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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
NSCH—National Survey of Children's Health
NHIS—National Health Interview Survey
OR—odds ratio
CI—confidence interval

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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 110 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;124:000

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.[1] Previous studies have documented a high level of functional limitations and poor health status in children with autism,[2] an accompanying high level of health care use[2,3] and unmet health needs,[3] and increased parenting stress and family burden.[3,4] The lifetime health care costs for a person with autism have been estimated to be more than $1.6 million,[5] and the estimated total expense burden to the health care system associated with ASD rose 142% from 2000 to 2004.[6]

Numerous studies have suggested that the prevalence of diagnosed ASD, in the United States and elsewhere, has increased dramatically in the past decades.[7–21] 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.[7–9] 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.[10–13] 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.[3,16,21]

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.[16,19] 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.[16,19] 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.[22]

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 ASD 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-

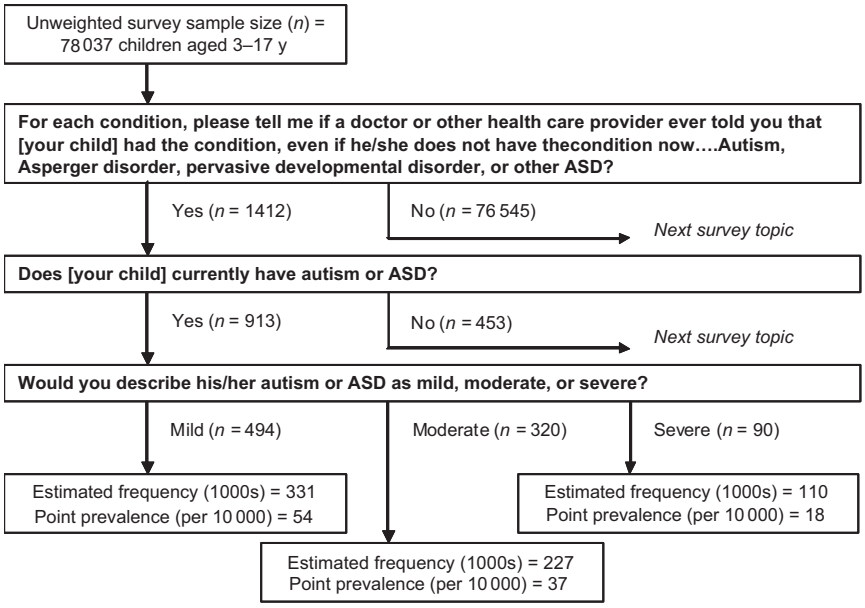

FIGURE 1
Flow diagram of survey-participant progress through the ASD questions, NSCH, 2007. Responses indicating that the parent did not know the answer or refused to provide the answer are not shown. Estimated frequencies and point-prevalence estimates are based on weighted data.

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[23]: (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. Estimates were weighted by using survey sampling weights available from the National Center for Health Statistics. These weights reflect the inverse of the probability of being selected for the survey and were adjusted to account for nonresponse and noncoverage of households without landline telephones. Weighted estimates are representative of the US noninstitutionalized population of children aged 3 to 17 years. Estimates were produced by using SUDAAN software (Research Triangle Institute, Research Triangle Park, NC) to account for the complex sample design and obtain appropriate variance estimates. The statistical significance of differences between estimates was assessed by using logistic regression; odds ratios (ORs) and 95% confidence intervals (CIs) are reported.

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."

TABLE 1 Point Prevalence of Parent-Reported ASD Among Children Aged 3 to 17 Years According to Selected Demographic Characteristics: United States, 2007

