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Abstract

Objectives—This report presents data on the prevalence of diagnosed autism spectrum disorder (ASD) as reported by parents of school-aged children (ages 6–17 years) in 2011–2012. Prevalence changes from 2007 to 2011–2012 were evaluated using cohort analyses that examine the consistency in the 2007 and 2011–2012 estimates for children whose diagnoses could have been reported in both surveys (i.e., those born in 1994–2005 and diagnosed in or before 2007).

Data sources—Data were drawn from the 2007 and 2011–2012 National Survey of Children’s Health (NSCH), which are independent nationally representative telephone surveys of households with children. The surveys were conducted by the Centers for Disease Control and Prevention’s National Center for Health Statistics with funding and direction from the Health Resources and Services Administration’s Maternal and Child Health Bureau.

Results—The prevalence of parent-reported ASD among children aged 6–17 was 2.00% in 2011–2012, a significant increase from 2007 (1.16%). The magnitude of the increase was greatest for boys and for adolescents aged 14–17. Cohort analyses revealed consistent estimates of both the prevalence of parent-reported ASD and autism severity ratings over time. Children who were first diagnosed in or after 2008 accounted for much of the observed prevalence increase among school-aged children (those aged 6–17). School-aged children diagnosed in or after 2008 were more likely to have milder ASD and less likely to have severe ASD than those diagnosed in or before 2007.

Conclusions—The results of the cohort analyses increase confidence that differential survey measurement error over time was not a major contributor to observed changes in the prevalence of parent-reported ASD. Rather, much of the prevalence increase from 2007 to 2011–2012 for school-aged children was the result of diagnoses of children with previously unrecognized ASD.

Keywords: autism prevalence • pervasive developmental disabilities • national estimates • State and Local Area Integrated Telephone Survey

Introduction

Autism spectrum disorder (ASD) is a set of complex neurodevelopment disorders that include autistic disorder, Asperger disorder, and pervasive developmental disorder not otherwise specified (1). Children who have ASD display mild to severe impairments in social interaction and communication along with restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities. Diagnosis of ASD should be based on comprehensive behavioral evaluations, making diagnostic assessment complex and time-consuming.

ASD symptoms typically can be identified in children as young as 18 months (2), and the American Academy of Pediatrics recommends developmental screening of all children by age 24 months (3). Nevertheless, many children with ASD—especially those with only mild or limited speech delays—may not be diagnosed until they are of school age, when parents become concerned about an inability to make friends and teachers notice difficulties with peer interactions (3). Formal diagnoses may also occur at this age because a named disability (such as ASD) is needed for
school-aged children to qualify for special education services under the Individuals with Disabilities Education Act (4).

The reported prevalence of ASD has increased in recent decades. For example, data from the Centers for Disease Control and Prevention’s (CDC) National Health Interview Survey (NHIS) revealed a nearly fourfold increase in parent-reported ASD between the 1997–1999 and 2006–2008 surveillance periods (5), and CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network revealed a 78% increase in ASD prevalence between 2002 and 2008 (6).

This report is the first to estimate the change in prevalence of parent-reported ASD from 2007 to 2011–2012 and is based on newly released data from the 2011–2012 National Survey of Children’s Health (NSCH). Estimates are presented for the prevalence and severity of parent-reported ASD diagnoses for school-aged children (those aged 6–17 years). Detailed analysis of ASD prevalence in this group of children allowed for comparisons with 2007 estimates for the same birth cohort and an evaluation of whether observed changes in prevalence could be due to changes in survey-based measurement error.

Methods

The data were drawn from the 2007 and 2011–2012 NSCH. NSCH is a nationally representative survey conducted by CDC’s National Center for Health Statistics (NCHS) as a module of the State and Local Area Integrated Telephone Survey, with direction and principal funding from the Health Resources and Services Administration’s Maternal and Child Health Bureau (7,8). In both 2007 and 2011–2012, NSCH was fielded as a random-digit-dial telephone survey of households with children aged 0–17 years in the United States; the 2011–2012 NSCH included both landlines and cell phones, whereas the 2007 NSCH included landlines only.

