

See the related commentary "Prevalence Counts" by Diana L. Robins on page XXX.

Prevalence and Characteristics of Autism Spectrum Disorder Among 4-Year-Old Children in the Autism and Developmental Disabilities Monitoring Network

Deborah L. Christensen, PhD,* Deborah A. Bilder, MD,† Walter Zahorodny, PhD,‡ Sydney Pettygrove, PhD,§ Maureen S. Durkin, PhD,||¶** Robert T. Fitzgerald, PhD,†† Catherine Rice, PhD,* Margaret Kurzius-Spencer, PhD,§ Jon Baio, EdS,* Marshalyn Yeargin-Allsopp, MD*

ABSTRACT: *Objective:* Early identification of children with autism spectrum disorder (ASD) facilitates timely access to intervention services. Yet, few population-based data exist on ASD identification among preschool-aged children. The authors aimed to describe ASD prevalence and characteristics among 4-year-old children in 5 of 11 sites participating in the 2010 Autism and Developmental Disabilities Monitoring Network. *Method:* Children with ASD were identified through screening of health and education records for ASD indicators, data abstraction and compilation for each child, and clinician review of records. ASD prevalence estimates, ages at first evaluation and ASD diagnosis, cognitive test scores, and demographics were compared for 4-year-old children and 8-year-old children living in the same areas. *Results:* Among 58,467 children in these 5 sites, 4-year-old ASD prevalence was 13.4 per 1000, which was 30% lower than 8-year-old ASD prevalence. Prevalence of ASD without cognitive impairment was 40% lower among 4-year-olds compared with 8-year-olds, but prevalence of ASD with cognitive impairment was 20% higher among 4-year-olds compared with 8-year-olds. Among 4-year-olds with ASD, female and non-Hispanic white children were more likely to receive their first comprehensive evaluation by age 36 months compared with male and non-Hispanic black children, respectively. Among children diagnosed with ASD by age 48 months, median age at first comprehensive evaluation was 27 months for 4-year-olds compared with 32 months for 8-year-olds. *Conclusion:* Population-based ASD surveillance among 4-year-old children provides valuable information about the early identification of children with ASD and suggests progression toward lowering the age of first ASD evaluation within participating Autism and Developmental Disabilities Monitoring communities.

(*J Dev Behav Pediatr* 0:1–8, 2015) **Index terms:** prevalence, autism spectrum disorder, developmental disabilities, population-based surveillance.

The reported prevalence of autism spectrum disorder (ASD) has risen markedly in recent decades, resulting in substantial public concern and increased levels of ASD surveillance and research. Population-based data on prevalence and characteristics of ASD among 8-year-old chil-

dren have been collected every 2 years since 2000 by the Autism and Developmental Disabilities Monitoring (ADDM) Network, which conducts records-based surveillance for ASD and other developmental disabilities in communities across the United States.^{1–5} In 2000, measured ASD

From the *Division of Birth Defects and Developmental Disabilities, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA; †Department of Psychiatry, University of Utah, Salt Lake City, UT; ‡Department of Pediatrics, Rutgers-New Jersey Medical School, Newark, NJ; §Department of Pediatrics, University of Arizona, Tucson, AZ; ||Department of Population Health Sciences, University of Wisconsin-Madison, Madison, WI; ¶Department of Pediatrics, University of Wisconsin-Madison, Madison, WI; **Waisman Center, University of Wisconsin-Madison, Madison, WI; ††Department of Psychiatry, Washington University School of Medicine, St Louis, MO.

Received June 2015; accepted October 2015.

Supported by the Centers for Disease Control and Prevention.

The authors declare no conflict of interest.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.jdbp.org).

The findings and conclusions in this study are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Address for reprints: Deborah L. Christensen, PhD, Division of Birth Defects and Developmental Disabilities, 4770 Buford Highway, MS E-86, Atlanta, GA 30341; e-mail: dqc3@cdc.gov.

Copyright © 2015 Wolters Kluwer Health, Inc. All rights reserved.

prevalence was 6.7 per 1000 8-year-old children living in the ADDM Network surveillance areas²; the most recent ADDM Network estimate was 14.7 per 1000 8-year-olds measured in 2010.⁵ The degree to which the increase in ASD prevalence represents changes in the definition and ascertainment of ASD, an increase in risk, or both, remains unclear.⁶⁻¹⁰ Nevertheless, data on the number and characteristics of children identified with ASD provide valuable information for monitoring prevalence trends, generating research hypotheses, and planning for service and resource needs, including the resources needed for ASD identification and intervention services.

