4.0

Abbreviations: CI = confidence interval.

* Per 1,000 children aged 8 years.

† All children are included in the total regardless of race or ethnicity.

§ All sites identified significantly higher prevalence among males compared to females (p<0.01).

TABLE 3. Estimated prevalence* of autism spectrum disorder (ASD) per 1,000 children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014

Site	Race/ethnicity								Prevalence Ratio		
	White		Black		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			
Arizona	16.2	(14.1 - 18.6)	19.5	(13.3 - 28.6)	10.3	(8.5 - 12.5)	10.3	(5.5 - 19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6 - 15.5)	10.4	(8.3 - 12.9)	8.4	(6.2 - 11.3)	14.2	(8.1 - 25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5 - 16.7)	11.4	(8.0 - 16.2)	10.6	(9.0 - 12.5)	7.9	(4.8 - 12.9)	1.3	1.4†	1.1
Georgia	17.9	(16.0 - 20.2)	17.1	(15.4 - 18.9)	12.6	(10.6 - 15.0)	11.9	(8.9 - 16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0 - 23.8)	16.5	(12.7 - 21.4)	15.7	(9.1 - 27.0)	13.9	(7.5 - 25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8 - 29.8)	27.2	(21.7 - 34.2)	20.9	(14.7 - 29.7)	17.8	(12.3 - 25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4 - 16.0)	10.8	(8.6 - 13.6)	4.9	(2.2 - 10.9)	10.7	(5.8 - 20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4 - 33.3)	26.8	(23.3 - 30.9)	29.3	(26.2 - 32.9)	19.2	(13.9 - 26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5 - 20.9)	16.1	(13.5 - 19.2)	11.9	(9.3 - 15.2)	19.1	(13.7 - 26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3 - 18.2)	12.5	(9.7 - 16.0)	10.5	(7.6 - 14.7)	12.5	(6.7 - 23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6 - 17.0)	11.3	(8.9 - 14.2)	12.5	(10.0 - 15.6)	10.2	(6.1 - 16.9)	1.3†	1.2	0.9
All Sites Combined	17.2	(16.5 - 17.8)	16.0	(15.1 - 16.9)	14.0	(13.1 - 14.9)	13.5	(11.8 - 15.4)	1.1†	1.2§	1.1§

Abbreviations: CI = confidence interval

* Per 1,000 children aged 8 years.

† Prevalence ratio significant at p<0.05.

§ Prevalence ratio significant at p<0.01.

TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder (ASD) who received a comprehensive evaluation by a qualified professional before age 3 years, 4 years, or later – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Earliest age when child received a comprehensive evaluation						Mention of general delay	
	<=36mos		37-48mos		>48mos		<=36mos	
	No	%	No	%	No	%	No	%
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All Sites Combined	1737	(41.9)	790	(19.0)	1620	(39.1)	3525	(85.0)

*Includes children identified with ASD who were linked to an in-state birth certificate

TABLE 5. Median age (in months) of earliest known autism spectrum disorder (ASD) diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic Disorder			ASD/PDD			Asperger Disorder			Any Specified ASD Diagnosis		
	Median Age	No.	%	Median Age	No.	%	Median Age	No.	%	Median Age	No.	%
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All Sites Combined	46	1810	(47.7)	56	1746	(46.0)	67	238	(6.3)	52	3794	(69.3)

Abbreviation: PDD = pervasive developmental disorder - not otherwise specified.

TABLE 6. Number and percentage of children aged 8 years identified with autism spectrum disorder (ASD) for whom special education data were available, by primary special education eligibility category* – Autism and Developmental Disabilities Monitoring Network, 10 sites with access to education records, United States, 2014

	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	N. Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with Special Education records	311 (89.1)	455† (87.2)†	148§ (NR)¶	752 (86.5)	159 (79.9)	201 (85.9)	851 (88.3)	444 (84.3)	293† (75.7)†	167§ (NR)¶
Primary Exceptionality										
Autism (%)	65.3	65.1	43.2	57.8	66.0	65.2	47.7	74.3	68.9	39.5
Emotional Disturbance (%)	2.9	0.9	7.4	2.0	2.5	4.5	1.5	2.5	0.3	5.4
Specific Learning Disability (%)	6.8	3.1	14.2	4.0	11.9	1.0	8.0	2.7	0.7	2.4
Speech or Language Impairment (%)	5.5	10.3	10.1	2.4	3.8	5.0	13.6	3.6	10.9	19.2
Hearing or Visual Impairment (%)	0.0	0.2	0.0	0.1	0.0	1.0	0.6	0.5	0.0	0.6
Health, Physical or Other Disability (%)	6.8	13.2	15.5	3.6	8.8	14.4	19.3	10.6	5.5	15.0
Multiple Disabilities (%)	0.3	4.2	4.7	0.0	4.4	1.5	6.9	1.6	0.0	0.0
Intellectual Disability (%)	3.2	3.1	4.1	2.0	1.9	7.0	1.8	2.7	2.0	0.6
Developmental Delay / Preschool (%)	9.3	0.0	0.7	28.1	0.6	0.5	0.6	1.6	11.6	17.4

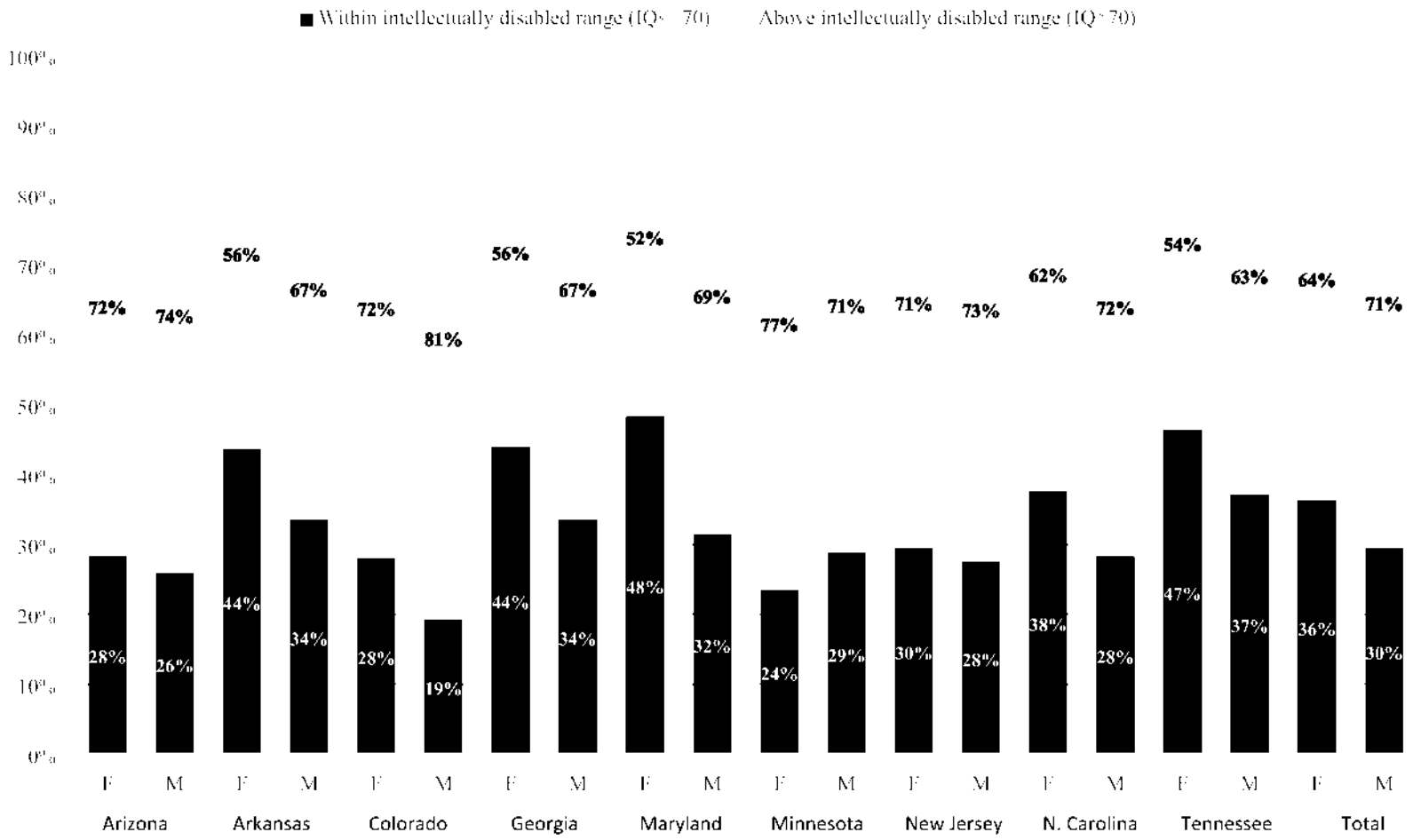
* Some state-specific categories were recoded or combined to match current U.S. Department of Education categories.

† Includes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 12% Tennessee)

§ Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 67% Colorado, 74% Wisconsin)

¶ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed)

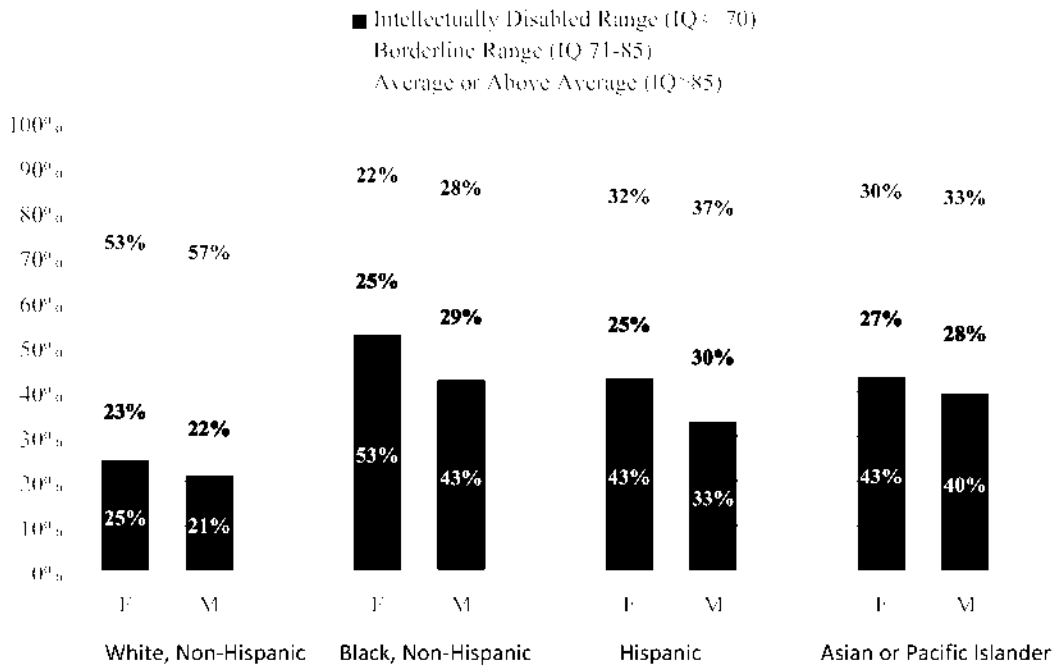
Figure 1. Most recent intelligence quotient score as of age 8 years among children with autism spectrum disorder for whom test data were available, by sex and site — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



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 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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



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.

TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — ADDM Network, 11 Sites, United States, 2014

Site	Site Institution	Surveillance Area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	%	No.	%	No.	%	No.	%	No.	%
Arizona	Univ of Arizona	† Part of 1 county in metropolitan Phoenix	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	Univ of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Dept of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	Centers for Disease Control and Prevention	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins Univ	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	† Parts of 2 counties in Minneapolis-St. Paul	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	Univ of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	Univ of Wisconsin – Madison	10 counties in south-eastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All Sites Combined			**263,775**	130,930	(49.6)	67,246	(25.5)	50,258	(19.1)	13,903	(5.3)	1,438	(0.5)

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics (NCHS) Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — ADDM Network, 11 Sites, United States, 2014

	Met DSM-IV or DSM-5	Met Both DSM-IV and DSM-5		Met DSM-IV Only		Met DSM-5 Only		DSM-IV vs. DSM-5	
ADDM Site	n	n	%	n	%	n	%	Ratio	Kappa
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All Sites Combined	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85

TABLE 9. Stratified comparison of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — ADDM Network, 11 Sites, United States, 2014

	Met DSM-IV or DSM-5	Met Both DSM-IV and DSM-5		Met DSM-IV Only		Met DSM-5 Only		DSM-IV vs. DSM-5	
Characteristic	**n**	**n**	**%**	**n**	**%**	**n**	**%**	**Ratio**	**Kappa**
Met ASD case definition under DSM-IV and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Sex									
Male	3978	3452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
Race/Ethnicity									
White, non-Hispanic	2486	2159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian / Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
Earliest comprehensive evaluation on record*									
<=36 months	1509	1372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37-48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1503	1195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Documented ASD Classification									
Autism special education eligibility	2270	2156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement†									
Earliest ASD diagnosis <=36 months	951	936	(98.4)	0	(0.0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis Autistic Disorder	1577	1526	(96.8)	0	(0.0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ASD-NOS	1564	1525	(97.5)	0	(0.0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger Disorder	221	210	(95.0)	0	(0.0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Most recent intelligence quotient score§									
Intellectual disability (IQ <=70)	1191	1089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71-85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1620	1391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

* Includes children identified with ASD who were linked to an in-state birth certificate

† A DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder automatically qualifies a child as meeting the DSM-5 surveillance case definition for ASD

§ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases

Diagram 1. ASD case determination criteria under DSM-IV-TR

DSM-IV-TR Behavioral Criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted Behavior/Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental History	Child had identified delays or any concern with development in the following areas at or before the age of three years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism Discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR Case Determination	At least 6 behaviors coded with a minimum of 2 Social, 1 Communication, and 1 Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of three years OR At least 2 behaviors coded with a minimum of 1 Social and either 1 Communication and/or 1 Restricted Behavior/Interest; AND at least one Autism Discriminator coded

Diagram 2. ASD case determination criteria under DSM-5

DSM-5 Behavioral Criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD Diagnosis	A well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder - not otherwise specified (PDD-NOS)
DSM-5 Case Determination	All 3 behavioral criteria coded under part A, and at least 2 behavioral criteria coded under part B OR A DSM-IV diagnosis of autistic disorder, Asperger's disorder, or PDD-NOS

BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted behavior/Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the age of 3 years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive

Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least 6 behaviors coded with a minimum of 2 Social, 1 Communication, and 1 Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of 3 years OR At least 2 behaviors coded with a minimum of 1 Social and either 1 Communication and/or 1 Restricted Behavior/Interest; AND at least 1 Autism Discriminator coded

Abbreviation: DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (Text Revision).

BOX 2. Autism Spectrum Disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	A well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder–not otherwise specified (PDD-NOS)
DSM-5 case determination	All 3 behavioral criteria coded under part A, and at least 2 behavioral criteria coded under part B OR A DSM-IV diagnosis of autistic disorder, Asperger's disorder, or PDD-NOS

Abbreviation: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders 5th ed.

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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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties in Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in south-eastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**	**16,596**	**(5.1)**	**1,907**	**(0.6)**

Abbreviation: CDC = Centers for Disease Control and Prevention.

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics (NCHS) Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014–2015 school year.

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TABLE 2. Estimated prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Overall†		Sex				Male-to-female prevalence ratio§
					Males		Females		
			Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	
Arizona	**24,952**	**349**	14.0	(12.6–15.5)	21.1	(18.7–23.8)	6.6	(5.3–8.2)	3.2
Arkansas	**39,992**	**522**	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	3.8
Colorado	**41,128**	**572**	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	3.9
Georgia	**51,161**	**869**	17.0	(15.9–18.2)	27.9	(25.9–30.0)	5.7	(4.8–6.7)	4.9
Maryland	**9,955**	**199**	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	4.5
Minnesota	**9,767**	**234**	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	4.6
Missouri	**25,333**	**356**	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	4.0
New Jersey	**32,935**	**964**	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	3.7
North Carolina	**30,283**	**527**	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	4.3
Tennessee	**24,940**	**387**	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	4.7
Wisconsin	**35,037**	**494**	14.1	(12.9–15.4)	21.4	(19.4–23.7)	6.4	(5.3–7.7)	3.4
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	**4.0**

Abbreviation: CI = confidence interval.

* Per 1,000 children aged 8 years.

† All children are included in the total regardless of race or ethnicity.

§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

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TABLE 3. Estimated prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/ethnicity								Prevalence ratio		
	White		Black		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			
Arizona	16.2	(14.1–18.6)	19.5	(13.3–28.6)	10.3	(8.5–12.5)	10.3	(5.5–19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3	1.4†	1.1
Georgia	17.9	(16.0–20.2)	17.1	(15.4–18.9)	12.6	(10.6–15.0)	11.9	(8.9–16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6–17.0)	11.3	(8.9–14.2)	12.5	(10.0–15.6)	10.2	(6.1–16.9)	1.3†	1.2	0.9
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1†**	**1.2§**	**1.1§**

Abbreviation: CI = confidence interval.

* Per 1,000 children aged 8 years.

† Pearson chi-square test of prevalence ratio significant at p<0.05.

§ Pearson chi-square test of prevalence ratio significant at p<0.01.

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TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional before age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

*Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

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TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder			ASD/PDD			Asperger disorder			Any specified ASD diagnosis		
Site	**Median age**	**No.**	**(%)**	**Median age**	**No.**	**(%)**	**Median age**	**No.**	**(%)**	**Median age**	**No.**	**(%)**
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**	**52**	**3,794**	**(69.3)**

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

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TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	North Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with	311	455†	148§	752	159	201	851	444	293†	167§
Special education records	(89.1)	(87.2)†	—¶	(86.5)	(79.9)	(85.9)	(88.3)	(84.3)	(75.7)†	—
Primary exceptionality (%)										
Autism	65.3	65.1	43.2	57.8	66.0	65.2	47.7	74.3	68.9	39.5
Emotional disturbance	2.9	0.9	7.4	2.0	2.5	4.5	1.5	2.5	0.3	5.4
Specific learning disability	6.8	3.1	14.2	4.0	11.9	1.0	8.0	2.7	0.7	2.4
Speech or language impairment	5.5	10.3	10.1	2.4	3.8	5.0	13.6	3.6	10.9	19.2
Hearing or visual impairment	0	0.2	0	0.1	0	1.0	0.6	0.5	0	0.6
Health, physical or other disability	6.8	13.2	15.5	3.6	8.8	14.4	19.3	10.6	5.5	15.0
Multiple disabilities	0.3	4.2	4.7	0	4.4	1.5	6.9	1.6	0	0
Intellectual disability	3.2	3.1	4.1	2.0	1.9	7.0	1.8	2.7	2.0	0.6
Developmental delay/Preschool	9.3	0	0.7	28.1	0.6	0.5	0.6	1.6	11.6	17.4

Abbreviation: ASD = autism spectrum disorder.

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

† Includes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 12% Tennessee).

§ Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 67% Colorado, 74% Wisconsin).

¶ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

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TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties in Minneapolis–St. Paul§	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in south-eastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**	**13,903**	**(5.3)**	**1,438**	**(0.5)**

Abbreviation: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5th Edition.

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics (NCHS) Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

§ Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

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TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV or DSM-5	Met both DSM-IV and DSM-5		Met DSM-IV only		Met DSM-5 only		DSM-IV vs. DSM-5	
Site	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**Ratio**	**Kappa**
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All sites combined	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85

Abbreviations: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5th Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision.

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TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV or DSM-5	Met both DSM-IV and DSM-5		Met DSM-IV only		Met DSM-5 only		DSM-IV vs. DSM-5	
Characteristic	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**Ratio**	**Kappa**
Met ASD case definition under DSM-IV and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Sex									
Male	3,978	3,452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
Race/Ethnicity									
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian / Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
Earliest comprehensive evaluation on record*									
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37–48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1,503	1,195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Documented ASD Classification									
Autism special education eligibility	2,270	2,156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement†									
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis Autistic Disorder	1,577	1,526	(96.8)	0	(0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ASD-NOS	1,564	1,525	(97.5)	0	(0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger Disorder	221	210	(95.0)	0	(0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Most recent intelligence quotient score§									
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

Abbreviations: ASD = autism spectrum disorder; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders 5th ed.; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (Text Revision); PDD-NOS = pervasive developmental disorder–not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† A DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder automatically qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

§ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Jon Baio, EdS[1]; Lisa Wiggins, PhD[1]; Deborah L. Christensen, PhD[1]; Julie Daniels, PhD[2]; Zachary Warren, PhD[3]; Margaret Kurzius-Spencer, PhD[4]; Walter Zahorodny, PhD[5]; Cordelia Robinson Rosenberg, PhD[6]; Tiffany White, PhD[7]; Maureen Durkin, PhD[8]; Pamela Imm, MS[8]; Loizos Nikolaou, MPH[1,9]; Marshalyn Yeargin-Allsopp, MD[1]; Li-Ching Lee, PhD[10]; Rebecca Harrington, PhD[10]; Maya Lopez, MD[11]; Robert T. Fitzgerald, PhD[12]; Amy Hewitt, PhD[13]; Sydney Pettygrove, PhD[4]; John N. Constantino, MD[12]; Alison Vehorn, MS[3]; Josephine Shenouda, MS[5]; Jennifer Hall-Lande[13]; Kim Van Naarden Braun, PhD[1]; Nicole F. Dowling, PhD[1]

[1]National Center on Birth Defects and Developmental Disabilities, CDC; [2]University of North Carolina, Chapel Hill; [3]Vanderbilt University Medical Center, Nashville, Tennessee; [4]University of Arizona, Tucson; [5]Rutgers University, Newark, New Jersey; [6]University of Colorado School of Medicine at the Anschutz Medical Campus; [7]Colorado Department of Public Health and Environment, Denver; [8]University of Wisconsin, Madison; [9]Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee; [10]Johns Hopkins University, Baltimore, Maryland; [11]University of Arkansas for Medical Sciences, Little Rock; [12]Washington University in St. Louis, Missouri; [13]University of Minnesota, Minneapolis

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within multiple ADDM sites in the United States. The Centers for Disease Control and Prevention (CDC) has funded universities and public health departments in 16 states since 2000, and CDC also serves as the Georgia ADDM site. The current report is based on data from 11 sites, which completed surveillance of ASD in parts of Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee and Wisconsin. ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the Diagnostic and Statistical Manual of Mental Disorders 5th ed. (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria

might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the DSM-5 diagnostic criteria, which include the presence of an established DSM-IV-TR diagnosis of Autistic Disorder, PDD-NOS, or Asperger Disorder. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ]: ≤70), 25% were in the borderline range (IQ: 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ: >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from CDC's ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar estimate of ASD prevalence. Questions remain about the long-term impact of the revised diagnostic criteria on population-based estimates of the number and characteristics of children with ASD, as DSM-IV-TR diagnoses such as Autistic Disorder, PDD-NOS, and Asperger Disorder will abate while documentation of symptoms consistent with DSM-5 terminology will increase over time.

Public Health Action: The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of

ASD and characteristics of children with ASD in the United States in 1998 (*2,3*). The first CDC study was based on an investigation in Brick Township, New Jersey (*2*), which identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study was conducted in metropolitan Atlanta, Georgia (*3*), which identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. 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 (*4,5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5 (*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have risen from approximately one in 150 children during 2000–2002 to one in 68 during 2010-2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence substantiates a need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD from 2006 to 2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000-2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by about 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by about 50% in 2008, 2010 and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time

at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change between 2002 and 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9,10,11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ: ≤70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008 this proportion was closer to 40%, and during 2010-2012 less than one third of children with ASD had IQ ≤70 (*9,10,11*). This trend was more pronounced for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from about 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (9,*10,11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with the Diagnostic and Statistical Manual of Mental Disorders–Fourth Edition (Text Revision) (DSM-IV-TR) diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including atypical autism); or Asperger Disorder. In the American Psychiatric Association's 2013 publication of its Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included several diagnostic subtypes, to Autism Spectrum Disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by severity levels. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons who have ASD under DSM-5 diagnosed must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input). According to the DSM-5 Workgroup on Neurodevelopmental Disorders, the need for new criteria for autism and related disorders was identified long before the Workgroup was convened in 2007 (*18*).

Although the DSM-IV-TR criteria proved useful in identifying ASD in children aged 5–8 years, they performed less well when used in the diagnosis of toddlers and preschool-aged children, adolescents, and young adults (*18*). Further, the DSM-IV-TR criteria were insufficient to accurately identify girls and women with autism and lacked the cultural sensitivity needed to identify cases in ethnic or racial minorities (*18*). The DSM-5 changes introduced a more focused diagnostic framework compared with that of DSM-IV-TR; however, DSM-5 states that any person with an established DSM-IV-TR diagnosis of Autistic Disorder, Asperger Disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of Autism Spectrum Disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude some children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

The purpose of this report is to provide the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and to assert the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge which led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network. The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Some minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight ADDM Network surveillance years (2000, 2002, 2004, 2006, 2008, 2010, 2012 and 2014), 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD; 2) to monitor the prevalence of ASD in different areas of the United States; and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data are collected for children aged 8 years during the 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational

records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee and Wisconsin) received permission to review education records in only some school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites, 33% in Colorado and 26% in Wisconsin. In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources is abstracted into a single composite record for each child.

In the second phase of surveillance, the abstracted composite evaluation files are de-identified and reviewed systematically by experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians) (*26*). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. Behavioral and diagnostic components of the DSM-IV-TR and DSM-5 ASD case definitions operationalized for ADDM surveillance are outlined (Boxes 1 and 2). In practice, DSM-5 criteria automatically include children with an established DSM-IV-TR diagnosis of ASD, thus, the ADDM coding scheme similarly accommodated those with a previous DSM-IV-TR diagnosis in the DSM-5 case definition, regardless of whether documented symptoms independently met

either the DSM-IV-TR or DSM-5 diagnostic criteria. The coding scheme allowed differentiation of children who met DSM-5 criteria on the basis of behavioral characteristics from those who met DSM-5 criteria solely through a previous DSM-IV-TR diagnosis.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (*5*). For 2014, interrater agreement on case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined ($k = 0.77$), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined ($k = 0.84$). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*27*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age,

race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*28*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Pearson chi-square tests were also performed for testing significance in comparisons of proportions, and Mantel-Haenszel common odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 of 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3), Minnesota (24.0) and Maryland (20.0). Five sites reported prevalence estimates in the range of 13.1 to 14.1 per 1,000 (Arizona, Arkansas, Colorado, Missouri, and Wisconsin), and three sites reported prevalence estimates ranging from 15.5 to 17.4 per 1,000 (Georgia, North Carolina, and Tennessee).

Prevalence by Sex and Race/Ethnicity

When data from all 11 ADDM sites are combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence 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 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites. In nine sites, the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites. In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability are reported only for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least

70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ: ≤70), 25% were in the borderline range (IQ: 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4, p<0.01), though among individual sites this proportion differed significantly in only one (Georgia, OR = 1.6, p<0.05). The proportion of children with ASD with borderline intellectual ability (IQ: 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2, p<0.05).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all nine sites and when combining their data (OR = 2.9, p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9, p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8, p = 0.09), North Carolina (OR = 1.8, p = 0.07) and Tennessee (OR = 2.1, p = 0.10). The proportion of children with borderline intellectual ability (IQ = 71 85) did not differ by race/ethnicity in any of these nine sites or when combining their data; however, when combining data from these nine sites the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR − 3.4, p<0.01) or Hispanic (36%, OR − 2.2, p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV, DSM-5 or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR − 1.4; p<0.01). When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR − 0.9; p−0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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

(48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

Sites with access to education records collected information about the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from 40% in Wisconsin to 74% in North Carolina. Most other sites noted approximately half of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (43%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in five sites (Arkansas, Colorado, Missouri, New Jersey, and North Carolina), about 8% higher in Maryland, and nearly 20% higher in Tennessee, where investigators did not obtain permission to review children's records in one of the 14 school districts comprising the 11-county surveillance area.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%) and Colorado (14%). Kappa statistics indicated

strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were about 3% lower than DSM-IV-TR counts for males, and about 6% lower for females (kappa = 0.85 for both). Case counts were about 3% lower among white and black children on DSM-5 compared with DSM-IV, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV. Slightly over 3% of children whose earliest ASD diagnosis was Autistic Disorder met DSM-5 criteria but not DSM-IV, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger Disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed an increase in ASD prevalence estimates during 2012–2014, with a nearly 10% prevalence increase in Georgia and Maryland, 19% in New Jersey, 23% in Missouri, 29% in Colorado and 31% in Wisconsin. The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative increase in prevalence are remarkable in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall Colorado surveillance area), and Wisconsin was granted access to review education records in parts of two of the 10 counties comprising their 2014 surveillance area. Although this represented only 26% of the population aged 8 years within the overall Wisconsin surveillance area, 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Some characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20% 30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and about 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be due, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1 14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 8-year-olds. Those sites with limited or no access to education data sources (Colorado, Missouri, and Wisconsin) had prevalence estimates near the lower range among all sites. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted on the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors such as regional and socioeconomic disparities in access to services (*13,14*).

Case Definitions

Agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype or level of intellectual ability. Overall, ASD prevalence estimates based on the new DSM-5 case definition were very similar in

magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented DSM-IV-TR diagnosis of ASD automatically qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented DSM-IV-TR diagnosis. This element of the DSM-5 case definition will carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing DSM-IV-TR diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published. Using this approach, agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for Autistic Disorder, PDD-NOS or Asperger Disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison With National Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that may affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*29*). An estimate of 20.0 per 1,000 children aged 6–17 years was reported from the 2011–2012 NSCH (*30*). The study samples for the two phone surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6 11,29,30*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral,

developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to several limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, it is possible that some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for evaluating policy changes, treatments or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3,6 11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

When the ADDM methodology was originally developed, estimating ASD prevalence among children aged 8 years was determined to represent the peak prevalence, based on estimates for multiple ages in metropolitan Atlanta in 1996 (*3*). Estimating prevalence among children aged 8 years requires quality data

from both health and educational agencies and likely captures most children whose adaptive performance is impacted by ASD. However, because prevalence estimation takes considerable time and effort, reporting of estimates lags behind the surveillance year by 3–4 years. Thus, opportunities for policy or programmatic enhancements to impact key health indicators also lag. Focusing on younger cohorts might allow earlier assessment of systematic changes (e.g., policies, insurance, and programs) that impact younger children, rather than waiting until cohorts impacted by these changes reach age 8 years. Surveillance of ASD in older populations is also important but might require different methodological approaches.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*31*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*32*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD are evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*33*), might inform how policy initiatives such as screening recommendations and other social determinants of health impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD has increased compared with previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing behavioral, educational, residential and occupational needs of this population.