Contacted households were screened for the presence of children, and one child was randomly selected from identified households with children to be the subject of the survey. The respondent was a parent or guardian in the household who was knowledgeable about the child’s health. These respondents are referred to as “parents” throughout this report. A total of 91,642 NSCH 2007 interviews were completed from April 2007 through July 2008. A total of 95,677 NSCH 2011–2012 interviews were completed from February 2011 through June 2012.

The overall response rate for 2011–2012 (23.0%) was lower than the rate for 2007 (46.7%) primarily due to the inclusion of cell-phone interviews in 2011–2012. Nonresponse bias analyses suggest that, although the potential for bias cannot be ruled out, differences between respondents and nonrespondents should not have a major impact on the conclusions in this report. Please see Technical Notes for details.

This report is based on parent report of ASD diagnoses, ASD severity, age when first diagnosed with ASD, and approximate year of that first diagnosis. Survey question wording and the derivation of calculated variables are described in the Technical Notes. Children classified as having ASD were those with a parent report of ever being told by a doctor or other health care provider that the child had ASD, and a parent report that the child currently has ASD. This measure of parent-reported ASD is analogous to measures of “parent-reported ASD” (9) and “current ASD” (10) used in previously published reports on NSCH-based estimates of ASD prevalence and trends.


A sampling weight was provided by NCHS with the data record for each child. This weight is based on the probability of selection of the child’s telephone number, with adjustments for known survey response biases and further adjustments to ensure that weighted estimates match demographic control totals from the U.S. Census Bureau’s American Community Survey. Estimates based on these weights, including all national estimates produced for this report, are representative of the noninstitutionalized population of U.S. children.

For more information about NSCH, including its sample design, data collection procedures, and questionnaire content, visit http://www.cdc.gov/nchs/slaits/nsch.htm.

Results

Based on parent reports, the prevalence of diagnosed ASD in 2011–2012 was estimated to be 2.00% for children aged 6–17. This prevalence estimate (1 in 50) is significantly higher than the estimate (1.16%, or 1 in 86) for children in that age group in 2007.

As shown in Figure 1, statistically significant increases in the prevalence of parent-reported ASD were observed for all age groups (from 1.31% to 1.82% for ages 6–9; 1.45% to 2.39% for ages 10–13; and 0.73% to 1.78% for ages 14–17) and for boys (from 1.80% to 3.23%). The increase for girls (from 0.49% to 0.70%) was not statistically significant. The increase in prevalence was greater for boys (1.43 percentage points) than girls (0.21 percentage points) and greater for children aged 14–17 (1.05 percentage points) than for children aged 6–9 (0.51 percentage points).

In 2011–2012, school-aged boys were more than 4 times as likely as school-aged girls to have ASD (3.23% compared with 0.70%). Comparisons of the prevalence of ASD between the narrower age groups (ages 6–9, 10–13, and 14–17) that compose the school-age group (ages 6–17) did not reveal any significant differences in 2011–2012. In contrast, age-related differences were observed in 2007. At that time, children aged 14–17 were less likely to have ASD than children aged 10–13 (0.73% compared with 1.45%).

Cohort analyses of prevalence

The observed prevalence increases in parent-reported ASD could be due to
Figure 1. Percentage of children aged 6–17 years with parent-reported autism spectrum disorder, by age group and sex: United States, 2007 and 2011–2012

Figure 2. Percentage of children born in 1994–2005 who have parent-reported autism spectrum disorder, by survey and approximate year when child was first diagnosed with ASD: United States, 2007 and 2011–2012


survey-based measurement changes over time. One way to evaluate the potential impact of measurement change is to compare independent estimates from the 2007 and 2011–2012 NSCH survey years for the same population (or birth cohort) of children for diagnoses that could have been reported in both survey years. If these prevalence estimates from 2007 and 2011–2012 are identical, this would suggest that the observed prevalence increases are not due to survey-based measurement error.

Children aged 6–17 in 2011–2012 were born in 1994–2005 (approximately) and would have been about ages 2–13 in 2007 when the previous NSCH was conducted. The estimated prevalence of parent-reported ASD for that birth cohort in 2007 was 1.16% (Figure 2).