Although ASD is considered a lifelong condition, evidence suggests that early intervention can improve outcomes.¹¹⁻¹⁴ This implies that absence of or delay in ASD identification that impedes early access to interventions and initiation of special services could have negative developmental consequences. Therefore, early identification of ASD is a priority and the American Academy of Pediatrics recommends screening all children for ASD at 18 and 24 months followed by a comprehensive evaluation for children with developmental concerns.¹⁵ The prioritization of early identification of ASD is reflected in the Healthy People 2020 goal to increase the percentage of children with ASD who have a first comprehensive evaluation by age 36 months (www.healthypeople.gov/2020/topics-objectives/topic/maternal-infant-and-child-health/objectives). Much of the recent population-based data on the prevalence and characteristics of ASD comes from surveillance among school-aged children¹⁻⁵; there are fewer recent data on the characteristics of children with ASD at the age that is targeted for ASD identification.¹⁶⁻¹⁸ More detailed information about these young children, including comparisons with older children, could help inform efforts to improve early identification and thereby increase earlier use of developmentally appropriate services shown to benefit children with ASD. Surveillance among preschool-aged children provides timely information that can be used by local communities and in public health campaigns, such as the Learn the Signs. Act Early program of the Centers for Disease Control and Prevention (CDC) (www.cdc.gov/ncbddd/actearly/).

In 2010, the CDC began population-based surveillance for ASD among 4-year-old children living in communities across the United States through a selection of sites participating in the ADDM Network. The purpose of this surveillance is to provide population-based information on the prevalence and characteristics of preschool-aged children with ASD. The specific goals of the study were to: (1) describe the prevalence and characteristics of 4-year-old children with ASD living in selected ADDM Network communities; (2) compare ASD prevalence and characteristics of 4-year-old children to 8-year-old children living in the same communities; and (3) evaluate efforts to improve early identification by comparing median age at first comprehensive evaluation among children with ASD born in 2006 compared with children born in 2002.

METHODS

Study Sites

The Early Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that identifies 4-year-olds with autism spectrum disorder (ASD) based on screening and review of comprehensive developmental evaluations from health and education records, using methods developed by the CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).¹⁹ The Early ADDM Network included 5 of the 11 ADDM sites in 2010 (Arizona, Missouri, New Jersey, Utah, and Wisconsin). Each Early ADDM site covered a subsection of its total ADDM Network geographic area, including at least 8000 4-year-old children. Both ADDM and Early ADDM Network sites were selected through a competitive process. Each ADDM site functioned as a public health authority under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable Institutional Review Board, privacy, and confidentiality requirements.

Case Ascertainment

Children were eligible for case ascertainment if they were born in 2006 and their parents or guardians lived in an Early ADDM surveillance area at any time during 2010, regardless of place of birth. Children's records were classified as (1) education records, including developmental evaluations to determine eligibility for special education or early intervention services, or (2) health records, including diagnostic and developmental evaluations. All Early ADDM Network sites had agreements in place to access records from health sources. Arizona, New Jersey, and Utah had access to Individuals with Disabilities Education Act (IDEA) Part B special education records and New Jersey and Utah additionally had access to IDEA Part C early intervention program records (<http://idea.ed.gov/>).

Like the ADDM Network, the Early ADDM Network used a two-phase ascertainment process.¹⁹ In brief, records for children in special education or with a number of *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) billing codes were reviewed for the presence of an ASD diagnosis or descriptions of behaviors consistent with ASD. Records containing such triggers were abstracted and then underwent systematic clinician review to determine case status based on *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)*²⁰ diagnostic criteria for an ASD (i.e., Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder—Not Otherwise Specified).

Descriptive Characteristics

Children were considered to have a previous ASD diagnosis by a community provider or educational classification if an ASD diagnosis was documented in an abstracted evaluation or by an ICD-9-CM billing code at any time from birth through the year when they reached the

surveillance age (4 or 8 years), or if they received special education services under an autism eligibility during the surveillance year, respectively. Among children with a previous ASD diagnosis by a community provider, data were restricted to those children with a previous diagnosis by age 48 months to allow direct comparisons of ages at earliest comprehensive evaluation and ASD diagnosis between children born in 2006 (4-year-olds) and 2002 (8-year-olds). Children were considered to have cognitive impairment if the score was ≤ 70 on the most recently available cognitive test.²¹ Information on race/ethnicity was obtained from either source records or birth certificates. At each site, surveillance data were linked to 2006 birth certificate records from the respective state to obtain information on birth characteristics. Children with a birth certificate match were coded as being born in the state of residence during the surveillance year, whereas those without a birth certificate match were assumed to have been born out-of-state and were coded as such.

Quality Assurance

Early ADDM Network sites follow the same quality assurance conventions established by the ADDM Network.^{5,19}

Analytic Methods

Autism spectrum disorder prevalence among 4-year-olds was calculated as the number of 4-year-olds who met the surveillance ASD case definition in the Early ADDM Network sites in 2010 divided by the number of 4-year-olds residing in the counties included in the surveillance areas according to the US Census Bureau 2010 decennial census.²² In 2 sites with access to education records (Arizona and Utah), the surveillance areas included some, but not all of the school districts in two counties. Therefore, the number of children who lived outside the surveillance area in these 2 counties was identified to determine the appropriate denominator. This was performed by linking the excluded school districts to their respective census tracts, calculating the number of 4-year-old children living in these census tracts, and subtracting this number from the overall county population of 4-year-old children. Population counts of 4-year-olds in each specific census race/ethnicity category were adjusted to the distribution of the CDC bridged-race categories (non-Hispanic white, non-Hispanic black, Hispanic, American Indian/Alaska Native, and Asian/Pacific Islander).²³ The same methods were used to estimate ASD prevalence among 8-year-olds living in the Early ADDM Network surveillance area. Data from Early ADDM sites were pooled to produce combined ASD prevalence estimates. Prevalence estimates were stratified by surveillance site, sex, and race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic) and presence of cognitive impairment. Other race/ethnicity groups had too few children to generate stable ASD prevalence estimates. Overall ASD prevalence estimates included all children identified with ASD regardless of sex, race/ethnicity, or cognitive ability. Statistical tests were selected and confidence interval estimates were calculated under the