Contrary to some predictions, the redefinition of ASD provided by the DSM-5 might have had a relatively small contribution to the overall ASD estimate provided by the ADDM Network. This might be a result of the carryover effect of including all DSM-IV-TR-diagnosed cases in the DSM-5 count. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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FIGURE 1. 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, nine sites,* United States, 2014

Abbreviations: F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014

Abbreviations: F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

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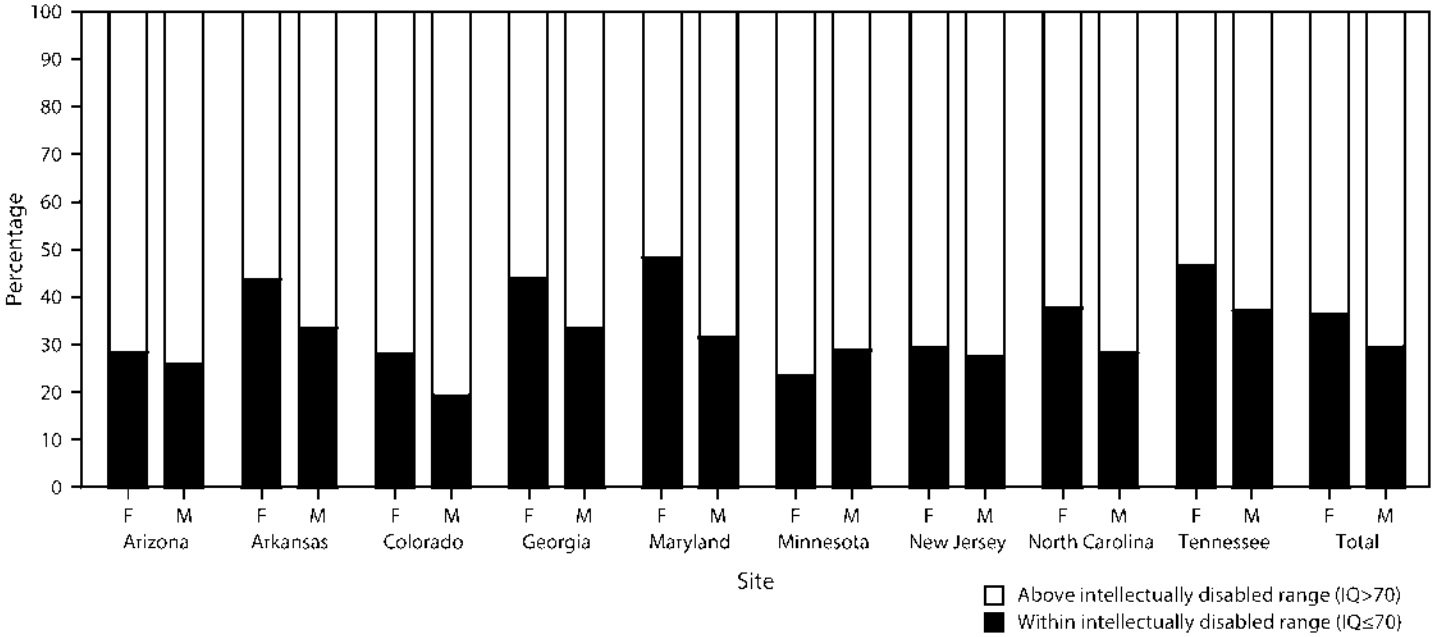
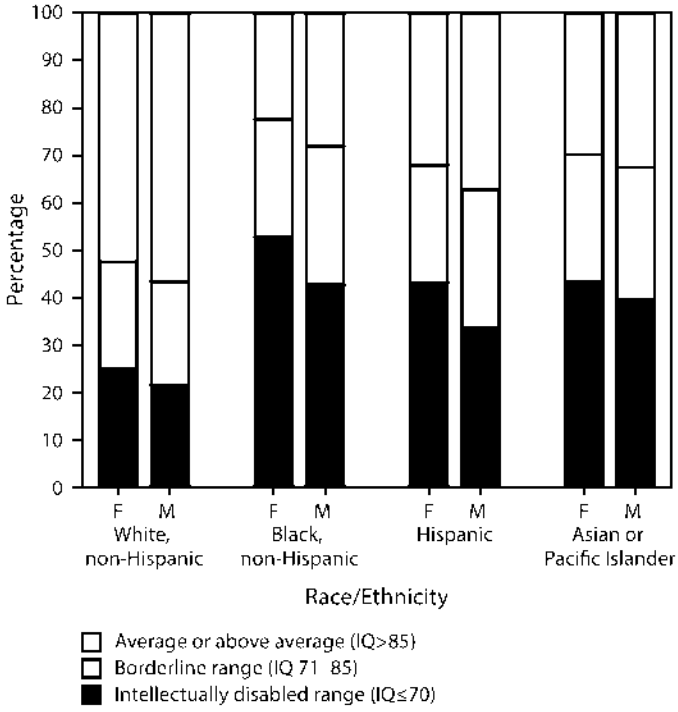
FIGURE 1. Most recent intelligence quotient score as of age 8 years among children with autism spectrum disorder (ASD) for whom test data were available, by sex and site — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



Abbreviations: 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 2. Most recent intelligence quotient score as of age 8 years among children with autism spectrum disorder (ASD) for whom test data were available, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



Abbreviations: 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.

Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Jon Baio, EdS[1]; Lisa Wiggins, PhD[1]; Deborah L. Christensen, PhD[1]; Julie Daniels, PhD[2]; Zachary Warren, PhD[3]; Margaret Kurzius-Spencer, PhD[4]; Walter Zahorodny, PhD[5]; Cordelia Robinson Rosenberg, PhD[6]; Tiffany White, PhD[7]; Maureen Durkin, PhD[8]; Pamela Imm, MS[8]; Loizos Nikolaou, MPH[1,9]; Marshalyn Yeargin-Allsopp, MD[1]; Li-Ching Lee, PhD[10]; Rebecca Harrington, PhD[10]; Maya Lopez, MD[11]; Robert T. Fitzgerald, PhD[12]; Amy Hewitt, PhD[13]; Sydney Pettygrove, PhD[4]; John N. Constantino, MD[12]; Alison Vehorn, MS[3]; Josephine Shenouda, MS[5]; Jennifer Hall-Lande[13]; Kim Van Naarden Braun, PhD[1]; Nicole F. Dowling, PhD[1]

[1]National Center on Birth Defects and Developmental Disabilities, CDC; [2]University of North Carolina, Chapel Hill; [3]Vanderbilt University Medical Center, Nashville, Tennessee; [4]University of Arizona, Tucson; [5]Rutgers University, Newark, New Jersey; [6]University of Colorado School of Medicine at the Anschutz Medical Campus; [7]Colorado Department of Public Health and Environment, Denver; [8]University of Wisconsin, Madison; [9]Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee; [10]Johns Hopkins University, Baltimore, Maryland; [11]University of Arkansas for Medical Sciences, Little Rock; [12]Washington University in St. Louis, Missouri; [13]University of Minnesota, Minneapolis

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders 5th ed.* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the

DSM-5 diagnostic criteria, which include the presence of an established DSM-IV-TR diagnosis of Autistic Disorder, PDD-NOS, or Asperger Disorder. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1 29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar estimate of ASD prevalence.

Public Health Action: The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD. Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence as reported in biennial *MMWR Surveillance Summaries*. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses such as Autistic Disorder, PDD-NOS, and Asperger Disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2,3*). The first CDC study,

which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5 (*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence substantiates a need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD from 2006 to 2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000–2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high,

middle, and lower SES did not change between 2002 and 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9,10,11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ ≤70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008 this proportion was closer to 40%, and during 2010–2012 less than one third of children with ASD had IQ ≤70 (*9,10,11*). This trend was more pronounced for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (9,*10,11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including atypical autism); or Asperger Disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to Autism Spectrum Disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by severity levels. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons who have ASD under DSM-5 diagnosed must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input). According to the DSM-5 Workgroup on Neurodevelopmental Disorders, the need for new criteria for autism and related disorders was identified long before the Workgroup was convened in 2007 (*18*).

Although the DSM-IV-TR criteria proved useful in identifying ASD in children aged 5–8 years, they performed less well when used in the diagnosis of toddlers and preschool-aged children, adolescents, and young adults (*18*). Further, the DSM-IV-TR criteria were insufficient to accurately identify girls and women with autism and lacked the cultural sensitivity needed to identify cases in ethnic or racial minorities (*18*). The DSM-5 changes introduced a more focused framework compared with that of DSM-IV-TR; however, DSM-5 states that any person with an established DSM-IV-TR diagnosis of Autistic Disorder, Asperger Disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of Autism Spectrum Disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and to assert the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge which led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight biennial ADDM Network surveillance years spanning 2000–2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD; 2) to monitor the prevalence of ASD in different areas of the United States; and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data are collected for children aged 8 years during the 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites,

some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians) (*26*). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. Behavioral and diagnostic components of the DSM-IV-TR and DSM-5 ASD case definitions operationalized for ADDM surveillance are outlined (Boxes 1 and 2). In practice, DSM-5 criteria automatically include children with an established DSM-IV-TR diagnosis of ASD, thus, the ADDM coding scheme similarly accommodated those with a previous DSM-IV-TR

diagnosis in the DSM-5 case definition, regardless of whether documented symptoms independently met either the DSM-IV-TR or DSM-5 diagnostic criteria. The coding scheme allowed differentiation of children who met DSM-5 criteria on the basis of behavioral characteristics from those who met DSM-5 criteria solely through a previous DSM-IV-TR diagnosis.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (*5*). For 2014, interrater agreement on case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined (k = 0.77), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined (k = 0.84). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*27*). CDC's

National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*28*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Pearson chi-square tests were also performed for testing significance in comparisons of proportions, and Mantel-Haenszel common odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 of 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3), Minnesota (24.0), and Maryland (20.0). Five sites reported prevalence estimates in the range of 13.1 to 14.1 per 1,000 (Arizona, Arkansas, Colorado, Missouri, and Wisconsin), and three sites reported prevalence estimates ranging from 15.5 to 17.4 per 1,000 (Georgia, North Carolina, and Tennessee).

Prevalence by Sex and Race/Ethnicity

When data from all 11 ADDM sites are combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence 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 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites. In nine sites, the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites. In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability are reported only for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least

70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4; p<0.01), though among individual sites this proportion differed significantly in only one (Georgia, OR = 1.6; p<0.05). The proportion of children with ASD with borderline intellectual ability (IQ 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2; p<0.05).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all nine sites and when combining their data (OR = 2.9; p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9; p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8, p = 0.09), North Carolina (OR = 1.8, p = 0.07) and Tennessee (OR = 2.1, p = 0.10). The proportion of children with borderline intellectual ability (IQ = 71 85) did not differ by race/ethnicity in any of these nine sites or when combining their data; however, when combining data from these nine sites the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR − 3.4; p<0.01) or Hispanic (36%, OR − 2.2; p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV, DSM-5 or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR − 1.4; p<0.01). When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR − 0.9; p−0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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

(48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

Sites with access to education records collected information approximately the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from 40% in Wisconsin to 74% in North Carolina. Most other sites noted approximately half of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (43%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in five sites (Arkansas, Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Tennessee, where investigators did not obtain permission to review children's records in one of the 14 school districts comprising the 11-county surveillance area.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated

strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV. Slightly over 3% of children whose earliest ASD diagnosis was Autistic Disorder met DSM-5 criteria but not DSM-IV, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger Disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed an increase in ASD prevalence estimates during 2012–2014, with a nearly 10% prevalence increase in Georgia and Maryland, 19% in New Jersey, 23% in Missouri, 29% in Colorado, and 31% in Wisconsin. The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative increase in prevalence are remarkable in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall Colorado surveillance area), and Wisconsin was granted access to review education records in parts of two of the 10 counties comprising their 2014 surveillance area. Although this represented only 26% of the population aged 8 years within the overall Wisconsin surveillance area, 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20% 30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1 14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 8-year-olds. Those sites with limited or no access to education data sources (Colorado, Missouri, and Wisconsin) had prevalence estimates near the lower range among all sites. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted on the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors such as regional and socioeconomic disparities in access to services (*13,14*).

Case Definitions

Agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype or level of intellectual ability. Overall, ASD prevalence estimates based on the new DSM-5 case definition were very similar in

magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented DSM-IV-TR diagnosis of ASD automatically qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented DSM-IV-TR diagnosis. This element of the DSM-5 case definition will carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing DSM-IV-TR diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published. Using this approach, agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for Autistic Disorder, PDD-NOS or Asperger Disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison With National Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that may affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*29*). An estimate of 20.0 per 1,000 children aged 6–17 years was reported from the 2011–2012 NSCH (*30*). The study samples for the two phone surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6 11,29,30*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral,

developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to several limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, it is possible that some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for evaluating policy changes, treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3,6 11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

When the ADDM methodology was originally developed, estimating ASD prevalence among children aged 8 years was determined to represent the peak prevalence, based on estimates for multiple ages in metropolitan Atlanta in 1996 (*3*). Estimating prevalence among children aged 8 years requires quality data

from both health and educational agencies and likely captures most children whose adaptive performance is impacted by ASD. However, because prevalence estimation takes considerable time and effort, reporting of estimates lags behind the surveillance year by 3–4 years. Thus, opportunities for policy or programmatic enhancements to impact key health indicators also lag. Focusing on younger cohorts might allow earlier assessment of systematic changes (e.g., policies, insurance, and programs) that impact younger children, rather than waiting until cohorts impacted by these changes reach age 8 years. Surveillance of ASD in older populations is also important but might require different methodological approaches.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*31*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*32*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD are evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*33*), might inform how policy initiatives such as screening recommendations and other social determinants of health impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD has increased compared with previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing behavioral, educational, residential and occupational needs of this population.

Contrary to some predictions, the redefinition of ASD provided by the DSM-5 might have had a relatively limited contribution to the overall ASD estimate provided by the ADDM Network. This might be a result of the carryover effect of including all DSM-IV-TR-diagnosed cases in the DSM-5 count. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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FIGURE 1. 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, nine sites,* United States, 2014

Abbreviations: F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014

Abbreviations: F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

BOX 1

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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Jon Baio, EdS[1]; Lisa Wiggins, PhD[1]; Deborah L. Christensen, PhD[1]; Julie Daniels, PhD[2]; Zachary Warren, PhD[3]; Margaret Kurzius-Spencer, PhD[4]; Walter Zahorodny, PhD[5]; Cordelia Robinson Rosenberg, PhD[6]; Tiffany White, PhD[7]; Maureen Durkin, PhD[8]; Pamela Imm, MS[8]; Loizos Nikolaou, MPH[1,9]; Marshalyn Yeargin-Allsopp, MD[1]; Li-Ching Lee, PhD[10]; Rebecca Harrington, PhD[10]; Maya Lopez, MD[11]; Robert T. Fitzgerald, PhD[12]; Amy Hewitt, PhD[13]; Sydney Pettygrove, PhD[4]; John N. Constantino, MD[12]; Alison Vehorn, MS[3]; Josephine Shenouda, MS[5]; Jennifer Hall-Lande[13]; Kim Van Naarden Braun, PhD[1]; Nicole F. Dowling, PhD[1]

[1]National Center on Birth Defects and Developmental Disabilities, CDC; [2]University of North Carolina, Chapel Hill; [3]Vanderbilt University Medical Center, Nashville, Tennessee; [4]University of Arizona, Tucson; [5]Rutgers University, Newark, New Jersey; [6]University of Colorado School of Medicine at the Anschutz Medical Campus; [7]Colorado Department of Public Health and Environment, Denver; [8]University of Wisconsin, Madison; [9]Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee; [10]Johns Hopkins University, Baltimore, Maryland; [11]University of Arkansas for Medical Sciences, Little Rock; [12]Washington University in St. Louis, Missouri; [13]University of Minnesota, Minneapolis

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders 5th ed.* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the

DSM-5 diagnostic criteria, which include the presence of an established DSM-IV-TR diagnosis of Autistic Disorder, PDD-NOS, or Asperger Disorder. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1 29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar estimate of ASD prevalence.

Public Health Action: The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD. Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence as reported in biennial *MMWR Surveillance Summaries*. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses such as Autistic Disorder, PDD-NOS, and Asperger Disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2,3*). The first CDC study,

which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5 (*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence substantiates a need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD from 2006 to 2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000–2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high,

middle, and lower SES did not change between 2002 and 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9,10,11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ ≤70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008 this proportion was closer to 40%, and during 2010–2012 less than one third of children with ASD had IQ ≤70 (*9,10,11*). This trend was more pronounced for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (9,*10,11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including atypical autism); or Asperger Disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to Autism Spectrum Disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by severity levels. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons who have ASD under DSM-5 diagnosed must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input). According to the DSM-5 Workgroup on Neurodevelopmental Disorders, the need for new criteria for autism and related disorders was identified long before the Workgroup was convened in 2007 (*18*).

Although the DSM-IV-TR criteria proved useful in identifying ASD in children aged 5–8 years, they performed less well when used in the diagnosis of toddlers and preschool-aged children, adolescents, and young adults (*18*). Further, the DSM-IV-TR criteria were insufficient to accurately identify girls and women with autism and lacked the cultural sensitivity needed to identify cases in ethnic or racial minorities (*18*). The DSM-5 changes introduced a more focused framework compared with that of DSM-IV-TR; however, DSM-5 states that any person with an established DSM-IV-TR diagnosis of Autistic Disorder, Asperger Disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of Autism Spectrum Disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and to assert the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge which led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight biennial ADDM Network surveillance years spanning 2000–2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD; 2) to monitor the prevalence of ASD in different areas of the United States; and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data are collected for children aged 8 years during the 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites,

some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians) (*26*). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. Behavioral and diagnostic components of the DSM-IV-TR and DSM-5 ASD case definitions operationalized for ADDM surveillance are outlined (Boxes 1 and 2). In practice, DSM-5 criteria automatically include children with an established DSM-IV-TR diagnosis of ASD, thus, the ADDM coding scheme similarly accommodated those with a previous DSM-IV-TR

diagnosis in the DSM-5 case definition, regardless of whether documented symptoms independently met either the DSM-IV-TR or DSM-5 diagnostic criteria. The coding scheme allowed differentiation of children who met DSM-5 criteria on the basis of behavioral characteristics from those who met DSM-5 criteria solely through a previous DSM-IV-TR diagnosis.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (*5*). For 2014, interrater agreement on case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined (k = 0.77), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined (k = 0.84). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*27*). CDC's

National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*28*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Pearson chi-square tests were also performed for testing significance in comparisons of proportions, and Mantel-Haenszel common odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 of 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3), Minnesota (24.0), and Maryland (20.0). Five sites reported prevalence estimates in the range of 13.1 to 14.1 per 1,000 (Arizona, Arkansas, Colorado, Missouri, and Wisconsin), and three sites reported prevalence estimates ranging from 15.5 to 17.4 per 1,000 (Georgia, North Carolina, and Tennessee).

Prevalence by Sex and Race/Ethnicity

When data from all 11 ADDM sites are combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence 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 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites. In nine sites, the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites. In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability are reported only for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least

70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4; p<0.01), though among individual sites this proportion differed significantly in only one (Georgia, OR = 1.6; p<0.05). The proportion of children with ASD with borderline intellectual ability (IQ 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2; p<0.05).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all nine sites and when combining their data (OR = 2.9; p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9; p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8, p = 0.09), North Carolina (OR = 1.8, p = 0.07) and Tennessee (OR = 2.1, p = 0.10). The proportion of children with borderline intellectual ability (IQ = 71 85) did not differ by race/ethnicity in any of these nine sites or when combining their data; however, when combining data from these nine sites the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR − 3.4; p<0.01) or Hispanic (36%, OR − 2.2; p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV, DSM-5 or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR − 1.4; p<0.01). When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR − 0.9; p−0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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

(48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

Sites with access to education records collected information approximately the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from 40% in Wisconsin to 74% in North Carolina. Most other sites noted approximately half of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (43%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in five sites (Arkansas, Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Tennessee, where investigators did not obtain permission to review children's records in one of the 14 school districts comprising the 11-county surveillance area.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated

strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV. Slightly over 3% of children whose earliest ASD diagnosis was Autistic Disorder met DSM-5 criteria but not DSM-IV, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger Disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed an increase in ASD prevalence estimates during 2012–2014, with a nearly 10% prevalence increase in Georgia and Maryland, 19% in New Jersey, 23% in Missouri, 29% in Colorado, and 31% in Wisconsin. The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative increase in prevalence are remarkable in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall Colorado surveillance area), and Wisconsin was granted access to review education records in parts of two of the 10 counties comprising their 2014 surveillance area. Although this represented only 26% of the population aged 8 years within the overall Wisconsin surveillance area, 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20% 30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1 14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 8-year-olds. Those sites with limited or no access to education data sources (Colorado, Missouri, and Wisconsin) had prevalence estimates near the lower range among all sites. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted on the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors such as regional and socioeconomic disparities in access to services (*13,14*).

Case Definitions

Agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype or level of intellectual ability. Overall, ASD prevalence estimates based on the new DSM-5 case definition were very similar in

magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented DSM-IV-TR diagnosis of ASD automatically qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented DSM-IV-TR diagnosis. This element of the DSM-5 case definition will carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing DSM-IV-TR diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published. Using this approach, agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for Autistic Disorder, PDD-NOS or Asperger Disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison With National Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that may affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*29*). An estimate of 20.0 per 1,000 children aged 6–17 years was reported from the 2011–2012 NSCH (*30*). The study samples for the two phone surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6 11,29,30*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral,

developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to several limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, it is possible that some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for evaluating policy changes, treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3,6 11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

When the ADDM methodology was originally developed, estimating ASD prevalence among children aged 8 years was determined to represent the peak prevalence, based on estimates for multiple ages in metropolitan Atlanta in 1996 (*3*). Estimating prevalence among children aged 8 years requires quality data

from both health and educational agencies and likely captures most children whose adaptive performance is impacted by ASD. However, because prevalence estimation takes considerable time and effort, reporting of estimates lags behind the surveillance year by 3–4 years. Thus, opportunities for policy or programmatic enhancements to impact key health indicators also lag. Focusing on younger cohorts might allow earlier assessment of systematic changes (e.g., policies, insurance, and programs) that impact younger children, rather than waiting until cohorts impacted by these changes reach age 8 years. Surveillance of ASD in older populations is also important but might require different methodological approaches.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*31*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*32*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD are evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*33*), might inform how policy initiatives such as screening recommendations and other social determinants of health impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD has increased compared with previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing behavioral, educational, residential and occupational needs of this population.

Contrary to some predictions, the redefinition of ASD provided by the DSM-5 might have had a relatively limited contribution to the overall ASD estimate provided by the ADDM Network. This might be a result of the carryover effect of including all DSM-IV-TR-diagnosed cases in the DSM-5 count. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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FIGURE 1. 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, nine sites,* United States, 2014

Abbreviations: F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014

Abbreviations: F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

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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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties in Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in south-eastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**	**16,596**	**(5.1)**	**1,907**	**(0.6)**

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics (NCHS) Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014–2015 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Overall†		Sex				Male-to-female prevalence ratio§
					Males		Females		
			Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	
Arizona	**24,952**	**349**	14.0	(12.6–15.5)	21.1	(18.7–23.8)	6.6	(5.3–8.2)	3.2
Arkansas	**39,992**	**522**	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	3.8
Colorado	**41,128**	**572**	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	3.9
Georgia	**51,161**	**869**	17.0	(15.9–18.2)	27.9	(25.9–30.0)	5.7	(4.8–6.7)	4.9
Maryland	**9,955**	**199**	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	4.5
Minnesota	**9,767**	**234**	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	4.6
Missouri	**25,333**	**356**	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	4.0
New Jersey	**32,935**	**964**	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	3.7
North Carolina	**30,283**	**527**	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	4.3
Tennessee	**24,940**	**387**	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	4.7
Wisconsin	**35,037**	**494**	14.1	(12.9–15.4)	21.4	(19.4–23.7)	6.4	(5.3–7.7)	3.4
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	**4.0**

Abbreviation: CI = confidence interval.

* Per 1,000 children aged 8 years.

† All children are included in the total regardless of race or ethnicity.

§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

TABLE 3. Estimated prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/ethnicity								Prevalence ratio		
	White		Black		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			
Arizona	16.2	(14.1–18.6)	19.5	(13.3–28.6)	10.3	(8.5–12.5)	10.3	(5.5–19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3	1.4†	1.1
Georgia	17.9	(16.0–20.2)	17.1	(15.4–18.9)	12.6	(10.6–15.0)	11.9	(8.9–16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6–17.0)	11.3	(8.9–14.2)	12.5	(10.0–15.6)	10.2	(6.1–16.9)	1.3†	1.2	0.9
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1†**	**1.2§**	**1.1§**

Abbreviation: CI = confidence interval.

* Per 1,000 children aged 8 years.

† Pearson chi-square test of prevalence ratio significant at p<0.05.

§ Pearson chi-square test of prevalence ratio significant at p<0.01.

TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional before age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

*Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder			ASD/PDD			Asperger disorder			Any specified ASD diagnosis		
Site	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**	**52**	**3,794**	**(69.3)**

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

TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	North Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with	311	455†	148§	752	159	201	851	444	293†	167§
Special education records	(89.1)	(87.2)†	—¶	(86.5)	(79.9)	(85.9)	(88.3)	(84.3)	(75.7)†	—
Primary exceptionality (%)										
Autism	65.3	65.1	43.2	57.8	66.0	65.2	47.7	74.3	68.9	39.5
Emotional disturbance	2.9	0.9	7.4	2.0	2.5	4.5	1.5	2.5	0.3	5.4
Specific learning disability	6.8	3.1	14.2	4.0	11.9	1.0	8.0	2.7	0.7	2.4
Speech or language impairment	5.5	10.3	10.1	2.4	3.8	5.0	13.6	3.6	10.9	19.2
Hearing or visual impairment	0	0.2	0	0.1	0	1.0	0.6	0.5	0	0.6
Health, physical or other disability	6.8	13.2	15.5	3.6	8.8	14.4	19.3	10.6	5.5	15.0
Multiple disabilities	0.3	4.2	4.7	0	4.4	1.5	6.9	1.6	0	0
Intellectual disability	3.2	3.1	4.1	2.0	1.9	7.0	1.8	2.7	2.0	0.6
Developmental delay/Preschool	9.3	0	0.7	28.1	0.6	0.5	0.6	1.6	11.6	17.4

Abbreviation: ASD = autism spectrum disorder.

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

† Includes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 12% Tennessee).

§ Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 67% Colorado, 74% Wisconsin).

¶ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties in Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in south-eastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**	**13,903**	**(5.3)**	**1,438**	**(0.5)**

Abbreviation: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5th Edition.

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics (NCHS) Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV or DSM-5	Met both DSM-IV and DSM-5		Met DSM-IV only		Met DSM-5 only		DSM-IV vs. DSM-5	
Site	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**Ratio**	**Kappa**
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All sites combined	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85

Abbreviations: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5th Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision.

TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV or DSM-5	Met both DSM-IV and DSM-5		Met DSM-IV only		Met DSM-5 only		DSM-IV vs. DSM-5	
Characteristic	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**Ratio**	**Kappa**
Met ASD case definition under DSM-IV and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Sex									
Male	3,978	3,452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
Race/Ethnicity									
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian / Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
Earliest comprehensive evaluation on record*									
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37–48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1,503	1,195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Documented ASD Classification									
Autism special education eligibility	2,270	2,156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement†									
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis Autistic Disorder	1,577	1,526	(96.8)	0	(0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ASD-NOS	1,564	1,525	(97.5)	0	(0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger Disorder	221	210	(95.0)	0	(0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Most recent intelligence quotient score§									
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

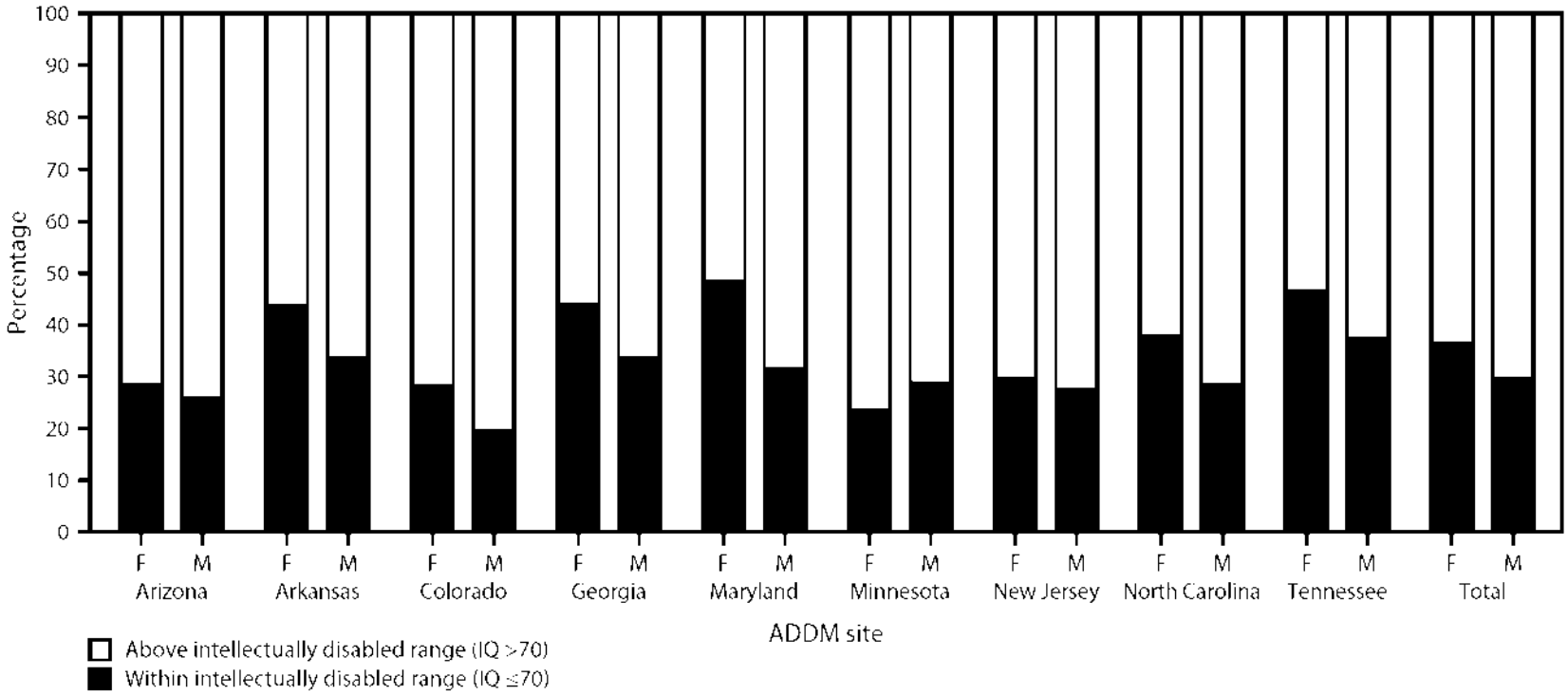
Abbreviations: ASD = autism spectrum disorder; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders 5th ed.; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (Text Revision); PDD-NOS = pervasive developmental disorder–not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† A DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder automatically qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

§ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

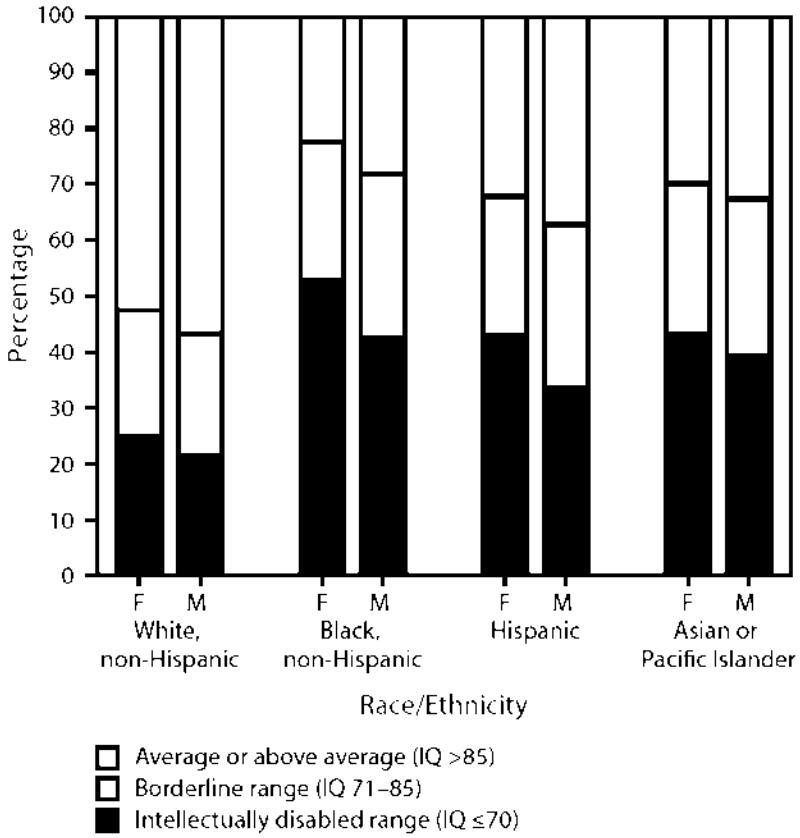
FIGURE 1. Most recent intelligence quotient score as of age 8 years among children with autism spectrum disorder for whom test data were available, by sex and site — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



Abbreviations: ADDM = Autism and Developmental Disabilities Monitoring Network; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for >70% of children who met the ASD case definition (n = 3,714).