The appropriate comparison group for those who were aged 2–13 in 2007 would be those children aged 6–17 in 2011–2012 whose ASD diagnosis could have been reported in 2007. That is, the appropriate comparison group in 2011–2012 consists of children who were first identified as having ASD in or before 2007. The estimated
prevalence of parent-reported ASD for children aged 6–17 in 2011–2012 whose ASD was diagnosed in or before 2007 was 1.37% (Figure 2). This estimate is statistically indistinguishable ($p > 0.10$) from the estimate for that same birth cohort from the 2007 NSCH, suggesting that survey-based measurement error was unlikely to have been a major contributor to the observed prevalence increases.

The results shown in Figure 2 and detailed in Table 1 also suggest that the observed increase in ASD prevalence between 2007 and 2011–2012 among children included in the 1994–2005 birth cohort is related to relatively recent diagnoses. The 0.61% of children aged 6–17 diagnosed with ASD in or after 2008 largely accounts for the prevalence increase from 2007 to 2011–2012 for this group.

Table 1 provides estimates for similar comparisons within the three narrower birth cohorts subsumed within the total 1994–2005 birth cohort group. For example, for children aged 6–9 in 2011–2012 (the cohort born in 2002–2005), a comparison to the 2007 estimate for children from the same birth cohort (that is, children aged 2–5 in 2007) illustrates that, for diagnoses received in or before 2007, the 2011–2012 ASD estimate (0.89%) was not significantly different from the 2007 estimate (0.70%). Similar nonsignificant differences were observed for children aged 10–13 in 2011–2012 (1.68% compared with 1.31%) and for children aged 14–17 in 2011–2012 (1.53% compared with 1.45%).

Table 1 also shows that, as expected, relatively recent diagnoses (that is, those occurring in or after 2008) were more common for the cohorts of children aged 6–9 (0.89%) and 10–13 (0.71%) in 2011–2012 than for the cohort of children aged 14–17 in 2011–2012 (0.24%). These relatively recent diagnoses largely account for the prevalence increases from 2007 to 2011–2012 for these age groups. Children diagnosed in or after 2008 represent 50.0%, 29.8%, and 13.5% of children with parent-reported ASD who were aged 6–9, 10–13, and 14–17 in 2011–2012, respectively.

### Cohort analyses of severity

Cohort analyses can also be used to examine the consistency of NSCH estimates of the distribution of children’s ASD severity, as judged by their parents. The first two columns of Figure 3 present a comparison of ASD severity ratings between 2007 and 2011–2012 for the cohort of children born in 1994–2005, where the 2011–2012 estimates are restricted to those children whose ASD diagnosis was first received in or before 2007. The consistency was confirmed: No differences in ASD severity were observed between children aged 2–13 in 2007 and children aged 6–17 in 2011–2012 who first received an ASD diagnosis in or before 2007.

The second and third columns of Figure 3 show the distribution of parent-reported ASD severity levels by the approximate year when the ASD was diagnosed. Relative to other

![Figure 3. Percent distribution of parent-rated severity of autism spectrum disorder for children born in 1994–2005 who currently have autism spectrum disorder, by survey and approximate year when child was first diagnosed with ASD: United States, 2007 and 2011–2012](image-url)
school-aged children with ASD in 2011–2012, those children aged 6–17 who were diagnosed in or after 2008 were more likely to have mild ASD and less likely to have severe ASD, and stratum-adjusted Cochran-Mantel-Haenszel tests reveal that this trend toward less severe ASD for more recent diagnoses was statistically significant. Children aged 6–17 who were diagnosed in or after 2008 were less than one-half as likely as children diagnosed in or before 2007 to have severe ASD (6.9% compared with 16.9%).

Table 2 reveals that this trend is most notable for older children. Among children aged 14–17, almost none (1%) of the children with diagnoses in or after 2008 were classified as having severe ASD, yet 18% of children whose ASD diagnosis was received in or before 2007 were classified as having severe ASD.

Summary and Discussion

Between 2007 and 2011–2012, the prevalence estimate for parent-reported ASD diagnoses among U.S. children aged 6–17 increased significantly, from 1.16% to 2.00%. Increases were observed in all age groups, and among boys aged 6–17.

The increases in ASD prevalence reported here extend an ongoing trend observed in the United States and other developed countries over the past several decades (5,6,11). Assessment of the NSCH age-specific changes in parent-reported ASD prevalence reveals two key components of this trend.