assumption that the observed counts of ASD surveillance cases were drawn from an underlying Poisson sampling distribution. The association between ASD prevalence estimates and characteristics of children with ASD by surveillance area, sex, and race/ethnicity were examined with Pearson χ^2 tests and prevalence ratios. Exact tests were used when the number of children was less than 5. Differences in median age at first ASD evaluation and earliest known ASD diagnosis by sex and race/ethnicity were determined by nonparametric median tests. Significance was set at $p < .05$. All analyses were performed using SAS version 9.3 statistical software (SAS Institute Inc., Cary, NC).

RESULTS

Population Distribution

The 2010 geographic catchment areas for the Early Autism and Developmental Disabilities Monitoring Network included 58,467 4-year-olds and 56,727 8-year-olds, which were 1.4% of the 2010 U.S. populations of both 4-year-old and 8-year-old children. The population distribution of children by race/ethnicity varied by study site (see Appendix, Supplemental Digital Content, <http://links.lww.com/JDBP/A91>) but was similar within each site for 4- and 8-year-old children. In 4 of 5 sites, approximately 30% of children were classified as either non-Hispanic black or Hispanic.

Autism Spectrum Disorder Prevalence by Age, Sex, and Race/Ethnicity

Estimated autism spectrum disorder (ASD) prevalence among 4-year-olds in 2010 was 13.4 per 1000 (Table 1). Prevalence varied across surveillance sites, from 8.5 per 1000 4-year-olds in Missouri to 19.7 per 1000 4-year-olds in New Jersey. Prevalence was higher for sites with access to both education and health records (Arizona, New Jersey, and Utah; estimated prevalence 15.9 per 1000; 95% confidence interval [CI], 14.7–17.3) compared to sites with access to health records only (Missouri and Wisconsin; estimated prevalence 8.6 per 1000; 95% CI, 7.4–10.0). Estimated prevalence for New Jersey (19.7 per 1000) was significantly higher ($p < .001$) than those for all other sites. Overall estimated prevalence was 20.3 per 1000 male and 6.1 per 1000 female 4-year-olds. The male-to-female prevalence ratio (PR) was statistically significantly greater than 1.0 in all sites, ranging from 2.6 in Arizona, Missouri, and Wisconsin to 4.4 in New Jersey, with an overall male-to-female PR of 3.3. Overall ASD prevalence did not vary significantly by race/ethnicity, but prevalence was significantly higher among non-Hispanic white children compared with Hispanic children in Arizona and Wisconsin and was higher among non-Hispanic white children compared with non-Hispanic black children in Missouri. At each site, estimated ASD prevalence was lower among 4-year-olds than 8-year-olds (Fig. 1); overall, the 4-year-old prevalence estimate was 30% lower than the 8-year-old prevalence estimate. Among

Table 1. Estimated Prevalence* of Autism Spectrum Disorder Among 4-Year-Old Children, by Sex, Race/Ethnicity, and Site—Early Autism and Developmental Disabilities Monitoring (ADDM) Network, 5 Sites, United States, 2010

| | Overall | Arizona | Missouri† | New Jersey | Utah | Wisconsin‡ |
|---------------------------------|------------------|------------------|-----------------|------------------|------------------|-----------------|
| Total with ASD | 783 | 123 | 103 | 352 | 132 | 73 |
| Total population | 58,467 | 9265 | 12,095 | 17,860 | 10,944 | 8303 |
| Total prevalence‡ (95% CI) | 13.4 (12.5–14.4) | 13.3 (11.1–15.8) | 8.5 (7.0–10.3) | 19.7 (17.8–21.9) | 12.1 (10.2–14.3) | 8.8 (7.0–11.1) |
| Male prevalence (95% CI) | 20.3 (18.7–22.0) | 18.9 (15.4–23.3) | 12.2 (9.8–15.3) | 31.6 (28.2–35.5) | 17.9 (14.7–21.7) | 12.5 (9.6–16.4) |
| Female prevalence (95% CI) | 6.1 (5.2–7.1) | 7.3 (5.2–10.3) | 4.6 (3.2–6.7) | 7.2 (5.6–9.2) | 5.8 (4.1–8.3) | 4.8 (3.0–7.4) |
| Male:female prevalence ratio | 1.4 (1.3–1.6) | 2.6 (1.7–3.9) | 2.6 (1.7–4.1) | 4.4 (3.3–5.8) | 3.1 (2.0–4.6) | 2.6 (1.6–4.4) |
| White prevalence (95% CI) | 13.0 (11.8–14.4) | 15.7 (12.6–19.7) | 9.4 (7.4–11.9) | 18.9 (15.7–22.7) | 14.0 (11.4–17.2) | 8.2 (6.2–10.9) |
| Black prevalence (95% CI) | 10.8 (9.1–12.9) | 11.8 (4.4–31.3) | 3.8 (3.3–6.4) | 16.7 (13.7–20.4) | 5.1 (1.3–20.4) | 3.4 (1.1–10.5) |
| Hispanic prevalence (95% CI) | 13.9 (12.1–16.1) | 9.1 (6.4–12.9) | 14.4 (7.2–28.8) | 22.5 (18.7–27.0) | 9.8 (6.9–13.8) | 1.8 (0.4–7.2) |
| White:black prevalence ratio | 1.2 (1.0–1.5) | 1.3 (0.5–3.6) | 2.5 (1.4–4.4) | 1.1 (0.9–1.5) | 2.7 (0.7–11.1) | 2.4 (0.8–7.8) |
| White:Hispanic prevalence ratio | 0.9 (0.8–1.1) | 1.7 (1.1–2.6) | 0.6 (0.3–1.4) | 0.8 (0.6–1.1) | 1.4 (1.0–2.1) | 4.6 (1.1–18.8) |

