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WHAT’S KNOWN ON THIS SUBJECT: Numerous studies have suggested that the prevalence of diagnosed ASD in the United States has increased dramatically in the past decades. Given the associated impact on children and families, continual monitoring of ASD remains an urgent public health priority.

WHAT THIS STUDY ADDS: Based on a recent national survey with parents of children aged 3 to 17 years, the point prevalence of diagnosed ASD is higher than previous US estimates. Many children who had been diagnosed with ASD were reported to not currently have the condition.

abstract

OBJECTIVES: The reported increasing prevalence of autism spectrum disorder (ASD) and attendant health and family impact make monitoring of ASD prevalence a public health priority.

METHODS: The prevalence of parent-reported diagnosis of ASD among US children aged 3 to 17 years was estimated from the 2007 National Survey of Children’s Health (sample size: 78,037). A child was considered to have ASD if a parent/guardian reported that a doctor or other health care provider had ever said that the child had ASD and that the child currently had the condition. The point-prevalence for ASD was calculated for those children meeting both criteria. We examined sociodemographic factors associated with current ASD and with a past (but not current) ASD diagnosis. The health care experiences for children in both ASD groups were explored.

RESULTS: The weighted current ASD point-prevalence was 11.0 per 10,000. We estimate that 673,000 US children have ASD. Odds of having ASD were 4 times as large for boys than girls. Non-Hispanic (NH) black and multiracial children had lower odds of ASD than NH white children. Nearly 40% of those ever diagnosed with ASD did not currently have the condition; NH black children were more likely than NH white children to not have current ASD. Children in both ASD groups were less likely than children without ASD to receive care within a medical home.

CONCLUSIONS: The observed point-prevalence is higher than previous US estimates. More inclusive survey questions, increased population awareness, and improved screening and identification by providers may partly explain this finding. Pediatrics 2009;124:1395–1403

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KEY WORDS
autism spectrum disorder, prevalence, children with special health care needs, disability, national estimates, access to health care

ABBREVIATIONS
ASD—autism spectrum disorder
PDD-NOS—pervasive developmental disorder not otherwise specified
ADDM—Autism and Developmental Disabilities Monitoring
NSC—National Survey of Children’s Health
NHIS—National Health Interview Survey
OR—odds ratio
CI—confidence interval

The opinions expressed in this article are those of the authors and do not necessarily reflect the views of the institutions with which the authors are affiliated.

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Autism spectrum disorder (ASD) is a group of neurodevelopmental disorders comprising autistic disorder and 2 related but less severe disorders: Asperger disorder and pervasive developmental disorder not otherwise specified (PDD-NOS). Children who have ASD exhibit characteristic impairments in social interactions and communication and restricted, repetitive, and stereotyped patterns of behavior. Previous studies have documented a high level of functional limitations and poor health status in children with autism, an accompanying high level of health care use and unmet health needs, and increased parenting stress and family burden. The lifetime health care costs for a person with autism have been estimated to be more than $1.6 million, and the estimated total expense burden to the health care system associated with ASD rose 142% from 2000 to 2004.

Numerous studies have suggested that the prevalence of diagnosed ASD, in the United States and elsewhere, has increased dramatically in the past decades. Most studies conducted in the 1960s to 1980s reported prevalences ranging from 2 to 5 in 10,000; however, these studies typically assessed the more narrowly defined condition of autistic disorder. Studies published in the early 2000s reported prevalences ranging from 30 to 60 in 10,000, more than a 10-fold increase compared with the results of earlier studies. Recent US studies reported prevalences ranging from 50 to 90 in 10,000 children, with notable variation according to child age, gender, race/ethnicity, and socioeconomic status. Nationally representative surveys of parents have produced ASD-prevalence estimates comparable to population-based studies that relied on medical and special education record abstraction in defined communities.