First, the prevalence of parent-reported ASD for adolescents aged 14–17 in 2011–2012 was greater than the prevalence for adolescents aged 14–17 in 2007. The observed increase in this cross-sectional comparison is due largely to differences between the two birth cohorts that are being compared, rather than a recent rise in new diagnoses in adolescence. The birth cohort that was aged 14–17 in 2007 (that is, children born in 1990–1993) had the lowest prevalence of parent-reported ASD among all birth cohorts in 2007, but as young adults aged 18–21 in 2011–2012, they were too old to be part of the 2011–2012 survey. The birth cohort that was aged 14–17 in 2011–2012 (children born in 1994–1997) had the highest prevalence of parent-reported ASD in 2007, when they were aged 10–13. As adolescents aged 14–17 in 2011–2012, this birth cohort continued to have a similarly high prevalence of parent-reported ASD, and this prevalence was significantly higher than the observed prevalence for the birth cohort that aged out of the survey.

Second, significant increases in parent-reported ASD prevalence were observed in both cross-sectional and cohort analyses for children aged 6–9 and 10–13 in 2011–2012. While it is not possible to definitively determine the underlying reason for this trend, several previous studies that also examined changes over time in ASD prevalence estimates within selected birth cohorts suggest that increasing recognition of children with ASD has had an important impact (10,12,13). Evidence from epidemiologic, genetic, and neuroscience research points to the prenatal period as the key exposure window for ASD risk factors (14,15). If the causes of ASD are related to factors that exist prior to or occur just after birth, it is unlikely that changes in ASD prevalence within the cohorts of children aged 6–13 in 2011–2012 reflect “true” increases in susceptibility to the condition at these ages. Rather, changes in prevalence of parent-reported ASD within these birth cohorts (children born in 1998–2005) likely reflect either changes in the recognition of ASD by health professionals or survey-based measurement changes over time.

Closer examination of the parent-reported data confirm that ASD prevalence increases for the majority of children were driven by new (post-2007) diagnoses rather than changes in survey reliability, such as changes in how parents reported earlier (pre-2008) diagnoses. The change (or lack thereof) in how parents reported earlier diagnoses was evaluated by comparing 2007 and 2011–2012 estimates for a subgroup of the population limited to children represented in both surveys (that is, children from the same birth cohorts) and limited to those ASD diagnoses that ostensibly could have been reported in both surveys (that is, diagnoses first received in or before 2007). For this group of comparable children, the prevalence estimate and severity distribution from the 2011–2012 NSCH were not statistically different from the prevalence estimate and severity distribution from the 2007 NSCH. The 2007 and 2011–2012 NSCH samples were independent cross-sectional samples weighted to be representative of the U.S. population of noninstitutionalized children in the respective survey years, and the slight differences observed across surveys are within the range of possible sampling variation.

ASD prevalence increases due to relatively recent diagnoses (that is, those occurring in or after 2008) were most common for the cohorts of children aged 6–9 and 10–13 in 2011–2012, but were also observed to a smaller degree for children aged 14–17. Nearly one-third of the school-aged children reported to have ASD in 2011–2012 were reported to have been diagnosed in or after 2008. While this is understandable for many of the youngest children (those aged 6–9), 30% of children aged 10–13 and 14% of children aged 14–17 were first diagnosed in or after 2008 at age 7 or over, well beyond the age when ASD signs and symptoms should be clearly notable. More than one-half of these children were classified by their parents as having “mild” ASD, and very few were classified as having “severe” ASD. Together, these findings suggest that the increase in prevalence of parent-reported ASD may have resulted from improved ascertainment of ASD by doctors and other health care professionals in recent years, especially when the symptoms are mild. Changes in the ascertainment of ASD could occur because of changes in ASD awareness among parents or health care professionals, increased access to diagnostic services, changes in how screening tests or diagnostic criteria are used, or increased special education placements in the community.