*Per 1000 children. †Reviewed health care records only. ‡All children are included regardless of race or ethnicity. ASD, autism spectrum disorder; CI, confidence interval.

8-year-old children, overall ASD prevalence estimates were significantly higher among non-Hispanic white children compared with non-Hispanic black children (PR 1.4, 95% CI, 1.2–1.7) and compared with Hispanic children (PR 1.2, 95% CI, 1.0–1.4; $p = .05$) (data not shown in table format).

Prevalence of Autism Spectrum Disorder with and Without Cognitive Impairment

Scores on cognitive tests were available for at least 70% of children in Arizona, New Jersey, and Utah. Among children with available test scores, 46% of 4-year-olds and 28% of 8-year-olds had a score consistent with cognitive impairment. The prevalence of ASD without

cognitive impairment was 6.7 per 1000 4-year-olds and 12.3 per 1000 8-year-olds (PR = 0.6; $p < .05$) (Fig. 2). In contrast, the prevalence of ASD with cognitive impairment was 5.9 per 1000 4-year-olds and 4.8 per 1000 8-year-olds (PR = 1.2; $p < .05$). In each of these 3 sites, there was a smaller difference in the prevalence of ASD with and without cognitive impairment among 4-year-old children compared with 8-year-old children.

Early Developmental Concerns and Previous ASD Diagnosis

Among 4-year-olds and 8-year-olds with ASD, 93% and 87%, respectively, had a record of developmental

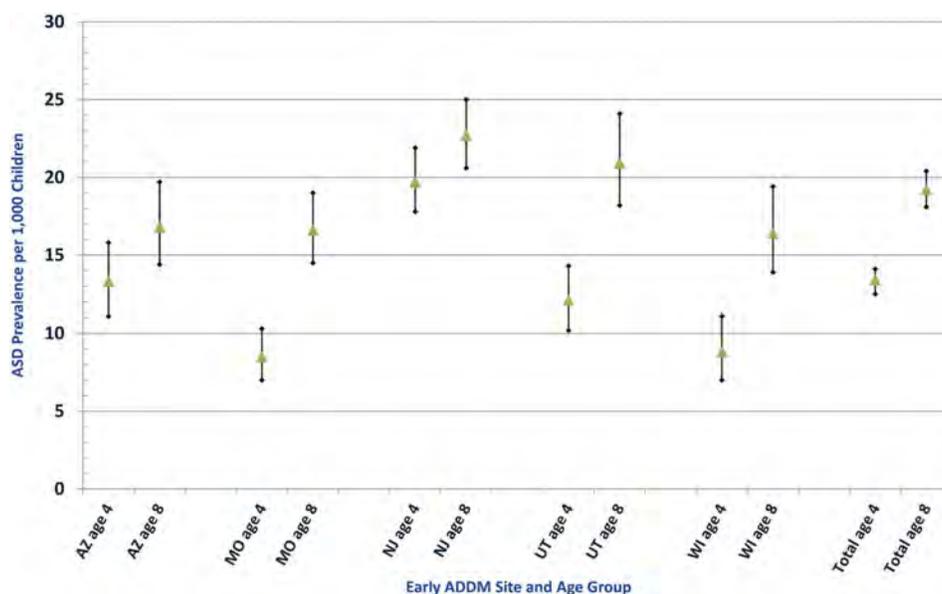


Figure 1. Estimated prevalence (per 1000 population) of autism spectrum disorder (ASD) among children aged 4 and 8 years—Early Autism and Developmental Disabilities Monitoring (ADDM) Network, 5 sites, United States, 2010.