The most recent ASD estimate from 1 such study, reported by the Autism and Developmental Disabilities Monitoring (ADDM) Network (66 in 10,000 children aged 8 years in 2002 from 14 US sites), is comparable to parent-reported autism estimates from 2 national surveys (75 and 76 in 10,000 children aged 6–8 years, based on the 2003 National Survey of Children’s Health [NSCH] and the 2003–2004 National Health Interview Survey [NHIS], respectively). Moreover, the ADDM Network, NSCH, and NHIS estimates showed strikingly consistent demographic patterns: very high male/female ratios and lower prevalence among minority and socially disadvantaged children. The most current available data source, the 2007 NSCH, offers several methodologic strengths. Parents reported whether their children had ever been diagnosed with ASD, whether they currently had the condition, and the severity of the condition. The 2003 NSCH and the NHIS only asked parents if a doctor or other health care provider had ever said that their child had autism. In addition, the NSCH provides national US data, whereas the ADDM Network provides detailed data from select local US populations.

Given the reported increasing prevalence and associated impact on children and families, continual monitoring of ASD remains an urgent public health priority. Further understanding of the groups at highest risk for being diagnosed with ASD and the factors associated with current ASD symptoms, severity, and health care impact could lead to more effective interventions.

METHODS

With funding and direction from the Health Resources and Services Administration’s Maternal and Child Health Bureau, the Centers for Disease Control and Prevention’s National Center for Health Statistics conducted the 2007 NSCH. This random-digit-dial telephone survey provides national and state-specific information on the health and well-being of children <18 years of age based on interviews with their parents or guardians; verbal consent was obtained from all participants. Interviews were conducted in English, Spanish, and 4 Asian languages. When households with children were identified, 1 child from each household was randomly selected to be the subject of the interview. From April 2007 to July 2008, interviews were completed for 91,642 children. The overall weighted response rate (American Association for Public Opinion Research rate 4) was 51.2%, assuming that telephone numbers that rang with no answer or were busy on all call attempts were nonresidential. Additional details about the survey methodology are available elsewhere.

Analyses for this study were limited to the 78,037 children who were aged 3 to 17 years. Parents were asked if they had ever been told by a doctor or other health care provider that their child had “autism, Asperger disorder, pervasive developmental disorder, or other autism spectrum disorder.” If parents responded affirmatively, they were asked if their child currently had autism or ASD (see Fig 1 for question text) and, if so, to provide a qualitative ranking of severity. Children classified as having ASD were those with a parent report of (1) ever being told by a doctor or other health care provider that their child had autism and (2) the child currently having ASD. The prevalence of ASD was examined overall and according to selected demographic and socioeconomic characteristics. We also analyzed the prevalence of ASD according to the severity of the condition as described by the parents (mild, moderate, or severe).

A similar analytic approach was used to examine children whose parents re-
ported that they had been diagnosed with ASD in the past but did not currently have the disorder to determine how this population of children differed according to selected demographic and socioeconomic covariates from children with a current diagnosis. The analysis also explored how the prevalence of co-occurring emotional, behavioral, and developmental problems varied among children currently with and without ASD. This analysis was restricted to children aged 6 to 17 years, because many of the disorders are not identified until school age. These co-occurring conditions were defined analogously to ASD: affirmative responses to both questions of whether “ever told child had condition” and whether “child currently has condition.”

Finally, we compared the health care experiences of children who currently had ASD to the experiences of those who once had the diagnosis and those who never had an ASD diagnosis by using the 5 components used to measure the American Academy of Pediatrics medical home framework: (1) whether the child had a personal physician or nurse; (2) whether the child had a usual place for care when sick; (3) whether the family experienced problems obtaining needed referrals for care; (4) if the family reported receipt of family-centered care; and (5) if the family reported receipt of effective care coordination. Health insurance status at the time of the survey, whether the child had received any treatment or counseling during the previous 12 months from a mental health professional, and whether the child currently had an individualized education plan (IEP) were also used to characterize the child’s and family’s health care experience.

Estimated point prevalence for ASD was calculated as the number of children who currently had the condition (on the basis of parent report), divided by the number of 3- to 17-year-old children represented by the survey. Children whose parents did not know or refused to answer either of the ASD questions (0.2% of the age group) were excluded from the denominator.