The analyses in this report have several strengths, including a large,
nationally representative sample, with sufficient sample size to explore ASD within selected strata defined by age or birth cohort. Major limitations of the NSCH estimates are that they are potentially subject to survey nonresponse bias and that parents’ reports were not substantiated through clinical evaluation or educational records. Though the validity of parent reports may be uncertain, other studies reporting previous NSCH autism estimates support their use. For example, parent-reported autism prevalence estimates from the 2003 NSCH were highly concordant with NHIS estimates from the same time period and were related as expected to social, emotional, and developmental difficulties experienced by children (16). Moreover, NSCH estimates from the 2007 NSCH were comparable to the ADDM Network estimates from the same time period (6,9). The ADDM Network tracks children aged 8 residing in selected areas in the United States; ASD case finding is through expert clinical review of special education and medical records from specialist providers who serve children with developmental disabilities. The 2011–2012 NSCH estimates cannot be compared in a similar manner because the autism-focused questions in NHIS differ substantially from those in the recent NSCH, and ADDM data for comparable years are not yet available.

Data from the ADDM Network support the inference that there has been an increase in ASD recognition by community providers. While all children defined as ASD cases in ADDM have previously come to the attention of a special education or health care provider in their communities, not all of these children had a previous diagnosis or school classification specific to ASD. Each surveillance year, a percentage of children who had clear documentation of autism traits in their records, but not a specific ASD diagnosis or educational placement, are nonetheless classified as ASD cases by ADDM clinical reviewers. This proportion of “ASD, but no previous diagnosis” cases has declined steadily as total ASD prevalence rates have shown marked increases (6).

In conclusion, the consistency in independent estimates of parent-reported ASD prevalence for children born in 1994–2005 and diagnosed in or before 2007 increases confidence that NSCH data were not subject to differential survey measurement error over time and therefore can be used to monitor changes in the prevalence of parent-reported ASD over time. Increases in the prevalence of parent-reported ASD continued through 2011–2012, and much of the recent increase—especially for children aged 6–13—was the result of diagnoses of children with previously unrecognized ASD. A more detailed report will further explore these findings within sociodemographic subgroups and with further consideration of the relationship between health care system factors and ASD case ascertainment.

References
17. Keeter S, Kennedy C, Dimock M, Best J, Craighill P. Gauging the impact of growing nonresponse on estimates from a national RDD
Table 1. Percentage of children with parent-reported autism spectrum disorder, by age cohort, approximate year of ASD diagnosis, and survey: United States, 2007 and 2011–2012

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Child age in years</td>
<td>Number of children with ASD in sample</td>
<td>Diagnosis in or before 2007</td>
<td>Child age in years</td>
<td>Number of children with ASD in sample</td>
<td>In or before 2007</td>
</tr>
<tr>
<td>1994–2005</td>
<td>2–13</td>
<td>672</td>
<td>1.16</td>
<td>6–17</td>
<td>1,393</td>
<td>1.37</td>
</tr>
<tr>
<td>2002–2005</td>
<td>2–5</td>
<td>162</td>
<td>0.70</td>
<td>6–9</td>
<td>440</td>
<td>0.89</td>
</tr>
<tr>
<td>1998–2001</td>
<td>6–9</td>
<td>259</td>
<td>1.31</td>
<td>10–13</td>
<td>513</td>
<td>1.68</td>
</tr>
<tr>
<td>1994–1997</td>
<td>10–13</td>
<td>251</td>
<td>1.45</td>
<td>14–17</td>
<td>440</td>
<td>1.53</td>
</tr>
</tbody>
</table>

1Date of birth was not asked in the survey, so birth year was approximated from child’s age at interview.

NOTES: ASD is autism spectrum disorder. Age cohort is defined by child’s age at interview. Year of ASD diagnosis is approximated from date of interview, child’s age at time of interview, and child’s age when first diagnosed with ASD. See Technical Notes for more detail. The National Survey of Children’s Health (NSCH) is a cross-sectional survey. Because of the random sampling method, it is unlikely that any child was included in the survey in both 2007 and 2011–2012. Data are based on telephone interviews of parents or guardians of a sample of the noninstitutionalized population of U.S. children. All population estimates are based on sampling weights assigned to the data for each child.