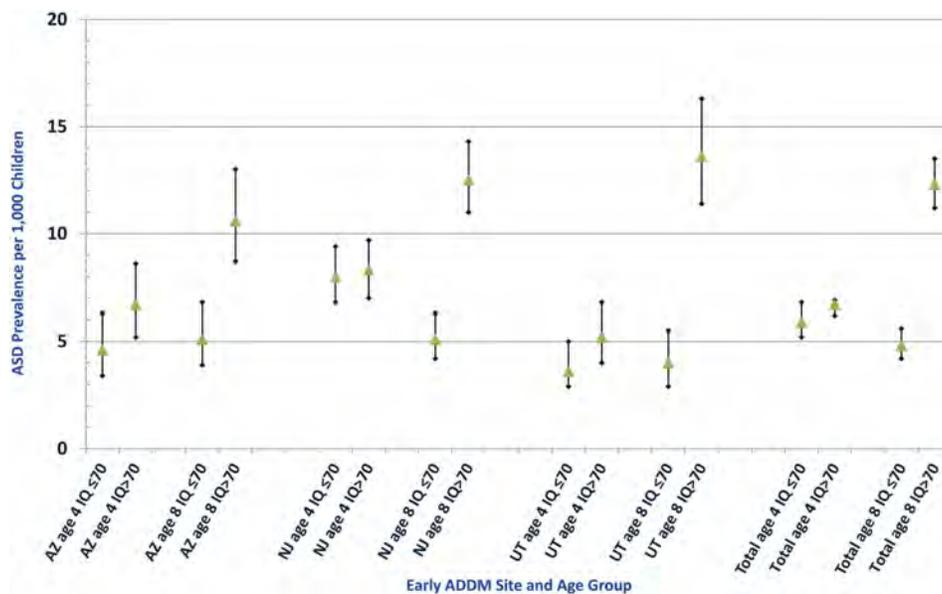


Figure 2. Estimated prevalence (per 1000 population) of autism spectrum disorder (ASD) among children aged 4 and 8 years, by the presence of cognitive impairment—Early Autism and Developmental Disabilities Monitoring (ADDM) Network, 3 sites, United States, 2010.

concerns before age 3 years; these percentages did not vary by sex, race/ethnicity, or study site. Among 4-year-olds with ASD, 621 (79%) had either a previous ASD diagnosis by a community provider or educational classification (67%) or a suspicion of ASD (12%) noted in an evaluation. Among 8-year-olds with ASD, 974 (89%) had either a previous ASD diagnosis by a community pro-

vider or educational classification (81%) or suspicion of ASD (8%) (data not shown in table form).

First Comprehensive Evaluation by Age 36 Months

Among 4-year-old children, 71.3% had their first comprehensive evaluation by age 36 months, ranging from 60% to 76% ($p < .001$) across sites (Table 2).

Table 2. Percentage of Children with First Evaluation by 36 Months of Age, by Sex, Race/Ethnicity, Place of Birth in State of Residence, and Surveillance Site—Early Autism and Developmental Disabilities Monitoring (ADDM) Network, 5 Sites*, United States, 2010

| | 4-Year-Old Children | | | 8-Year-Old Children | | |
|--------------------|---------------------|--|----------|---------------------|--|----------|
| | No. | N (%) with First Comprehensive Evaluation by Age 36 mo | <i>p</i> | No. | N (%) with First Comprehensive Evaluation by Age 36 mo | <i>p</i> |
| Total | 783 | 558 (71.3) | | 1091 | 465 (42.6) | |
| Sex | | | | | | |
| Male | 610 | 432 (69.2) | .02 | 884 | 391 (44.2) | .03 |
| Female | 173 | 136 (78.6) | | 207 | 74 (35.8) | |
| Race/ethnicity | | | | | | |
| Non-Hispanic white | 395 | 300 (76.0) | | 609 | 301 (49.4) | |
| Non-Hispanic black | 121 | 77 (63.6) | .008† | 160 | 65 (40.6) | .048† |
| Hispanic | 189 | 130 (68.8) | | 204 | 65 (31.9) | <.0001† |
| Place of birth | | | | | | |
| In state | 655 | 487 (71.6) | >.05 | 902 | 403 (44.7) | .003 |
| Out of state | 128 | 193 (69.5) | | 189 | 62 (32.8) | |
| Surveillance site | | | | | | |
| Arizona | 123 | 74 (60.2) | .02‡ | 155 | 71 (45.8) | .002‡ |
| Missouri | 103 | 72 (69.9) | | 207 | 101 (48.8) | |
| New Jersey | 352 | 268 (76.1) | | 404 | 162 (40.1) | |
| Utah | 132 | 93 (70.4) | | 190 | 62 (36.6) | |
| Wisconsin | 73 | 51 (69.9) | | 135 | 69 (51.1) | |

*Arizona, Missouri, New Jersey, Utah, and Wisconsin. †Compared with non-Hispanic white. ‡Overall difference among surveillance sites. ASD, autism spectrum disorder.

Non-Hispanic white children and females were more likely to have a first comprehensive evaluation by age 36 months compared with non-Hispanic black children and males, respectively (76.0% vs 63.6%, $p = .02$; 78.6% vs 69.2%, $p = .02$, respectively). A substantially lower proportion of 8-year-old children, 42.6%, had a first comprehensive evaluation by age 36 months. This proportion ranged from 36.6% to 51.1% ($p = .002$) across surveillance sites and was higher among non-Hispanic white compared with non-Hispanic black and Hispanic children (49.4% vs 40.6% and 31.9%, respectively; $p = .048$ and $p < .0001$, respectively), among male compared with female children (44.2% vs 35.8%; $p = .03$), and among children born in the state where surveillance was conducted compared with those born in other states (44.7% vs 32.8%; $p = .003$).