Results
In this nationally representative study of US children, the weighted point prevalence of ASD based on parent reports of currently having ASD was 110 per 10,000 children, representing an estimated 673,000 US children aged 3 to 17 years with a current diagnosis of ASD in 2007 (Table 1). After adjustment for selected demographic characteristics, the odds of a child having ASD were 54% greater for children aged 6 to 8 years and 83% greater for children aged 9 to 11 years than for 15- to 17-year-olds. Odds for boys having ASD were 4 times as large as the odds for girls. Non-Hispanic black and non-Hispanic multiracial children had 57% and 42% lower odds, respectively, of having ASD than non-Hispanic white children. Children living in the Midwest and Northeast had marginally higher odds of having ASD than children living in the West.

Parents of half the children with ASD (49.6% [95% CI: 41.8–57.5]) described the severity of the condition as “mild.”

FIGURE 1
Flow diagram of survey-participant progress through the ASD questions, NSCH, 2007. Responses indicating that the parent did not know the answer or refused to provide the answer are not shown. Estimated frequencies and point-prevalence estimates are based on weighted data.
The condition was described as moderate for one third (33.9% [27.1–41.5]) and as severe for the remaining children (16.5% [10.2–25.4]). We found no significant difference in severity according to sociodemographic factors (data available on request), except that children with ASD whose parents had 12 years of education were significantly more likely to have ASD rated as moderate or severe than children with ASD whose parents had more education (68.0% and 43.5%, respectively).

As shown in Fig 1, parents of 453 children in the survey reported that their child had previously been diagnosed with ASD by a health care professional but the child did not currently have that condition, representing 38.2% of all children who met the ever-reported criterion (Table 2). This percentage did not vary significantly according to age or gender of the child. However, among all children reported as ever diagnosed with ASD, non-Hispanic black children were more likely and Hispanic children were less likely than non-Hispanic white children to not have current ASD. Children whose parents had <12 years of education had twice the odds as children with higher parental education of being reported as not currently having ASD.

Children aged 6 to 17 years who currently had ASD and those who once had the diagnosis (but did not currently) were much more likely than children who had never been diagnosed with ASD to experience other developmental or mental health conditions (Table 3). Overall, 87.3% of the children with ASD and 81.6% of the children ever diagnosed but not currently reported to have ASD had attention-deficit disorder or attention-deficit/hyperactivity disorder, anxiety problems, behavioral or conduct problems, depression,
and/or developmental delay affecting the child’s ability to learn. The only significant difference in co-occurring conditions between children with current ASD and those who once had an ASD diagnosis was more developmental delay among those with ASD currently (64.8% and 47.7%, respectively).

Examining the same co-occurring developmental, emotional, and behavioral conditions according to severity of ASD, those with moderate or severe ASD were more likely than those with mild ASD to have at least 1 of the 5 co-occurring conditions (93.0% vs 80.9%), which largely reflects differences in the prevalence of developmental delay (74.5% vs 53.6%); no other significant associations between severity and the prevalence of co-occurring conditions were identified (data available on request).

There were distinct differences in health care characteristics between children who currently had ASD, children who once had the diagnosis, and children who had never been diagnosed with ASD (Table 4). Relative to children never diagnosed, children with current ASD had better access to care, as reflected by greater odds of having a personal doctor or nurse, a usual place for care, and health insurance. However, children with current ASD had poorer perceived quality of care, as indicated by lower odds of having received family-centered care, needed care coordination, and care in a medical home. Although children with ASD were much more likely than children never diagnosed to have received treatment from a mental health professional in the past year, more than half of all the children with parent-reported ASD did not receive such treatment.

Children who once had an ASD diagnosis (but did not currently) were similar to children with current ASD on many health care characteristics. For example, children with current ASD were as likely as children who once had the diagnosis to have received treatment from a mental health professional in the past year, more than half of all the children with parent-reported ASD did not receive such treatment.

**DISCUSSION**

In 2007, 1.1% of US children aged 3 to 17 years (1 of 91 children in this age group) were reported to have currently diagnosed ASD. In addition, for nearly 40% of all the children reported to have ever had an ASD diagnosis, a parent or caregiver reported a past but not current ASD diagnosis.