Table 2. Percent distribution of parent-reported severity of child’s autism spectrum disorder, by child’s age and approximate year of ASD diagnosis: United States, 2011–2012

<table>
<thead>
<tr>
<th>Age of child in years, and severity, at time of interview</th>
<th>In or before 2007</th>
<th>In or after 2008</th>
<th>All dates</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>6–17</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>49.5</td>
<td>58.3</td>
<td>52.5</td>
</tr>
<tr>
<td>Moderate</td>
<td>33.6</td>
<td>34.8</td>
<td>33.8</td>
</tr>
<tr>
<td>Severe</td>
<td>16.9</td>
<td>*6.9</td>
<td>13.7</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>6–9</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>47.8</td>
<td>63.0</td>
<td>56.1</td>
</tr>
<tr>
<td>Moderate</td>
<td>42.3</td>
<td>27.1</td>
<td>34.1</td>
</tr>
<tr>
<td>Severe</td>
<td>9.9</td>
<td>*9.9</td>
<td>9.7</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>10–13</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>47.4</td>
<td>48.6</td>
<td>47.8</td>
</tr>
<tr>
<td>Moderate</td>
<td>32.7</td>
<td>46.3</td>
<td>36.7</td>
</tr>
<tr>
<td>Severe</td>
<td>*19.9</td>
<td>*9.1</td>
<td>15.5</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>14–17</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>52.8</td>
<td>69.3</td>
<td>55.1</td>
</tr>
<tr>
<td>Moderate</td>
<td>29.6</td>
<td>29.5</td>
<td>29.6</td>
</tr>
<tr>
<td>Severe</td>
<td>17.6</td>
<td>*1.2</td>
<td>15.3</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

* Estimate has a relative standard error greater than 30% and does not meet NCHS standards for reliability or precision. However, unreliable estimates can still differ significantly and reliably from other estimates if the differences are sufficiently large.

1Year of ASD diagnosis is approximated from date of interview, child’s age at time of interview, and child’s age when first diagnosed with ASD. See Technical Notes for more detail.

NOTES: ASD is autism spectrum disorder. Data are based on telephone interviews of parents or guardians of a sample of the noninstitutionalized population of U.S. children. All population estimates are based on sampling weights assigned to the data for each child.

Technical Notes

Response rates and analysis of nonresponse

Response rates provide one measure of the potential for nonresponse bias, the possibility that the characteristics of the sample interviewed differ from the characteristics of the population of interest in some meaningful way. The 2007 overall response rate was 46.7% and the 2011–2012 overall response rate was 23.0%. The reduction in the response rate was due primarily to the inclusion of cell-phone interviews in 2011–2012, which provided better coverage of the population of children at the expense of lower response rates. The lower overall response rates for cell-phone interviews were largely the result of differences in the proportion of telephone numbers that were not answered and therefore provided no indication of whether the number belonged to a household. This nonresolution rate was 19.1% for the landline sample and 51.4% for the cell-phone sample.

The resolution rate (i.e., the complement of the nonresolution rate) is one component of the overall response rate, which is calculated as the product of the resolution rate, the screening completion rate (i.e., the proportion of known households where the presence or absence of children was successfully determined), and the interview completion rate [i.e., the proportion of known households with children that completed the National Survey of Children’s Health (NSCH) interview]. Relative to the nonresolution rates, the landline (54.1%) and cell-phone (41.2%) interview completion rates were more similar. For the landline sample, the interview completion rate was comparable to the 66.0% interview completion rate from 2007.

In general, differences between respondents and nonrespondents are only weakly associated with response rates for telephone surveys, and meaningful nonresponse bias will exist only when the likelihood of survey response is related to the survey variables of interest (17). Therefore, regardless of the response rate, it is recommended that survey researchers evaluate the possible impact of such differences on the quality of survey estimates (18).

Nonresponse bias analyses were conducted with the 2011–2012 NSCH data (8) using several recommended approaches (18). Analyses using contextual information in the sampling frame (such as sociodemographic characteristics of the geographic areas associated with landline telephone numbers) suggested that response biases in these characteristics would have little effect on prevalence estimates of parent-reported autism spectrum disorder (ASD). However, another approach—comparing ASD prevalence estimates for responders who readily participated with estimates for those who required more effort to encourage participation—revealed the possibility of a small effect. Children whose parents participated after five or more calls (1.58%) were less likely to have parent-reported ASD than those whose parents participated with fewer calls (2.10%). If one assumes that high-effort respondents are similar to nonrespondents, this finding would suggest that nonresponse may have increased the 2011–2012 ASD prevalence estimate by up to 0.16 percentage points. This assumption cannot be validated with the current data, but if true, this potential bias is still only one-fifth of the magnitude of the observed increase in parent-reported ASD over time (0.84 percentage points) and is smaller than potential sampling error (the half-width of the 95% confidence interval was 0.20 percentage points).