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



Abbreviations: F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted behavior/Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines, or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the age of 3 years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive

Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least six behaviors coded with a minimum of two Social, one Communication, and one Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of 3 years OR At least two behaviors coded with a minimum of one Social and either one Communication and/or one Restricted Behavior/Interest; AND at least one Autism Discriminator coded

Abbreviation: DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (Text Revision).*

BOX 2. Autism spectrum disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	A well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder–not otherwise specified (PDD-NOS)
DSM-5 case determination	All three behavioral criteria coded under part A, and at least two behavioral criteria coded under part B OR A DSM-IV diagnosis of autistic disorder, Asperger's disorder, or PDD-NOS

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders 5th ed.*

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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Jon **Baio**, EdS[1]; Lisa **Wiggins**, PhD[1]; Deborah L. **Christensen**, PhD[1]; Matthew J Maenner, PhD[1], Julie **Daniels**, PhD[2]; Zachary **Warren**, PhD[3]; Margaret **Kurzius-Spencer**, PhD[4]; Walter **Zahorodny**, PhD[5]; Cordelia **Robinson Rosenberg**, PhD[6]; Tiffany **White**, PhD[7]; Maureen S. **Durkin**, PhD[8]; Pamela **Imm**, MS[8]; Loizos **Nikolaou**, MPH[1,9]; Marshalyn **Yeargin-Allsopp**, MD[1]; Li-Ching Lee, PhD[10]; Rebecca **Harrington**, PhD[10]; Maya **Lopez**, MD[11]; Robert T. **Fitzgerald**, PhD[12]; Amy **Hewitt**, PhD[13]; Sydney **Pettygrove**, PhD[4]; John N. **Constantino**, MD[12]; Alison Vehorn, MS[3]; Josephine **Shenouda**, MS[5]; Jennifer Hall-Lande, PhD[13]; Kim Van Naarden **Braun**, PhD[1]; Nicole F. **Dowling**, PhD[1]

[1]National Center on Birth Defects and Developmental Disabilities, CDC; [2]University of North Carolina, Chapel Hill; [3]Vanderbilt University Medical Center, Nashville, Tennessee; [4]University of Arizona, Tucson; [5]Rutgers University, Newark, New Jersey; [6]University of Colorado School of Medicine at the Anschutz Medical Campus; [7]Colorado Department of Public Health and Environment, Denver; [8]University of Wisconsin, Madison; [9]Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee; [10]Johns Hopkins University, Baltimore, Maryland; [11]University of Arkansas for Medical Sciences, Little Rock; [12]Washington University in St. Louis, Missouri; [13]University of Minnesota, Minneapolis

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for autistic disorder; pervasive developmental disorder not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the DSM-5 diagnostic criteria. Children meeting this new surveillance case definition could qualify on the basis of one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD

diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar estimate of ASD prevalence.

Public Health Action: Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence in future surveillance reports. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses, such as autistic disorder, PDD-NOS, and Asperger disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time. The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2*,*3*). The first CDC study, which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental

Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5 (*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence underscores the need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD during 2006–2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000 2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change from 2002 to 2010 (*14*,*15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9*,*10*,*11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ $\leq$70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008, this proportion was closer to 40%; and during 2010–2012, less than one third of children with ASD had IQ $\leq$70 (9,*10*,*11*). This trend was more pronounced

for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (*9,10,11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to autism spectrum disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by level of support needed by the individual. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons diagnosed with ASD under DSM-5 must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors; and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input).

Although the DSM-IV-TR criteria proved useful in identifying ASD in some children, there was a lack of clinical agreement on ASD subtypes, poor diagnostic specificity in some subtypes (e.g., PDD-NOS), and strong empirical support to the notion of two, rather than three, diagnostic domains. The DSM-5 changes introduced a framework to address these concerns (*18*), while maintaining that any person with an established DSM-IV-TR diagnosis of autistic disorder, Asperger disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of autism spectrum disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and asserts the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge that led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight biennial ADDM Network surveillance years spanning 2000 2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD, 2) to monitor the prevalence of ASD in different areas of the United States, and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data were collected for children aged 8 years during 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 selected eligibility classifications for special education or *International Classification of*

Diseases, Ninth Revision (ICD-9) billing codes for select childhood disabilities or psychological conditions. Children's records are first reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder (Box 1). A child may be disqualified from meeting the surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. A child could meet the DSM-5 surveillance case definition for ASD under one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria (Box 2). Children with a documented ASD diagnosis were included as meeting the DSM-5 surveillance case definition for two reasons. First, published DSM-5 diagnostic criteria include the presence of a DSM-IV-TR diagnosis of autistic disorder, PDD-NOS, or Asperger disorder, to ensure continuity of diagnoses and services. Second, sensitivity of the DSM-5 surveillance case definition is increased when counting children diagnosed with ASD by a qualified professional, based on either DSM-IV-TR or DSM-5 criteria, whether or not all DSM-5 social and behavioral criteria are documented in abstracted comprehensive evaluations. For these reasons, a case definition that includes documented ASD diagnoses reflects actual clinical practice more closely than a case definition based exclusively on documented social and behavioral symptoms. The ADDM Network methods allow differentiation of those meeting the surveillance case status based on one or both criteria. Consistent with the DSM-IV-TR case definition, a child may be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms. In this report, prevalence estimates are based on the DSM-IV-TR case definition, whereas case counts are presented and compared for children meeting the DSM-IV-TR and/or DSM-5 case definitions.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (*5*). For 2014, interrater agreement on DSM-IV-TR case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined ($k = 0.77$), which was slightly below quality

assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined (k = 0.84). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*26*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*27*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution with an asymptotic approximation to the normal. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Kappa statistics were computed to describe concordance between the DSM-IV-TR and DSM-5 case definitions, as well as to describe interrater agreement on either case definition for quality assurance. Pearson chi-square tests also were performed for testing significance in comparisons of proportions, and unadjusted odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (**Table 1**). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and

education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3) compared to each of the other ten sites ($P<0.01$).

Prevalence by Sex and Race/Ethnicity

When data from all 11 ADDM sites were combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence 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 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites (Arizona, Arkansas, Colorado, Georgia, Missouri, North Carolina and Tennessee). In nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, North Carolina and Tennessee), the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites (Arizona, Georgia and North Carolina). In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability were reported for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least 70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ $\leq$70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ $\leq$70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4; $p<0.01$), though among individual sites this proportion differed significantly in only one (Georgia, OR = 1.6; $p<0.05$). The proportion of children with ASD with borderline intellectual ability (IQ 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2; $p<0.05$).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure

2). The proportion of blacks and whites with ID differed significantly in all sites except Colorado, and when combining their data (OR = 2.9; p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9; p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8; p = 0.10), North Carolina (OR = 1.8; p = 0.07), and Tennessee (OR = 2.1; p = 0.09). The proportion of children with borderline intellectual ability (IQ = 71–85) did not differ between black and Hispanic children, although a lower proportion of white children (22%) were classified in the range of borderline intellectual ability compared to black (28.4%; OR = 0.7; p<0.01) or Hispanic (28.7%; OR = 0.7; p<0.01) children. When combining data from these nine sites, the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR = 3.4; p<0.01) or Hispanic (36%, OR = 2.2; p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV-TR, DSM-5, or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR = 1.4; p<0.01). When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9; p=0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

Sites with access to education records collected information on the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from 37% in Wisconsin to 75% in North Carolina. Most other sites noted more than half of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (44%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

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Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in four sites (Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Arkansas and Tennessee, where investigators were able to access education records throughout most, but not all, of the surveillance area and received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV-TR:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. Among 4,498 children who met DSM-5 case criteria, 3,817 (85%) met the DSM-5 behavioral criteria (Box 2), whereas 681 (15%) qualified on the basis of an established ASD diagnosis but did not have sufficient DSM-5 behavioral criteria documented in comprehensive evaluations. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV-TR:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV-TR, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV-TR, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV-TR. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV-TR. Slightly over 3% of children whose earliest ASD diagnosis was autistic disorder met DSM-5 criteria but not DSM-IV-TR, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than

DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed higher ASD prevalence estimates for 2012 compared to 2014, with a nearly 10% higher prevalence in Georgia ($p=0.06$) and Maryland ($p=0.35$), 19% in New Jersey ($p<0.01$), 22% in Missouri ($p=0.01$), 29% in Colorado ($p<0.01$), and 31% in Wisconsin ($p<0.01$). When combining data from these six sites, ASD prevalence estimates for 2014 were 20% higher for 2014 compared to 2012 ($p<0.01$). The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative difference in prevalence are noteworthy in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall Colorado surveillance area), and Wisconsin was granted access to review education records for more than a quarter of its surveillance population, and 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20%–30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30%

of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1–14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 8-year-olds. Of the six sites with prevalence estimates below the 16.8 per 1,000 estimate for all sites combined, five had reduced or no access to education data sources (Arkansas, Colorado, Missouri, Tennessee and Wisconsin), whereas only one of the six sites will full access to education data sources had a prevalence estimate below 16.8 per 1,000 (Arizona). Such differences cannot be attributed solely to source access, as other factors (e.g., demographic differences and service availability) also might have influenced these findings. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted in the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors, such as regional and socioeconomic disparities in access to services (*13*,*14*).

Case Definitions

Results from application of the DSM-IV-TR and DSM-5 case definitions were similar, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. Overall, ASD prevalence estimates based on the new DSM-5 case definition were very similar in magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV-TR. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented diagnosis of ASD may qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented ASD diagnosis. This element of the DSM-5 case definition may carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing ASD diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published and because professionals may diagnose children with ASD without necessarily recording every behavior supporting that diagnosis. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for autistic disorder, PDD-NOS or Asperger disorder, while at

the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison of Autism Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that might affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3 17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*28*). An estimate of 20.0 per 1,000 children aged 6 17 years was reported from the 2011 2012 NSCH (*29*). The study samples for the two phone surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6–11*,*28*,*29*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral, developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to at least three limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, some descriptions of historical diagnoses (i.e., those

not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for policy changes, individual treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3,6 11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*30*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*31*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD be evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*32*), might inform how policy initiatives, such as screening recommendations and other social determinants of health, impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing behavioral, educational, residential and occupational needs of this population.

Implementation of the new DSM-5 case definition had little effect on the overall number of children identified with ASD for the ADDM 2014 surveillance year. This might be a result of including documented ASD diagnoses in the DSM-5 surveillance case definition. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-

IV-TR diagnosis, such as autistic disorder, PDD-NOS or Asperger disorder, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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FIGURE 1. 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, nine sites,* United States, 2014

Abbreviations: ADDM =Autism and Developmental Disabilities Monitoring Network; ASD= autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014

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

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

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BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted behavior/Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines, or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the age of 3 years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least six behaviors coded with a minimum of two Social, one Communication, and one Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of 3 years OR At least two behaviors coded with a minimum of one Social and either one Communication and/or one Restricted Behavior/Interest; AND at least one autism discriminator coded Note: A child may be disqualified from meeting the DSM-IV-TR surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision).*

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BOX 2. Autism spectrum disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	Any ASD diagnosis documented in a comprehensive evaluation, including a DSM-IV diagnosis of autistic disorder, Asperger disorder, or pervasive developmental disorder–not otherwise specified (PDD-NOS)
DSM-5 case determination	All three behavioral criteria coded under part A, and at least two behavioral criteria coded under part B OR Any ASD diagnosis documented in a comprehensive evaluation, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Note: A child may be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.*

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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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**	**16,596**	**(5.1)**	**1,907**	**(0.6)**

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014–2015 school year.

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TABLE 2. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Overall†		Sex				Male-to-female prevalence ratio§
					Males		Females		
			Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	
Arizona	**24,952**	**349**	14.0	(12.6–15.5)	21.1	(18.7–23.8)	6.6	(5.3–8.2)	3.2
Arkansas	**39,992**	**522**	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	3.8
Colorado	**41,128**	**572**	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	3.9
Georgia	**51,161**	**869**	17.0	(15.9–18.2)	27.9	(25.9–30.0)	5.7	(4.8–6.7)	4.9
Maryland	**9,955**	**199**	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	4.5
Minnesota	**9,767**	**234**	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	4.6
Missouri	**25,333**	**356**	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	4.0
New Jersey	**32,935**	**964**	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	3.7
North Carolina	**30,283**	**527**	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	4.3
Tennessee	**24,940**	**387**	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	4.7
Wisconsin	**35,037**	**494**	14.1	(12.9–15.4)	21.4	(19.4–23.7)	6.4	(5.3–7.7)	3.4
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	**4.0**

Abbreviations: ASD = autism spectrum disorder; CI = confidence interval.

* Per 1,000 children aged 8 years.

† All children are included in the total regardless of race or ethnicity.

§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

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TABLE 3. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/Ethnicity								Prevalence ratio		
	White		Black		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			
Arizona	16.2	(14.1–18.6)	19.5	(13.3–28.6)	10.3	(8.5–12.5)	10.3	(5.5–19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3	1.4§	1.1
Georgia	17.9	(16.0–20.2)	17.1	(15.4–18.9)	12.6	(10.6–15.0)	11.9	(8.9–16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6–17.0)	11.3	(8.9–14.2)	12.5	(10.0–15.6)	10.2	(6.1–16.9)	1.3†	1.2	0.9
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1†**	**1.2§**	**1.1§**

Abbreviation: CI = confidence interval.

* Per 1,000 children aged 8 years.

† Pearson chi-square test of prevalence ratio significant at p<0.05.

§ Pearson chi-square test of prevalence ratio significant at p<0.01.

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TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional at age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

* Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

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TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder			ASD/PDD			Asperger disorder			Any specified ASD diagnosis		
Site	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**	**52**	**3,794**	**(69.3)**

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

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TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	North Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with	308	327†	139†	708	149	188	822	420	218†	156†
Special education records	(88.3)	—§	—§	(81.5)	(74.9)	(80.3)	(85.3)	(79.7)	—§	—§
Primary exceptionality (%)										
Autism	64.9	65.4	43.9	58.9	67.1	67.0	48.4	75.0	79.8	36.5
Emotional disturbance	2.9	0.9	7.2	2.0	2.7	3.7	1.6	2.6	0.5	5.8
Specific learning disability	6.8	3.7	13.7	4.0	12.8	1.1	8.2	2.9	0.9	2.6
Speech or language impairment	5.5	8.9	10.8	1.0	3.4	2.7	13.7	2.4	3.2	20.5
Hearing or visual impairment	0	0.3	0	0.1	0	1.1	0.6	0.5	0	0.6
Health, physical or other disability	6.8	13.5	14.4	3.5	8.1	15.4	18.5	11.2	3.2	14.7
Multiple disabilities	0.3	3.4	5.0	0	4.0	1.6	6.7	1.7	0	0
Intellectual disability	3.2	4.0	4.3	2.0	2.0	6.9	1.7	2.4	2.8	0.6
Developmental delay/Preschool	9.4	0	0.7	28.5	0	0.5	0.6	1.4	9.6	18.6

Abbreviation: ASD = autism spectrum disorder.

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

† Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 67% Colorado, 12% Tennessee, 74% Wisconsin).

§ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

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TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**	**13,903**	**(5.3)**	**1,438**	**(0.5)**

Abbreviation: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

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TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Site	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**Ratio**	**Kappa**
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All sites combined	**4,920**	**4,236**	**(86.1)**	**422**	**(8.6)**	**262**	**(5.3)**	**1.04**	**0.85**

Abbreviations: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision.

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TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Characteristic	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**Ratio**	**Kappa**
Met ASD case definition under DSM-IV-TR and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Sex									
Male	3,978	3,452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
Race/Ethnicity									
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian / Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
Earliest comprehensive evaluation on record*									
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37–48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1,503	1,195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Documented ASD Classification									
Autism special education eligibility†	2,270	2,156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement§									
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis autistic disorder	1,577	1,526	(96.8)	0	(0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ASD-NOS	1,564	1,525	(97.5)	0	(0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger disorder	221	210	(95.0)	0	(0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Most recent intelligence quotient score¶									
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

Abbreviations: ASD = autism spectrum disorder; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision; PDD-NOS = pervasive developmental disorder–not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† Includes children with autism as the Primary Exceptionality (Table 6) as well as children documented to meet eligibility criteria for autism special education services.

§ An ASD diagnosis documented in abstracted comprehensive evaluations, including DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

¶ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

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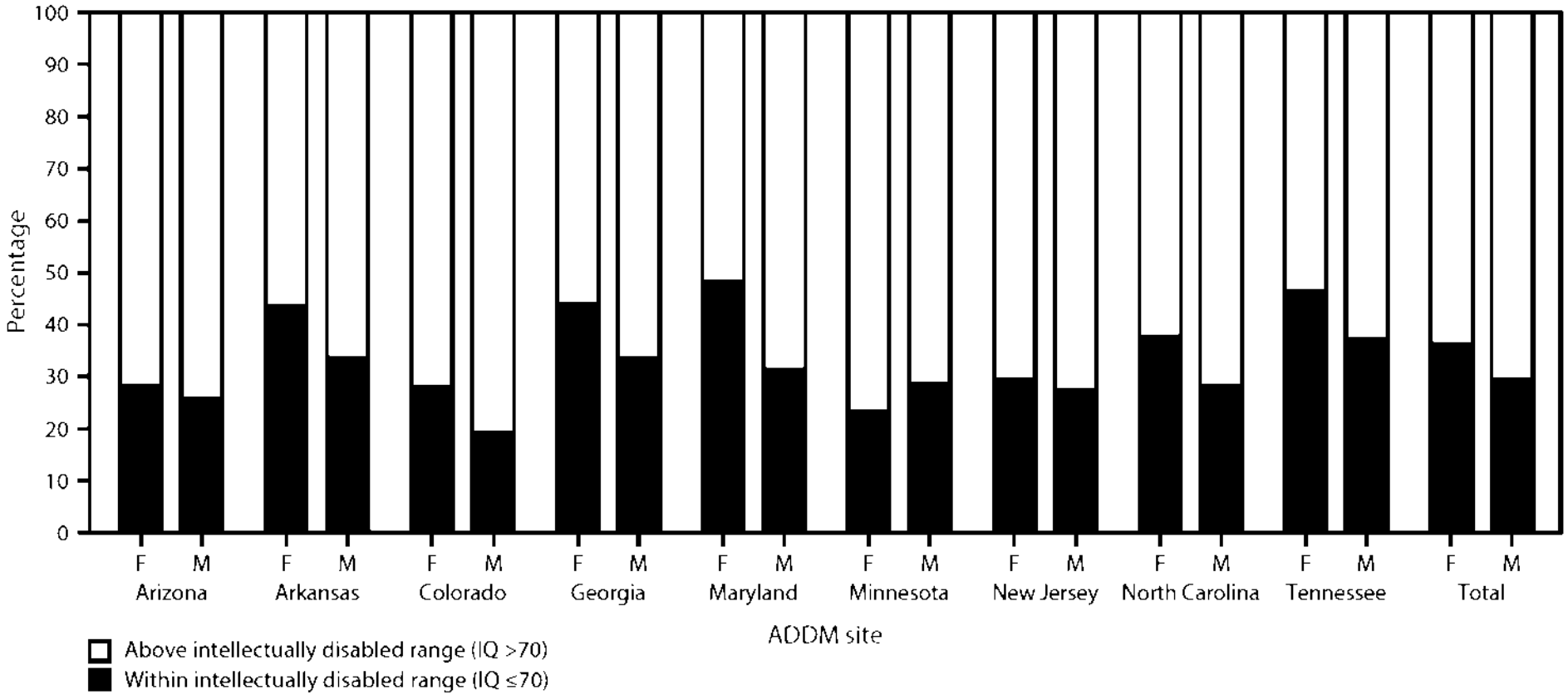
FIGURE 1. Most recent intelligence quotient score as of age 8 years among children with autism spectrum disorder for whom test data were available, by sex and site — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



Abbreviations: ADDM = Autism and Developmental Disabilities Monitoring Network; F = female; IQ = intelligence quotient; M = male.
* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

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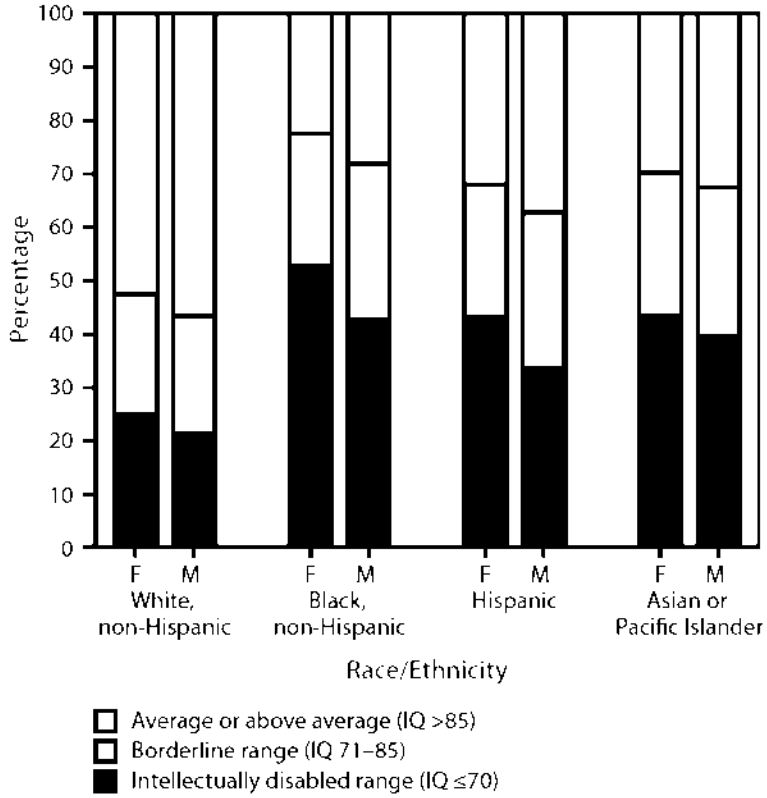
FIGURE 2. Most recent intelligence quotient score as of age 8 years among children with autism spectrum disorder for whom test data were available, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



Abbreviations: F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Jon Baio, EdS[1]; Lisa Wiggins, PhD[1]; Deborah L. Christensen, PhD[1]; Julie Daniels, PhD[2]; Zachary Warren, PhD[3]; Margaret Kurzius-Spencer, PhD[4]; Walter Zahorodny, PhD[5]; Cordelia Robinson Rosenberg, PhD[6]; Tiffany White, PhD[7]; Maureen Durkin, PhD[8]; Pamela Imm, MS[8]; Loizos Nikolaou, MPH[1,9]; Marshalyn Yeargin-Allsopp, MD[1]; Li-Ching Lee, PhD[10]; Rebecca Harrington, PhD[10]; Maya Lopez, MD[11]; Robert T. Fitzgerald, PhD[12]; Amy Hewitt, PhD[13]; Sydney Pettygrove, PhD[4]; John N. Constantino, MD[12]; Alison Vehorn, MS[3]; Josephine Shenouda, MS[5]; Jennifer Hall-Lande[13]; Kim Van Naarden Braun, PhD[1]; Nicole F. Dowling, PhD[1]

[1]National Center on Birth Defects and Developmental Disabilities, CDC; [2]University of North Carolina, Chapel Hill; [3]Vanderbilt University Medical Center, Nashville, Tennessee; [4]University of Arizona, Tucson; [5]Rutgers University, Newark, New Jersey; [6]University of Colorado School of Medicine at the Anschutz Medical Campus; [7]Colorado Department of Public Health and Environment, Denver; [8]University of Wisconsin, Madison; [9]Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee; [10]Johns Hopkins University, Baltimore, Maryland; [11]University of Arkansas for Medical Sciences, Little Rock; [12]Washington University in St. Louis, Missouri; [13]University of Minnesota, Minneapolis

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the DSM-5 diagnostic criteria, which include the presence of an established DSM-IV-TR diagnosis of Autistic Disorder, PDD-NOS, or Asperger Disorder. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar estimate of ASD prevalence.

Public Health Action: The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD. Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence in future surveillance reports. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses such as Autistic Disorder, PDD-NOS, and Asperger Disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2*,*3*). The first CDC study, which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5 (*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence underscores the need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD during 2006–2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000–2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change from 2002 to 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9,10,11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ ≤70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008 this proportion was closer to 40%, and during 2010–2012 less than one third of children with ASD had IQ ≤70 (*9,10,11*). This trend was more pronounced for females as compared with males (9). The proportion of males with ASD and ID declined from approximately

40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (*9,10,11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including atypical autism); or Asperger Disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to Autism Spectrum Disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by severity levels. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons who have ASD under DSM-5 diagnosed must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors; and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input). According to the DSM-5 Workgroup on Neurodevelopmental Disorders, the need for new criteria for autism and related disorders was identified long before the Workgroup was convened in 2007 (*18*).

Although the DSM-IV-TR criteria proved useful in identifying ASD in children aged 5–8 years, they performed less well when used in the diagnosis of toddlers and preschool-aged children, adolescents, and young adults (*18*). Further, the DSM-IV-TR criteria were insufficient to accurately identify girls and women with autism and lacked the cultural sensitivity needed to identify cases in ethnic or racial minorities (*18*). The DSM-5 changes introduced a more focused framework compared with that of DSM-IV-TR; however, DSM-5 states that any person with an established DSM-IV-TR diagnosis of Autistic Disorder, Asperger Disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of Autism Spectrum Disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and underscores the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge which led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in

each of the eight biennial ADDM Network surveillance years spanning 2000–2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD, 2) to monitor the prevalence of ASD in different areas of the United States, and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data were collected for children aged 8 years during the 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 selected eligibility classifications for special education or *International Classification of Diseases, Ninth Revision* (ICD-9) billing codes for select childhood disabilities or psychological conditions. Children's records are first reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians) (*26*). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. Behavioral and diagnostic components of the DSM-IV-TR and DSM-5 ASD case definitions operationalized for ADDM surveillance are outlined (Boxes 1 and 2). In practice, DSM-5 criteria automatically include children with an established DSM-IV-TR diagnosis of ASD; thus, the ADDM coding scheme similarly accommodated those with a previous DSM-IV-TR diagnosis in the DSM-5 case definition, regardless of whether documented symptoms independently met either the DSM-IV-TR or DSM-5 diagnostic criteria. The coding scheme allowed differentiation of children who met DSM-5 criteria on the basis of behavioral characteristics from those who met DSM-5 criteria solely through a previous DSM-IV-TR diagnosis.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (*5*). For 2014, interrater agreement on case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined ($k = 0.77$), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined ($k = 0.84$). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by

race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*27*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*28*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Pearson chi-square tests also were performed for testing significance in comparisons of proportions, and Mantel-Haenszel common odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians

were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 of 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3), Minnesota (24.0), and Maryland (20.0). Five sites reported prevalence estimates ranging from 13.1 to 14.1 per 1,000 (Arizona, Arkansas, Colorado, Missouri, and Wisconsin), and three sites reported prevalence estimates ranging from 15.5 to 17.4 per 1,000 (Georgia, North Carolina, and Tennessee).

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Prevalence by Sex and Race/Ethnicity

When data from all 11 ADDM sites were combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence 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 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites. In nine sites, the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites. In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

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Intellectual Ability

Data on intellectual ability were reported for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least 70% of children who met the ASD case definition (range: 70.8% |Tennessee| to 89.2% |North Carolina|). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio |OR| = 1.4; $p<0.01$), though among individual sites this proportion differed significantly in only one (Georgia, OR = 1.6; $p<0.05$). The proportion of children with ASD with borderline intellectual ability (IQ 71 85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR 1.2; $p<0.05$).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all nine sites and when combining their data (OR – 2.9; $p<0.01$). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR 1.9; $p<0.01$), and among individual sites it reached significance ($p<0.05$) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8; $p = 0.09$), North Carolina (OR = 1.8; $p = 0.07$), and Tennessee (OR = 2.1; $p = 0.10$). The proportion of children with borderline intellectual ability (IQ = 71–85) did not differ by race/ethnicity in any of these nine sites or when combining their data; however, when combining data from these nine sites the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR 3.4; $p<0.01$) or Hispanic (36%, OR 2.2; $p<0.01$) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n – 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 children did not have a comprehensive evaluation on record

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until after age 48 months; however, mention of developmental concerns by age 36 months was documented for 85% (range: 61% [Tennessee] to 94% [Arizona]).

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Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV, DSM-5, or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR 1.4; p<0.01). When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9; p=0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

Sites with access to education records collected information approximately the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from 40% in Wisconsin to 74% in North Carolina. Most other sites noted approximately half of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (43%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in five sites (Arkansas, Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Tennessee, where investigators did not obtain permission to review children's records in one of the 14 school districts comprising the 11-county surveillance area.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had

some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV. Slightly over 3% of children whose earliest ASD diagnosis was Autistic Disorder met DSM-5 criteria but not DSM-IV, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger Disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed an increase in ASD prevalence estimates during 2012–2014, with a nearly 10% prevalence increase in Georgia and Maryland, 19% in New Jersey, 23% in Missouri, 29% in Colorado, and 31% in Wisconsin. The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative increase in prevalence are remarkable in that both gained access to

children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall Colorado surveillance area), and Wisconsin was granted access to review education records in parts of two of the 10 counties comprising their 2014 surveillance area. Although this represented only 26% of the population aged 8 years within the overall Wisconsin surveillance area, 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006 2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20%–30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1–14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 8-year-olds. Those sites with limited or no access to education data sources (Colorado, Missouri, and Wisconsin) had prevalence estimates near the lower range among all sites. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted in the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and

other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors such as regional and socioeconomic disparities in access to services (*13*,*14*).

Case Definitions

Agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. Overall, ASD prevalence estimates based on the new DSM-5 case definition were very similar in magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented DSM-IV-TR diagnosis of ASD automatically qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented DSM-IV-TR diagnosis. This element of the DSM-5 case definition will carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing DSM-IV-TR diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published. Using this approach, agreement in the application of the DSM-IV-TR and DSM-5 case definitions was remarkably close, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for Autistic Disorder, PDD-NOS or Asperger Disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison of Autism Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that might affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*29*). An estimate of 20.0 per 1,000 children aged 6–17 years was reported from the 2011–2012 NSCH (*30*). The study samples for the two phone surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6 11*,*29*,*30*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental

concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral, developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to at least three limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for evaluating policy changes, treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3*,*6*–*11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

When the ADDM methodology was originally developed, estimating ASD prevalence among children aged 8 years was determined to represent the peak prevalence, based on estimates for multiple ages in metropolitan Atlanta

in 1996 (*3*). Estimating prevalence among children aged 8 years requires quality data from both health and educational agencies and likely captures most children whose adaptive performance is impacted by ASD. However, because prevalence estimation takes considerable time and effort, reporting of estimates lags behind the surveillance year by 3–4 years. Thus, opportunities for policy or programmatic enhancements to impact key health indicators also lag. Focusing on younger cohorts might allow earlier assessment of systematic changes (e.g., policies, insurance, and programs) that impact younger children, rather than waiting until cohorts impacted by these changes reach age 8 years. Surveillance of ASD in older populations is also important but might require different methodological approaches.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*31*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*32*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD be evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*33*), might inform how policy initiatives such as screening recommendations and other social determinants of health impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD has increased compared with previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing behavioral, educational, residential and occupational needs of this population.

Contrary to some predictions, the redefinition of ASD provided by the DSM-5 might have had a relatively limited contribution to the overall ASD estimate provided by the ADDM Network. This might be a result of the carryover effect of including all DSM-IV-TR-diagnosed cases in the DSM-5 count. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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FIGURE 1. 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, nine sites,* United States, 2014
Abbreviations: ADDM =Autism and Developmental Disabilities Monitoring Network; ASD= autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014
Abbreviations: ASD = autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

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BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expr gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e. or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to c modes of communication such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conv 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to development
Restricted behavior/Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines, or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the ag Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least six behaviors coded with a minimum of two Social, one Communication, and one Restricted Be developmental delay or concern at or before the age of 3 years OR At least two behaviors coded with a minimum of one Social and either one Communication and/or one AND at least one Autism Discriminator coded

Abbreviation: DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision).*

BOX 2. Autism spectrum disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	A well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder–not (PDD-NOS)
DSM-5 case determination	All three behavioral criteria coded under part A, and at least two behavioral criteria coded under part B OR A DSM-IV diagnosis of autistic disorder, Asperger's disorder, or PDD-NOS

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.*

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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)

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Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)
Minnesota	University of Minnesota	Parts of 2 counties in Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014–2015 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Overall†		Sex				Male
					Males		Females		
			Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	preva
Arizona	**24,952**	**349**	14.0	(12.6–15.5)	21.1	(18.7–23.8)	6.6	(5.3–8.2)	
Arkansas	**39,992**	**522**	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	
Colorado	**41,128**	**572**	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	
Georgia	**51,161**	**869**	17.0	(15.9–18.2)	27.9	(25.9–30.0)	5.7	(4.8–6.7)	
Maryland	**9,955**	**199**	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	
Minnesota	**9,767**	**234**	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	
Missouri	**25,333**	**356**	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	
New Jersey	**32,935**	**964**	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	
North Carolina	**30,283**	**527**	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	
Tennessee	**24,940**	**387**	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	
Wisconsin	**35,037**	**494**	14.1	(12.9–15.4)	21.4	(19.4–23.7)	6.4	(5.3–7.7)	
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	

Abbreviations: ASD = autism spectrum disorder; CI = confidence interval.