To help us interpret our findings, we examined several potential reasons why parents might not have reported a current ASD diagnosis for this subgroup. Although previous research suggested that, overall, an ASD diagnosis at young ages (2–5 years, depend-

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**TABLE 2** Percentage of Children Aged 3 to 17 Years Who Do Not Currently Have ASD, Among Those Who Have Ever Been Diagnosed With the Condition According to Selected Demographic Characteristics

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>No. in Sample (Unweighted)</th>
<th>Weighted % Without Current ASD Among All Children Aged 3–17 y Ever Diagnosed With ASD</th>
<th>Adjusted OR*</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>453</td>
<td>38.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3–5</td>
<td>53</td>
<td>48.1</td>
<td>1.72</td>
<td>0.77–3.87</td>
</tr>
<tr>
<td>6–8</td>
<td>86</td>
<td>29.8</td>
<td>0.92</td>
<td>0.41–2.07</td>
</tr>
<tr>
<td>9–11</td>
<td>103</td>
<td>40.3</td>
<td>1.33</td>
<td>0.58–3.04</td>
</tr>
<tr>
<td>12–14</td>
<td>86</td>
<td>35.2</td>
<td>1.18</td>
<td>0.52–2.69</td>
</tr>
<tr>
<td>15–17</td>
<td>125</td>
<td>38.3</td>
<td>1.00</td>
<td>Referent</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>321</td>
<td>36.5</td>
<td>0.88</td>
<td>0.50–1.56</td>
</tr>
<tr>
<td>Female</td>
<td>132</td>
<td>44.3</td>
<td>1.00</td>
<td>Referent</td>
</tr>
<tr>
<td>Ethnicity/race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>42</td>
<td>20.5</td>
<td>0.35</td>
<td>0.14–0.87</td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>296</td>
<td>33.7</td>
<td>1.00</td>
<td>Referent</td>
</tr>
<tr>
<td>Non-Hispanic black</td>
<td>71</td>
<td>67.8</td>
<td>3.97</td>
<td>1.67–9.47</td>
</tr>
<tr>
<td>Non-Hispanic multiracial</td>
<td>20</td>
<td>35.6</td>
<td>1.15</td>
<td>0.46–2.87</td>
</tr>
<tr>
<td>Non-Hispanic other single race</td>
<td>18</td>
<td>63.0</td>
<td>2.51</td>
<td>0.89–6.40</td>
</tr>
<tr>
<td>Highest level of education achieved by parent in household</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate or less</td>
<td>119</td>
<td>50.7</td>
<td>1.98</td>
<td>1.07–3.66</td>
</tr>
<tr>
<td>More than high school</td>
<td>331</td>
<td>31.8</td>
<td>1.00</td>
<td>Referent</td>
</tr>
<tr>
<td>Family income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤100% of poverty level</td>
<td>68</td>
<td>44.5</td>
<td>0.73</td>
<td>0.31–1.72</td>
</tr>
<tr>
<td>&gt;100% to ≤200%</td>
<td>90</td>
<td>47.7</td>
<td>0.79</td>
<td>0.38–1.72</td>
</tr>
<tr>
<td>&gt;200% to ≤400%</td>
<td>139</td>
<td>26.1</td>
<td>0.51</td>
<td>0.28–0.93</td>
</tr>
<tr>
<td>&gt;400% of poverty level</td>
<td>156</td>
<td>39.9</td>
<td>1.00</td>
<td>Referent</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 biological or adoptive parents</td>
<td>251</td>
<td>35.7</td>
<td>1.00</td>
<td>Referent</td>
</tr>
<tr>
<td>2 parents, 1 step-parent</td>
<td>47</td>
<td>46.5</td>
<td>1.51</td>
<td>0.69–3.55</td>
</tr>
<tr>
<td>Single mother</td>
<td>109</td>
<td>40.3</td>
<td>0.94</td>
<td>0.49–1.85</td>
</tr>
<tr>
<td>Other family structure</td>
<td>43</td>
<td>45.9</td>
<td>1.57</td>
<td>0.71–3.46</td>
</tr>
<tr>
<td>Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>99</td>
<td>43.2</td>
<td>0.68</td>
<td>0.29–1.59</td>
</tr>
<tr>
<td>Midwest</td>
<td>100</td>
<td>32.8</td>
<td>0.54</td>
<td>0.25–1.15</td>
</tr>
<tr>
<td>South</td>
<td>142</td>
<td>34.9</td>
<td>0.54</td>
<td>0.25–1.18</td>
</tr>
<tr>
<td>West</td>
<td>112</td>
<td>44.4</td>
<td>1.00</td>
<td>Referent</td>
</tr>
</tbody>
</table>