Similar nonresponse bias analyses are not available for prevalence estimates from the 2007 NSCH, but it is not unreasonable to expect that, as in 2011–2012, parents of children with ASD might have been somewhat more likely to readily respond to the survey. Analyses for other health and health care variables from the 2007 survey indicate that estimated biases in these survey estimates were small (within the range of potential sampling error) and inconsistent in direction depending on the approach used to estimate bias (19). Together, these results from the 2007 and 2011–2012 surveys suggest that any differences between survey respondents and survey nonrespondents should not have had a major impact on the conclusions in this report; however, the potential for such impact cannot be completely ruled out.

Impact of change in sample design

The 2011–2012 NSCH sample included both landlines and cell phones, whereas the 2007 NSCH included landlines only. This change in sample design was necessitated by the increased proportion of children living in cell-phone-only households in 2011–2012 (20); however, this change prompts the question of whether the observed increase in prevalence of parent-reported ASD may have been related to the inclusion of cell-phone sample or to the necessary changes to weighting procedures to account for dual-frame sampling. If ASD prevalence was higher among children in cell-phone-only households than among children in households with landlines, then their omission from the 2007 sample and inclusion in the 2011–2012 sample would have inflated the observed ASD prevalence difference. However, the ASD prevalence for children aged 6–17 in cell-phone-only households (1.91%) in 2011–2012 was nonsignificantly lower than for children in landline households (2.10%). Furthermore, unweighted analysis of the 2007 and 2011–2012 data for children aged 6–17 showed a 78% increase in ASD prevalence, similar to the observed increase of 72% based on analyses with the sampling weights. This suggests that changes in the weighting procedures due to dual-frame sampling were unlikely to have contributed to the observed increase.

Definition of terms

Autism spectrum disorder (ASD)—Children with parent-reported ASD were identified based on parents’ or guardians’ responses to two questions.
First, parents were asked if they had ever been told by a doctor or other health care provider that their child had “autism, Asperger’s disorder, pervasive developmental disorder, or other autism spectrum disorder.” If parents responded affirmatively, they were asked: “Does [child] currently have autism or autism spectrum disorder?” Children classified as having ASD were those with a parent report of (a) ever being told by a doctor or other health care provider that their child had ASD and (b) the child currently having ASD. These two questions were included in both the 2007 and 2011–2012 NSCH.

Age at diagnosis—In the 2011–2012 NSCH, parents or guardians who reported ever being told by a doctor or other health care provider that their child had ASD were asked: “How old was [child] when you were first told by a doctor or other health care provider that [he/she] had autism or autism spectrum disorder?” This question was preceded by a reminder about the definition of ASD: “Earlier you told me that [child] has been diagnosed with autism or an autism spectrum disorder, such as Asperger’s disorder or pervasive developmental disorder.” The question about age at diagnosis was asked after the parent reported that the child had ever been diagnosed and before the parent was asked if the child currently had ASD. This question did not appear on the 2007 NSCH.

Approximate year of diagnosis—For the 2011–2012 NSCH, the year when the child was first identified as having ASD was approximated using data on the child’s age at diagnosis, the child’s age at the time of the interview, and the date of the interview. The difference between the age at interview (in years) and the age at diagnosis (in years) was calculated. If the survey was completed in 2011 and the difference was 3 years or less, or if the survey was completed in 2012 and the difference was 4 years or less, then the year when the child was first diagnosed was calculated as in or after 2008. Otherwise, the year the child was first diagnosed was calculated as in or before 2007.

The 2007 NSCH did not include a question about age at diagnosis. All children reported to have ASD in the 2007 NSCH were assumed to have a year of diagnosis that was in or before 2007; that is, the year of diagnosis was assumed to be in or before the year of the survey.

Severity of ASD—Parents or guardians who reported that the child currently has ASD were asked to provide a qualitative ranking of severity: “Would you describe [his/her] autism or autism spectrum disorder as mild, moderate, or severe?”
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