* Per 1,000 children aged 8 years.

† All children are included in the total regardless of race or ethnicity.

§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

TABLE 3. Estimated prevalence* of autism spectrum disorder amng children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/Ethnicity

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	White		Black		Hispanic		Asian/Pacific Islander		White-
	Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	blac
Arizona	16.2	(14.1–18.6)	19.5	(13.3–28.6)	10.3	(8.5–12.5)	10.3	(5.5–19.1)	0.8
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3
Georgia	17.9	(16.0–20.2)	17.1	(15.4–18.9)	12.6	(10.6–15.0)	11.9	(8.9–16.1)	1.1
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3
Wisconsin	15.2	(13.6–17.0)	11.3	(8.9–14.2)	12.5	(10.0–15.6)	10.2	(6.1–16.9)	1.3
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1**

Abbreviation: CI = confidence interval.

* Per 1,000 children aged 8 years.

† Pearson chi-square test of prevalence ratio significant at p<0.05.

§ Pearson chi-square test of prevalence ratio significant at p<0.01.

TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional at age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

* Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder	ASD/PDD	Asperger disorder

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Site	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**

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

TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey
Total no. of ASD cases	349	522	572	869	199	234	964
Total no. (%) of ASD cases with	311	455[†]	148[§]	752	159	201	851
Special education records	(89.1)	(87.2)[†]	—[¶]	(86.5)	(79.9)	(85.9)	(88.3)
Primary exceptionality (%)							
Autism	65.3	65.1	43.2	57.8	66.0	65.2	47.7
Emotional disturbance	2.9	0.9	7.4	2.0	2.5	4.5	1.5
Specific learning disability	6.8	3.1	14.2	4.0	11.9	1.0	8.0
Speech or language impairment	5.5	10.3	10.1	2.4	3.8	5.0	13.6
Hearing or visual impairment	0	0.2	0	0.1	0	1.0	0.6
Health, physical or other disability	6.8	13.2	15.5	3.6	8.8	14.4	19.3
Multiple disabilities	0.3	4.2	4.7	0	4.4	1.5	6.9
Intellectual disability	3.2	3.1	4.1	2.0	1.9	7.0	1.8
Developmental delay/Preschool	9.3	0	0.7	28.1	0.6	0.5	0.6

Abbreviation: ASD = autism spectrum disorder.

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

† Includes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 12% Tennessee).

§ Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 67% Colorado, 74% Wisconsin).

¶ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic	Black, non-Hispanic	Hispanic

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			No.	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)
Minnesota	University of Minnesota	Parts of 2 counties in Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)
Tennessee	Vanderbilt University	11 counties in central Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**

Abbreviation: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	**Met both DSM-IV-TR and DSM-5**		**Met DSM-IV only**		**Met DSM-5 only**	
Site	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)
All sites combined	**4,920**	**4,236**	**(86.1)**	**422**	**(8.6)**	**262**	**(5.3)**

Abbreviations: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision.

TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or	**Met both DSM-IV-TR and DSM-5**	**Met DSM-IV only**	**Met DSM-5**

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		DSM-5			
Characteristic	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**
Met ASD case definition under DSM-IV and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262
Sex						
Male	3,978	3,452	(86.8)	316	(7.9)	210
Female	942	784	(83.2)	106	(11.3)	52
Race/Ethnicity						
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31
Asian / Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5
Earliest comprehensive evaluation on record*						
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22
37–48 months	723	640	(88.5)	61	(8.4)	22
>48 months	1,503	1,195	(79.5)	154	(10.2)	154
Documented ASD Classification						
Autism special education eligibility	2,270	2,156	(95.0)	35	(1.5)	79
ASD diagnostic statement†						
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15
Earliest ASD diagnosis Autistic Disorder	1,577	1,526	(96.8)	0	(0)	51
Earliest ASD diagnosis PDD-NOS/ASD-NOS	1,564	1,525	(97.5)	0	(0)	39
Earliest ASD diagnosis Asperger Disorder	221	210	(95.0)	0	(0)	11
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97
Most recent intelligence quotient score§						
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86

Abreviations: ASD = autism spectrum disorder; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision; PDD-NOS = pervasive developmental disorder–not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† A DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder automatically qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

§ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

Summary of Revisions to 1st Proof of ADDM SY2014 MMWR

(Note: page numbers refer to edits in marked version of manuscript)

Changes made in response to co-author suggestions from review of 1st proof:

1. Updated author line (added Matt Maenner per his contributions related to statistical methods and replication of analyses, middle initial for Maureen Durkin, and credentials for Jen Hall-Lande).
2. Throughout manuscript and tables, used proper case for diagnoses, e.g., autistic disorder, Asperger disorder, autism spectrum disorder, cerebral palsy, intellectual disability, etc.
3. Throughout manuscript and tables, inserted *"-TR"* in several places where it was missing from DSM-IV.
4. Throughout manuscript and tables, commas were inserted as needed.
5. Page 1: Clarified separate components of DSM-5 case definition in Description of System section of Abstract.
6. Page 2: Re-ordered Public Health Action section of Abstract.
7. Page 4: Clarified content and grammar in third-to-last paragraph under Introduction heading, and removed the last sentence.
8. Page 4: Revised second-to-last paragraph under Introduction heading.
9. Page 4: Changed *"underscores"* to *"asserts"* in last paragraph under Introduction heading.
10. Page 4: Changed *"which"* to *"that"* in first sentence under Study Sites heading.
11. Page 5: Removed *"the"* from paragraph before Case Ascertainment heading.
12. Page 6: Added sentence about clinical judgment to fourth paragraph under Case Ascertainment heading. Also added this to case definition criteria in Boxes 1 and 2.
13. Page 6: Removed citation #26 and re-numbered all subsequent citations.
14. Page 6: Added extensive content to last paragraph under Case Ascertainment heading clarifying multiple components of DSM-5 case definition.
15. Page 7: Inserted *"In this report, prevalence estimates are based on the DSM-IV-TR case definition, whereas case counts are presented and compared for children meeting the DSM-IV-TR and/or DSM-5 case definitions."* as last sentence of Case Ascertainment heading.
16. Page 7: Inserted *"DSM-IV-TR"* in first paragraph under Quality Assurance heading.
17. Page 9: Inserted "population" in first sentence under Results heading.
18. Page 9: Revised last sentence under Overall ASD Prevalence Estimates heading.
19. Page 9: Listed sites under Prevalence by Sex and Race/Ethnicity heading, as requested by MMWR editor.
20. Page 10: Replaced *"approximately"* in two places with *"on"* and *"more than"* under Special Education Eligibility heading.
21. Page 11: Updated content under Sensitivity Analyses heading per analysis completed in December. In consultation with AR-ADDM investigators, several records were updated from DNR to FNF, consistent with coding applied at other ADDM sites that were unable to access records at all schools/districts throughout the surveillance area.
22. Page 11: *"Among 4,498 children who met DSM-5 case criteria, 3,817 (85%) met the DSM-5 behavioral criteria (Box 2), whereas 681 (15%) qualified on the basis of an established ASD diagnosis but did not have sufficient DSM-5 behavioral criteria documented in comprehensive evaluations."* added to first paragraph under Comparison of Case Counts heading.
23. Page 12: Revised language under Changes in Estimated Prevalence heading from *"increase"* to *"higher"* or *"difference"* (note: this terminology has switched back and forth based on comments from different reviewers).

24. Page 12: Added p-values and new sentence under Changes in Estimated Prevalence heading in Discussion section: *"When combining data from these six sites, ASD prevalence estimates for 2014 were 20% higher for 2014 compared to 2012 (p<0.01).".*
25. Page 12: Updated description of Wisconsin access to education data sources for SY2014.
26. Page 13: Clarified description and added qualifying statement under Variation in Prevalence Among ADDM Sites heading.
27. Page 13: Changed *"DSM-IV-TR"* to *"ASD"* in two places and removed *"DSM-IV-TR"* in one place to clarify that all previous ASD diagnoses are not known to be based on DSM-IV-TR criteria.
28. Page 13: Changed *"was remarkably close"* to *"were similar"* and *"will"* to *"may"* in first paragraph under Case Definitions heading. Also removed *"automatically"* from this paragraph.
29. Page 13: Removed redundant sentence under Case Definitions heading.
30. Page 15: Minor revision to last sentence of second paragraph under Limitations heading.
31. Page 15: Removed second paragraph under Future Surveillance Directions heading. Multiple author comments on 1st proof supported totally dropping this paragraph.
32. Page 15-16: Revised language under Conclusion heading based on suggestions from multiple authors.
33. Page 16: Corrected spelling of one name and removed duplicated staff under Acknowledgments heading.
34. Page 19: Inserted text in Box 2 to clarify that the DSM-5 case definition did not differentiate between DSM-IV or DSM-5 when an established ASD diagnosis was used in determining case status.
35. Page 20: Inserted *"Medical Center"* to site institution listing for Vanderbilt University, changed *"in"* to *"including"* and *"Central"* to *"middle"* under surveillance area descriptions for Minnesota and Tennessee, respectively. Also made these same changes to Table 7 on Page 23.
36. Page 21: Corrected typo *"among"* in title of Table 3.
37. Page 24: Updated description of ASD diagnosis in footnote of Table 9.

Changes made in response to replication analysis:

1. Page 8: Inserted *"with an asymptotic approximation to the normal"* in first sentence of last paragraph under Analytic Methods heading, inserted *"Kappa statistics were computed to describe concordance between the DSM-IV-TR and DSM-5 case definitions, as well as to describe interrater agreement on either case definition for quality assurance."* and changed *"Mantel-Haenszel common"* to *"unadjusted"* in the following sentence.
2. Page 10: Corrected statements of statistical significance comparing IQ levels stratified by race/ethnicity.
3. Page 10: Updated proportions under Special Education Eligibility heading to be consistent with Table 6 (original values from earlier drafts, which excluded tracking exceptionality).
4. Page 21: Changed footnote from *p<.05* to *p<.01* for Colorado White:Hispanic prevalence ratio in Table 3.
5. Page 22: Changed Table 6 back to the content submitted in earlier drafts prior to 11/8/17 SIG discussion. That discussion resulted in pulling Tracking Exceptionality into the table; however, Tracking Exceptionality was never incorporated into any of the other "previous ASD classification" variables, so the proposed solution is to exclude it from Table 6 and revert to the original values.
6. Page 24: Added footnote to Table 9 clarifying that "Autism special education eligibility" includes children with Autism as the Primary Exceptionality (Table 6) as well as children documented to meet eligibility criteria for Autism special education services.
7. Edits to raw data: Identified 11 outliers in the distribution of values for earliest known ASD diagnosis. These were implausible values at both the low and high ends of the distribution. Ten of the 11 values were confirmed to be data entry errors and were easily corrected by sites. One value could not be verified without accessing the source record so it was set to missing. All statistics based on this variable were recalculated and did not require any changes to tables or text descriptions.

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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Jon **Baio**, EdS[1]; Lisa **Wiggins**, PhD[1]; Deborah L. **Christensen**, PhD[1]; Matthew J Maenner, PhD[1], Julie **Daniels**, PhD[2]; Zachary **Warren**, PhD[3]; Margaret **Kurzius-Spencer**, PhD[4]; Walter **Zahorodny**, PhD[5]; Cordelia **Robinson Rosenberg**, PhD[6]; Tiffany **White**, PhD[7]; Maureen S. **Durkin**, PhD[8]; Pamela **Imm**, MS[8]; Loizos **Nikolaou**, MPH[1,9]; Marshalyn **Yeargin-Allsopp**, MD[1]; Li-Ching Lee, PhD[10]; Rebecca **Harrington**, PhD[10]; Maya **Lopez**, MD[11]; Robert T. **Fitzgerald**, PhD[12]; Amy **Hewitt**, PhD[13]; Sydney **Pettygrove**, PhD[4]; John N. **Constantino**, MD[12]; Alison Vehorn, MS[3]; Josephine **Shenouda**, MS[5]; Jennifer Hall-Lande, PhD[13]; Kim Van Naarden **Braun**, PhD[1]; Nicole F. **Dowling**, PhD[1]

[1]National Center on Birth Defects and Developmental Disabilities, CDC; [2]University of North Carolina, Chapel Hill; [3]Vanderbilt University Medical Center, Nashville, Tennessee; [4]University of Arizona, Tucson; [5]Rutgers University, Newark, New Jersey; [6]University of Colorado School of Medicine at the Anschutz Medical Campus; [7]Colorado Department of Public Health and Environment, Denver; [8]University of Wisconsin, Madison; [9]Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee; [10]Johns Hopkins University, Baltimore, Maryland; [11]University of Arkansas for Medical Sciences, Little Rock; [12]Washington University in St. Louis, Missouri; [13]University of Minnesota, Minneapolis

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for autistic disorder; pervasive developmental disorder not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the DSM-5 diagnostic criteria. Children meeting this new surveillance case definition could qualify on the basis of one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD

diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar estimate of ASD prevalence.

Public Health Action: Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence in future surveillance reports. Although the DSM-IV-TR case definition will eventually be phased out, it will be applied in a limited geographic area to offer additional data for comparison. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses, such as autistic disorder, PDD-NOS, and Asperger disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time. The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2*,*3*). The first CDC study, which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental

Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5 (*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence underscores the need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD during 2006–2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000 2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change from 2002 to 2010 (*14*,*15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9*,*10*,*11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ $\leq$70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008, this proportion was closer to 40%; and during 2010–2012, less than one third of children with ASD had IQ $\leq$70 (9,*10*,*11*). This trend was more pronounced

for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (*9,10,11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to autism spectrum disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by level of support needed by the individual. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons diagnosed with ASD under DSM-5 must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors; and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input).

Although the DSM-IV-TR criteria proved useful in identifying ASD in some children, clinical agreement and diagnostic specificity in some subtypes (e.g., PDD-NOS) was poor, offering empirical support to the notion of two, rather than three, diagnostic domains. The DSM-5 introduced a framework to address these concerns (*18*), while maintaining that any person with an established DSM-IV-TR diagnosis of autistic disorder, Asperger disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of autism spectrum disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and asserts the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge that led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight biennial ADDM Network surveillance years spanning 2000 2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD, 2) to monitor the prevalence of ASD in different areas of the United States, and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data were collected for children aged 8 years during 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 selected eligibility classifications for special education or *International Classification of*

Diseases, Ninth Revision (ICD-9) billing codes for select childhood disabilities or psychological conditions. Children's records are first reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder (Box 1). A child might be disqualified from meeting the surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. A child could meet the DSM-5 surveillance case definition for ASD under one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria (Box 2). Children with a documented ASD diagnosis were included as meeting the DSM-5 surveillance case definition for two reasons. First, published DSM-5 diagnostic criteria include the presence of a DSM-IV-TR diagnosis of autistic disorder, PDD-NOS, or Asperger disorder, to ensure continuity of diagnoses and services. Second, sensitivity of the DSM-5 surveillance case definition might be increased when counting children diagnosed with ASD by a qualified professional, based on either DSM-IV-TR or DSM-5 criteria, whether or not all DSM-5 social and behavioral criteria are documented in abstracted comprehensive evaluations. The ADDM Network methods allow differentiation of those meeting the surveillance case status based on one or both criteria. Consistent with the DSM-IV-TR case definition, a child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms. In this report, prevalence estimates are based on the DSM-IV-TR case definition, whereas case counts are presented and compared for children meeting the DSM-IV-TR and/or DSM-5 case definitions.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (*5*). For 2014, interrater agreement on DSM-IV-TR case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined ($k = 0.77$), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from

all sites were combined (k = 0.84). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*26*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (**Table 1**).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*27*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution with an asymptotic approximation to the normal. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Kappa statistics were computed to describe concordance between the DSM-IV-TR and DSM-5 case definitions, as well as to describe interrater agreement on either case definition for quality assurance. Pearson chi-square tests also were performed for testing significance in comparisons of proportions, and unadjusted odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (**Table 1**). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of

evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3) compared to each of the other ten sites (P<0.01).

Prevalence by Sex and Race/Ethnicity

When data from all 11 ADDM sites were combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence 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 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites (Arizona, Arkansas, Colorado, Georgia, Missouri, North Carolina and Tennessee). In nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, North Carolina and Tennessee), the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites (Arizona, Georgia and North Carolina). In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability were reported for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least 70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4; p<0.01), though among individual sites this proportion differed significantly in only one (Georgia, OR = 1.6; p<0.05). The proportion of children with ASD with borderline intellectual ability (IQ 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2; p<0.05).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all sites except Colorado, and when combining their data (OR = 2.9; p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9; p<0.01), and among individual sites it reached significance

($p<0.05$) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8; p = 0.10), North Carolina (OR = 1.8; p = 0.07), and Tennessee (OR = 2.1; p = 0.09). The proportion of children with borderline intellectual ability (IQ = 71–85) did not differ between black and Hispanic children, although a lower proportion of white children (22%) were classified in the range of borderline intellectual ability compared to black (28.4%; OR = 0.7; $p<0.01$) or Hispanic (28.7%; OR = 0.7; $p<0.01$) children. When combining data from these nine sites, the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR = 3.4; $p<0.01$) or Hispanic (36%, OR = 2.2; $p<0.01$) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV-TR, DSM-5, or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR = 1.4; $p<0.01$). When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9; p=0.09) and 76% of Hispanic children (OR = 1.3; $p<0.01$); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; $p<0.01$).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

Sites with access to education records collected information on the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from approximately 37% in Wisconsin to 80% in Tennessee. Most other sites noted approximately 60% to 75% of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (44%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in four

sites (Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Arkansas and Tennessee, where investigators were able to access education records throughout most, but not all, of the surveillance area and received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV-TR:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. Among 4,498 children who met DSM-5 case criteria, 3,817 (85%) met the DSM-5 behavioral criteria (Box 2), whereas 681 (15%) qualified on the basis of an established ASD diagnosis but did not have sufficient DSM-5 behavioral criteria documented in comprehensive evaluations. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV-TR:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV-TR, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV-TR, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV-TR. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV-TR. Slightly over 3% of children whose earliest ASD diagnosis was autistic disorder met DSM-5 criteria but not DSM-IV-TR, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

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Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed higher ASD prevalence estimates for 2012 compared to 2014, with a nearly 10% higher prevalence in Georgia ($p = 0.06$) and Maryland ($p = 0.35$), 19% in New Jersey ($p<0.01$), 22% in Missouri ($p=0.01$), 29% in Colorado ($p<0.01$), and 31% in Wisconsin ($p<0.01$). When combining data from these six sites, ASD prevalence estimates for 2014 were 20% higher for 2014 compared to 2012 ($p<0.01$). The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative difference in prevalence are noteworthy in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall Colorado surveillance area), and Wisconsin was granted access to review education records for more than a quarter of its surveillance population, and 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20%–30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

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Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1–14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 8-year-olds. Of the six sites with prevalence estimates below the 16.8 per 1,000 estimate for all sites combined, five did not have full access to education data sources (Arkansas, Colorado, Missouri, Tennessee, and Wisconsin), whereas only one of the six sites will full access to education data sources had a prevalence estimate below 16.8 per 1,000 (Arizona). Such differences cannot be attributed solely to source access, as other factors (e.g., demographic differences and service availability) also might have influenced these findings. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted in the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors, such as regional and socioeconomic disparities in access to services (*13*,*14*).

Case Definitions

Results from application of the DSM-IV-TR and DSM-5 case definitions were similar, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. Overall, ASD prevalence estimates based on the new DSM-5 case definition were very similar in magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV-TR. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented diagnosis of ASD might qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented ASD diagnosis. This element of the DSM-5 case definition might carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing ASD diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published and because professionals might diagnose children with ASD without necessarily recording every behavior supporting that diagnosis. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for autistic disorder, PDD-NOS or Asperger disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

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Comparison of Autism Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that might affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*28*). An estimate of 20.0 per 1,000 children aged 6 17 years was reported from the 2011 2012 NSCH (*29*). The study samples for the two phone surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6–11*,*28*,*29*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral, developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to at least three limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that

impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for policy changes, individual treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3,6–11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*30*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*31*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD be evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*32*), might inform how policy initiatives, such as screening recommendations and other social determinants of health, impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing behavioral, educational, residential and occupational needs of this population.

Implementation of the new DSM-5 case definition had little effect on the overall number of children identified with ASD for the ADDM 2014 surveillance year. This might be a result of including documented ASD diagnoses in the DSM-5 surveillance case definition. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, such as autistic disorder, PDD-NOS or Asperger disorder, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined

under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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FIGURE 1. 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, nine sites,* United States, 2014

Abbreviations: ADDM =Autism and Developmental Disabilities Monitoring Network; ASD= autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014

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

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

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BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted behavior/Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines, or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the age of 3 years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least six behaviors coded with a minimum of two Social, one Communication, and one Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of 3 years OR At least two behaviors coded with a minimum of one Social and either one Communication and/or one Restricted Behavior/Interest; AND at least one autism discriminator coded Note: A child might be disqualified from meeting the DSM-IV-TR surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision).*

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BOX 2. Autism spectrum disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	Any ASD diagnosis documented in a comprehensive evaluation, including a DSM-IV diagnosis of autistic disorder, Asperger disorder, or pervasive developmental disorder–not otherwise specified (PDD-NOS)
DSM-5 case determination	All three behavioral criteria coded under part A, and at least two behavioral criteria coded under part B OR Any ASD diagnosis documented in a comprehensive evaluation, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Note: A child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.*

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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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**	**16,596**	**(5.1)**	**1,907**	**(0.6)**

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014–2015 school year.

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TABLE 2. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Overall†		Sex				Male-to-female prevalence ratio§
					Males		Females		
			Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	
Arizona	**24,952**	**349**	14.0	(12.6–15.5)	21.1	(18.7–23.8)	6.6	(5.3–8.2)	3.2
Arkansas	**39,992**	**522**	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	3.8
Colorado	**41,128**	**572**	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	3.9
Georgia	**51,161**	**869**	17.0	(15.9–18.2)	27.9	(25.9–30.0)	5.7	(4.8–6.7)	4.9
Maryland	**9,955**	**199**	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	4.5
Minnesota	**9,767**	**234**	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	4.6
Missouri	**25,333**	**356**	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	4.0
New Jersey	**32,935**	**964**	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	3.7
North Carolina	**30,283**	**527**	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	4.3
Tennessee	**24,940**	**387**	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	4.7
Wisconsin	**35,037**	**494**	14.1	(12.9–15.4)	21.4	(19.4–23.7)	6.4	(5.3–7.7)	3.4
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	**4.0**

Abbreviations: ASD = autism spectrum disorder; CI = confidence interval.

* Per 1,000 children aged 8 years.

† All children are included in the total regardless of race or ethnicity.

§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

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TABLE 3. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/Ethnicity								Prevalence ratio		
	White		Black		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			
Arizona	16.2	(14.1–18.6)	19.5	(13.3–28.6)	10.3	(8.5–12.5)	10.3	(5.5–19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3	1.4§	1.1
Georgia	17.9	(16.0–20.2)	17.1	(15.4–18.9)	12.6	(10.6–15.0)	11.9	(8.9–16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6–17.0)	11.3	(8.9–14.2)	12.5	(10.0–15.6)	10.2	(6.1–16.9)	1.3†	1.2	0.9
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1†**	**1.2§**	**1.1§**

Abbreviation: CI = confidence interval.

* Per 1,000 children aged 8 years.

† Pearson chi-square test of prevalence ratio significant at p<0.05.

§ Pearson chi-square test of prevalence ratio significant at p<0.01.

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TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional at age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

* Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

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TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder			ASD/PDD			Asperger disorder			Any specified ASD diagnosis		
Site	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**	**52**	**3,794**	**(69.3)**

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

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TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	North Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with	308	327†	139†	708	149	188	822	420	218†	156†
Special education records	(88.3)	—§	—§	(81.5)	(74.9)	(80.3)	(85.3)	(79.7)	—§	—§
Primary exceptionality (%)										
Autism	64.9	65.4	43.9	58.9	67.1	67.0	48.4	75.0	79.8	36.5
Emotional disturbance	2.9	0.9	7.2	2.0	2.7	3.7	1.6	2.6	0.5	5.8
Specific learning disability	6.8	3.7	13.7	4.0	12.8	1.1	8.2	2.9	0.9	2.6
Speech or language impairment	5.5	8.9	10.8	1.0	3.4	2.7	13.7	2.4	3.2	20.5
Hearing or visual impairment	0	0.3	0	0.1	0	1.1	0.6	0.5	0	0.6
Health, physical or other disability	6.8	13.5	14.4	3.5	8.1	15.4	18.5	11.2	3.2	14.7
Multiple disabilities	0.3	3.4	5.0	0	4.0	1.6	6.7	1.7	0	0
Intellectual disability	3.2	4.0	4.3	2.0	2.0	6.9	1.7	2.4	2.8	0.6
Developmental delay/Preschool	9.4	0	0.7	28.5	0	0.5	0.6	1.4	9.6	18.6

Abbreviation: ASD = autism spectrum disorder.

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

† Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 67% Colorado, 12% Tennessee, 74% Wisconsin).

§ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

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TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**	**13,903**	**(5.3)**	**1,438**	**(0.5)**

Abbreviation: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of 3rd graders during the 2014-2015 school year.

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TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Site	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**Ratio**	**Kappa**
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All sites combined	**4,920**	**4,236**	**(86.1)**	**422**	**(8.6)**	**262**	**(5.3)**	**1.04**	**0.85**

Abbreviations: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision.

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TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Characteristic	**No.**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**Ratio**	**Kappa**
Met ASD case definition under DSM-IV-TR and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Sex									
Male	3,978	3,452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
Race/Ethnicity									
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian / Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
Earliest comprehensive evaluation on record*									
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37–48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1,503	1,195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Documented ASD Classification									
Autism special education eligibility†	2,270	2,156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement§									
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis autistic disorder	1,577	1,526	(96.8)	0	(0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ASD-NOS	1,564	1,525	(97.5)	0	(0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger disorder	221	210	(95.0)	0	(0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Most recent intelligence quotient score¶									
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

Abbreviations: ASD = autism spectrum disorder; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision; PDD-NOS = pervasive developmental disorder–not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† Includes children with autism as the Primary Exceptionality (Table 6) as well as children documented to meet eligibility criteria for autism special education services.

§ An ASD diagnosis documented in abstracted comprehensive evaluations, including DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

¶ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Jon Baio, EdS[1]; Lisa Wiggins, PhD[1]; Deborah L. Christensen, PhD[1]; Matthew J Maenner, PhD[1]; Julie Daniels, PhD[2]; Zachary Warren, PhD[3]; Margaret Kurzius-Spencer, PhD[4]; Walter Zahorodny, PhD[5]; Cordelia Robinson Rosenberg, PhD[6]; Tiffany White, PhD[7]; Maureen S. Durkin, PhD[8]; Pamela Imm, MS[8]; Loizos Nikolaou, MPH[1,9]; Marshalyn Yeargin-Allsopp, MD[1]; Li-Ching Lee, PhD[10]; Rebecca Harrington, PhD[10]; Maya Lopez, MD[11]; Robert T. Fitzgerald, PhD[12]; Amy Hewitt, PhD[13]; Sydney Pettygrove, PhD[4]; John N. Constantino, MD[12]; Alison Vehorn, MS[3]; Josephine Shenouda, MS[5]; Jennifer Hall-Lande, PhD[13]; Kim Van Naarden Braun, PhD[1]; Nicole F. Dowling, PhD[1]

[1]*National Center on Birth Defects and Developmental Disabilities, CDC;* [2]*University of North Carolina, Chapel Hill;* [3]*Vanderbilt University Medical Center, Nashville, Tennessee;* [4]*University of Arizona, Tucson;* [5]*Rutgers University, Newark, New Jersey;* [6]*University of Colorado School of Medicine at the Anschutz Medical Campus;* [7]*Colorado Department of Public Health and Environment, Denver;* [8]*University of Wisconsin, Madison;* [9]*Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee;* [10]*Johns Hopkins University, Baltimore, Maryland;* [11]*University of Arkansas for Medical Sciences, Little Rock;* [12]*Washington University in St. Louis, Missouri;* [13]*University of Minnesota, Minneapolis*

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the DSM-5 diagnostic criteria. Children meeting this new surveillance case definition could qualify on the basis of one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar estimate of ASD prevalence.

Public Health Action: Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence in future surveillance reports. Although the DSM-IV-TR case definition will eventually be phased out, it will be applied in a limited geographic area to offer additional data for comparison. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses, such as autistic disorder, PDD-NOS, and Asperger disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time. The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2*,*3*). The first CDC study, which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5 (*1*). Although standard diagnostic tools have been validated

to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence underscores the need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD during 2006–2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000–2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change from 2002 to 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9–11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ ≤70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008, this proportion was closer to 40%; and during 2010–2012, less than one third of children with ASD had IQ ≤70 (*9–11*). This trend was more pronounced for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (*9–11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to autism spectrum disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by level of support needed by the individual. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons diagnosed with ASD under DSM-5 must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors; and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive

behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input).

Although the DSM-IV-TR criteria proved useful in identifying ASD in some children, clinical agreement and diagnostic specificity in some subtypes (e.g., PDD-NOS) was poor, offering empirical support to the notion of two, rather than three, diagnostic domains. The DSM-5 introduced a framework to address these concerns (*18*), while maintaining that any person with an established DSM-IV-TR diagnosis of autistic disorder, Asperger disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of autism spectrum disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and asserts the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge that led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight biennial ADDM Network surveillance years spanning 2000–2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD, 2) to monitor the prevalence of ASD in different areas of the United States, and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data were collected for children aged 8 years during 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 selected eligibility classifications for special education or *International Classification of Diseases, Ninth Revision* (ICD-9) billing codes for select childhood disabilities or psychological conditions. Children's records are first reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder (Box 1). A child might be disqualified from meeting the surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. A child could meet the DSM-5 surveillance case definition for ASD under one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria (Box 2). Children with a documented ASD diagnosis were included as meeting the DSM-5 surveillance case definition for two reasons. First, published DSM-5 diagnostic criteria include the presence of a DSM-IV-TR diagnosis of autistic disorder, PDD-NOS, or Asperger disorder, to ensure continuity

BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted behavior/ Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines, or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the age of 3 years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least six behaviors coded with a minimum of two Social, one Communication, and one Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of 3 years OR At least two behaviors coded with a minimum of one Social and either one Communication and/or one Restricted Behavior/Interest; AND at least one autism discriminator coded Note: A child might be disqualified from meeting the DSM-IV-TR surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision)*.

of diagnoses and services. Second, sensitivity of the DSM-5 surveillance case definition might be increased when counting children diagnosed with ASD by a qualified professional, based on either DSM-IV-TR or DSM-5 criteria, whether or not all DSM-5 social and behavioral criteria are documented in abstracted comprehensive evaluations. The ADDM Network methods allow differentiation of those meeting the surveillance case status based on one or both criteria. Consistent with the DSM-IV-TR case definition, a child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's

BOX 2. Autism spectrum disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	Any ASD diagnosis documented in a comprehensive evaluation, including a DSM-IV diagnosis of autistic disorder, Asperger disorder, or pervasive developmental disorder–not otherwise specified (PDD-NOS)
DSM-5 case determination	All three behavioral criteria coded under part A, and at least two behavioral criteria coded under part B OR Any ASD diagnosis documented in a comprehensive evaluation, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Note: A child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.

symptoms. In this report, prevalence estimates are based on the DSM-IV-TR case definition, whereas case counts are presented and compared for children meeting the DSM-IV-TR and/or DSM-5 case definitions.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (5). For 2014, interrater agreement on DSM-IV-TR case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined (k = 0.77), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined (k = 0.84). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*26*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*27*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution with an asymptotic approximation to the normal. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Kappa statistics were computed to describe concordance between the DSM-IV-TR and DSM-5 case definitions, as well as to describe interrater agreement on either case definition for quality assurance. Pearson chi-square tests also were performed for testing significance in comparisons of proportions, and unadjusted odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3) compared to each of the other ten sites (P<0.01).