* Among children ever diagnosed with autism/ASD, the adjusted OR reflects the relative odds that the child did not have autism/ASD at the time of the interview, adjusted for all of the other demographic characteristics shown. The comparison group was children aged 3 to 17 years who had never received a parent-reported diagnosis of ASD. Data source: Maternal and Child Health Bureau and National Center for Health Statistics, NSCH, 2007.
TABLE 3  Point Prevalence of Selected Conditions Among Children Aged 6 to 17 Years According to Parent-Reported ASD Status

<table>
<thead>
<tr>
<th>ASD Status</th>
<th>Percentage of Children Aged 6 to 17 Years Who Had Selected Characteristics, According to Parent-Reported ASD Status</th>
<th>Relative Odds of Having Had the Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently has autism/ASD</td>
<td>Developmental Delay Affecting Ability to Learn</td>
<td>ADD/ADHD&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>No. in sample</td>
<td>438</td>
<td>299</td>
</tr>
<tr>
<td>Weighted prevalence per 100</td>
<td>64.8</td>
<td>47.2</td>
</tr>
<tr>
<td>95% CI</td>
<td>56.6–72.2</td>
<td>38.5–56.3</td>
</tr>
<tr>
<td>Ever diagnosed with autism/ASD</td>
<td>183</td>
<td>165</td>
</tr>
<tr>
<td>but does not currently have the condition</td>
<td>Weighted prevalence per 100</td>
<td>47.7</td>
</tr>
<tr>
<td>95% CI</td>
<td>35.3–60.5</td>
<td>36.0–61.5</td>
</tr>
<tr>
<td>Never diagnosed with autism/ASD</td>
<td>1324</td>
<td>4832</td>
</tr>
<tr>
<td>Weighted prevalence per 100</td>
<td>2.4</td>
<td>7.4</td>
</tr>
<tr>
<td>95% CI</td>
<td>2.1–2.7</td>
<td>6.9–7.9</td>
</tr>
</tbody>
</table>

ADD indicates attention-deficit disorder; ADHD, attention-deficit/hyperactivity disorder.
<sup>a</sup> Although Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV) criteria state that a diagnosis of ADHD should not be given if the ADHD symptoms occur during the course of a pervasive developmental disorder, we had no data on the temporal sequence of diagnoses. In addition, the application of DSM-IV criteria may not be uniformly used in a consistent manner in the general clinical population.


Table 4 Percentage of Children Aged 3 to 17 Years Who Had Selected Characteristics, According to Parent-Reported ASD Status, With Relative Odds of Having Had the Characteristic