To directly compare the ages at earliest known comprehensive evaluation and ASD diagnosis between children born in 2006 (4-year-olds) and children born in 2002 (8-year-olds), data were restricted to those children with a previous ASD diagnosis by a community provider by age 48 months. For 4-year-old children, the median age at earliest known comprehensive evaluation was 5 months earlier than median age for 8-year-olds (27 months vs 32 months, $p < .001$). Median age at earliest known ASD diagnosis by a community provider was 32 months for 4-year-olds and 35 months for 8-year-olds ($p < .01$) (data not shown in table format).

DISCUSSION

This report is the first to describe autism spectrum disorder (ASD) prevalence and characteristics among 4-year-olds across 5 sites participating in the Early Autism and Developmental Disabilities Monitoring (ADDM) Network. Overall estimated ASD prevalence was 13.4 per 1000 4-year-olds, which is higher than earlier estimates for preschool-aged children reported by studies in Georgia and South Carolina that used the ADDM Network surveillance methodology.^{18,19} Because previous reports^{1-5,24} indicate that many children with ASD are not evaluated until after age 4, ASD prevalence in this 4-year-old age cohort will likely rise when measured at a later age. Combined ASD prevalence among 4-year-olds at sites with access to health and education records was nearly double that for sites that reviewed health records only, indicating the important role played by the special education system in the evaluation of preschool-age children and the contribution of education records to estimation of ASD prevalence. Special education records for children up to age 4 years are often generated through evaluations and services provided through Early Intervention or the Child Find program, the latter being a mandate of the Individuals with Disabilities Education Act (IDEA) that requires school districts to identify, locate, and evaluate all children with disabilities regardless of whether the child is currently enrolled in educational programs, such as prekindergarten (www.idea.ed.gov).

Among all sites, estimated ASD prevalence for 4-year-old children was 30% lower than that of 8-year-old children, but this ratio was smaller in sites with access to education records, suggesting that ascertainment of children with ASD by the Early ADDM Network was more complete in sites with education records access.

Several previous studies have reported an increase in estimated ASD prevalence over time.^{16-19,25,26} Consistent with results from the ADDM Network, ASD prevalence in 8-year-olds has risen in recent data collected by the US National Survey of Children's Health (NSCH) which bases ASD prevalence on parent/caregiver reports of an autism (2003 survey) or ASD (2007 and later surveys) diagnosis. These national surveys provide a complementary means of estimating ASD prevalence in nationally representative samples. The prevalence of autism reported by NSCH rose from 4.4 per 1000 (95% confidence interval [CI], 3.0-6.3) children aged 4 to 5 years in 2003²⁵ to 8.5 per 1000 (95% CI, 6.0-12.0) children aged 3 to 5 years in 2007.²⁶ The prevalence of ASD among 8-year-old children in 2007 (21.4 per 1000) was substantially higher than the prevalence of autism among 4-year-old children in 2003 (5.0 per 1000).²⁷ The change in questionnaire language between the 2 surveys limits the interpretation of this difference; nevertheless, the magnitude of the prevalence difference between these 2 ages for children born in the same year suggests a role for increased recognition of ASD characteristics as children age and/or increased ASD awareness among providers during this time interval. Where possible, data for children ascertained by the Early ADDM Network at age 4 years (in 2010) and by the ADDM Network at age 8 years (in 2014) will be compared to investigate the completeness of ascertainment and characteristics of ASD between the 2 ages in the same cohort of children. It may also be possible to assess whether there is a subset of children who met the Early ADDM Network ASD surveillance case criteria at age 4 years but not at age 8 years (e.g., because of an alternate diagnosis or evidence of resolution or improvement in ASD-related behaviors documented in an evaluation performed after age 4 years).

Comparison of ASD prevalence and characteristics between 4- and 8-year-old children in the same geographic area may provide important information on the characteristics of children with ASD who are identified by Early ADDM Network surveillance before and after the age of entry into kindergarten. In contrast to 8-year-olds, overall ASD prevalence among 4-year-olds did not differ by race/ethnicity and prevalence ratios by sex were smaller. If these findings indicate trends in ASD recognition and diagnostic practices, ASD awareness in the non-Hispanic black and Hispanic communities and recognition of ASD among girls may have improved during the interval separating the 2 birth cohorts. In addition, children with more severe impairment may be evaluated at a younger age, which is supported by the higher rate of cognitive impairment among 4-year-olds

with ASD compared with 8-year-olds with ASD. Previous reports have indicated that observed differences in ASD prevalence by sex and race/ethnicity are greater for ASD without cognitive impairment.²⁻⁵ Children with less severe social and behavioral impairments may be more challenging to identify by age 4 years, and healthcare providers caring for young children should be alert for subtle signs of developmental problems.