Demographic Characteristic	No. in Sample (Unweighted)	No. With Autism/ASD (Unweighted)	Estimated Frequency in Population, Thousands	Weighted ASD Prevalence per 10 000	95% CI	Adjusted OR[a]	95% CI
Total	77 911	913	673	110	94–128		
Age, y							
3–5	13 944	154	104	85	60–120	1.07	0.66–1.73
6–8	13 567	197	159	132	96–183	1.54	1.00–2.38
9–11	14 179	176	164	138	96–198	1.83	1.13–2.96
12–14	16 497	200	151	118	83–166	1.54	0.96–2.48
15–17	19 724	186	95	77	57–104	1.00	Referent
Gender							
Male	40 405	746	544	173	144–207	3.98	2.82–5.62
Female	37 404	167	129	43	33–57	1.00	Referent
Ethnicity/race							
Hispanic	9380	93	124	103	64–167	0.96	0.56–1.64
Non-Hispanic white	52 593	660	428	125	105–148	1.00	Referent
Non-Hispanic black	7711	56	54	61	37–101	0.43	0.24–0.78
Non-Hispanic multiracial	3549	49	17	71	44–112	0.58	0.35–0.96
Non-Hispanic other single race	3335	35	19	66	37–116	0.58	0.31–1.06
Highest level of education achieved by parent in household							
High school graduate or less	17 839	187	186	92	68–125	0.77	0.56–1.08
More than high school	59 160	715	479	118	98–142	1.00	Referent
Family income							
≤100% of poverty level	8803	123	114	106	67–166	1.15	0.66–2.02
>100% to ≤200%	13 155	154	124	97	70–132	1.04	0.66–1.63
>200% to ≤400%	26 559	344	249	128	97–170	1.26	0.83–1.91
>400% of poverty level	29 394	292	186	101	76–133	1.00	Referent
Family structure							
2 biological or adoptive parents	52 771	582	429	108	88–132	1.00	Referent
2 parents, ≥1 step-parent	6430	66	34	62	41–94	0.59	0.36–0.98
Single mother	12 898	190	171	145	104–200	1.53	1.01–2.34
Other family structure	5341	70	36	92	63–132	1.04	0.65–1.65
Region							
Northeast	13 779	218	138	132	99–175	1.59	0.99–2.53
Midwest	18 549	231	166	123	99–151	1.49	1.00–2.23
South	26 089	248	249	110	80–151	1.36	0.85–2.20
West	19 494	216	120	81	56–116	1.00	Referent

[a] The adjusted OR reflects the relative odds that the child had 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.

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,

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

Demographic Characteristic	No. in Sample (Unweighted)	Weighted % Without Current ASD Among All Children Aged 3–17 y Ever Diagnosed With ASD	Adjusted OR[a]	95% CI
Total	453	38.2		
Age, y				
3–5	53	48.1	1.72	0.77–3.87
6–8	86	29.8	0.92	0.41–2.07
9–11	103	40.3	1.33	0.58–3.04
12–14	86	35.2	1.18	0.52–2.69
15–17	125	38.3	1.00	Referent
Gender				
Male	321	36.5	0.89	0.50–1.56
Female	132	44.3	1.00	Referent
Ethnicity/race				
Hispanic	42	20.5	0.35	0.14–0.87
Non-Hispanic white	296	33.7	1.00	Referent
Non-Hispanic black	71	67.8	3.97	1.67–9.47
Non-Hispanic multiracial	20	35.6	1.15	0.46–2.87
Non-Hispanic other single race	18	63.0	2.51	0.99–6.40
Highest level of education achieved by parent in household				
High school graduate or less	119	50.7	1.98	1.07–3.66
More than high school	331	31.8	1.00	Referent
Family income				
≤100% of poverty level	68	44.5	0.73	0.31–1.72
>100% to ≤200%	90	47.7	0.79	0.36–1.72
>200% to ≤400%	139	26.1	0.51	0.28–0.93
>400% of poverty level	156	39.9	1.00	Referent
Family structure				
2 biological or adoptive parents	251	35.7	1.00	Referent
2 parents, ≥1 step-parent	47	46.5	1.51	0.68–3.35
Single mother	109	40.3	0.94	0.48–1.85
Other family structure	43	45.9	1.57	0.71–3.46
Region				
Northeast	99	43.2	0.68	0.29–1.59
Midwest	100	32.8	0.54	0.25–1.15
South	142	34.9	0.54	0.25–1.18
West	112	44.4	1.00	Referent

[a] 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.

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. However, children with current ASD were significantly more likely to have had a usual place for care and a current individualized education plan.