Prevalence by Sex and Race/Ethnicity

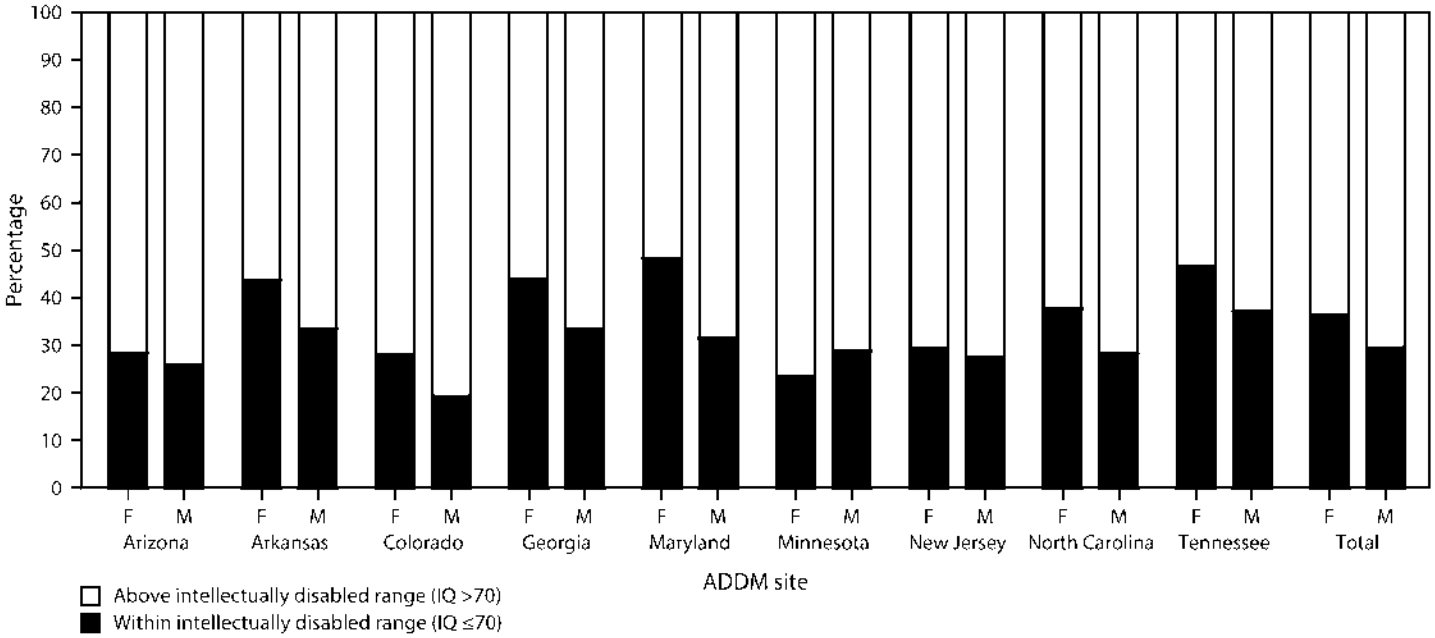
When data from all 11 ADDM sites were combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence was significantly (p<0.01) higher among boys than among girls in all 11 ADDM sites (Table 2), with male-to-female prevalence ratios ranging from 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites (Arizona, Arkansas, Colorado, Georgia, Missouri, North Carolina and Tennessee). In nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, North Carolina and Tennessee), the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites (Arizona, Georgia and North Carolina). In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability were reported for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least 70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4; p<0.01), though among individual sites this proportion differed significantly in only

FIGURE 1. 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, nine sites,* United States, 2014



Abbreviations: ADDM = Autism and Developmental Disabilities Monitoring Network; ASD = autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

one (Georgia, OR = 1.6; p<0.05). The proportion of children with ASD with borderline intellectual ability (IQ 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2; p<0.05).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all sites except Colorado, and when combining their data (OR = 2.9; p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9; p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8; p = 0.10), North Carolina (OR = 1.8; p = 0.07), and Tennessee (OR = 2.1; p = 0.09). The proportion of children with borderline intellectual ability (IQ = 71–85) did not differ between black and Hispanic children, although a lower proportion of white children (22%) were classified in the range of borderline intellectual ability compared to black (28.4%; OR = 0.7; p<0.01) or Hispanic (28.7%; OR = 0.7; p<0.01) children. When combining data from these nine sites, the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR = 3.4; p<0.01) or Hispanic (36%, OR = 2.2; p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV-TR, DSM-5, or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR = 1.4; p<0.01).

When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9; p=0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

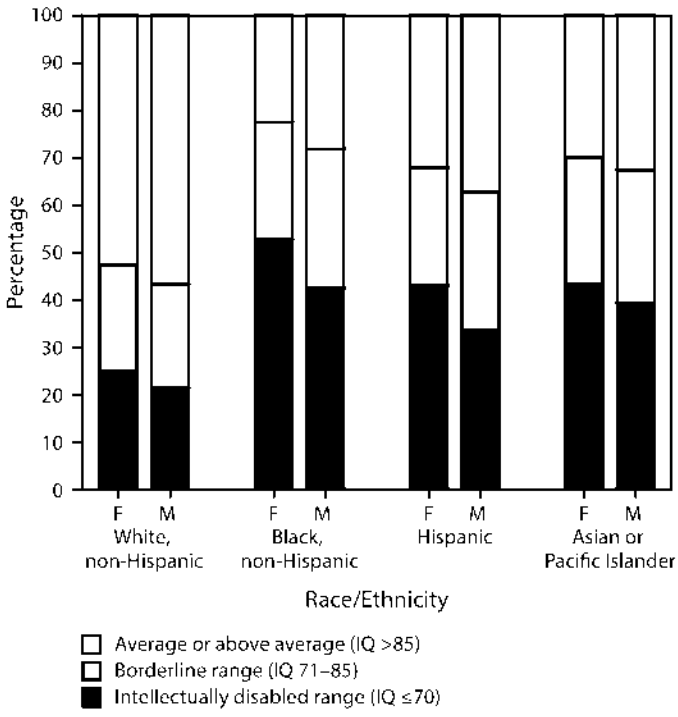
Sites with access to education records collected information on the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from approximately 37% in Wisconsin to 80% in Tennessee. Most other sites noted approximately 60% to 75% of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (44%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in four sites (Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Arkansas and Tennessee, where investigators were able to access education records throughout most, but not all, of the surveillance area and received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



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

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for >70 of children who met the ASD case definition (n = 3,714).

requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV-TR:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. Among 4,498 children who met DSM-5 case criteria, 3,817 (85%) met the DSM-5 behavioral criteria (Box 2), whereas 681 (15%) qualified on the basis of an established ASD diagnosis but did not have sufficient DSM-5 behavioral criteria documented in comprehensive evaluations. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV-TR:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV-TR, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV-TR, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV-TR. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV-TR. Slightly over 3% of children whose earliest ASD diagnosis was autistic disorder met DSM-5 criteria but not DSM-IV-TR, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed higher ASD prevalence estimates for 2012 compared to 2014, with a nearly 10% higher prevalence in Georgia ($p = 0.06$) and Maryland ($p = 0.35$), 19% in New Jersey ($p<0.01$), 22% in Missouri ($p=0.01$), 29% in Colorado ($p<0.01$), and 31% in Wisconsin ($p<0.01$). When combining data from these six sites, ASD prevalence estimates for 2014 were 20% higher for 2014 compared to 2012 ($p<0.01$). The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative difference in prevalence are noteworthy in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall

Colorado surveillance area), and Wisconsin was granted access to review education records for more than a quarter of its surveillance population, and 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20%–30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1–14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 8-year-olds. Of the six sites with prevalence estimates below the 16.8 per 1,000 estimate for all sites combined, five did not have full access to education data sources (Arkansas, Colorado, Missouri, Tennessee, and Wisconsin), whereas only one of the six sites will full access to education data sources had a prevalence estimate below 16.8 per 1,000 (Arizona). Such differences cannot be attributed solely to source access, as other factors (e.g., demographic differences and service availability) also might have influenced these findings. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted in the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors, such as regional and socioeconomic disparities in access to services (*13,14*).

Case Definitions

Results from application of the DSM-IV-TR and DSM-5 case definitions were similar, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. Overall, ASD prevalence estimates

based on the new DSM-5 case definition were very similar in magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV-TR. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented diagnosis of ASD might qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented ASD diagnosis. This element of the DSM-5 case definition might carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing ASD diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published and because professionals might diagnose children with ASD without necessarily recording every behavior supporting that diagnosis. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for autistic disorder, PDD-NOS or Asperger disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison of Autism Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that might affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*28*). An estimate of 20.0 per 1,000 children aged 6–17 years was reported from the 2011–2012 NSCH (*29*). The study samples for the two phone surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6–11,28,29*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral, developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to at least three limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders

and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for policy changes, individual treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3*,*6*–*11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*30*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*31*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD be evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*32*), might inform how policy initiatives, such as screening recommendations and other social determinants of health, impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing

behavioral, educational, residential and occupational needs of this population.

Implementation of the new DSM-5 case definition had little effect on the overall number of children identified with ASD for the ADDM 2014 surveillance year. This might be a result of including documented ASD diagnoses in the DSM-5 surveillance case definition. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, such as autistic disorder, PDD-NOS or Asperger disorder, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix[†]	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis St. Paul[§]	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**	**16,596**	**(5.1)**	**1,907**	**(0.6)**

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of third graders during the 2014–2015 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Sex: Overall† Prevalence	Overall† 95% CI	Males Prevalence	Males 95% CI	Females Prevalence	Females 95% CI	Male-to-female prevalence ratio§
Arizona	24,952	349	14.0	(12.6 15.5)	21.1	(18.7 23.8)	6.6	(5.3 8.2)	3.2
Arkansas	39,992	522	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	3.8
Colorado	41,128	572	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	3.9
Georgia	51,161	869	17.0	(15.9 18.2)	27.9	(25.9 30.0)	5.7	(4.8 6.7)	4.9
Maryland	9,955	199	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	4.5
Minnesota	9,767	234	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	4.6
Missouri	25,333	356	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	4.0
New Jersey	32,935	964	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	3.7
North Carolina	30,283	527	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	4.3
Tennessee	24,940	387	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	4.7
Wisconsin	35,037	494	14.1	(12.9 15.4)	21.4	(19.4 23.7)	6.4	(5.3 7.7)	3.4
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	**4.0**

Abbreviations: ASD = autism spectrum disorder; CI = confidence interval.
* Per 1,000 children aged 8 years.
† All children are included in the total regardless of race or ethnicity.
§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

TABLE 3. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/Ethnicity: White Prevalence	White 95% CI	Black Prevalence	Black 95% CI	Hispanic Prevalence	Hispanic 95% CI	Asian/Pacific Islander Prevalence	Asian/Pacific Islander 95% CI	Prevalence ratio: White-to-Black	White-to-Hispanic	Black-to-Hispanic
Arizona	16.2	(14.1 18.6)	19.5	(13.3 28.6)	10.3	(8.5 12.5)	10.3	(5.5 19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3	1.4§	1.1
Georgia	17.9	(16.0 20.2)	17.1	(15.4 18.9)	12.6	(10.6 15.0)	11.9	(8.9 16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6 17.0)	11.3	(8.9 14.2)	12.5	(10.0 15.6)	10.2	(6.1 16.9)	1.3†	1.2	0.9
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1†**	**1.2§**	**1.1§**

Abbreviation: CI = confidence interval.
* Per 1,000 children aged 8 years.
† Pearson chi-square test of prevalence ratio significant at p<0.05.
§ Pearson chi-square test of prevalence ratio significant at p<0.01.

TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional at age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
Site	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

* Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder			ASD/PDD			Asperger disorder			Any specified ASD diagnosis		
Site	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**	**52**	**3,794**	**(69.3)**

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

TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	North Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with Special education records	308 (88.3)	327† —§	139† —§	708 (81.5)	149 (74.9)	188 (80.3)	822 (85.3)	420 (79.7)	218† —§	156† —§
Primary exceptionality (%)										
Autism	64.9	65.4	43.9	58.9	67.1	67.0	48.4	75.0	79.8	36.5
Emotional disturbance	2.9	0.9	7.2	2.0	2.7	3.7	1.6	2.6	0.5	5.8
Specific learning disability	6.8	3.7	13.7	4.0	12.8	1.1	8.2	2.9	0.9	2.6
Speech or language impairment	5.5	8.9	10.8	1.0	3.4	2.7	13.7	2.4	3.2	20.5
Hearing or visual impairment	0	0.3	0	0.1	0	1.1	0.6	0.5	0	0.6
Health, physical or other disability	6.8	13.5	14.4	3.5	8.1	15.4	18.5	11.2	3.2	14.7
Multiple disabilities	0.3	3.4	5.0	0	4.0	1.6	6.7	1.7	0	0
Intellectual disability	3.2	4.0	4.3	2.0	2.0	6.9	1.7	2.4	2.8	0.6
Developmental delay/Preschool	9.4	0	0.7	28.5	0	0.5	0.6	1.4	9.6	18.6

Abbreviation: ASD = autism spectrum disorder.

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

† Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 67% Colorado, 12% Tennessee, 74% Wisconsin).

§ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

			Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
Site	Site institution	Surveillance area	No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**	**13,903**	**(5.3)**	**1,438**	**(0.5)**

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of third graders during the 2014–2015 school year.

TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Site	No.	No.	(%)	No.	(%)	No.	(%)	Ratio	Kappa
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All sites combined	**4,920**	**4,236**	**(86.1)**	**422**	**(8.6)**	**262**	**(5.3)**	**1.04**	**0.85**

Abbreviations: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*; DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*.

TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Characteristic	No.	No.	(%)	No.	(%)	No.	(%)	Ratio	Kappa
Met ASD case definition under DSM-IV-TR and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Male	3,978	3,452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian/Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37–48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1,503	1,195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Autism special education eligibility[†]	2,270	2,156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement[§]									
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis autistic disorder	1,577	1,526	(96.8)	0	(0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ ASD NOS	1,564	1,525	(97.5)	0	(0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger disorder	221	210	(95.0)	0	(0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

Abbreviations: ASD = autism spectrum disorder; DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*; DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*; PDD-NOS = pervasive developmental disorder not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† Includes children with autism as the Primary Exceptionality (Table 6) as well as children documented to meet eligibility criteria for autism special education services.

§ An ASD diagnosis documented in abstracted comprehensive evaluations, including DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

¶ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Jon Baio, EdS[1]; Lisa Wiggins, PhD[1]; Deborah L. Christensen, PhD[1]; Matthew J Maenner, PhD[1]; Julie Daniels, PhD[2]; Zachary Warren, PhD[3]; Margaret Kurzius-Spencer, PhD[4]; Walter Zahorodny, PhD[5]; Cordelia Robinson Rosenberg, PhD[6]; Tiffany White, PhD[7]; Maureen S. Durkin, PhD[8]; Pamela Imm, MS[8]; Loizos Nikolaou, MPH[1,9]; Marshalyn Yeargin-Allsopp, MD[1]; Li-Ching Lee, PhD[10]; Rebecca Harrington, PhD[10]; Maya Lopez, MD[11]; Robert T. Fitzgerald, PhD[12]; Amy Hewitt, PhD[13]; Sydney Pettygrove, PhD[4]; John N. Constantino, MD[12]; Alison Vehorn, MS[3]; Josephine Shenouda, MS[5]; Jennifer Hall-Lande, PhD[13]; Kim Van Naarden Braun, PhD[1]; Nicole F. Dowling, PhD[1]

[1]*National Center on Birth Defects and Developmental Disabilities, CDC;* [2]*University of North Carolina, Chapel Hill;* [3]*Vanderbilt University Medical Center, Nashville, Tennessee;* [4]*University of Arizona, Tucson;* [5]*Rutgers University, Newark, New Jersey;* [6]*University of Colorado School of Medicine at the Anschutz Medical Campus;* [7]*Colorado Department of Public Health and Environment, Denver;* [8]*University of Wisconsin, Madison;* [9]*Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee;* [10]*Johns Hopkins University, Baltimore, Maryland;* [11]*University of Arkansas for Medical Sciences, Little Rock;* [12]*Washington University in St. Louis, Missouri;* [13]*University of Minnesota, Minneapolis*

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the DSM-5 diagnostic criteria. Children meeting this new surveillance case definition could qualify on the basis of one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. The new case definition for ASD based on DSM-5 criteria resulted in a similar estimate of ASD prevalence.

Public Health Action: Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence in future surveillance reports. Although the DSM-IV-TR case definition will eventually be phased out, it will be applied in a limited geographic area to offer additional data for comparison. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses, such as autistic disorder, PDD-NOS, and Asperger disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time. The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2*,*3*). The first CDC study, which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5 (*1*). Although standard diagnostic tools have been validated

to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence underscores the need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD during 2006–2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000–2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006 and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change from 2002 to 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9–11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ ≤70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008, this proportion was closer to 40%; and during 2010–2012, less than one third of children with ASD had IQ ≤70 (*9–11*). This trend was more pronounced for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (*9–11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to autism spectrum disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by level of support needed by the individual. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons diagnosed with ASD under DSM-5 must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors; and deficits in developing, understanding, and maintaining relationships) and at least two of the four criteria under the restrictive/repetitive

behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input).

Although the DSM-IV-TR criteria proved useful in identifying ASD in some children, clinical agreement and diagnostic specificity in some subtypes (e.g., PDD-NOS) was poor, offering empirical support to the notion of two, rather than three, diagnostic domains. The DSM-5 introduced a framework to address these concerns (*18*), while maintaining that any person with an established DSM-IV-TR diagnosis of autistic disorder, Asperger disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of autism spectrum disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and asserts the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge that led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight biennial ADDM Network surveillance years spanning 2000–2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD, 2) to monitor the prevalence of ASD in different areas of the United States, and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data were collected for children aged 8 years during 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 selected eligibility classifications for special education or *International Classification of Diseases, Ninth Revision* (ICD-9) billing codes for select childhood disabilities or psychological conditions. Children's records are first reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder (Box 1). A child might be disqualified from meeting the surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. A child could meet the DSM-5 surveillance case definition for ASD under one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria (Box 2). Children with a documented ASD diagnosis were included as meeting the DSM-5 surveillance case definition for two reasons. First, published DSM-5 diagnostic criteria include the presence of a DSM-IV-TR diagnosis of autistic disorder, PDD-NOS, or Asperger disorder, to ensure continuity

BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted behavior/ Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines, or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the age of 3 years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least six behaviors coded with a minimum of two Social, one Communication, and one Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of 3 years OR At least two behaviors coded with a minimum of one Social and either one Communication and/or one Restricted Behavior/Interest; AND at least one autism discriminator coded Note: A child might be disqualified from meeting the DSM-IV-TR surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision)*.

of diagnoses and services. Second, sensitivity of the DSM-5 surveillance case definition might be increased when counting children diagnosed with ASD by a qualified professional, based on either DSM-IV-TR or DSM-5 criteria, whether or not all DSM-5 social and behavioral criteria are documented in abstracted comprehensive evaluations. The ADDM Network methods allow differentiation of those meeting the surveillance case status based on one or both criteria. Consistent with the DSM-IV-TR case definition, a child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's

BOX 2. Autism spectrum disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	Any ASD diagnosis documented in a comprehensive evaluation, including a DSM-IV diagnosis of autistic disorder, Asperger disorder, or pervasive developmental disorder–not otherwise specified (PDD-NOS)
DSM-5 case determination	All three behavioral criteria coded under part A, and at least two behavioral criteria coded under part B OR Any ASD diagnosis documented in a comprehensive evaluation, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Note: A child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.

symptoms. In this report, prevalence estimates are based on the DSM-IV-TR case definition, whereas case counts are presented and compared for children meeting the DSM-IV-TR and/or DSM-5 case definitions.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (5). For 2014, interrater agreement on DSM-IV-TR case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined (k = 0.77), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined (k = 0.84). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*26*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number 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 (*27*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution with an asymptotic approximation to the normal. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Kappa statistics were computed to describe concordance between the DSM-IV-TR and DSM-5 case definitions, as well as to describe interrater agreement on either case definition for quality assurance. Pearson chi-square tests also were performed for testing significance in comparisons of proportions, and unadjusted odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3) compared to each of the other ten sites ($P<0.01$).

Prevalence by Sex and Race/Ethnicity

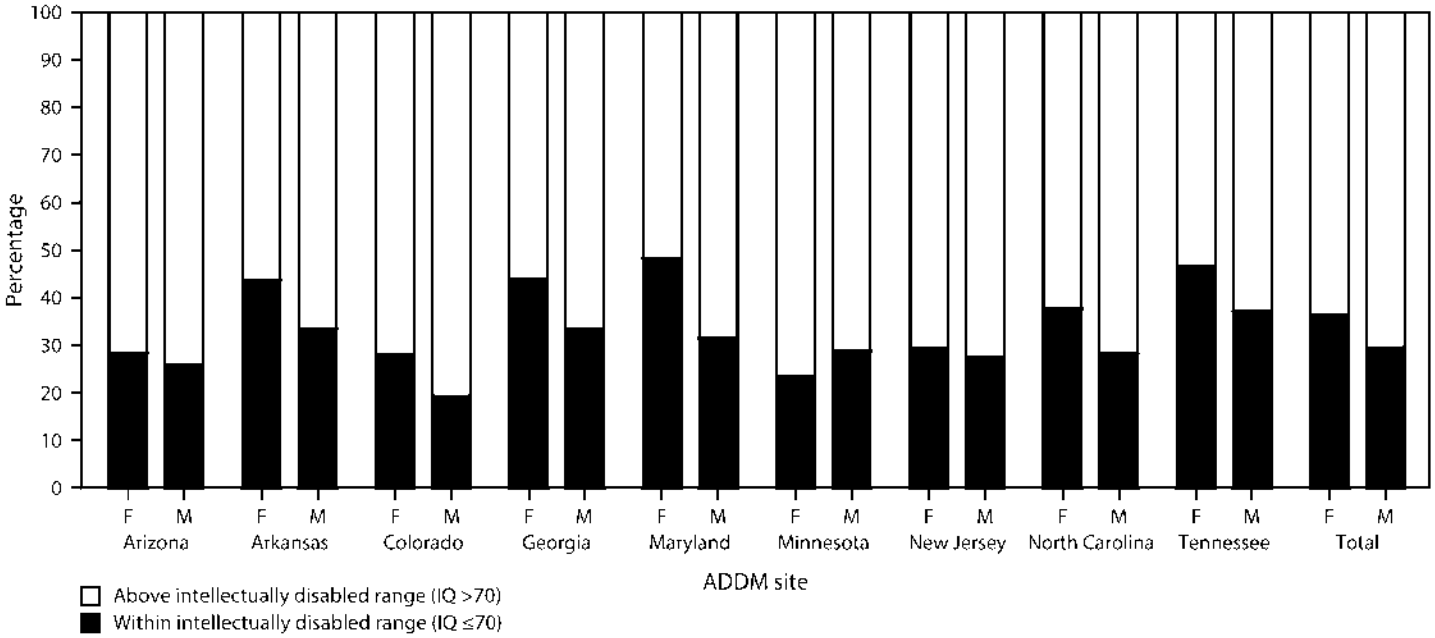
When data from all 11 ADDM sites were combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence was significantly ($p<0.01$) higher among boys than among girls in all 11 ADDM sites (Table 2), with male-to-female prevalence ratios ranging from 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites (Arizona, Arkansas, Colorado, Georgia, Missouri, North Carolina and Tennessee). In nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, North Carolina and Tennessee), the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites (Arizona, Georgia and North Carolina). In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability were reported for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least 70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4; $p<0.01$), though among individual sites this proportion differed significantly in only

FIGURE 1. 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, nine sites,* United States, 2014



Abbreviations: ADDM = Autism and Developmental Disabilities Monitoring Network; ASD = autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

one (Georgia, OR = 1.6; p<0.05). The proportion of children with ASD with borderline intellectual ability (IQ 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2; p<0.05).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all sites except Colorado, and when combining their data (OR = 2.9; p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9; p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8; p = 0.10), North Carolina (OR = 1.8; p = 0.07), and Tennessee (OR = 2.1; p = 0.09). The proportion of children with borderline intellectual ability (IQ = 71–85) did not differ between black and Hispanic children, although a lower proportion of white children (22%) were classified in the range of borderline intellectual ability compared to black (28.4%; OR = 0.7; p<0.01) or Hispanic (28.7%; OR = 0.7; p<0.01) children. When combining data from these nine sites, the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR = 3.4; p<0.01) or Hispanic (36%, OR = 2.2; p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV-TR, DSM-5, or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR = 1.4; p<0.01).

When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9; p=0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

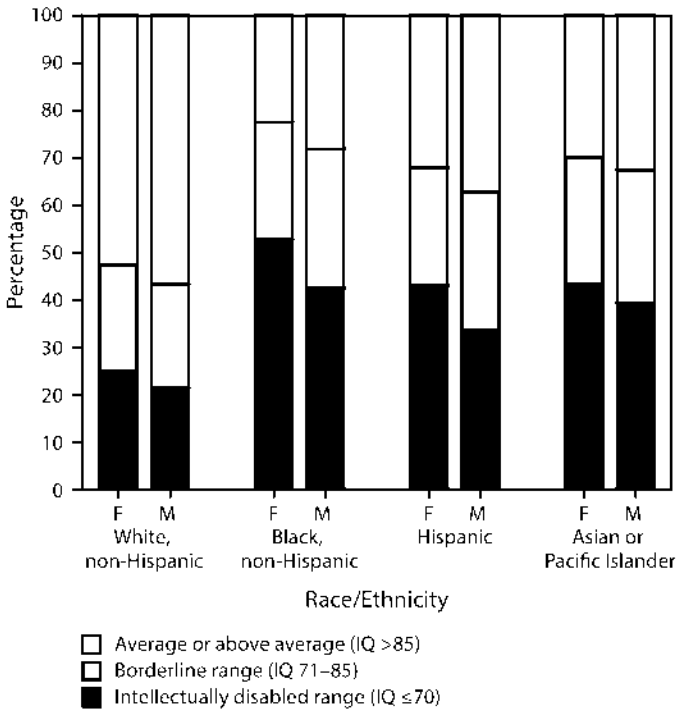
Sites with access to education records collected information on the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from approximately 37% in Wisconsin to 80% in Tennessee. Most other sites noted approximately 60% to 75% of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (44%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in four sites (Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Arkansas and Tennessee, where investigators were able to access education records throughout most, but not all, of the surveillance area and received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



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

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for >70 of children who met the ASD case definition (n = 3,714).

requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, a total of 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV-TR:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. Among 4,498 children who met DSM-5 case criteria, 3,817 (85%) met the DSM-5 behavioral criteria (Box 2), whereas 681 (15%) qualified on the basis of an established ASD diagnosis but did not have sufficient DSM-5 behavioral criteria documented in comprehensive evaluations. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in phase 1 of the study who were reviewed in phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV-TR:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV-TR, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV-TR, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV-TR. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV-TR. Slightly over 3% of children whose earliest ASD diagnosis was autistic disorder met DSM-5 criteria but not DSM-IV-TR, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed higher ASD prevalence estimates for 2012 compared to 2014, with a nearly 10% higher prevalence in Georgia ($p = 0.06$) and Maryland ($p = 0.35$), 19% in New Jersey ($p<0.01$), 22% in Missouri ($p=0.01$), 29% in Colorado ($p<0.01$), and 31% in Wisconsin ($p<0.01$). When combining data from these six sites, ASD prevalence estimates for 2014 were 20% higher for 2014 compared to 2012 ($p<0.01$). The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative difference in prevalence are noteworthy in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall

Colorado surveillance area), and Wisconsin was granted access to review education records for more than a quarter of its surveillance population, and 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20%–30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1–14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 8-year-olds. Of the six sites with prevalence estimates below the 16.8 per 1,000 estimate for all sites combined, five did not have full access to education data sources (Arkansas, Colorado, Missouri, Tennessee, and Wisconsin), whereas only one of the six sites will full access to education data sources had a prevalence estimate below 16.8 per 1,000 (Arizona). Such differences cannot be attributed solely to source access, as other factors (e.g., demographic differences and service availability) also might have influenced these findings. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted in the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors, such as regional and socioeconomic disparities in access to services (*13,14*).

Case Definitions

Results from application of the DSM-IV-TR and DSM-5 case definitions were similar, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. Overall, ASD prevalence estimates

based on the new DSM-5 case definition were very similar in magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV-TR. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented diagnosis of ASD might qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented ASD diagnosis. This element of the DSM-5 case definition might carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing ASD diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published and because professionals might diagnose children with ASD without necessarily recording every behavior supporting that diagnosis. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for autistic disorder, PDD-NOS or Asperger disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison of Autism Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that might affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*28*). An estimate of 20.0 per 1,000 children aged 6–17 years was reported from the 2011–2012 NSCH (*29*). The study samples for the two phone surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6–11,28,29*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral, developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to at least three limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders

and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for policy changes, individual treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3*,*6*–*11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*30*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*31*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD be evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*32*), might inform how policy initiatives, such as screening recommendations and other social determinants of health, impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing

behavioral, educational, residential and occupational needs of this population.

Implementation of the new DSM-5 case definition had little effect on the overall number of children identified with ASD for the ADDM 2014 surveillance year. This might be a result of including documented ASD diagnoses in the DSM-5 surveillance case definition. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, such as autistic disorder, PDD-NOS or Asperger disorder, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix[†]	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis St. Paul[§]	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**	**16,596**	**(5.1)**	**1,907**	**(0.6)**

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of third graders during the 2014–2015 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Sex: Overall† Prevalence	Overall† 95% CI	Males Prevalence	Males 95% CI	Females Prevalence	Females 95% CI	Male-to-female prevalence ratio§
Arizona	24,952	349	14.0	(12.6 15.5)	21.1	(18.7 23.8)	6.6	(5.3 8.2)	3.2
Arkansas	39,992	522	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	3.8
Colorado	41,128	572	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	3.9
Georgia	51,161	869	17.0	(15.9 18.2)	27.9	(25.9 30.0)	5.7	(4.8 6.7)	4.9
Maryland	9,955	199	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	4.5
Minnesota	9,767	234	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	4.6
Missouri	25,333	356	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	4.0
New Jersey	32,935	964	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	3.7
North Carolina	30,283	527	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	4.3
Tennessee	24,940	387	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	4.7
Wisconsin	35,037	494	14.1	(12.9 15.4)	21.4	(19.4 23.7)	6.4	(5.3 7.7)	3.4
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	**4.0**

Abbreviations: ASD = autism spectrum disorder; CI = confidence interval.
* Per 1,000 children aged 8 years.
† All children are included in the total regardless of race or ethnicity.
§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

TABLE 3. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/Ethnicity: White Prevalence	White 95% CI	Black Prevalence	Black 95% CI	Hispanic Prevalence	Hispanic 95% CI	Asian/Pacific Islander Prevalence	Asian/Pacific Islander 95% CI	Prevalence ratio: White-to-Black	White-to-Hispanic	Black-to-Hispanic
Arizona	16.2	(14.1 18.6)	19.5	(13.3 28.6)	10.3	(8.5 12.5)	10.3	(5.5 19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3	1.4§	1.1
Georgia	17.9	(16.0 20.2)	17.1	(15.4 18.9)	12.6	(10.6 15.0)	11.9	(8.9 16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6 17.0)	11.3	(8.9 14.2)	12.5	(10.0 15.6)	10.2	(6.1 16.9)	1.3†	1.2	0.9
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1†**	**1.2§**	**1.1§**

Abbreviation: CI = confidence interval.
* Per 1,000 children aged 8 years.
† Pearson chi-square test of prevalence ratio significant at p<0.05.
§ Pearson chi-square test of prevalence ratio significant at p<0.01.

TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional at age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
Site	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

* Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder			ASD/PDD			Asperger disorder			Any specified ASD diagnosis		
Site	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**	**52**	**3,794**	**(69.3)**

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

TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	North Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with Special education records	308 (88.3)	327† —§	139† —§	708 (81.5)	149 (74.9)	188 (80.3)	822 (85.3)	420 (79.7)	218† —§	156† —§
Primary exceptionality (%)										
Autism	64.9	65.4	43.9	58.9	67.1	67.0	48.4	75.0	79.8	36.5
Emotional disturbance	2.9	0.9	7.2	2.0	2.7	3.7	1.6	2.6	0.5	5.8
Specific learning disability	6.8	3.7	13.7	4.0	12.8	1.1	8.2	2.9	0.9	2.6
Speech or language impairment	5.5	8.9	10.8	1.0	3.4	2.7	13.7	2.4	3.2	20.5
Hearing or visual impairment	0	0.3	0	0.1	0	1.1	0.6	0.5	0	0.6
Health, physical or other disability	6.8	13.5	14.4	3.5	8.1	15.4	18.5	11.2	3.2	14.7
Multiple disabilities	0.3	3.4	5.0	0	4.0	1.6	6.7	1.7	0	0
Intellectual disability	3.2	4.0	4.3	2.0	2.0	6.9	1.7	2.4	2.8	0.6
Developmental delay/Preschool	9.4	0	0.7	28.5	0	0.5	0.6	1.4	9.6	18.6

Abbreviation: ASD = autism spectrum disorder.

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

† Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 67% Colorado, 12% Tennessee, 74% Wisconsin).

§ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

			Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
Site	Site institution	Surveillance area	No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**	**13,903**	**(5.3)**	**1,438**	**(0.5)**

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of third graders during the 2014–2015 school year.

TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Site	No.	No.	(%)	No.	(%)	No.	(%)	Ratio	Kappa
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All sites combined	**4,920**	**4,236**	**(86.1)**	**422**	**(8.6)**	**262**	**(5.3)**	**1.04**	**0.85**

Abbreviations: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*; DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*.

TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Characteristic	No.	No.	(%)	No.	(%)	No.	(%)	Ratio	Kappa
Met ASD case definition under DSM-IV-TR and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Male	3,978	3,452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian/Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37–48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1,503	1,195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Autism special education eligibility[†]	2,270	2,156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement[§]									
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis autistic disorder	1,577	1,526	(96.8)	0	(0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ ASD NOS	1,564	1,525	(97.5)	0	(0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger disorder	221	210	(95.0)	0	(0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

Abbreviations: ASD = autism spectrum disorder; DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*; DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*; PDD-NOS = pervasive developmental disorder not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† Includes children with autism as the Primary Exceptionality (Table 6) as well as children documented to meet eligibility criteria for autism special education services.

§ An ASD diagnosis documented in abstracted comprehensive evaluations, including DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

¶ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014

Jon Baio, EdS[1]; Lisa Wiggins, PhD[1]; Deborah L. Christensen, PhD[1]; Matthew J Maenner, PhD[1]; Julie Daniels, PhD[2]; Zachary Warren, PhD[3]; Margaret Kurzius-Spencer, PhD[4]; Walter Zahorodny, PhD[5]; Cordelia Robinson Rosenberg, PhD[6]; Tiffany White, PhD[7]; Maureen S. Durkin, PhD[8]; Pamela Imm, MS[8]; Loizos Nikolaou, MPH[1,9]; Marshalyn Yeargin-Allsopp, MD[1]; Li-Ching Lee, PhD[10]; Rebecca Harrington, PhD[10]; Maya Lopez, MD[11]; Robert T. Fitzgerald, PhD[12]; Amy Hewitt, PhD[13]; Sydney Pettygrove, PhD[4]; John N. Constantino, MD[12]; Alison Vehorn, MS[3]; Josephine Shenouda, MS[5]; Jennifer Hall-Lande, PhD[13]; Kim Van Naarden Braun, PhD[1]; Nicole F. Dowling, PhD[1]

[1]*National Center on Birth Defects and Developmental Disabilities, CDC;* [2]*University of North Carolina, Chapel Hill;* [3]*Vanderbilt University Medical Center, Nashville, Tennessee;* [4]*University of Arizona, Tucson;* [5]*Rutgers University, Newark, New Jersey;* [6]*University of Colorado School of Medicine at the Anschutz Medical Campus;* [7]*Colorado Department of Public Health and Environment, Denver;* [8]*University of Wisconsin, Madison;* [9]*Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee;* [10]*Johns Hopkins University, Baltimore, Maryland;* [11]*University of Arkansas for Medical Sciences, Little Rock;* [12]*Washington University in St. Louis, Missouri;* [13]*University of Minnesota, Minneapolis*

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the DSM-5 diagnostic criteria. Children meeting this new surveillance case definition could qualify on the basis of one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. For 2014, results from application of the DSM-IV-TR and DSM-5 case definitions were similar, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability.

Public Health Action: Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence in future surveillance reports. Although the DSM-IV-TR case definition will eventually be phased out, it will be applied in a limited geographic area to offer additional data for comparison. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses, such as autistic disorder, PDD-NOS, and Asperger disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time. The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2*,*3*). The first CDC study, which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5

(*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence underscores the need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD during 2006–2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000–2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006, and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change from 2002 to 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9–11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ ≤70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008, this proportion was closer to 40%; and during 2010–2012, less than one third of children with ASD had IQ ≤70 (*9–11*). This trend was more pronounced for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (*9–11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to autism spectrum disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by level of support needed by the individual. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons diagnosed with ASD under DSM-5 must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors; and deficits in developing, understanding, and maintaining relationships) and

at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input).

Although the DSM-IV-TR criteria proved useful in identifying ASD in some children, clinical agreement and diagnostic specificity in some subtypes (e.g., PDD-NOS) was poor, offering empirical support to the notion of two, rather than three, diagnostic domains. The DSM-5 introduced a framework to address these concerns (*18*), while maintaining that any person with an established DSM-IV-TR diagnosis of autistic disorder, Asperger disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of autism spectrum disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and asserts the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge that led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight biennial ADDM Network surveillance years spanning 2000–2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD, 2) to monitor the prevalence of ASD in different areas of the United States, and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data were collected for children aged 8 years during 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 selected eligibility classifications for special education or *International Classification of Diseases, Ninth Revision* (ICD-9) billing codes for select childhood disabilities or psychological conditions. Children's records are first reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder (Box 1). A child might be disqualified from meeting the surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. A child could meet the DSM-5 surveillance case definition for ASD under one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria (Box 2). Children with a documented ASD diagnosis were included as meeting the DSM-5 surveillance case definition for two reasons. First, published DSM-5 diagnostic criteria include the presence of a DSM-IV-TR diagnosis of autistic

BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted behavior/ Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines, or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the age of 3 years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least six behaviors coded with a minimum of two Social, one Communication, and one Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of 3 years OR At least two behaviors coded with a minimum of one Social and either one Communication and/or one Restricted Behavior/Interest; AND at least one autism discriminator coded Note: A child might be disqualified from meeting the DSM-IV-TR surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision)*.

disorder, PDD-NOS, or Asperger disorder, to ensure continuity of diagnoses and services. Second, sensitivity of the DSM-5 surveillance case definition might be increased when counting children diagnosed with ASD by a qualified professional, based on either DSM-IV-TR or DSM-5 criteria, whether or not all DSM-5 social and behavioral criteria are documented in abstracted comprehensive evaluations. The ADDM Network methods allow differentiation of those meeting the surveillance case status based on one or both criteria. Consistent with the DSM-IV-TR case definition, a child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or

BOX 2. Autism spectrum disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	Any ASD diagnosis documented in a comprehensive evaluation, including a DSM-IV diagnosis of autistic disorder, Asperger disorder, or pervasive developmental disorder–not otherwise specified (PDD-NOS)
DSM-5 case determination	All three behavioral criteria coded under part A, and at least two behavioral criteria coded under part B OR Any ASD diagnosis documented in a comprehensive evaluation, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Note: A child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.

more other diagnosed conditions better account for the child's symptoms. In this report, prevalence estimates are based on the DSM-IV-TR case definition, whereas case counts are presented and compared for children meeting the DSM-IV-TR and/or DSM-5 case definitions.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (5). For 2014, interrater agreement on DSM-IV-TR case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined (k = 0.77), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined (k = 0.84). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*26*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number of children living in outlying school districts was subtracted from the county-level census denominators using school enrollment data from the U.S. Department of Education's National Center for Education Statistics (*27*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution with an asymptotic approximation to the normal. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Kappa statistics were computed to describe concordance between the DSM-IV-TR and DSM-5 case definitions, as well as to describe interrater agreement on either case definition for quality assurance. Pearson chi-square tests also were performed for testing significance in comparisons of proportions, and unadjusted odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3) compared to each of the other ten sites ($p<0.01$).

Prevalence by Sex and Race/Ethnicity

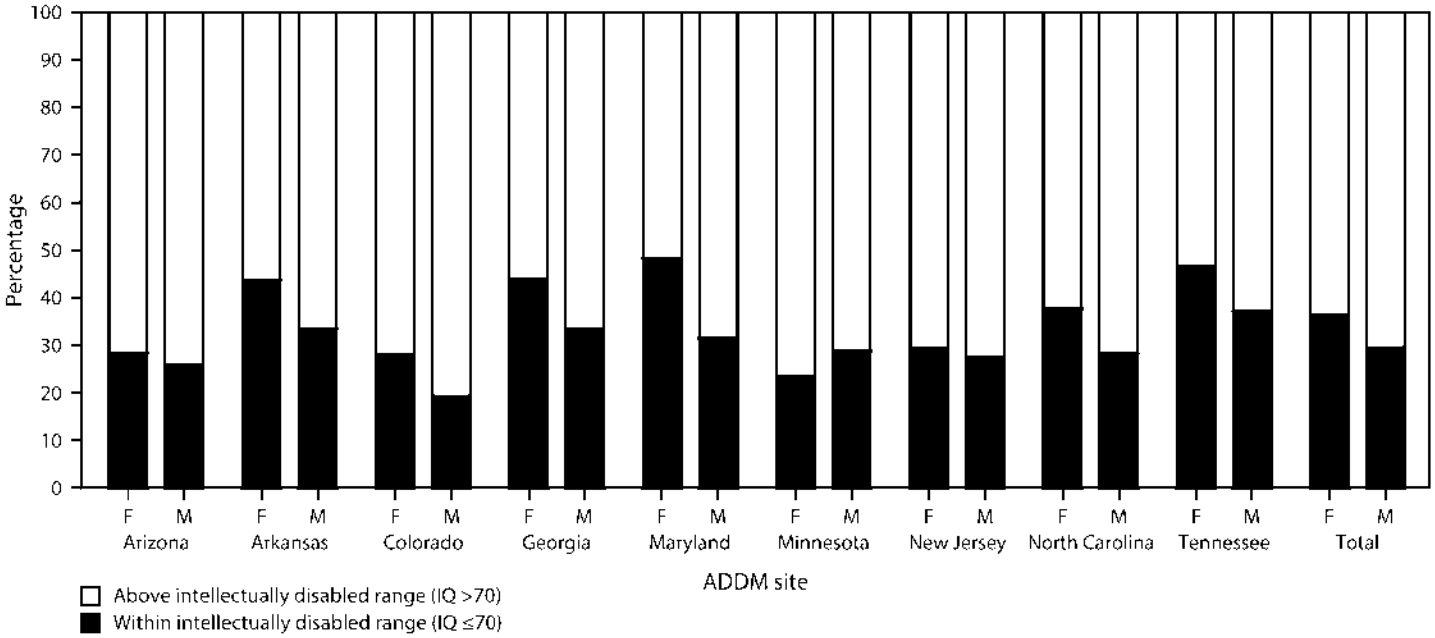
When data from all 11 ADDM sites were combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence was significantly ($p<0.01$) higher among boys than among girls in all 11 ADDM sites (Table 2), with male-to-female prevalence ratios ranging from 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites (Arizona, Arkansas, Colorado, Georgia, Missouri, North Carolina, and Tennessee). In nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, North Carolina, and Tennessee), the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites (Arizona, Georgia, and North Carolina). In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability were reported for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least 70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4; $p<0.01$), though among individual sites this proportion differed significantly in only

FIGURE 1. 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, nine sites,* United States, 2014



Abbreviations: ADDM = Autism and Developmental Disabilities Monitoring Network; ASD = autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

one (Georgia, OR = 1.6; p<0.05). The proportion of children with ASD with borderline intellectual ability (IQ 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2; p<0.05).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all sites except Colorado, and when combining their data (OR = 2.9; p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9; p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8; p = 0.10), North Carolina (OR = 1.8; p = 0.07), and Tennessee (OR = 2.1; p = 0.09). The proportion of children with borderline intellectual ability (IQ = 71–85) did not differ between black and Hispanic children, although a lower proportion of white children (22%) were classified in the range of borderline intellectual ability compared to black (28.4%; OR = 0.7; p<0.01) or Hispanic (28.7%; OR = 0.7; p<0.01) children. When combining data from these nine sites, the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR = 3.4; p<0.01) or Hispanic (36%, OR = 2.2; p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV-TR, DSM-5, or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR = 1.4; p<0.01).

When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9; p = 0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

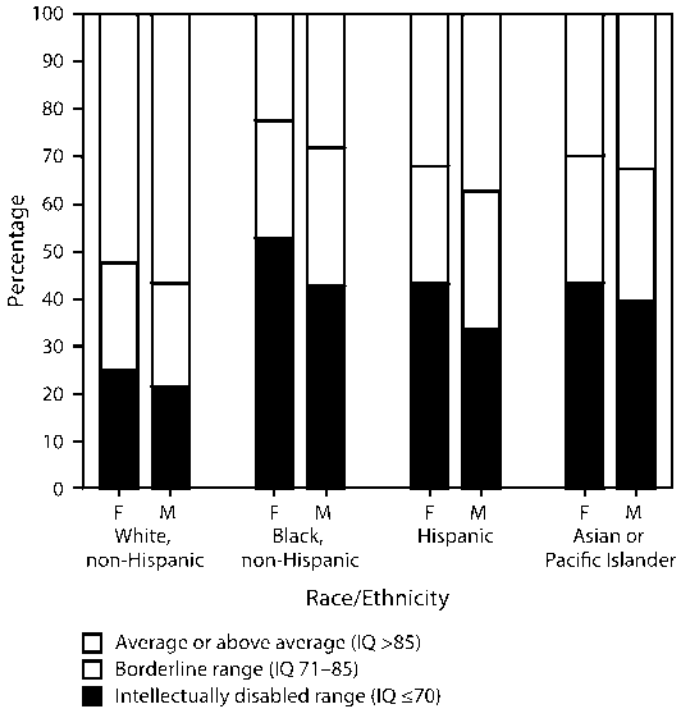
Sites with access to education records collected information on the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from approximately 37% in Wisconsin to 80% in Tennessee. Most other sites noted approximately 60% to 75% of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (44%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in four sites (Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Arkansas and Tennessee, where investigators were able to access education records throughout most, but not all, of the surveillance area and received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



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

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV-TR:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. Among 4,498 children who met DSM-5 case criteria, 3,817 (85%) met the DSM-5 behavioral criteria (Box 2), whereas 681 (15%) qualified on the basis of an established ASD diagnosis but did not have sufficient DSM-5 behavioral criteria documented in comprehensive evaluations. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in Phase 1 of the study who were reviewed in Phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV-TR:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV-TR, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV-TR, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV-TR. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV-TR. Slightly over 3% of children whose earliest ASD diagnosis was autistic disorder met DSM-5 criteria but not DSM-IV-TR, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed higher ASD prevalence estimates for 2012 compared to 2014, with a nearly 10% higher prevalence in Georgia ($p = 0.06$) and Maryland ($p = 0.35$), 19% in New Jersey ($p<0.01$), 22% in Missouri ($p = 0.01$), 29% in Colorado ($p<0.01$), and 31% in Wisconsin ($p<0.01$). When combining data from these six sites, ASD prevalence estimates for 2014 were 20% higher for 2014 compared to 2012 ($p<0.01$). The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative difference in prevalence are noteworthy in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall

Colorado surveillance area), and Wisconsin was granted access to review education records for more than a quarter of its surveillance population, and 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20%–30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1–14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 children aged 8 years. Of the six sites with prevalence estimates below the 16.8 per 1,000 estimate for all sites combined, five did not have full access to education data sources (Arkansas, Colorado, Missouri, Tennessee, and Wisconsin), whereas only one of the six sites will full access to education data sources had a prevalence estimate below 16.8 per 1,000 (Arizona). Such differences cannot be attributed solely to source access, as other factors (e.g., demographic differences and service availability) also might have influenced these findings. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted in the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors, such as regional and socioeconomic disparities in access to services (*13*,*14*).

Case Definitions

Results from application of the DSM-IV-TR and DSM-5 case definitions were similar, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. Overall, ASD prevalence estimates

based on the new DSM-5 case definition were very similar in magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV-TR. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented diagnosis of ASD might qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented ASD diagnosis. This element of the DSM-5 case definition might carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing ASD diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published and because professionals might diagnose children with ASD without necessarily recording every behavior supporting that diagnosis. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for autistic disorder, PDD-NOS, or Asperger disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison of Autism Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that might affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*28*). An estimate of 20.0 per 1,000 children aged 6–17 years was reported from the 2011–2012 NSCH (*29*). The study samples for both surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6–11,28,29*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral, developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to at least three limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders

and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for policy changes, individual treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3*,*6*–*11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*30*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*31*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD be evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*32*), might inform how policy initiatives, such as screening recommendations and other social determinants of health, impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing

behavioral, educational, residential and occupational needs of this population.

Implementation of the new DSM-5 case definition had little effect on the overall number of children identified with ASD for the ADDM 2014 surveillance year. This might be a result of including documented ASD diagnoses in the DSM-5 surveillance case definition. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, such as autistic disorder, PDD-NOS or Asperger disorder, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix[†]	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis St. Paul[§]	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**	**16,596**	**(5.1)**	**1,907**	**(0.6)**

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of third graders during the 2014–2015 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Sex						Male-to-female prevalence ratio§
			Overall†		Males		Females		
			Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI	
Arizona	24,952	349	14.0	(12.6 15.5)	21.1	(18.7 23.8)	6.6	(5.3 8.2)	3.2
Arkansas	39,992	522	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	3.8
Colorado	41,128	572	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	3.9
Georgia	51,161	869	17.0	(15.9 18.2)	27.9	(25.9 30.0)	5.7	(4.8 6.7)	4.9
Maryland	9,955	199	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	4.5
Minnesota	9,767	234	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	4.6
Missouri	25,333	356	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	4.0
New Jersey	32,935	964	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	3.7
North Carolina	30,283	527	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	4.3
Tennessee	24,940	387	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	4.7
Wisconsin	35,037	494	14.1	(12.9 15.4)	21.4	(19.4 23.7)	6.4	(5.3 7.7)	3.4
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	**4.0**

Abbreviations: ASD = autism spectrum disorder; CI = confidence interval.
* Per 1,000 children aged 8 years.
† All children are included in the total regardless of race or ethnicity.
§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

TABLE 3. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/Ethnicity								Prevalence ratio		
	White		Black		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			
Arizona	16.2	(14.1 18.6)	19.5	(13.3 28.6)	10.3	(8.5 12.5)	10.3	(5.5 19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3	1.4§	1.1
Georgia	17.9	(16.0 20.2)	17.1	(15.4 18.9)	12.6	(10.6 15.0)	11.9	(8.9 16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6 17.0)	11.3	(8.9 14.2)	12.5	(10.0 15.6)	10.2	(6.1 16.9)	1.3†	1.2	0.9
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1†**	**1.2§**	**1.1§**

Abbreviation: CI = confidence interval.
* Per 1,000 children aged 8 years.
† Pearson chi-square test of prevalence ratio significant at p<0.05.
§ Pearson chi-square test of prevalence ratio significant at p<0.01.

TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional at age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
Site	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

* Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder			ASD/PDD			Asperger disorder			Any specified ASD diagnosis		
Site	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**	**52**	**3,794**	**(69.3)**

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

TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	North Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with special education records	308 (88.3)	327† (—§)	139† (—§)	708 (81.5)	149 (74.9)	188 (80.3)	822 (85.3)	420 (79.7)	218† (—§)	156† (—§)
Primary exceptionality (%)										
Autism	64.9	65.4	43.9	58.9	67.1	67.0	48.4	75.0	79.8	36.5
Emotional disturbance	2.9	0.9	7.2	2.0	2.7	3.7	1.6	2.6	0.5	5.8
Specific learning disability	6.8	3.7	13.7	4.0	12.8	1.1	8.2	2.9	0.9	2.6
Speech or language impairment	5.5	8.9	10.8	1.0	3.4	2.7	13.7	2.4	3.2	20.5
Hearing or visual impairment	0	0.3	0	0.1	0	1.1	0.6	0.5	0	0.6
Health, physical or other disability	6.8	13.5	14.4	3.5	8.1	15.4	18.5	11.2	3.2	14.7
Multiple disabilities	0.3	3.4	5.0	0	4.0	1.6	6.7	1.7	0	0
Intellectual disability	3.2	4.0	4.3	2.0	2.0	6.9	1.7	2.4	2.8	0.6
Developmental delay/Preschool	9.4	0	0.7	28.5	0	0.5	0.6	1.4	9.6	18.6

Abbreviation: ASD = autism spectrum disorder.

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

† Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 67% Colorado, 12% Tennessee, 74% Wisconsin).

§ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

			Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
Site	Site institution	Surveillance area	No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**	**13,903**	**(5.3)**	**1,438**	**(0.5)**

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.*

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of third graders during the 2014–2015 school year.

TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Site	No.	No.	(%)	No.	(%)	No.	(%)	Ratio	Kappa
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All sites combined	**4,920**	**4,236**	**(86.1)**	**422**	**(8.6)**	**262**	**(5.3)**	**1.04**	**0.85**

Abbreviations: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*; DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*.

TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Characteristic	No.	No.	(%)	No.	(%)	No.	(%)	Ratio	Kappa
Met ASD case definition under DSM-IV-TR and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Male	3,978	3,452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian/Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37–48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1,503	1,195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Autism special education eligibility[†]	2,270	2,156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement[§]									
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis autistic disorder	1,577	1,526	(96.8)	0	(0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ ASD NOS	1,564	1,525	(97.5)	0	(0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger disorder	221	210	(95.0)	0	(0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

Abbreviations: ASD = autism spectrum disorder; DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*; DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*; PDD-NOS = pervasive developmental disorder not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† Includes children with autism as the Primary Exceptionality (Table 6) as well as children documented to meet eligibility criteria for autism special education services.

§ An ASD diagnosis documented in abstracted comprehensive evaluations, including DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

¶ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

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Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014

Jon Baio, EdS[1]; Lisa Wiggins, PhD[1]; Deborah L. Christensen, PhD[1]; Matthew J Maenner, PhD[1]; Julie Daniels, PhD[2]; Zachary Warren, PhD[3]; Margaret Kurzius-Spencer, PhD[4]; Walter Zahorodny, PhD[5]; Cordelia Robinson Rosenberg, PhD[6]; Tiffany White, PhD[7]; Maureen S. Durkin, PhD[8]; Pamela Imm, MS[8]; Loizos Nikolaou, MPH[8,9]; Marshalyn Yeargin-Allsopp, MD[1]; Li-Ching Lee, PhD[10]; Rebecca Harrington, PhD[10]; Maya Lopez, MD[11]; Robert T. Fitzgerald, PhD[12]; Amy Hewitt, PhD[13]; Sydney Pettygrove, PhD[4]; John N. Constantino, MD[12]; Alison Vehorn, MS[3]; Josephine Shenouda, MS[5]; Jennifer Hall-Lande, PhD[13]; Kim Van Naarden Braun, PhD[1]; Nicole F. Dowling, PhD[1]

[1]*National Center on Birth Defects and Developmental Disabilities, CDC;* [2]*University of North Carolina, Chapel Hill;* [3]*Vanderbilt University Medical Center, Nashville, Tennessee;* [4]*University of Arizona, Tucson;* [5]*Rutgers University, Newark, New Jersey;* [6]*University of Colorado School of Medicine at the Anschutz Medical Campus;* [7]*Colorado Department of Public Health and Environment, Denver;* [8]*University of Wisconsin, Madison;* [9]*Oak Ridge Institute for Science and Education, Oak Ridge, Tennessee;* [10]*Johns Hopkins University, Baltimore, Maryland;* [11]*University of Arkansas for Medical Sciences, Little Rock;* [12]*Washington University in St. Louis, Missouri;* [13]*University of Minnesota, Minneapolis*

Abstract

Problem/Condition: Autism spectrum disorder (ASD).

Period Covered: 2014.

Description of System: The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside within 11 ADDM sites in the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general pediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviors, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. This report provides updated ASD prevalence estimates for children aged 8 years during the 2014 surveillance year, on the basis of DSM-IV-TR criteria, and describes characteristics of the population of children with ASD. In 2013, the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), which made considerable changes to ASD diagnostic criteria. The change in ASD diagnostic criteria might influence ADDM ASD prevalence estimates; therefore, most (85%) of the records used to determine prevalence estimates based on DSM-IV-TR criteria underwent additional review under a newly operationalized surveillance case definition for ASD consistent with the DSM-5 diagnostic criteria. Children meeting this new surveillance case definition could qualify on the basis of one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria. Stratified comparisons of the number of children meeting either of these two case definitions also are reported.

Corresponding author: Jon Baio, National Center on Birth Defects and Developmental Disabilities, CDC. Telephone: 404-498-3873; E-mail: jbaio@cdc.gov.

Results: For 2014, the overall prevalence of ASD among the 11 ADDM sites was 16.8 per 1,000 (one in 59) children aged 8 years. Overall ASD prevalence estimates varied among sites, from 13.1–29.3 per 1,000 children aged 8 years. ASD prevalence estimates also varied by sex and race/ethnicity. Males were four times more likely than females to be identified with ASD. Prevalence estimates were higher for non-Hispanic white (henceforth, white) children compared with non-Hispanic black (henceforth, black) children, and both groups were more likely to be identified with ASD compared with Hispanic children. Among the nine sites with sufficient data on intellectual ability, 31% of children with ASD were classified in the range of intellectual disability (intelligence quotient [IQ] ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ scores in the average to above average range (i.e., IQ >85). The distribution of intellectual ability varied by sex and race/ethnicity. Although mention of developmental concerns by age 36 months was documented for 85% of children with ASD, only 42% had a comprehensive evaluation on record by age 36 months. The median age of earliest known ASD diagnosis was 52 months and did not differ significantly by sex or race/ethnicity. For the targeted comparison of DSM-IV-TR and DSM-5 results, the number and characteristics of children meeting the newly operationalized DSM-5 case definition for ASD were similar to those meeting the DSM-IV-TR case definition, with DSM-IV-TR case counts exceeding DSM-5 counts by less than 5% and approximately 86% overlap between the two case definitions (kappa = 0.85).

Interpretation: Findings from the ADDM Network, on the basis of 2014 data reported from 11 sites, provide updated population-based estimates of the prevalence of ASD among children aged 8 years in multiple communities in the United States. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. Because the ADDM 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. Consistent with reports from previous ADDM surveillance years, findings from 2014 were marked by variation in ASD prevalence when stratified by geographic area, sex, and level of intellectual ability. Differences in prevalence estimates between black and white children have diminished in most sites, but remained notable for Hispanic children. For 2014, results from application of the DSM-IV-TR and DSM-5 case definitions were similar, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability.

Public Health Action: Beginning with surveillance year 2016, the DSM-5 case definition will serve as the basis for ADDM estimates of ASD prevalence in future surveillance reports. Although the DSM-IV-TR case definition will eventually be phased out, it will be applied in a limited geographic area to offer additional data for comparison. Future analyses will examine trends in the continued use of DSM-IV-TR diagnoses, such as autistic disorder, PDD-NOS, and Asperger disorder in health and education records, documentation of symptoms consistent with DSM-5 terminology, and how these trends might influence estimates of ASD prevalence over time. The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported estimates and continues to vary among certain racial/ethnic groups and communities. With prevalence of ASD ranging from 13.1 to 29.3 per 1,000 children aged 8 years in different communities throughout the United States, the need for behavioral, educational, residential, and occupational services remains high, as does the need for increased research on both genetic and nongenetic risk factors for ASD.

Introduction

Autism spectrum disorder (ASD) is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life (*1*). CDC began tracking the prevalence of ASD and characteristics of children with ASD in the United States in 1998 (*2*,*3*). The first CDC study, which was based on an investigation in Brick Township, New Jersey (*2*), identified similar characteristics but higher prevalence of ASD compared with other studies of that era. The second CDC study, which was conducted in metropolitan Atlanta, Georgia (*3*), identified a lower prevalence of ASD compared with the Brick Township study but similar estimates compared with other prevalence studies of that era. In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (*4*,*5*).

Tracking the prevalence of ASD poses unique challenges because of the heterogeneity in symptom presentation, lack of biologic diagnostic markers, and changing diagnostic criteria (*5*). 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 (*1*). Features of ASD might overlap with or be difficult to distinguish from those of other psychiatric disorders, as described extensively in DSM-5

(*1*). Although standard diagnostic tools have been validated to inform clinicians' impressions of ASD symptomology, inherent complexity of measurement approaches and variation in clinical impressions and decision-making, combined with policy changes that affect eligibility for health benefits and educational programs, complicates identification of ASD as a behavioral health diagnosis or educational exceptionality. To reduce the influence of these factors on prevalence estimates, the ADDM Network has consistently tracked ASD by applying a surveillance case definition of ASD and using the same record-review methodology and behaviorally defined case inclusion criteria since 2000 (*5*).

ADDM estimates of ASD prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, more than doubling during this period (*6–11*). The observed increase in ASD prevalence underscores the need for continued surveillance using consistent methods to monitor the changing prevalence of ASD and characteristics of children with ASD in the population.

In addition to serving as a basis for ASD prevalence estimates, ADDM data have been used to describe characteristics of children with ASD in the population, to study how these characteristics vary with ASD prevalence estimates over time and among communities, and to monitor progress toward *Healthy People 2020* objectives (*12*). ADDM ASD prevalence estimates consistently estimated a ratio of approximately 4.5 male:1 female with ASD during 2006–2012 (*9–11*). Other characteristics that have remained relatively constant over time in the population of children identified with ASD by ADDM include the median age of earliest known ASD diagnosis, which remained close to 53 months during 2000–2012 (range: 50 months [2012] to 56 months [2002]), and the proportion of children receiving a comprehensive developmental evaluation by age 3 years, which remained close to 43% during 2006–2012 (range: 43% [2006 and 2012] to 46% [2008]).

ASD prevalence by race/ethnicity has been more varied over time among ADDM Network communities (*9–11*). Although ASD prevalence estimates have historically been greater among white children compared with black or Hispanic children (*13*), ADDM-reported white:black and white:Hispanic prevalence ratios have declined over time because of larger increases in ASD prevalence among black children and, to an even greater extent, among Hispanic children, as compared with the magnitude of increase in ASD prevalence among white children (*9*). Previous reports from the ADDM Network estimated ASD prevalence among white children to exceed that among black children by approximately 30% in 2002, 2006, and 2010, and by approximately 20% in 2008 and 2012. Estimated prevalence among white children exceeded that among Hispanic children by nearly 70% in 2002 and 2006, and by approximately 50% in 2008, 2010, and 2012. ASD prevalence estimates from the ADDM Network also have varied by socioeconomic status (SES). A consistent pattern observed in ADDM data has been higher identified ASD prevalence among residents of neighborhoods with higher socioeconomic status (SES). Although ASD prevalence has increased over time at all levels of SES, the absolute difference in prevalence between high, middle, and lower SES did not change from 2002 to 2010 (*14,15*). In the context of declining white:black and white:Hispanic prevalence ratios amidst consistent SES patterns, a complex three-way interaction among time, SES, and race/ethnicity has been proposed (*16*).

Finally, ADDM Network data have shown a shift toward children with ASD with higher intellectual ability (*9–11*), as the proportion of children with ASD whose intelligence quotient (IQ) scores fell within the range of intellectual disability (ID) (i.e., IQ ≤70) has decreased gradually over time. During 2000–2002, approximately half of children with ASD had IQ scores in the range of ID; during 2006–2008, this proportion was closer to 40%; and during 2010–2012, less than one third of children with ASD had IQ ≤70 (*9–11*). This trend was more pronounced for females as compared with males (9). The proportion of males with ASD and ID declined from approximately 40% during 2000–2008 (9) to 30% during 2010–2012 (*10,11*). The proportion of females with ASD and ID declined from approximately 60% during 2000–2002, to 45% during 2006–2008, and to 35% during 2010–2012 (*9–11*).