Early identification of ASD has been prioritized by the American Academy of Pediatrics through its recommendation for universal ASD screening at ages 18 and 24 months followed promptly by a comprehensive evaluation when screening identifies developmental concerns.¹⁵ Lowering the age at first evaluation may be more relevant than lowering the age at diagnosis given the challenges of diagnosing young children with ASD. A formal diagnosis may not be necessary for receipt of services related to social, language, and behavioral concerns associated with ASD. Through IDEA, special education services are available to infants, toddlers, and preschool-aged children meeting eligibility requirements, allowing interventions to begin and educational supports to be in place before school entry. Given that evidence links early intervention to improved outcomes,^{11,12,14} ensuring that at-risk children are evaluated and linked promptly to services is important. Ongoing communication between healthcare and education providers may help to accomplish this goal.

Few data exist on the age at first comprehensive evaluation among children with ASD. The greater median age at first comprehensive evaluation for males compared with females and non-Hispanic black compared with non-Hispanic white children, and variations by site are worthy of further investigation to aid in community efforts to ensure that all children showing signs of developmental delay are evaluated as early as possible. Encouragingly, we found that among all children diagnosed with ASD by age 48 months, the median age at first comprehensive evaluation was 27 months for 4-year-olds and 32 months for 8-year-olds, suggesting that children born in 2006 received comprehensive evaluations at younger ages than children born in 2002. There was a smaller difference in the median age at earliest known ASD diagnosis for 4-year-olds compared with 8-year-olds. Although promising, these trends reflect children diagnosed by age 48 months which may limit the relevance of these findings to children with more severe impairment. It is concerning that fewer than half of 8-year-old children with a previous ASD diagnosis had a comprehensive developmental evaluation before the age of 36 months, despite the finding that nearly all had a record of developmental concerns before the age of 36 months.

The availability of developmental evaluation records conducted to determine eligibility for IDEA Part C and Part B special education services and evaluations conducted through the healthcare system are essential to public health surveillance of ASD. By evaluating

information contained in existing professional evaluations in a systematic manner, investigators in the ADDM Network are able to conduct cost-effective population-based ASD surveillance in large and diverse populations. This methodology was validated compared with direct examination of children and the methods were found to result in a prevalence estimate that is likely conservative.²⁸ However, this study has limitations. First, the data are limited to the information available in the source records and the amount and quality of these data determine the extent to which the characteristics of the identified population can be described. Second, the lack of access to education records at some sites likely leads to underestimation of ASD prevalence in those sites and to underestimating the overall prevalence of ASD in this cohort. Third, information on cognitive ability test scores was not available for all children and measurement of cognitive ability among preschool-age children is not as reliable as measurement among school-age children.^{29,30} Fourth, the surveillance areas participating in the Early ADDM Network were not selected to be representative of the United States as a whole or their respective states, limiting the generalizability of the ASD estimates to 4-year-olds in other US regions. In addition, sites participating in the Early ADDM Network were a subset and not necessarily representative of sites in the entire ADDM Network. Estimated ASD prevalence among 8-year-olds in the Early ADDM Network differed from the estimated prevalence published for 8-year-olds in the greater ADDM Network (14.7 per 1000).⁵ This difference likely reflects the different surveillance area for Early ADDM compared with the greater ADDM Network. The ADDM Network that participated in the Early ADDM Network had higher combined ASD prevalence compared with the sites that did not participate in the Early ADDM Network. In addition, the Early ADDM surveillance areas had smaller populations, leading to greater variability of prevalence estimates, and were located closer to the universities hosting the surveillance program and therefore closer to diagnostic and treatment centers for children with disabilities. Results for 8-year-olds in the 2010 Early ADDM Network are provided for comparison only and should not be considered the primary source of information on ASD prevalence and characteristics among 8-year-olds in the 2010 ADDM Network.

CONCLUSION

Autism spectrum disorder (ASD) surveillance among 4-year-olds provides a baseline for assessing trends in ASD prevalence among children in this younger age group and informs health and education professionals of upcoming service needs. The Early Autism and Developmental Disabilities Monitoring (ADDM) Network offers valuable insight into the early identification of children with ASD and suggests some progression toward lowering the age of first ASD evaluation in participating communities. Continued efforts should be

made to promote early identification of children with ASD so that interventions can be initiated at the youngest age possible. Developmental evaluations and services provided through the special education system by local public school districts are an important resource for families to help ensure that services begin and educational supports are in place for children with ASD before kindergarten entry. Where possible, data for children ascertained by the Early ADDM Network at age 4 years in 2010 and by the ADDM Network at age 8 years in 2014 will provide additional information on ASD prevalence and characteristics at these different ages.