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Currently Has Autism/ASD</th>
<th>Ever Diagnosed With Autism/ASD but Does Not Currently Have the Condition</th>
<th>Never Diagnosed With Autism/ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. in Sample&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Weighted % (95% CI)</td>
<td>No. in Sample&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Had a personal doctor or nurse</td>
<td>868</td>
<td>96.2 (93.9–97.7)</td>
<td>427</td>
</tr>
<tr>
<td>Had a usual place for care</td>
<td>860</td>
<td>96.1 (94.1–97.4)</td>
<td>424</td>
</tr>
<tr>
<td>Received family-centered care&lt;sup&gt;c&lt;/sup&gt;</td>
<td>513</td>
<td>47.9 (40.5–55.8)</td>
<td>268</td>
</tr>
<tr>
<td>Had no problems obtaining referrals (if needed)&lt;sup&gt;d&lt;/sup&gt;</td>
<td>262</td>
<td>77.5 (69.1–84.2)</td>
<td>138</td>
</tr>
<tr>
<td>Received effective care coordination (if needed)&lt;sup&gt;e&lt;/sup&gt;</td>
<td>305</td>
<td>38.6 (30.7–47.2)</td>
<td>164</td>
</tr>
<tr>
<td>Received care within a medical home</td>
<td>290</td>
<td>31.8 (25.1–39.5)</td>
<td>156</td>
</tr>
<tr>
<td>Had health insurance at time of survey</td>
<td>871</td>
<td>95.8 (93.3–97.4)</td>
<td>419</td>
</tr>
<tr>
<td>Received treatment from mental health professional</td>
<td>492</td>
<td>48.4 (40.7–56.5)</td>
<td>211</td>
</tr>
<tr>
<td>Currently had an Individualized Education Program</td>
<td>781</td>
<td>88.4 (82.3–92.6)</td>
<td>309</td>
</tr>
</tbody>
</table>

<sup>a</sup> Sample size is the unweighted number of children with affirmative responses for the selected characteristic.

<sup>b</sup> These unadjusted ORs compare children who currently had autism/ASD to children in the given comparison group (ever diagnosed with autism/ASD but not currently or never diagnosed with autism/ASD).

<sup>c</sup> Family-centered care was inferred if parents reported that doctors usually or always spent enough time with the child, listened carefully to the parent, were sensitive to family values and customs, provided needed information, and made the parent feel like a partner.

<sup>d</sup> Effective care coordination was inferred if the parent reported receiving some help arranging or coordinating the child’s health care, reported not needing additional help, and reported satisfaction with the communication among the child’s doctors and between the doctors and the child’s school or education programs. Percent distributions do not include children whose parents reported that they did not receive help arranging or coordinating their children’s care and that they did not need such help.

portion of those who were previously diagnosed but not currently with ASD was 48%, 40%, and 38% for children aged 3 to 5, 9 to 11, and 15 to 17 years, respectively. Because the data are cross-sectional, these age effects may be confounded by birth-cohort differences that we could not assess. Also, we could not assess whether the relatively high proportion of children who had a previous ASD diagnosis was primarily attributable to children initially diagnosed on the basis of milder symptoms or with PDD-NOS, as has been suggested in clinical studies.24–27

Another possible explanation is that ASD may have been initially suspected on the basis of a developmental screening but subsequently ruled out and never truly diagnosed. The high rate of “lost” diagnoses among very young children supports this notion. We might expect that children with a past but not current ASD diagnosis would nonetheless have a high rate of other developmental and mental health conditions. Indeed, they did, although the rate was not significantly different overall from those with a current ASD diagnosis.

A third possibility is that some children with developmental delay, mental retardation, and learning disabilities may have been initially classified as having ASD to facilitate receipt of needed services, particularly from publicly funded programs such as Early Intervention and special education programs.28 This diagnostic-substitution hypothesis cannot be tested directly by our data.

Finally, and conversely, because parent-reported current ASD was not externally validated, we cannot rule out that some parents with children currently meeting criteria for ASD nonetheless responded “no” because their child no longer receives special education or other autism-specific services for the condition. Approximately one third of the children who once had an ASD diagnosis were not receiving special education services, which is substantially lower than the proportion of children with current ASD who were not receiving such services. Children who once had an ASD diagnosis were less likely than children with current ASD to have a usual place for care, and subgroups previously associated with less access to care (non-Hispanic black children and children from families with low parental education29) were also particularly likely to fall in the ever-but-not-current-ASD group.