All previously reported ASD prevalence estimates from the ADDM Network were based on a surveillance case definition aligned with DSM-IV-TR diagnostic criteria for autistic disorder; pervasive developmental disorder–not otherwise specified (PDD-NOS, including atypical autism); or Asperger disorder. In the American Psychiatric Association's 2013 publication of DSM-5, substantial changes were made to the taxonomy and diagnostic criteria for autism (*1,17*). Taxonomy changed from Pervasive Developmental Disorders, which included multiple diagnostic subtypes, to autism spectrum disorder, which no longer comprises distinct subtypes but represents one singular diagnostic category defined by level of support needed by the individual. Diagnostic criteria were refined by collapsing the DSM-IV-TR social and communication domains into a single, combined domain for DSM-5. Persons diagnosed with ASD under DSM-5 must meet all three criteria under the social communication/interaction domain (i.e., deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors; and deficits in developing, understanding, and maintaining relationships) and

at least two of the four criteria under the restrictive/repetitive behavior domain (i.e., repetitive speech or motor movements, insistence on sameness, restricted interests, or unusual response to sensory input).

Although the DSM-IV-TR criteria proved useful in identifying ASD in some children, clinical agreement and diagnostic specificity in some subtypes (e.g., PDD-NOS) was poor, offering empirical support to the notion of two, rather than three, diagnostic domains. The DSM-5 introduced a framework to address these concerns (*18*), while maintaining that any person with an established DSM-IV-TR diagnosis of autistic disorder, Asperger disorder, or PDD-NOS would automatically qualify for a DSM-5 diagnosis of autism spectrum disorder. Previous studies suggest that DSM-5 criteria for ASD might exclude certain children who would have qualified for a DSM-IV-TR diagnosis but had not yet received one, particularly those who are very young and those without ID (*19–23*). These findings suggest that ASD prevalence estimates will likely be lower under DSM-5 than they have been under DSM-IV-TR diagnostic criteria.

This report provides the latest available ASD prevalence estimates from the ADDM Network based on both DSM-IV-TR and DSM-5 criteria and asserts the need for future monitoring of ASD prevalence trends and efforts to improve early identification of ASD. The intended audiences for these findings include 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 inform policies that promote improved outcomes in health and education settings.

Methods

Study Sites

The Children's Health Act (*4*) authorized CDC to monitor prevalence of ASD in multiple areas of the United States, a charge that led to the formation of the ADDM Network in 2000. Since that time, CDC has funded grantees in 16 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin). CDC tracks ASD in metropolitan Atlanta and represents the Georgia site collaborating with competitively funded sites to form the ADDM Network.

The ADDM Network uses multisite, multisource, records-based surveillance based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (*24*). As feasible, the surveillance methods have remained consistent over time. Certain minor changes have been introduced to improve efficiency and data quality. Although a different array of geographic areas was covered in each of the eight biennial ADDM Network surveillance years spanning 2000–2014, 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 suggested that this is the age of peak prevalence (*3*). ADDM has multiple goals: 1) to provide descriptive data on classification and functioning of the population of children with ASD, 2) to monitor the prevalence of ASD in different areas of the United States, and 3) to understand the impact of ASD in U.S. communities.

Funding for ADDM Network sites participating in the 2014 surveillance year was awarded for a 4-year cycle covering 2015–2018, during which time data were collected for children aged 8 years during 2014 and 2016. 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 (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin). Each ADDM site participating in the 2014 surveillance year functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local Institutional Review Board and privacy and confidentiality requirements under 45 CFR 46 (*25*).

Case Ascertainment

ADDM is an active surveillance system that does not depend on family or practitioner reporting of an existing ASD diagnosis or classification to determine ASD case status. ADDM staff conduct surveillance to determine case status in a two-phase process. The first phase of ADDM involves review and abstraction of children's evaluation records from data sources in the community. In the second phase, all abstracted evaluations for each child are compiled in chronological order into a comprehensive record that is reviewed by one or more experienced clinicians to determine the child's ASD case status. 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 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 sources; however, despite the otherwise standardized approach, not all sites have permission to access education records. One ADDM site (Missouri) has not been granted access to records at any education sources. Among the remaining sites, some receive permission from their statewide Department of Education to access children's educational records, whereas other sites must negotiate permission from numerous individual school districts to access educational records. Six sites (Arizona, Georgia, Maryland, Minnesota, New Jersey, and North Carolina) reviewed education records for all school districts in their covered surveillance areas. Three ADDM sites (Colorado, Tennessee, and Wisconsin) received permission to review education records in only certain school districts within the overall geographic area covered for 2014. In Tennessee, permission to access education records was granted from 13 of 14 school districts in the 11-county surveillance area, representing 88% of the total population of children aged 8 years. Conversely, access to education records was limited to a small proportion of the population in the overall geographic area covered by two sites (33% in Colorado and 26% in Wisconsin). In the Colorado school districts where access to education records is permitted for ADDM, parents are directly notified about the ADDM system and can request that their children's education records be excluded. The Arkansas ADDM site received permission from their state Department of Education to access children's educational records statewide; however, time and travel constraints prevented investigators from visiting all 250 school districts in the 75-county surveillance area, resulting in access to education records for 69% of the statewide population of children aged 8 years. The two sites with access to education records throughout most, but not all, of the surveillance area (Arkansas and Tennessee) received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

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 selected eligibility classifications for special education or *International Classification of Diseases, Ninth Revision* (ICD-9) billing codes for select childhood disabilities or psychological conditions. Children's records are first reviewed to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting these requirements, the records are then reviewed 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 from all available sources 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 experienced clinicians who have undergone standardized training to determine ASD case status using a coding scheme based on the DSM-IV-TR guidelines. 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: autistic disorder, PDD-NOS (including atypical autism), or Asperger disorder (Box 1). A child might be disqualified from meeting the surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms.

Although new diagnostic criteria became available in 2013, the children under surveillance in 2014 would have grown up primarily under the DSM-IV-TR definitions for ASD, which are prioritized in this report. The 2014 surveillance year is the first to operationalize an ASD case definition based on DSM-5 diagnostic criteria, in addition to that based on DSM-IV-TR. Because of delays in developing information technology systems to manage data collected under this new case definition, the surveillance area for DSM-5 was reduced by 19% in an effort to include complete estimates for both DSM-IV-TR and DSM-5 in this report. Phase 1 record review and abstraction was the same for DSM-IV-TR and DSM-5; however, a coding scheme based on the DSM-5 definition of ASD was developed for Phase 2 of the ADDM methodology (i.e., systematic review by experienced clinicians). The new coding scheme was developed through a collaborative process and includes reliability measures, although no validation metrics have been published for this new ADDM Network DSM-5 case definition. A child could meet the DSM-5 surveillance case definition for ASD under one or both of the following criteria, as documented in abstracted comprehensive evaluations: 1) behaviors consistent with the DSM-5 diagnostic features; and/or 2) an ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria (Box 2). Children with a documented ASD diagnosis were included as meeting the DSM-5 surveillance case definition for two reasons. First, published DSM-5 diagnostic criteria include the presence of a DSM-IV-TR diagnosis of autistic

BOX 1. Autism spectrum disorder (ASD) case determination criteria under DSM-IV-TR

DSM-IV-TR behavioral criteria	
Social	1a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 1b. Failure to develop peer relationships appropriate to developmental level 1c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 1d. Lack of social or emotional reciprocity
Communication	2a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime) 2b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 2c. Stereotyped and repetitive use of language or idiosyncratic language 2d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
Restricted behavior/ Interest	3a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 3b. Apparently inflexible adherence to specific, nonfunctional routines, or rituals 3c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements) 3d. Persistent preoccupation with parts of objects
Developmental history	Child had identified delays or any concern with development in the following areas at or before the age of 3 years: Social, Communication, Behavior, Play, Motor, Attention, Adaptive, Cognitive
Autism discriminators	Oblivious to children Oblivious to adults or others Rarely responds to familiar social approach Language primarily echolalia or jargon Regression/loss of social, language, or play skills Previous ASD diagnosis, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Lack of showing, bringing, etc. Little or no interest in others Uses others as tools Repeats extensive dialog Absent or impaired imaginative play Markedly restricted interests Unusual preoccupation Insists on sameness Nonfunctional routines Excessive focus on parts Visual inspection Movement preoccupation Sensory preoccupation
DSM-IV-TR case determination	At least six behaviors coded with a minimum of two Social, one Communication, and one Restricted Behavior/Interest; AND evidence of developmental delay or concern at or before the age of 3 years OR At least two behaviors coded with a minimum of one Social and either one Communication and/or one Restricted Behavior/Interest; AND at least one autism discriminator coded Note: A child might be disqualified from meeting the DSM-IV-TR surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision)*.

disorder, PDD-NOS, or Asperger disorder, to ensure continuity of diagnoses and services. Second, sensitivity of the DSM-5 surveillance case definition might be increased when counting children diagnosed with ASD by a qualified professional, based on either DSM-IV-TR or DSM-5 criteria, whether or not all DSM-5 social and behavioral criteria are documented in abstracted comprehensive evaluations. The ADDM Network methods allow differentiation of those meeting the surveillance case status based on one or both criteria. Consistent with the DSM-IV-TR case definition, a child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or

BOX 2. Autism spectrum disorder case determination criteria under DSM-5

DSM-5 behavioral criteria	
A. Persistent deficits in social communication and social interaction	A1: Deficits in social emotional reciprocity A2. Deficits in nonverbal communicative behaviors A3. Deficits in developing, maintaining, and understanding relationships
B. Restricted, repetitive patterns of behavior, interests, or activities, currently or by history	B1: Stereotyped or repetitive motor movements, use of objects or speech B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior B3. Highly restricted interests that are abnormal in intensity or focus B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
Historical PDD diagnosis	Any ASD diagnosis documented in a comprehensive evaluation, including a DSM-IV diagnosis of autistic disorder, Asperger disorder, or pervasive developmental disorder–not otherwise specified (PDD-NOS)
DSM-5 case determination	All three behavioral criteria coded under part A, and at least two behavioral criteria coded under part B OR Any ASD diagnosis documented in a comprehensive evaluation, whether based on DSM-IV-TR or DSM-5 diagnostic criteria Note: A child might be disqualified from meeting the DSM-5 surveillance case definition for ASD if, based on the clinical judgment of one or more reviewers, there is insufficient or conflicting information in support of ASD, sufficient information to rule out ASD, or if one or more other diagnosed conditions better account for the child's symptoms

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.

more other diagnosed conditions better account for the child's symptoms. In this report, prevalence estimates are based on the DSM-IV-TR case definition, whereas case counts are presented and compared for children meeting the DSM-IV-TR and/or DSM-5 case definitions.

Quality Assurance

All sites follow the quality assurance standards established by the ADDM Network. In the first phase, the accuracy of record review and abstraction is checked periodically. 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 (5). For 2014, interrater agreement on DSM-IV-TR case status (confirmed ASD versus not ASD) was 89.1% when comparison samples from all sites were combined (k = 0.77), which was slightly below quality assurance standards established for the ADDM Network (90% agreement, 0.80 kappa). On DSM-5 reviews, interrater agreement on case status (confirmed ASD versus not ASD) was 92.3% when comparison samples from all sites were combined (k = 0.84). Thus, for the DSM-5 surveillance definition, reliability exceeded quality assurance standards established for the ADDM Network.

Descriptive Characteristics and Data Sources

Each ADDM site attempted to obtain birth certificate data for all children abstracted during Phase 1 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 birth certificate data on one or both parents. Children with race coded as "other" or "multiracial" were considered to be missing race information for all analyses that were stratified by race/ethnicity. For this report, data on timing of 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 errors in the estimate that were introduced by children for whom evaluation records were incomplete because they 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.

Information on children's functional skills 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 ASD have been widely adopted in clinical practice and because adaptive behavior rating scales are not sufficiently available in health and 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 ID 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.

Diagnostic conclusions from each evaluation record 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 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 if they were noted as meeting eligibility criteria for special education services under the classification of autism or ASD.

Analytic Methods

Population denominators for calculating ASD prevalence estimates were obtained from the National Center for Health Statistics Vintage 2016 Bridged-Race Postcensal Population Estimates (*26*). CDC's National Vital Statistics System provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2014 surveillance year were compiled from postcensal estimates of the number of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

In two sites (Arizona and Minnesota), geographic boundaries were defined by constituent school districts included in the surveillance area. The number of children living in outlying school districts was subtracted from the county-level census denominators using school enrollment data from the U.S. Department of Education's National Center for Education Statistics (*27*). Enrollment counts of students in third grade during the 2014–15 school year differed from the CDC bridged-race population estimates, attributable primarily to children being enrolled out of the customary grade for their age or in charter schools, home schools, or private 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 and Minnesota.

Race- or ethnicity-specific prevalence estimates were calculated for four groups: white, black, Hispanic (regardless of race), and Asian/Pacific Islander. 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 and 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 were obtained from an underlying Poisson distribution with an asymptotic approximation to the normal. Pearson chi-square tests were performed, and prevalence ratios and percentage differences were calculated to compare prevalence estimates from different strata. Kappa statistics were computed to describe concordance between the DSM-IV-TR and DSM-5 case definitions, as well as to describe interrater agreement on either case definition for quality assurance. Pearson chi-square tests also were performed for testing significance in comparisons of proportions, and unadjusted odds ratio (OR) estimates were calculated to further describe these comparisons. In an effort to reduce the effect of outliers, distribution medians were typically presented, although one-way ANOVA was used to test significance when comparing arithmetic means of these distributions. Significance was set at $p<0.05$. 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.

Sensitivity Analysis Methods

Certain 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 archived and deemed too costly to retrieve. A sensitivity analysis of the effect of these missing records on case ascertainment was conducted. All children initially identified for record review were first stratified by two factors closely associated with final case status: information source (health source type only, education source type 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 not identified because of missing records was estimated under the assumption that within each of the six strata, the proportion of children confirmed as ASD surveillance cases among those with missing records would be similar to the proportion of cases among children with no missing records. 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 sensitivity analysis 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 assumptions underlying the approach.

All ADDM sites identified records for review from health 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, ID, 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 325,483 children aged 8 years was covered by the 11 ADDM sites that provided data for the 2014 surveillance year (Table 1). This number represented 8% of the total U.S. population of children aged 8 years in 2014 (4,119,668) (*19*). A total of 53,120 records for 42,644 children were reviewed from health and education sources. Of these, the source records of 10,886 children met the criteria for abstraction, which was 25.5% of the total number of children whose source records were reviewed and 3.3% of the population under surveillance. Of the records reviewed by clinicians, 5,473 children met the ASD surveillance case definition. The number of evaluations abstracted for each child who was ultimately identified with ASD varied by site (median: five; range: three [Arizona, Minnesota, Missouri, and Tennessee] to 10 [Maryland]).

Overall ASD Prevalence Estimates

Overall ASD prevalence for the ADDM 2014 surveillance year varied widely among sites (range: 13.1 [Arkansas] to 29.3 [New Jersey]) (Table 2). On the basis of combined data from all 11 sites, ASD prevalence was 16.8 per 1,000 (one in 59) children aged 8 years. Overall estimated prevalence of ASD was highest in New Jersey (29.3) compared to each of the other ten sites ($p<0.01$).

Prevalence by Sex and Race/Ethnicity

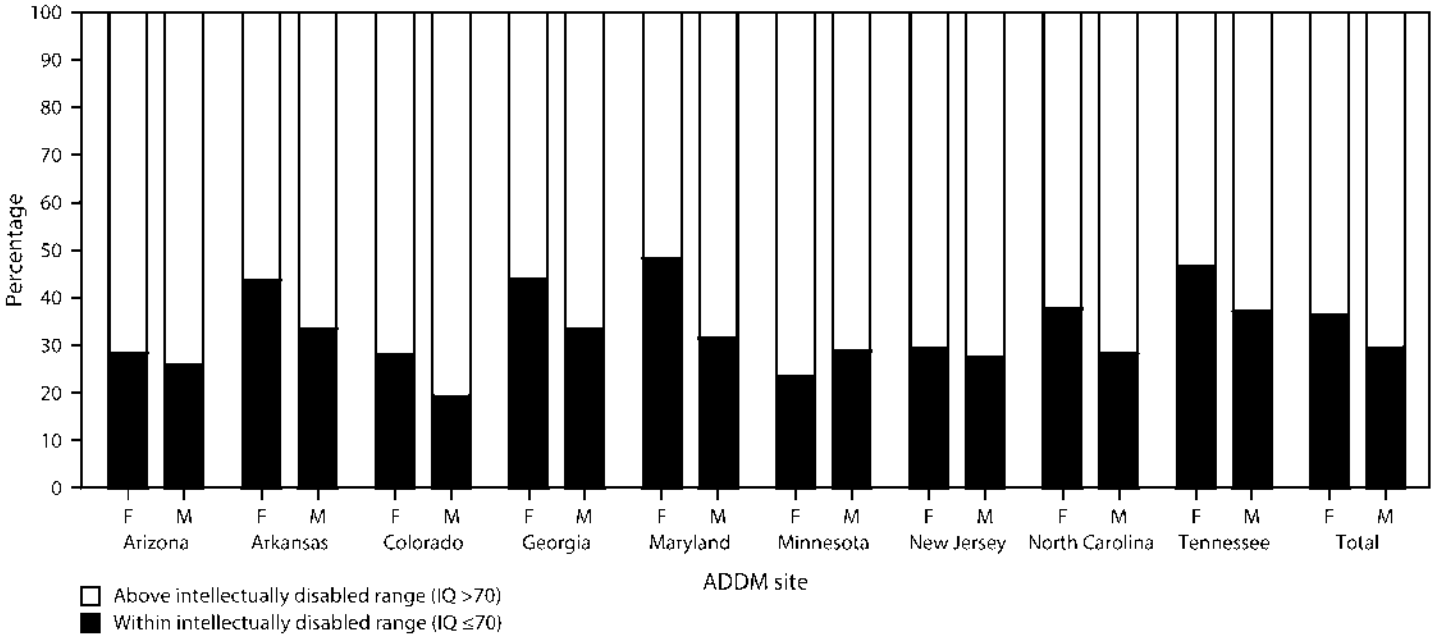
When data from all 11 ADDM sites were combined, ASD prevalence was 26.6 per 1,000 boys and 6.6 per 1,000 girls (prevalence ratio: 4.0). ASD prevalence was significantly ($p<0.01$) higher among boys than among girls in all 11 ADDM sites (Table 2), with male-to-female prevalence ratios ranging from 3.2 (Arizona) to 4.9 (Georgia). Estimated ASD prevalence also varied by race and ethnicity (Table 3). When data from all sites were combined, the estimated prevalence among white children (17.2 per 1,000) was 7% greater than that among black children (16.0 per 1,000) and 22% greater than that among Hispanic children (14.0 per 1,000). In nine sites, the estimated prevalence of ASD was higher among white children than black children. The white-to-black ASD prevalence ratios were statistically significant in three sites (Arkansas, Missouri, and Wisconsin), and the white-to-Hispanic prevalence ratios were significant in seven sites (Arizona, Arkansas, Colorado, Georgia, Missouri, North Carolina, and Tennessee). In nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, North Carolina, and Tennessee), the estimated prevalence of ASD was higher among black children than that among Hispanic children. The black-to-Hispanic prevalence ratio was significant in three of these nine sites (Arizona, Georgia, and North Carolina). In New Jersey, there was almost no difference in ASD prevalence estimates among white, black, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 7.9 per 1,000 (Colorado) to 19.2 per 1,000 (New Jersey) with notably wide CIs.

Intellectual Ability

Data on intellectual ability were reported for nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) having information available for at least 70% of children who met the ASD case definition (range: 70.8% [Tennessee] to 89.2% [North Carolina]). The median age of children's most recent IQ tests, on which the following results are based, was 73 months (6 years, 1 month). Data from these nine sites yielded accompanying data on intellectual ability for 3,714 (80.3%) of 4,623 children with ASD. This proportion did not differ by sex or race/ethnicity in any of the nine sites or when combining data from all nine sites. Among these 3,714 children, 31% were classified in the range of ID (IQ ≤70), 25% were in the borderline range (IQ 71–85), and 44% had IQ >85. The proportion of children classified in the range of ID ranged from 26.7% in Arizona to 39.4% in Tennessee.

Among children identified with ASD, the distribution by intellectual ability varied by sex, with girls more likely than boys to have IQ ≤70, and boys more likely than girls to have IQ >85 (Figure 1). In these nine sites combined, 251 (36.3%) of 691 girls with ASD had IQ scores or examiners' statements indicating ID compared with 891 (29.5%) of 3,023 males (odds ratio [OR] = 1.4; $p<0.01$), though among individual sites this proportion differed significantly in only

FIGURE 1. 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, nine sites,* United States, 2014



Abbreviations: ADDM = Autism and Developmental Disabilities Monitoring Network; ASD = autism spectrum disorder; F = female; IQ = intelligence quotient; M = male.

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70% of children who met the ASD case definition (n = 3,714).

one (Georgia, OR = 1.6; p<0.05). The proportion of children with ASD with borderline intellectual ability (IQ 71–85) did not differ by sex, whereas a significantly higher proportion of males (45%) compared with females (40%) had IQ >85 (i.e., average or above average intellectual ability) (OR = 1.2; p<0.05).

The distribution of intellectual ability also varied by race/ethnicity. Approximately 44% of black children with ASD were classified in the range of ID compared with 35% of Hispanic children and 22% of white children (Figure 2). The proportion of blacks and whites with ID differed significantly in all sites except Colorado, and when combining their data (OR = 2.9; p<0.01). The proportion of Hispanics and whites with ID differed significantly when combining data from all nine sites (OR = 1.9; p<0.01), and among individual sites it reached significance (p<0.05) in six of the nine sites, with the three exceptions being Arkansas (OR = 1.8; p = 0.10), North Carolina (OR = 1.8; p = 0.07), and Tennessee (OR = 2.1; p = 0.09). The proportion of children with borderline intellectual ability (IQ = 71–85) did not differ between black and Hispanic children, although a lower proportion of white children (22%) were classified in the range of borderline intellectual ability compared to black (28.4%; OR = 0.7; p<0.01) or Hispanic (28.7%; OR = 0.7; p<0.01) children. When combining data from these nine sites, the proportion of white children (56%) with IQ >85 was significantly higher than the proportion of black (27%, OR = 3.4; p<0.01) or Hispanic (36%, OR = 2.2; p<0.01) children with IQ>85.

First Comprehensive Evaluation

Among children with ASD who were born in the same state as the ADDM site (n = 4,147 of 5,473 confirmed cases), 42% had a comprehensive evaluation on record by age 36 months (range: 30% [Arkansas] to 66% [North Carolina]) (Table 4). Approximately 39% of these 4,147 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 85% (range: 61% [Tennessee] to 94% [Arizona]).

Previously Documented ASD Classification

Of the 5,473 children meeting the ADDM ASD surveillance case definition, 4,379 (80%) had either eligibility for autism special education services or a DSM-IV-TR, DSM-5, or ICD-9 autism diagnosis documented in their records (range among 11 sites: 58% [Colorado] to 92% [Missouri]). Combining data from all 11 sites, 81% of boys had a previous ASD classification on record, compared with 75% of girls (OR = 1.4; p<0.01).

When stratified by race/ethnicity, 80% of white children had a previously documented ASD classification, compared with nearly 83% of black children (OR = 0.9; p = 0.09) and 76% of Hispanic children (OR = 1.3; p<0.01); a significant difference was also found when comparing the proportion of black children with a previous ASD classification to that among Hispanic children (OR = 1.5; p<0.01).

The median age of earliest known ASD diagnosis documented in children's records (Table 5) varied by diagnostic subtype (autistic disorder: 46 months; ASD/PDD: 56 months; Asperger disorder: 67 months). Within these subtypes, the median age of earliest 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 (48%), ASD/PDD (46%), or Asperger disorder (6%). The median age of earliest known diagnosis and distribution of subtypes did vary by site. The median age of earliest known ASD diagnosis for all subtypes combined was 52 months, ranging from 40 months in North Carolina to 59 months in Arkansas.

Special Education Eligibility

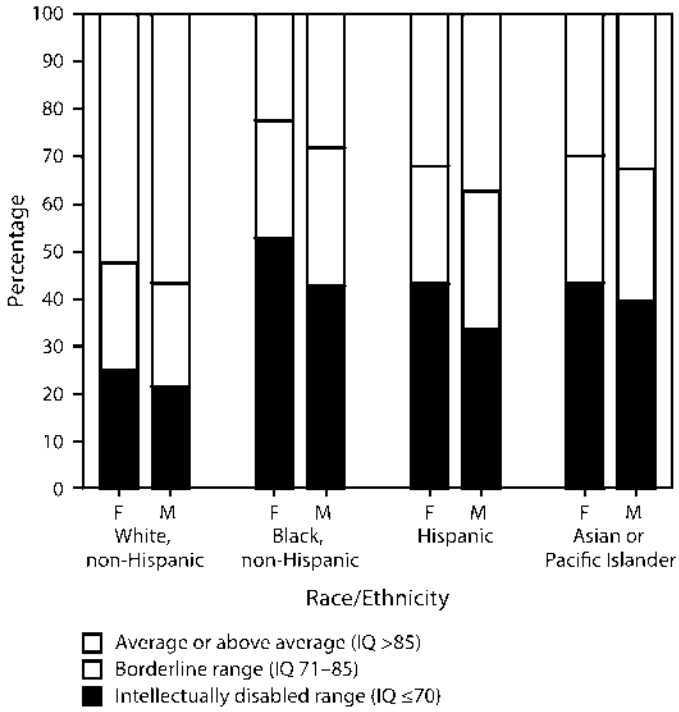
Sites with access to education records collected information on the most recent eligibility categories under which children received special education services (Table 6). Among children with ASD who were receiving special education services in public schools during 2014, the proportion of children with a primary eligibility category of autism ranged from approximately 37% in Wisconsin to 80% in Tennessee. Most other sites noted approximately 60% to 75% of children with ASD having autism listed as their most recent primary special education eligibility category, the exceptions being Colorado (44%) and New Jersey (48%). 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 many U.S. states. All ADDM sites reported <10% of children with ASD receiving special education services under a primary eligibility category of ID.

Sensitivity Analyses of Missing Records and Expanded ICD-9 Codes

A stratified analysis of records that could not be located for review was completed to assess the degree to which missing data might have potentially reduced prevalence estimates as reported by individual ADDM sites. Had all children's records identified in Phase 1 been located and reviewed, prevalence estimates would potentially have been <1% higher in four sites (Arizona, Georgia, Minnesota, and Wisconsin), between 1% to 5% higher in four sites (Colorado, Missouri, New Jersey, and North Carolina), approximately 8% higher in Maryland, and nearly 20% higher in Arkansas and Tennessee, where investigators were able to access education records throughout most, but not all, of the surveillance area and received data from their state Department of Education to evaluate the potential impact on reported ASD prevalence estimates attributed to missing records.

The impact on prevalence estimates of reviewing records based on an expanded list of ICD-9 codes varied from site to site. Colorado, Georgia, and Missouri were the only three sites that identified more than 1% of ASD surveillance cases partially or solely on the basis of the expanded code list. In Missouri, less than 2% of children identified with ASD had some of their records located on the basis of the expanded code list, and none were identified exclusively from these codes. In Colorado, approximately 2% of ASD surveillance cases had some abstracted records identified on the basis of the expanded code list, and 4% had records found exclusively from the expanded codes. In Georgia, where ICD-9 codes were

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 race/ethnicity — Autism and Developmental Disabilities Monitoring Network, nine sites,* United States, 2014



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

* Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina, and Tennessee) that had intellectual ability data available for ≥70 of children who met the ASD case definition (n = 3,714).

requested for surveillance of five distinct conditions (autism, cerebral palsy, ID, hearing loss, and vision impairment), approximately 10% of children identified with ASD had some of their records located on the basis of the expanded code list, and less than 1% were identified exclusively from these codes.

Comparison of Case Counts from DSM-IV-TR and DSM-5 Case Definitions

The DSM-5 analysis was completed for part of the overall ADDM 2014 surveillance area (Table 7), representing a total population of 263,775 children aged 8 years. This was 81% of the population on which DSM-IV-TR prevalence estimates were reported. Within this population, 4,920 children were confirmed to meet the ADDM Network ASD case definition for either DSM-IV-TR or DSM-5. Of these children, 4,236 (86%) met both case definitions, 422 (9%) met only the DSM-IV-TR criteria, and 262 (5%) met only the DSM-5 criteria (Table 8). This yielded a DSM-IV-TR:DSM-5 prevalence ratio of 1.04 in this population, indicating that ASD prevalence was approximately 4% higher based on the historical DSM-IV-TR case definition compared with the new DSM-5 case definition. Among 4,498 children who met DSM-5 case criteria, 3,817 (85%) met the DSM-5 behavioral criteria (Box 2), whereas 681 (15%) qualified on the basis of an established ASD diagnosis but did not have sufficient DSM-5 behavioral criteria documented in comprehensive evaluations. In six of the 11 ADDM sites, DSM-5 case counts were within approximately 5% of DSM-IV-TR counts (range: 5% lower [Tennessee] to 5% higher [Arkansas]), whereas DSM-5 case counts were more than 5% lower than DSM-IV-TR counts in Minnesota and North Carolina (6%), New Jersey (10%), and Colorado (14%). Kappa statistics indicated strong agreement between DSM-IV-TR and DSM-5 case status among children abstracted in Phase 1 of the study who were reviewed in Phase 2 for both DSM-IV-TR and DSM-5 (kappa for all sites combined: 0.85, range: 0.72 [Tennessee] to 0.93 [North Carolina]).

Stratified analysis of DSM-IV-TR:DSM-5 ratios were very similar compared with the overall sample (Table 9). DSM-5 estimates were approximately 3% lower than DSM-IV-TR counts for males, and approximately 6% lower for females (kappa = 0.85 for both). Case counts were approximately 3% lower among white and black children on DSM-5 compared with DSM-IV-TR, 5% lower among Asian children, and 8% lower among Hispanic children. Children who received a comprehensive evaluation by age 36 months were 7% less likely to meet DSM-5 than DSM-IV-TR, whereas those evaluated by age 4 years were 6% less likely to meet DSM-5, and those initially evaluated after age 4 years were just as likely to meet DSM-5 as DSM-IV-TR. Children with documentation of eligibility for autism special education services, and those with a documented diagnosis of ASD by age 3 years, were 2% more likely to meet DSM-5 than DSM-IV-TR. Slightly over 3% of children whose earliest ASD diagnosis was autistic disorder met DSM-5 criteria but not DSM-IV-TR, compared with slightly under 3% of those whose earliest diagnosis was PDD-NOS/ASD-NOS and 5% of those whose earliest diagnosis was Asperger disorder. Children with no previous ASD classification (diagnosis or eligibility) were 47% less likely to meet DSM-5 than DSM-IV-TR. Combining data from all 11 sites, children with IQ scores in the range of ID were 3% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.89), those with IQ scores in the borderline range were 6% less likely to meet DSM-5 than DSM-IV-TR (kappa = 0.88), and children with average or above average intellectual ability were 4% less likely to meet DSM-5 criteria compared with DSM-IV-TR (kappa = 0.86).

Discussion

Changes in Estimated Prevalence

The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previously reported estimates from the ADDM Network. An ASD case definition based on DSM-IV-TR criteria was used during the entire period of ADDM surveillance during 2000–2014, as were comparable study operations and procedures, although the geographic areas under surveillance have varied over time. During this period, ADDM ASD prevalence estimates increased from 6.7 to 16.8 per 1,000 children aged 8 years, an increase of approximately 150%.