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-

TABLE 3 Point Prevalence of Selected Conditions Among Children Aged 6 to 17 Years According to Parent-Reported ASD Status

ASD Status	Condition					Any of These Conditions
	Developmental Delay Affecting Ability to Learn	ADD/ ADHD[a]	Anxiety Problems	Behavioral or Conduct Problems	Depression	
Currently has autism/ASD						
No. in sample	438	299	279	214	111	631
Weighted prevalence per 100	64.8	47.2	36.9	36.9	14.1	87.3
95% CI	56.6–72.2	38.3–56.3	28.9–45.7	28.3–46.6	8.7–22.2	81.8–91.3
Ever diagnosed with autism/ASD but does not currently have the condition						
No. in sample	183	165	121	118	66	308
Weighted prevalence per 100	47.7	48.6	25.3	49.0	24.7	81.6
95% CI	35.3–60.5	36.0–61.5	16.1–37.4	36.4–61.7	13.7–40.5	74.1–87.3
Never diagnosed with autism/ASD						
No. in sample	1324	4832	2098	1816	1468	7533
Weighted prevalence per 100	2.4	7.4	2.9	3.3	2.2	12.0
95% CI	2.1–2.7	6.9–7.9	2.6–3.3	3.0–3.6	2.0–2.4	11.3–12.6

ADD indicates attention-deficit disorder; ADHD, attention-deficit/hyperactivity disorder.

[a] 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.

Data source: Maternal and Child Health Bureau and National Center for Health Statistics, NSCH, 2007.

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

Characteristic	Currently Has Autism/ASD		Ever Diagnosed With Autism/ASD but Does Not Currently Have the Condition			Never Diagnosed With Autism/ASD		
	No. in Sample[a]	Weighted % (95% CI)	No. in Sample[a]	Weighted % (95% CI)	OR for Current ASD vs This Comparison Group (95% CI)[b]	No. in Sample[a]	Weighted % (95% CI)	OR for Current ASD vs This Comparison Group (95% CI)[b]
Had a personal doctor or nurse	868	96.2 (93.9–97.7)	427	91.8 (80.7–96.8)	2.28 (0.75–6.88)	70 979	91.8 (91.3–92.4)	2.27 (1.36–3.76)
Had a usual place for care	860	96.1 (94.1–97.4)	424	88.7 (76.7–94.9)	3.16 (1.20–8.33)	72 495	93.2 (92.6–93.7)	1.82 (1.17–2.82)
Received family-centered care[c]	513	47.9 (40.3–55.8)	268	42.1 (31.3–53.7)	1.27 (0.72–2.23)	51 255	66.1 (65.1–67.0)	0.47 (0.35–0.65)
Had no problems obtaining referrals (if needed)[d]	262	77.5 (69.1–84.2)	138	66.5 (46.5–81.9)	1.74 (0.68–4.41)	10 083	81.6 (79.8–83.4)	0.78 (0.49–1.22)
Received effective care coordination (if needed)[e]	305	38.6 (30.7–47.2)	164	34.3 (24.4–45.7)	1.20 (0.66–2.19)	23 406	69.9 (68.6–71.2)	0.27 (0.19–0.39)
Received care within a medical home	290	31.8 (25.1–39.5)	156	23.4 (16.6–31.9)	1.53 (0.89–2.63)	44 608	56.4 (55.5–57.3)	0.36 (0.26–0.50)
Had health insurance at time of survey	871	95.8 (93.3–97.4)	419	93.0 (84.5–97.0)	1.73 (0.62–4.79)	70 505	90.6 (90.0–91.2)	2.37 (1.43–3.91)
Received treatment from mental health professional	492	48.4 (40.7–56.3)	211	48.2 (36.5–60.2)	1.01 (0.57–1.80)	6415	7.8 (7.4–8.2)	11.13 (8.07–15.35)
Currently had an Individualized Education Program	781	88.4 (82.3–92.6)	309	63.0 (50.9–73.8)	4.48 (2.21–9.08)	6693	8.7 (8.2–9.2)	80.00 (48.35–132.37)

[a] Sample size is the unweighted number of children with affirmative responses for the selected characteristic.

[b] 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).

[c] 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.

[d] Percent distributions do not include children who did not need referrals to see any doctors or receive any services.

[e] 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.

Data source: Maternal and Child Health Bureau and National Center for Health Statistics, NSCH, 2007.

ing on the study) is still valid at later ages, greater difficulties with and a lack of precision in diagnosing ASD at very young ages could result in a minority of children who no longer meet ASD criteria as they age.[24–27] If a diagnostic change occurred as children aged, we might expect the percentage of children previously diagnosed but not currently with ASD among those ever diagnosed to be greater in the older age groups. However, the pro-

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 education[29]) 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.[20,30,31] 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.[32–38] 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.[3,11,13,16,18,19] 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.[39] 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 diagnosis[29] 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[41] but that children with autism are less likely to have a medical home compared with other children with special health care needs.[42] 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.[3] 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.[16,19] A separate study reported moderate-to-high sensitivities for parent-reported behavioral disorders.[43]