REFERENCES

1. Autism and Developmental Disabilities Monitoring Network Principal Investigators, Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorders—autism and developmental disabilities monitoring network, 14 sites, United States, 2002. *MMWR Surveill Summ*. 2007;56:12–28.
2. Autism and Developmental Disabilities Monitoring Network Principal Investigators, Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorders—autism and developmental disabilities monitoring network, six sites, United States, 2000. *MMWR Surveill Summ*. 2007;56:1–11.
3. Autism and Developmental Disabilities Monitoring Network Principal Investigators, Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorders—autism and developmental disabilities monitoring network, United States, 2006. *MMWR Surveill Summ*. 2009;58:1–20.
4. Autism and Developmental Disabilities Monitoring Network Principal Investigators, Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorders—autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *MMWR Surveill Summ*. 2012;61:1–19.
5. Autism and Developmental Disabilities Monitoring Network Principal Investigators, Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveill Summ*. 2014;63:1–21.
6. Hertz-Picciotto I, Delwiche L. The rise in autism and the role of age at diagnosis. *Epidemiology*. 2009;20:84–90.
7. Hansen SN, Schendel DE, Parner ET. Explaining the increase in the prevalence of autism spectrum disorders: the proportion attributable to changes in reporting practices. *JAMA Pediatr*. 2015; 169:56–62.
8. Lundstrom S, Reichenberg A, Anckarsater H, et al. Autism phenotype versus registered diagnosis in Swedish children: prevalence trends over 10 years in general population samples. *BMJ*. 2015;350:h1961.
9. Fombonne E. Epidemiology of pervasive developmental disorders. *Pediatr Res*. 2009;65:591–598.
10. Gillberg C, Fernell E. Autism plus versus autism pure. *J Autism Dev Disord*. 2014;44:3274–3276.
11. Reichow B, Barton EE, Boyd BA, et al. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database Syst Rev*. 2012;10:CD009260.
12. Rogers SJ, Estes A, Lord C, et al. Effects of a brief Early Start Denver model (ESDM)-based parent intervention on toddlers at risk for autism spectrum disorders: a randomized controlled trial. *J Am Acad Child Adolesc Psychiatry*. 2012;51:1052–1065.
13. Schreibman L, Dawson G, Stahmer AC, et al. Naturalistic developmental behavioral interventions: empirically validated treatments for autism spectrum disorder. *J Autism Dev Disord*. 2015;45:2411–2428.
14. Eapen V, Crncec R, Walter A. Clinical outcomes of an early intervention program for preschool children with Autism Spectrum Disorder in a community group setting. *BMC Pediatr*. 2013;13:3.
15. Johnson CP, Myers SM; American Academy of Pediatrics Council on Children with Disabilities. Identification and evaluation of children with autism spectrum disorders. *Pediatrics*. 2007;120:1183–1215.
16. Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children. *JAMA*. 2001;285:3093–3099.
17. Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children: confirmation of high prevalence. *Am J Psychiatry*. 2005;162:1133–1141.
18. Nicholas JS, Carpenter LA, King LB, et al. Autism spectrum disorders in preschool-aged children: prevalence and comparison to a school-aged population. *Ann Epidemiol*. 2009;19:808–814.
19. Yeargin-Allsopp M, Rice C, Karapurkar T, et al. Prevalence of autism in a US metropolitan area. *JAMA*. 2003;289:49–55.
20. Association AP. *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*. Washington, DC: American Psychiatric Association; 2000.
21. Obi O, Van Naarden Braun K, Baio J, et al. Effect of incorporating adaptive functioning scores on the prevalence of intellectual disability. *Am J Intellect Dev Disabil*. 2011;116:360–370.
22. U.S. Census Bureau; *Census 2010, Summary File 1, Tables PCT12H-PCT120; generated by Deborah Christensen; using American FactFinder*; <http://factfinder2.census.gov>. Accessed November 14, 2013.
23. National Center for Health Statistics. *Estimates of the April 1, 2010 resident population of the United States, by county, single-year of age, bridged race, Hispanic origin, and sex. Prepared under a collaborative arrangement with the U.S. Census Bureau*. Available from: http://www.cdc.gov/nchs/nvss/bridged_race.htm. Accessed November 14, 2013.
24. Pringle B, Colpe IJ, Blumberg SJ, et al. *Diagnostic History and Treatment of School-aged Children with Autism Spectrum Disorder and Special Health Care Needs. NCHS Data Brief, No 97*. Hyattsville, MD: National Center for Health Statistics; 2012.
25. Centers for Disease C, Prevention. Mental health in the United States: parental report of diagnosed autism in children aged 4–17 years—United States, 2003–2004. *MMWR Morb Mortal Wkly Rep*. 2006;55:481–486.
26. Kogan MD, Blumberg SJ, Schieve LA, et al. Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*. 2009;124:1395–1403.
27. Schieve LA, Rice C, Yeargin-Allsopp M, et al. Parent-reported prevalence of autism spectrum disorders in US-born children: an assessment of changes within birth cohorts from the 2003 to the 2007 National Survey of Children's Health. *Matern Child Health J*. 2012;16(suppl 1):S151–S157.
28. Avchen RN, Wiggins LD, Devine O, et al. Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders. *J Autism Dev Disord*. 2011;41:227–236.
29. Sattler J. *Assessment of Children's Intelligence and Special Abilities*. Boston, MA: Allyn & Bacon; 1982.
30. Lord C, Schopler E. The role of age at assessment, developmental level, and test in the stability of intelligence scores in young autistic children. *J Autism Dev Disord*. 1989;19:483–499.