Because we lacked data to ascertain definitively which children in the ever-diagnosed-but-not-current group truly had a valid past ASD diagnosis, we present a prevalence estimate that required affirmative answers to both the ever and current questions. Still, our current estimate of 110 in 10 000 is higher than previous US estimates.16,18,19 Methodologic changes between the surveys (with the inclusion of Asperger disorder, PDD, and other ASD) and overall increases in public awareness and provider identification of ASD might partly explain the increased prevalence. Several previous studies have shown that the average age of diagnosis is decreasing, which leads to an increase in total prevalence at any 1 point in time.26,30,31 Although there were a number of important changes in the 1990s that influenced the increase in diagnoses, including broadening the diagnostic criteria for ASD, the last 10 years have seen dramatic increases in available diagnostic services; much greater awareness of the condition among parents, doctors, and educators; and a growing acceptance that autism can co-occur with other conditions. All of these factors have played a role in the continued rise in ASD-prevalence rates.22–28 Also, even within the current cohort, children born in or after 1993 (≤14 years of age) have higher ASD estimates than those born in the earliest years.

In addition to the age variation, we observed variation in prevalence according to other sociodemographic factors, including a higher prevalence among boys and among children in the Midwest and Northeast, and a lower prevalence in children from families with lower parental education. These findings are consistent with those of previous population-based studies.5,11,13,16,18,19 We also found higher prevalence among single mothers. However, we had no information on family structure at the time of birth or when the current family structure occurred in relation to the onset of ASD symptoms or diagnosis.

In this study, the ASD estimate for Hispanic children is only slightly lower than that for non-Hispanic white children, whereas previous studies reported larger contrasts between these groups.16 Supplemental subgroup analyses of the current data according to primary home language yielded unstable estimates but suggest that identification of ASD in Hispanic children from households in which the primary language is Spanish remains low (data available on request). We report a larger gap between non-Hispanic black and white children than some other studies.28 Our data further indicate that this black-white disparity is explained by the large differential in parental reporting of current ASD rather than by reporting of ever having ASD. These findings, in particular, indicate the need for further research on the validity of ASD diagnostic methods and the developmental trajectory according to race. Previous studies have demonstrated that children from families who are of low socioeconomic status and/or are racial/ethnic minorities have a later age at ASD diagnosis28 and have more limited access to and use of services related to their disability.40.
Regardless of whether the children currently had the diagnosis, children ever diagnosed with ASD were significantly less likely than other children to receive care in a medical home, for example they had significantly more problems obtaining needed referrals, effective care coordination, and family-centered care. Previous research has shown evidence that having a medical home has health-related benefits for children with special health care needs but that children with autism are less likely to have a medical home compared with other children with special health care needs. This may be driven by the unique circumstances of ASD, which require treatment and coordination among an unusually large number of health and other disciplines, including primary care, educational, rehabilitation, and behavioral health services. The much lower prevalence of having a medical home among children with ASD is noteworthy, because having one has been associated with ameliorating adverse impacts on the family. Because it is not clear if these concerns are unique to ASD or found for other children with special health care needs, future analyses should explore such questions.

This study has several limitations. The data are based on parent report of ASD and coexisting conditions without clinical validation. Data on the validity of parental report of developmental conditions are limited. However, as noted earlier, nationally representative surveys of parents (including the 2003 NSCH) have produced ASD-prevalence estimates and demographic patterns that are comparable with estimates from the ADDM Network. A separate study reported moderate-to-high sensitivities for parent-reported behavioral disorders.

The results are also subject to biases associated with landline telephone surveys, including noncoverage of households without landlines. These biases were minimized to the extent possible by incorporating nonresponse and noncoverage adjustments into the sampling weights. Similar weighting adjustments for the 2003 NSCH yielded ASD-prevalence estimates that matched those from a door-to-door survey with a substantially higher response rate.

Despite these limitations, this study has several strengths. The large population-based sample allowed us to examine parent-reported ASD prevalence among US children overall and within numerous sociodemographic strata. These data complement ongoing population-based surveillance within selected US sites, which provides more in-depth information on children with ASD at the community level, including information on identification, referral patterns, and assessment practices over time. In 2007, the American Academy of Pediatrics released 2 reports recommending earlier and more frequent surveillance for ASD and more aggressive educational and behavioral interventions. These recommendations reflect the recognition that earlier identification and intensive intervention can improve functioning. Ongoing monitoring of the prevalence of ASD among US children will help to evaluate the impact of these and other policy-level changes.

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