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.[16]

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.[18,19] 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.[44,45] These recommendations reflect the recognition that earlier identification and intensive intervention can improve functioning.[46–48] 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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REFERENCES

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR).* Washington, DC: American Psychiatric Publishing; 2000
2. Boulet SL, Boyle CA, Schieve LA. Health care use and health and functional impact of developmental disabilities among US children. *Arch Pediatr Adolesc Med.* 2009;163(1):19–26
3. Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics.* 2008;122(6). Available at: www.pediatrics.org/cgi/content/full/122/6/e1149
4. Schieve LA, Blumberg SJ, Rice C, Visser SN, Boyle C. The relationship between autism and parenting stress. *Pediatrics.* 2007; 119(suppl 1):S114–S121
5. Landrigan PJ, Schechter CB, Lipton JM, Fahs MC, Schwartz J. Environmental pollutants and disease in American children: estimates of morbidity, mortality, and costs for lead poisoning, asthma, cancer, and developmental disabilities. *Environ Health Perspect.* 2002;110(7):721–728
6. Leslie DL, Martin A. Health care expenditures associated with autism spectrum disorders. *Arch Pediatr Adolesc Med.* 2007; 161(4):350–355
7. Lotter V. Epidemiology of autistic conditions in young children. *Soc Psychiatry.* 1966; 1(3):124–137
8. Burd L, Fisher W, Kerbeshian J. A prevalence study of pervasive developmental disorders in North Dakota. *J Am Acad Child Adolesc Psychiatry.* 1987;26(5): 700–703
9. Ritvo ER, Freeman BJ, Pingree C, et al. The UCLA-University of Utah epidemiologic survey of autism: prevalence. *Am J Psychiatry.* 1989;146(2):194–199
10. Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children. *JAMA.* 2001;285(24):3093–3099
11. Bertrand J, Mars A, Boyle C, Bove F, Yeargin-Allsopp M, Decoufle P. Prevalence of autism in a United States population: the Brick Township, New Jersey, investigation. *Pediatrics.* 2001;108(5):1155–1161
12. Gurney JG, Fritz MS, Ness KK, Sievers P, Newschafffer CJ, Shapiro EG. Analysis of prevalence trends of autism spectrum disorder in Minnesota. *Arch Pediatr Adolesc Med.* 2003;157(7):622–627

13. Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. *JAMA*. 2003;289(1):49–55
14. Newschaffer CJ, Falb MD, Gurney JG. National autism prevalence trends from United States special education data. *Pediatrics*. 2005; 115(3). Available at: www.pediatrics.org/cgi/content/full/115/3/e277
15. Barbaresi WJ, Katusic SK, Colligan RC, Weaver AL, Jacobsen SJ. The incidence of autism in Olmstead County, Minnesota, 1976–1997: results from a population-based study. *Arch Pediatr Adolesc Med*. 2005;159(1):37–44
16. Centers for Disease Control and 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(17): 481–486
17. Fombonne E, Zakarian R, Bennett A, Meng L, McLean-Heywood D. Pervasive developmental disorders in Montreal, Quebec, Canada: prevalence and links with immunizations. *Pediatrics*. 2006;118(1). Available at: www.pediatrics.org/cgi/content/full/118/1/e139
18. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2000 Principal Investigators; Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000. *MMWR Surveill Summ*. 2007;56(1):1–11
19. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators; Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002. *MMWR Surveill Summ*. 2007;56(1):12–28
20. Parner ET, Schnedel DE, Thorsen P. Autism prevalence trends over time in Denmark. *Arch Pediatr Adolesc Med*. 2008;162(12): 1150–1156
21. Schechter R, Grether JK. Continuing increases in autism reported to California's developmental service system: mercury in retrograde. *Arch Gen Psychiatry*. 2008;65(1):19–24
22. Blumberg SJ, Foster EB, Frasier AM, et al. Design and operation of the National Survey of Children's Health, 2007. *Vital Health Stat 1*. 2009; In press
23. American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. The medical home. *Pediatrics*. 2004;113(5 suppl):1545–1547
24. Lord C, Risi S, DiLavore PS, Shulman C, Thurm A, Pickles A. Autism from 2 to 9 years of age. *Arch Gen Psychiatry*. 2006;63(6):694–701
25. Turner LM, Stone WL. Variability in outcome for children with an ASD diagnosis at age 2. *J Child Psychol Psychiatry*. 2007;48(8): 793–802
26. Kleinman JM, Ventola PE, Pandey J, et al. Diagnostic stability in very young children with autism spectrum disorders. *J Autism Dev Disord*. 2008;38(4):606–615
27. McGovern CW, Sigman M. Continuity and change from early childhood to adolescence in autism. *J Child Psychol Psychiatry*. 2005;46(4):401–408
28. Shattuck PT. The contribution of diagnostic substitution to the growing administrative prevalence of autism in US special education. *Pediatrics*. 2006;117(4):1028–1037
29. Mandell DS, Wiggins LD, Carpenter LA, et al. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *Am J Public Health*. 2009;99(3):493–498
30. Hertz-Picciotto I, Delwiche L. The rise in autism and the role of age at diagnosis. *Epidemiology*. 2009;20(1):84–90
31. Shattuck PT, Durkin M, Maenner M, et al. Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *J Am Acad Child Adolesc Psychiatry*. 2009;48(5):474–483
32. Newschaffer CJ, Croen LA, Daniels J, et al. The epidemiology of autism spectrum disorders. *Ann Rev Public Health*. 2007;28:235–258
33. Fombonne E. Past and future perspectives on autism epidemiology. In: Moldin SO, Rubenstein JLR, eds. *Understanding Autism: From Basic Neuroscience to Treatment*. Boca Raton, FL: Taylor and Francis Group; 2006:25–47
34. Fombonne E. Epidemiology of autistic disorder and other pervasive developmental disorders. *J Clin Psychiatry*. 2005;66(suppl 10):3–8
35. Blaxill MF. What's going on? The question of time trends in autism. *Public Health Rep*. 2004;119(6):536–551
36. Williams JG, Higgins JPT, Brayne CEG. Systematic review of prevalence studies of autism spectrum disorders. *Arch Dis Child*. 2006;91(1):8–15
37. Wing L, Potter D. The epidemiology of autistic spectrum disorders: is the prevalence rising? *Ment Retard Dev Disabil Res Rev*. 2002;8(3):151–161
38. Charman T. The prevalence of autism spectrum disorders: recent evidence and future challenges. *Eur Child Adolesc Psychiatry*. 2002;11(6):249–256
39. Croen LA, Grether JK, Selvin S. Descriptive epidemiology of autism in a California population: who is at risk? *J Autism Dev Disord*. 2002;32(3):217–224
40. Thomas KC, Ellis AR, McLaurin C, Daniels J, Morrissey JP. Access to care for autism related services. *J Autism Dev Disord*. 2007; 37(10):1902–1912
41. Homer CJ, Klatka K, Romm D, et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics*. 2008;122(4). Available at: www.pediatrics.org/cgi/content/full/122/4/e922
42. Brachlow AE, Ness KK, McPheeters ML, Gurney JG. Comparison of indicators for a primary care medical home between children with autism or asthma and other special health care needs. *Arch Pediatr Adolesc Med*. 2007;161(4):399–405
43. Ackland MJ, Wade RW. Health status of Victorian special school children. *J Paediatr Child Health*. 1995;31(6):571–575
44. Johnson CP, Myers SM; American Academy of Pediatrics, Council on Children With Disabilities. Identification and evaluation of children with autism spectrum disorder. *Pediatrics*. 2007;120(5):1183–1215
45. Myers SM, Johnson CP; American Academy of Pediatrics, Council on Children With Disabilities. Management of children with autism spectrum disorders. *Pediatrics*. 2007; 120(5):1162–1182
46. National Research Council, Committee on Educational Interventions for Children With Autism. *Educating Children With Autism*. Lord C, McGee JP, eds. Washington, DC: National Academies Press; 2001
47. Olley JG. Curriculum and classroom structure. In: Volkmar FR, Paul R, Klin A, Cohen D, eds. *Handbook of Autism and Pervasive Developmental Disorders*. NJ: John Wiley & Sons; 2005:863–8813rd ed, Vol II. Hoboken
48. Rickards AL, Walstab JE, Wright-Rossi RA, Simpson J, Reddihough DS. A randomized, controlled trial of a home-based intervention program for children with autism and developmental delay. *J Dev Behav Pediatr*. 2007;28(4):308–316

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Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the US, 2007

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