Among the six ADDM sites completing both the 2012 and 2014 studies for the same geographic area, all six showed higher ASD prevalence estimates for 2012 compared to 2014, with a nearly 10% higher prevalence in Georgia ($p = 0.06$) and Maryland ($p = 0.35$), 19% in New Jersey ($p<0.01$), 22% in Missouri ($p = 0.01$), 29% in Colorado ($p<0.01$), and 31% in Wisconsin ($p<0.01$). When combining data from these six sites, ASD prevalence estimates for 2014 were 20% higher for 2014 compared to 2012 ($p<0.01$). The ASD prevalence estimate from New Jersey continues to be one of the highest reported by a population-based surveillance system. The two sites with the greatest relative difference in prevalence are noteworthy in that both gained access to children's education records in additional geographic areas for 2014. Colorado was granted access to review children's education records in one additional county for the 2014 surveillance year (representing nearly 20% of the population aged 8 years within the overall

Colorado surveillance area), and Wisconsin was granted access to review education records for more than a quarter of its surveillance population, and 2014 marked the first time Wisconsin has included education data sources. Comparisons with earlier ADDM Network surveillance results should be interpreted cautiously because of changing composition of sites and geographic coverage over time. For example, three ADDM Network sites completing both the 2012 and 2014 surveillance years (Arizona, Arkansas, and North Carolina) covered a different geographic area each year, and two new sites (Minnesota and Tennessee) were awarded funding to monitor ASD in collaboration with the ADDM Network.

Certain characteristics of children with ASD were similar in 2014 compared with earlier surveillance years. The median age of earliest known ASD diagnosis remained close to 53 months in previous surveillance years and was 52 months in 2014. The proportion of children who received a comprehensive developmental evaluation by age 3 years was unchanged: 42% in 2014 and 43% during 2006–2012. There were a number of differences in the characteristics of the population of children with ASD in 2014. The male:female prevalence ratio decreased from 4.5:1 during 2002–2012 to 4:1 in 2014, driven by a greater relative increase in ASD prevalence among girls than among boys since 2012. Also, the decrease in the ratios of white:black and white:Hispanic children with ASD continued a trend observed since 2002. Among sites covering a population of at least 20,000 children aged 8 years, New Jersey reported no significant race- or ethnicity-based difference in ASD prevalence, suggesting more complete ascertainment among all children regardless of race/ethnicity. Historically, ASD prevalence estimates from combined ADDM sites have been approximately 20%–30% higher among white children as compared with black children. For surveillance year 2014, the difference was only 7%, the lowest difference ever observed for the ADDM Network. Likewise, prevalence among white children was almost 70% higher than that among Hispanic children in 2002 and 2006, and approximately 50% higher in 2008, 2010, and 2012, whereas for 2014 the difference was only 22%. Data from a previously reported comparison of ADDM Network ASD prevalence estimates from 2002, 2006, and 2008 (*9*) suggested greater increases in ASD prevalence among black and Hispanic children compared with those among white children. Reductions in disparities in ASD prevalence for black and Hispanic children might be attributable, in part, to more effective outreach directed to minority communities. Finally, the proportion of children with ASD and lower intellectual ability was similar in 2012 and 2014 at approximately 30% of males and 35% of females. These proportions were markedly lower than those reported in previous surveillance years.

Variation in Prevalence Among ADDM Sites

Findings from the 2014 surveillance year indicate that prevalence estimates still vary widely among ADDM Network sites, with the highest prevalence observed in New Jersey. Although five of the 11 ADDM sites conducting the 2014 surveillance year reported prevalence estimates within a very close range (from 13.1 to 14.1 per 1,000 children), New Jersey's prevalence estimate of 29.4 per 1,000 children was significantly greater than that from any other site, and four sites (Georgia, Maryland, Minnesota, and North Carolina) reported prevalence estimates that were significantly greater than those from any of the five sites in the 13.1–14.1 per 1,000 range. Two of the sites with prevalence estimates of 20.0 per 1,000 or higher (Maryland and Minnesota) conducted surveillance among a total population of <10,000 children aged 8 years. Concentrating surveillance efforts in smaller geographic areas, especially those in close proximity to diagnostic centers and those covering school districts with advanced staff training and programs to support children with ASD, might yield higher prevalence estimates compared with those from sites covering populations of more than 20,000 children aged 8 years. Of the six sites with prevalence estimates below the 16.8 per 1,000 estimate for all sites combined, five did not have full access to education data sources (Arkansas, Colorado, Missouri, Tennessee, and Wisconsin), whereas only one of the six sites will full access to education data sources had a prevalence estimate below 16.8 per 1,000 (Arizona). Such differences cannot be attributed solely to source access, as other factors (e.g., demographic differences and service availability) also might have influenced these findings. In addition to variation among sites in reported ASD prevalence, wide variation among sites is noted in the characteristics of children identified with ASD, including the proportion of children who received a comprehensive developmental evaluation by age 3 years, the median age of earliest known ASD diagnosis, and the distribution by intellectual ability. Some of this variation might be attributable to regional differences in diagnostic practices and other documentation of autism symptoms, although previous reports based on ADDM data have linked much of the variation to other extrinsic factors, such as regional and socioeconomic disparities in access to services (*13*,*14*).

Case Definitions

Results from application of the DSM-IV-TR and DSM-5 case definitions were similar, overall and when stratified by sex, race/ethnicity, DSM-IV-TR diagnostic subtype, or level of intellectual ability. Overall, ASD prevalence estimates

based on the new DSM-5 case definition were very similar in magnitude but slightly lower than those based on the historical DSM-IV-TR case definition. Three of the 11 ADDM sites had slightly higher case counts using the DSM-5 framework compared with the DSM-IV-TR. Colorado, where the DSM-IV-TR:DSM-5 ratio was highest compared with all other sites, was also the site with the lowest proportion of DSM-IV-TR cases having a previous ASD classification. This suggests that the diagnostic component of the DSM-5 case definition, whereby children with a documented diagnosis of ASD might qualify as DSM-5 cases regardless of social interaction/communication and restricted/repetitive behavioral criteria, might have influenced DSM-5 results to a lesser degree in that site, as a smaller proportion of DSM-IV-TR cases would meet DSM-5 case criteria based solely on the presence of a documented ASD diagnosis. This element of the DSM-5 case definition might carry less weight moving forward, as fewer children aged 8 years in health and education settings will have had ASD diagnosed under the DSM-IV-TR criteria. It is also possible that persons who conduct developmental evaluations of children in health and education settings will increasingly describe behavioral characteristics using language more consistent with DSM-5 terminology, yielding more ASD cases based on the behavioral component of ADDM's DSM-5 case definition. Prevalence estimates based on the DSM-5 case definition that incorporates an existing ASD diagnosis reflect the actual patterns of diagnosis and services for children in 2014, because children diagnosed under DSM-IV-TR did not lose their diagnosis when the updated DSM-5 criteria were published and because professionals might diagnose children with ASD without necessarily recording every behavior supporting that diagnosis. In the future, prevalence estimates will align more closely with the specific DSM-5 behavioral criteria, and might exclude some persons who would have met DSM-IV-TR criteria for autistic disorder, PDD-NOS, or Asperger disorder, while at the same time including persons who do not meet those criteria but who do meet the specific DSM-5 behavioral criteria.

Comparison of Autism Prevalence Estimates

The ADDM Network is the only ASD surveillance system in the United States providing robust prevalence estimates for specific areas of the country, including those for subgroups defined by sex and race/ethnicity, providing information about geographical variation that can be used to evaluate policies and diagnostic practices that might affect ASD prevalence. It is also the only comprehensive surveillance system to incorporate ASD diagnostic criteria into the case definition rather than relying entirely on parent or caregiver report of a previous ASD diagnosis, providing a unique contribution to the knowledge of ASD epidemiology and the impact of changes in diagnostic criteria. Two surveys of children's health, The National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH), report estimates of ASD prevalence based on caregiver report of being told by a doctor or other health care provider that their child has ASD, and, for the NSCH, if their child was also reported to currently have ASD. The most recent publication from NHIS indicated that 27.6 per 1,000 children aged 3–17 years had ASD in 2016, which did not differ significantly from estimates for 2015 or 2014 (24.1 and 22.4, respectively) (*28*). An estimate of 20.0 per 1,000 children aged 6–17 years was reported from the 2011–2012 NSCH (*29*). The study samples for both surveys are substantially smaller than the ADDM Network; however, they were intended to be nationally representative, whereas the ADDM Network surveillance areas were selected through a competitive process and, although large and diverse, were not intended to be nationally representative. Geographic differences in ASD prevalence have been observed in both the ADDM Network and national surveys, as have differences in ASD prevalence by age (*6–11,28,29*).

All three prevalence estimation systems (NHIS, NSCH, and ADDM) are subject to regional and policy-driven differences in the availability and utilization of evaluation and diagnostic services for children with developmental concerns. Phone surveys are likely more sensitive in identifying children who received a preliminary or confirmed diagnosis of ASD but are not receiving services (i.e., special education services). The ADDM Network method based on analysis of information contained in existing health and education records enables the collection of detailed, case-specific information reflecting children's behavioral, developmental and functional characteristics, which are not available from the national phone surveys. This detailed case level information might provide insight into temporal changes in the expression of ASD phenotypes, and offers the ability to account for differences based on changing diagnostic criteria.

Limitations

The findings in this report are subject to at least three limitations. First, ADDM Network sites were not selected to represent the United States as a whole, nor were the geographic areas within each ADDM site selected to represent that state as a whole (with the exception of Arkansas, where ASD is monitored statewide). Although a combined estimate is reported for the Network as a whole to inform stakeholders

and interpret the findings from individual surveillance years in a more general context, data reported by the ADDM Network should not be interpreted to represent a national estimate of the number and characteristics of children with ASD. Rather, it is more prudent to examine the wide variation among sites, between specific groups within sites, and across time in the number and characteristics of children identified with ASD, and to use these findings to inform public health strategies aimed at removing barriers to identification and treatment, and eliminating disparities among socioeconomic and racial/ethnic groups. Data from individual sites provide even greater utility for developing local policies in those states.

Second, it is important to acknowledge limitations of information available in children's health and education records when considering data on the characteristics of children with ASD. Age of earliest known ASD diagnosis was obtained from descriptions in children's developmental evaluations that were available in the health and education facilities where ADDM staff had access to review records. Some children might have had earlier diagnoses that were not recorded in these records. Likewise, some descriptions of historical diagnoses (i.e., those not made by the evaluating examiner) could be subject to recall error by a parent or provider who described the historical diagnosis to that examiner. Another characteristic featured prominently in this report, intellectual ability, is subject to measurement limitations. IQ test results should be interpreted cautiously because of myriad factors that impact performance on these tests, particularly language and attention deficits that are common among children with ASD, especially when testing was conducted before age 6 years. Because children were not examined directly nor systematically by ADDM staff as part of this study, descriptions of their characteristics should not be interpreted to serve as the basis for policy changes, individual treatments, or interventions.

Third, because comparisons with the results from earlier ADDM surveillance years were not restricted to a common geographic area, inferences about the changing number and characteristics of children with ASD over time should be made with caution. Findings for each unique ADDM birth cohort are very informative, and although study methods and geographic areas of coverage have remained generally consistent over time, temporal comparisons are subject to multiple sources of bias and should not be misinterpreted as representing precise measures that control for all sources of bias. Additional limitations to the records-based surveillance methodology have been described extensively in previous ADDM and MADDSP reports (*3*,*6*–*11*).

Future Surveillance Directions

Data collection for the 2016 surveillance year began in early 2017 and will continue through mid-2019. Beginning with surveillance year 2016, the DSM-5 case definition for ASD will serve as the basis for prevalence estimates. The DSM-IV-TR case definition will be applied in a limited geographic area to offer additional data for comparison, although the DSM-IV-TR case definition will eventually be phased out.

CDC's "Learn the Signs. Act Early" (LTSAE) campaign, launched in October 2004, aims to change perceptions among parents, health care professionals, and early educators regarding the importance of early identification and treatment of autism and other developmental disorders (*30*). In 2007, the American Academy of Pediatrics (AAP) recommended developmental screening specifically focused on social development and ASD at age 18 and 24 months (*31*). Both efforts are in accordance with the *Healthy People 2020* (HP2020) goal that children with ASD be evaluated by age 36 months and begin receiving community-based support and services by age 48 months (*12*). It is concerning that progress has not been made toward the HP2020 goal of increasing the percentage of children with ASD who receive a first evaluation by age 36 months to 47%; however, the cohort of children monitored under the ADDM 2014 surveillance year (i.e., children born in 2006) represents the first ADDM 8-year-old cohort impacted by the LTSAE campaign and the 2007 AAP recommendations. The effect of these programs in lowering age at evaluation might become more apparent when subsequent birth cohorts are monitored. Further exploration of ADDM data, including those collected on cohorts of children aged 4 years (*32*), might inform how policy initiatives, such as screening recommendations and other social determinants of health, impact the prevalence of ASD and characteristics of children with ASD, including the age at which most children receive an ASD diagnosis.

Conclusion

The latest findings from the ADDM Network provide evidence that the prevalence of ASD is higher than previously reported ADDM estimates and continues to vary among certain racial/ethnic groups and communities. The overall ASD prevalence estimate of 16.8 per 1,000 children aged 8 years in 2014 is higher than previous estimates from the ADDM Network. With prevalence of ASD reaching nearly 3% in some communities and representing an increase of 150% since 2000, ASD is an urgent public health concern that could benefit from enhanced strategies to help identify ASD earlier; to determine possible risk factors; and to address the growing

behavioral, educational, residential and occupational needs of this population.

Implementation of the new DSM-5 case definition had little effect on the overall number of children identified with ASD for the ADDM 2014 surveillance year. This might be a result of including documented ASD diagnoses in the DSM-5 surveillance case definition. Over time, the estimate might be influenced (downward) by a diminishing number of persons who meet the DSM-5 diagnostic criteria for ASD based solely on a previous DSM-IV-TR diagnosis, such as autistic disorder, PDD-NOS or Asperger disorder, and influenced (upward) by professionals aligning their clinical descriptions with the DSM-5 criteria. Although the prevalence of ASD and characteristics of children identified by each case definition were similar in 2014, the diagnostic features defined under DSM-IV-TR and DSM-5 appear to be quite different. The ADDM Network will continue to evaluate these similarities and differences in much greater depth, and will examine at least one more cohort of children aged 8 years to expand this comparison. Over time, the ADDM Network will be well positioned to evaluate the effects of changing ASD diagnostic parameters on prevalence.

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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, 2014

Site	Site institution	Surveillance area	Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
			No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix[†]	**24,952**	12,308	(49.3)	1,336	(5.4)	9,792	(39.2)	975	(3.9)	541	(2.2)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	7 counties in metropolitan Denver	**41,128**	22,410	(54.5)	2,724	(6.6)	13,735	(33.4)	2,031	(4.9)	228	(0.6)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis St. Paul[§]	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	5 counties including metropolitan St. Louis	**25,333**	16,529	(65.2)	6,577	(26.0)	1,220	(4.8)	931	(3.7)	76	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin–Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**325,483**	**167,048**	**(51.3)**	**72,751**	**(22.4)**	**67,181**	**(20.6)**	**16,596**	**(5.1)**	**1,907**	**(0.6)**

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged-Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of third graders during the 2014–2015 school year.

TABLE 2. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by sex — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Total population	Total no. with ASD	Sex: Overall† Prevalence	Overall† 95% CI	Males Prevalence	Males 95% CI	Females Prevalence	Females 95% CI	Male-to-female prevalence ratio§
Arizona	24,952	349	14.0	(12.6 15.5)	21.1	(18.7 23.8)	6.6	(5.3 8.2)	3.2
Arkansas	39,992	522	13.1	(12.0–14.2)	20.5	(18.6–22.5)	5.4	(4.5–6.5)	3.8
Colorado	41,128	572	13.9	(12.8–15.1)	21.8	(19.9–23.9)	5.5	(4.6–6.7)	3.9
Georgia	51,161	869	17.0	(15.9 18.2)	27.9	(25.9 30.0)	5.7	(4.8 6.7)	4.9
Maryland	9,955	199	20.0	(17.4–23.0)	32.7	(28.1–38.2)	7.2	(5.2–10.0)	4.5
Minnesota	9,767	234	24.0	(21.1–27.2)	39.0	(33.8–44.9)	8.5	(6.3–11.6)	4.6
Missouri	25,333	356	14.1	(12.7–15.6)	22.2	(19.8–25.0)	5.6	(4.4–7.0)	4.0
New Jersey	32,935	964	29.3	(27.5–31.2)	45.5	(42.4–48.9)	12.3	(10.7–14.1)	3.7
North Carolina	30,283	527	17.4	(16.0–19.0)	28.0	(25.5–30.8)	6.5	(5.3–7.9)	4.3
Tennessee	24,940	387	15.5	(14.0–17.1)	25.3	(22.6–28.2)	5.4	(4.2–6.9)	4.7
Wisconsin	35,037	494	14.1	(12.9 15.4)	21.4	(19.4 23.7)	6.4	(5.3 7.7)	3.4
All sites combined	**325,483**	**5,473**	**16.8**	**(16.4–17.3)**	**26.6**	**(25.8–27.4)**	**6.6**	**(6.2–7.0)**	**4.0**

Abbreviations: ASD = autism spectrum disorder; CI = confidence interval.
* Per 1,000 children aged 8 years.
† All children are included in the total regardless of race or ethnicity.
§ All sites identified significantly higher prevalence among males compared with females (p<0.01).

TABLE 3. Estimated prevalence* of autism spectrum disorder among children aged 8 years, by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

Site	Race/Ethnicity: White Prevalence	White 95% CI	Black Prevalence	Black 95% CI	Hispanic Prevalence	Hispanic 95% CI	Asian/Pacific Islander Prevalence	Asian/Pacific Islander 95% CI	Prevalence ratio: White-to-Black	White-to-Hispanic	Black-to-Hispanic
Arizona	16.2	(14.1 18.6)	19.5	(13.3 28.6)	10.3	(8.5 12.5)	10.3	(5.5 19.1)	0.8	1.6§	1.9§
Arkansas	13.9	(12.6–15.5)	10.4	(8.3–12.9)	8.4	(6.2–11.3)	14.2	(8.1–25.1)	1.3†	1.7§	1.2
Colorado	15.0	(13.5–16.7)	11.4	(8.0–16.2)	10.6	(9.0–12.5)	7.9	(4.8–12.9)	1.3	1.4§	1.1
Georgia	17.9	(16.0 20.2)	17.1	(15.4 18.9)	12.6	(10.6 15.0)	11.9	(8.9 16.1)	1.1	1.4§	1.4§
Maryland	19.5	(16.0–23.8)	16.5	(12.7–21.4)	15.7	(9.1–27.0)	13.9	(7.5–25.8)	1.2	1.2	1.1
Minnesota	24.3	(19.8–29.8)	27.2	(21.7–34.2)	20.9	(14.7–29.7)	17.8	(12.3–25.7)	0.9	1.2	1.3
Missouri	14.1	(12.4–16.0)	10.8	(8.6–13.6)	4.9	(2.2–10.9)	10.7	(5.8–20.0)	1.3†	2.9†	2.2
New Jersey	30.2	(27.4–33.3)	26.8	(23.3–30.9)	29.3	(26.2–32.9)	19.2	(13.9–26.6)	1.1	1.0	0.9
North Carolina	18.6	(16.5–20.9)	16.1	(13.5–19.2)	11.9	(9.3–15.2)	19.1	(13.7–26.8)	1.2	1.6§	1.4†
Tennessee	16.1	(14.3–18.2)	12.5	(9.7–16.0)	10.5	(7.6–14.7)	12.5	(6.7–23.3)	1.3	1.5†	1.2
Wisconsin	15.2	(13.6 17.0)	11.3	(8.9 14.2)	12.5	(10.0 15.6)	10.2	(6.1 16.9)	1.3†	1.2	0.9
All sites combined	**17.2**	**(16.5–17.8)**	**16.0**	**(15.1–16.9)**	**14.0**	**(13.1–14.9)**	**13.5**	**(11.8–15.4)**	**1.1†**	**1.2§**	**1.1§**

Abbreviation: CI = confidence interval.
* Per 1,000 children aged 8 years.
† Pearson chi-square test of prevalence ratio significant at p<0.05.
§ Pearson chi-square test of prevalence ratio significant at p<0.01.

TABLE 4. Number and percentage of children aged 8 years* identified with autism spectrum disorder who received a comprehensive evaluation by a qualified professional at age ≤36 months, 37–48 months, or >48 months, and those with a mention of general delay concern by age 36 months — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Earliest age when child received a comprehensive evaluation						Mention of general developmental delay	
	≤36 mos		37–48 mos		>48 mos		≤36 mos	
Site	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	87	(34.1)	56	(22.0)	112	(43.9)	240	(94.1)
Arkansas	117	(30.5)	98	(25.6)	168	(43.9)	354	(92.4)
Colorado	200	(46.4)	66	(15.3)	165	(38.3)	383	(88.9)
Georgia	240	(37.6)	126	(19.7)	273	(42.7)	549	(85.9)
Maryland	96	(56.1)	19	(11.1)	56	(32.7)	158	(92.4)
Minnesota	57	(33.5)	36	(21.2)	77	(45.3)	124	(72.9)
Missouri	88	(32.1)	39	(14.2)	147	(53.6)	196	(71.5)
New Jersey	318	(40.5)	174	(22.2)	293	(37.3)	645	(82.2)
North Carolina	260	(66.2)	42	(10.7)	91	(23.2)	364	(92.6)
Tennessee	80	(34.0)	47	(20.0)	108	(46.0)	144	(61.3)
Wisconsin	194	(47.2)	87	(21.2)	130	(31.6)	368	(89.5)
All sites combined	**1,737**	**(41.9)**	**790**	**(19.0)**	**1,620**	**(39.1)**	**3,525**	**(85.0)**

* Includes children identified with autism spectrum disorder who were linked to an in-state birth certificate.

TABLE 5. Median age (in months) of earliest known autism spectrum disorder diagnosis and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Autistic disorder			ASD/PDD			Asperger disorder			Any specified ASD diagnosis		
Site	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)	Median age	No.	(%)
Arizona	55	186	(76.2)	61	50	(20.5)	74	8	(3.3)	56	244	(69.9)
Arkansas	55	269	(63.0)	63	129	(30.2)	75	29	(6.8)	59	427	(81.8)
Colorado	40	192	(61.7)	65	104	(33.4)	61	15	(4.8)	51	311	(54.4)
Georgia	46	288	(48.1)	56	261	(43.6)	65	50	(8.3)	53	599	(68.9)
Maryland	43	52	(32.3)	61	104	(64.6)	65	5	(3.1)	52	161	(80.9)
Minnesota	51	50	(45.9)	65	54	(49.5)	62	5	(4.6)	56	109	(46.6)
Missouri	54	81	(26.7)	55	197	(65.0)	65	25	(8.3)	56	303	(85.1)
New Jersey	42	227	(32.7)	51	428	(61.6)	66	40	(5.8)	48	695	(72.1)
North Carolina	32	165	(52.5)	49	130	(41.4)	67	19	(6.1)	40	314	(59.6)
Tennessee	51	157	(57.1)	63	100	(36.4)	60	18	(6.5)	56	275	(71.1)
Wisconsin	46	143	(40.2)	55	189	(53.1)	67	24	(6.7)	51	356	(72.1)
All sites combined	**46**	**1,810**	**(47.7)**	**56**	**1,746**	**(46.0)**	**67**	**238**	**(6.3)**	**52**	**3,794**	**(69.3)**

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

TABLE 6. 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, 10 sites, United States, 2014

Characteristic	Arizona	Arkansas	Colorado	Georgia	Maryland	Minnesota	New Jersey	North Carolina	Tennessee	Wisconsin
Total no. of ASD cases	349	522	572	869	199	234	964	527	387	494
Total no. (%) of ASD cases with special education records	308 (88.3)	327† (—§)	139† (—§)	708 (81.5)	149 (74.9)	188 (80.3)	822 (85.3)	420 (79.7)	218† (—§)	156† (—§)
Primary exceptionality (%)										
Autism	64.9	65.4	43.9	58.9	67.1	67.0	48.4	75.0	79.8	36.5
Emotional disturbance	2.9	0.9	7.2	2.0	2.7	3.7	1.6	2.6	0.5	5.8
Specific learning disability	6.8	3.7	13.7	4.0	12.8	1.1	8.2	2.9	0.9	2.6
Speech or language impairment	5.5	8.9	10.8	1.0	3.4	2.7	13.7	2.4	3.2	20.5
Hearing or visual impairment	0	0.3	0	0.1	0	1.1	0.6	0.5	0	0.6
Health, physical or other disability	6.8	13.5	14.4	3.5	8.1	15.4	18.5	11.2	3.2	14.7
Multiple disabilities	0.3	3.4	5.0	0	4.0	1.6	6.7	1.7	0	0
Intellectual disability	3.2	4.0	4.3	2.0	2.0	6.9	1.7	2.4	2.8	0.6
Developmental delay/Preschool	9.4	0	0.7	28.5	0	0.5	0.6	1.4	9.6	18.6

Abbreviation: ASD = autism spectrum disorder.

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

† Excludes children residing in school districts where educational records were not reviewed (proportion of surveillance population: 31% Arkansas, 67% Colorado, 12% Tennessee, 74% Wisconsin).

§ Proportion not reported because numerator is not comparable to other sites (excludes children residing in school districts where educational records were not reviewed).

TABLE 7. Number* and percentage of children aged 8 years, by race/ethnicity and site in the DSM-5 Surveillance Area — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

			Total	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian or Pacific Islander, non-Hispanic		American Indian or Alaska Native, non-Hispanic	
Site	Site institution	Surveillance area	No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Arizona	University of Arizona	Part of 1 county in metropolitan Phoenix†	**9,478**	5,340	(56.3)	321	(3.4)	3,244	(34.2)	296	(3.1)	277	(2.9)
Arkansas	University of Arkansas for Medical Sciences	All 75 counties in Arkansas	**39,992**	26,103	(65.3)	7,705	(19.3)	5,012	(12.5)	843	(2.1)	329	(0.8)
Colorado	Colorado Department of Public Health and Environment	1 county in metropolitan Denver	**8,022**	2,603	(32.4)	1,018	(12.7)	4,019	(50.1)	322	(4.0)	60	(0.7)
Georgia	CDC	5 counties including metropolitan Atlanta	**51,161**	15,495	(30.3)	22,042	(43.1)	9,913	(19.4)	3,599	(7.0)	112	(0.2)
Maryland	Johns Hopkins University	1 county in metropolitan Baltimore	**9,955**	4,977	(50.0)	3,399	(34.1)	829	(8.3)	719	(7.2)	31	(0.3)
Minnesota	University of Minnesota	Parts of 2 counties including Minneapolis–St. Paul†	**9,767**	3,793	(38.8)	2,719	(27.8)	1,486	(15.2)	1,576	(16.1)	193	(2.0)
Missouri	Washington University	1 county in metropolitan St. Louis	**12,205**	7,186	(58.9)	3,793	(31.1)	561	(4.6)	626	(5.1)	39	(0.3)
New Jersey	Rutgers University	4 counties including metropolitan Newark	**32,935**	13,593	(41.3)	7,166	(21.8)	10,226	(31.0)	1,874	(5.7)	76	(0.2)
North Carolina	University of North Carolina–Chapel Hill	6 counties in central North Carolina	**30,283**	15,241	(50.3)	7,701	(25.4)	5,463	(18.0)	1,778	(5.9)	100	(0.3)
Tennessee	Vanderbilt University Medical Center	11 counties in middle Tennessee	**24,940**	15,867	(63.6)	4,896	(19.6)	3,324	(13.3)	799	(3.2)	54	(0.2)
Wisconsin	University of Wisconsin Madison	10 counties in southeastern Wisconsin	**35,037**	20,732	(59.2)	6,486	(18.5)	6,181	(17.6)	1,471	(4.2)	167	(0.5)
All sites combined			**263,775**	**130,930**	**(49.6)**	**67,246**	**(25.5)**	**50,258**	**(19.1)**	**13,903**	**(5.3)**	**1,438**	**(0.5)**

Abbreviation: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.*

* Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics Vintage 2016 Bridged Race Population Estimates for July 1, 2014.

† Denominator excludes school districts that were not included in the surveillance area, calculated from National Center for Education Statistics enrollment counts of third graders during the 2014–2015 school year.

TABLE 8. Number and percentage of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Site	No.	No.	(%)	No.	(%)	No.	(%)	Ratio	Kappa
Arizona	179	143	(79.9)	17	(9.5)	19	(10.6)	0.99	0.83
Arkansas	560	514	(91.8)	8	(1.4)	38	(6.8)	0.95	0.92
Colorado	116	92	(79.3)	19	(16.4)	5	(4.3)	1.14	0.79
Georgia	937	790	(84.3)	79	(8.4)	68	(7.3)	1.01	0.83
Maryland	207	187	(90.3)	12	(5.8)	8	(3.9)	1.02	0.89
Minnesota	254	200	(78.7)	34	(13.4)	20	(7.9)	1.06	0.79
Missouri	209	179	(85.6)	12	(5.7)	18	(8.6)	0.97	0.74
New Jersey	995	842	(84.6)	122	(12.3)	31	(3.1)	1.10	0.85
North Carolina	532	493	(92.7)	34	(6.4)	5	(0.9)	1.06	0.93
Tennessee	408	348	(85.3)	39	(9.6)	21	(5.1)	1.05	0.72
Wisconsin	523	448	(85.7)	46	(8.8)	29	(5.5)	1.04	0.83
All sites combined	**4,920**	**4,236**	**(86.1)**	**422**	**(8.6)**	**262**	**(5.3)**	**1.04**	**0.85**

Abbreviations: DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*; DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*.

TABLE 9. Characteristics of children meeting DSM-IV-TR and/or DSM-5 surveillance case definition — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014

	Met DSM-IV-TR or DSM-5	Met both DSM-IV-TR and DSM-5		Met DSM-IV-TR only		Met DSM-5 only		DSM-IV-TR vs. DSM-5	
Characteristic	No.	No.	(%)	No.	(%)	No.	(%)	Ratio	Kappa
Met ASD case definition under DSM-IV-TR and/or DSM-5	4,920	4,236	(86.1)	422	(8.6)	262	(5.3)	1.04	0.85
Male	3,978	3,452	(86.8)	316	(7.9)	210	(5.3)	1.03	0.85
Female	942	784	(83.2)	106	(11.3)	52	(5.5)	1.06	0.85
White, non-Hispanic	2,486	2,159	(86.8)	193	(7.8)	134	(5.4)	1.03	0.85
Black, non-Hispanic	1,184	994	(84.0)	109	(9.2)	81	(6.8)	1.03	0.84
Hispanic, regardless of race	817	695	(85.1)	91	(11.1)	31	(3.8)	1.08	0.86
Asian/Pacific Islander, non-Hispanic	207	188	(90.8)	14	(6.8)	5	(2.4)	1.05	0.88
≤36 months	1,509	1,372	(90.9)	115	(7.6)	22	(1.5)	1.07	0.89
37–48 months	723	640	(88.5)	61	(8.4)	22	(3.0)	1.06	0.86
>48 months	1,503	1,195	(79.5)	154	(10.2)	154	(10.2)	1.00	0.81
Autism special education eligibility[†]	2,270	2,156	(95.0)	35	(1.5)	79	(3.5)	0.98	0.57
ASD diagnostic statement[§]									
Earliest ASD diagnosis ≤36 months	951	936	(98.4)	0	(0)	15	(1.6)	0.98	0.71
Earliest ASD diagnosis autistic disorder	1,577	1,526	(96.8)	0	(0)	51	(3.2)	0.97	0.50
Earliest ASD diagnosis PDD-NOS/ ASD NOS	1,564	1,525	(97.5)	0	(0)	39	(2.5)	0.98	0.72
Earliest ASD diagnosis Asperger disorder	221	210	(95.0)	0	(0)	11	(5.0)	0.95	0.72
No previous ASD diagnosis or eligibility on record	950	484	(50.9)	369	(38.8)	97	(10.2)	1.47	0.62
Intellectual disability (IQ ≤70)	1,191	1,089	(91.4)	67	(5.6)	35	(2.9)	1.03	0.89
Borderline range (IQ 71–85)	881	778	(88.3)	74	(8.4)	29	(3.3)	1.06	0.88
Average or above average (IQ >85)	1,620	1,391	(85.9)	143	(8.8)	86	(5.3)	1.04	0.86

Abbreviations: ASD = autism spectrum disorder; DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*; DSM-IV-TR = *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*; PDD-NOS = pervasive developmental disorder not otherwise specified.

* Includes children identified with ASD who were linked to an in-state birth certificate.

† Includes children with autism as the Primary Exceptionality (Table 6) as well as children documented to meet eligibility criteria for autism special education services.

§ An ASD diagnosis documented in abstracted comprehensive evaluations, including DSM-IV-TR diagnosis of autistic disorder, PDD-NOS or Asperger disorder qualifies a child as meeting the DSM-5 surveillance case definition for ASD.

¶ Includes data from all 11 sites, including those with IQ data available for <70% of confirmed cases.

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