

Parental Report of Health Conditions and Health Care Use Among Children With and Without Autism

National Survey of Children's Health

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Objective: To compare parent-reported prevalence of health conditions and health care use between children with and without autism.

Design: Cross-sectional analysis of the 2003 to 2004 National Survey of Children's Health.

Setting: Population-based sample across the United States.

Participants: More than 100 000 parents. The main exposure was "autism" (not further defined), from response to the question: "Has a doctor or health professional ever told you that your child has autism?"

Main Outcome Measures: Medical and mental health conditions and measures of health care use.

Results: Autism prevalence among children aged 3 to 17 years was 53 per 10 000 (95% confidence interval, 45-61 per 10 000), equating to a national estimate of 324 000 children (95% confidence interval, 274 000-375 000 children). Children with autism had a signifi-

cantly ($P < .001$) higher prevalence of depression or anxiety problems (38.9% vs 4.2%) and behavioral or conduct problems (58.9% vs 5.2%) than children without autism. Respiratory, food, and skin allergies were reported by parents more often for children with autism, with food allergies having the strongest relative difference between the groups (odds ratio, 4.5; 95% confidence interval, 3.0-7.0). Children with autism had significantly ($P < .001$) higher mean physician visits over 12 months for preventive care, nonemergency care, and hospital emergency care, and were far more likely than children without autism to receive physical, occupational, or speech therapy (76.0% vs 6.3%), to need treatment or counseling for an emotional, developmental, or behavioral problem (75.4% vs 7.0%), and, among those taking a prescribed medication, to be using a medication long-term (51.4% vs 14.5%).

Conclusion: We found markedly higher reports of concurrent conditions and health care use associated with childhood autism in this study.

Arch Pediatr Adolesc Med. 2006;160:825-830

AUTISM SPECTRUM DISORDERS (ASDs) represent a wide range of neurobehavioral conditions that, depending on phenotype, are characterized by limitations in reciprocal social interactions and social functioning, stereotypical repetitive behaviors, and language and speech impairments.^{1(pp65-78)} Autism spectrum disorders, with subtypes classified under the rubric of "pervasive developmental disorders" in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*,^{1(pp65-78)} are generally identifiable by the age of 3 years and are lifelong chronic conditions. In the clinical and psychological literature, children with ASD are often described as having 1 or more of a variety of medical and psychological comorbidities,³ including higher than expected rates of mental retarda-

tion,⁴ epilepsy,^{5,6} gastrointestinal problems,^{7,8} attention-deficit/hyperactivity disorder (ADHD),⁹ depression,¹⁰ anxiety, and sleep disorders.¹¹

The term *comorbidities*, however, implies a condition that is distinct from the disease itself. Many conditions associated with ASD may not be discrete from the phenotypic expression of the disorder, so henceforth we use the term *concurrent conditions* to include the spectrum of physical and mental health disorders evaluated in this study. If, in fact, this propensity for concurrent conditions is true, children with ASD likely require a high degree of health care and mental health services, with associated costs and burdens to their families and to health care systems. To our knowledge, however, no prior study has attempted to broadly characterize concurrent condi-

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Table 1. Descriptive Characteristics of US Children Aged 3 to 17 Years, From the National Survey of Children's Health*

Characteristic	Children With Autism (n = 324 000)	Children Without Autism (n = 61 100 000)	P Value
Age, y			
3-5	15.0	20.5	<.001
6-10	52.8	38.8	
11-17	32.3	40.6	
Sex			
Male	79.0	51.0	<.001
Female	21.0	49.0	
Missing	0	0.07	
Race			
White	73.9	67.3	.25
Black	15.3	15.0	
Multiracial	1.6	3.2	
Other	2.6	4.6	
Missing	6.7	9.9	
Primary language			
English	98.0	87.9	<.001
Other	2.1	12.1	
Missing	0	0	
Respondent			
Mother	83.2	79.3	.18
Father	13.8	16.1	
Other relative	3.0	4.6	
Poverty level of household, %			
<100	27.7	22.3	.24
100-199	9.2	13.5	
200-299	14.2	16.0	
300-399	16.1	14.0	
≥400	24.9	24.1	
Missing	7.9	10.1	
Highest level of educational attainment in household			
<High school	2.2	7.6	.02
High school graduate (12 y)	23.2	26.3	
>High school	72.3	65.6	
Missing	2.3	0.5	
Medical insurance during the past 12 mo			
Fully insured			
Private	57.3	64.7	<.001
Medicaid or S-CHIP	32.8	23.7	
Insured part of the year	9.5	6.3	
No insurance throughout the year	0.4	5.3	

Abbreviation: S-CHIP, State Children's Health Insurance Program.

*Data are given as percentage of each group unless otherwise indicated. Percentages may not total 100 because of rounding. Prevalences are based on sampling fractions and weighted extrapolation from parent report of 483 children with autism and 84 789 children without autism.

tions of children with autism or, in particular, to compare their health care use with that of children without autism.

This study describes and evaluates the extent to which children with an ASD have, according to parental report, a higher prevalence of common childhood conditions and higher health care use than children without an ASD. To accomplish this aim, we analyzed data from the National Survey of Children's Health (NSCH), a population-based survey of more than 100 000 randomly selected parents or guardians in the United States. This study

includes information on 483 children described by the parent to have been diagnosed as having autism by a doctor or other health professional. The data set includes weighting measures to allow extrapolation of prevalence estimates to the general pediatric population of the United States.

METHODS

The NSCH was a population-based, cross-sectional, telephone survey using a complex, multicluster, probability sampling design.¹² The NSCH was sponsored by the Maternal and Child Health Bureau in partnership with the National Center for Health Statistics, which is part of the Centers for Disease Control and Prevention. The purpose of the NSCH was to produce national and state-specific prevalence estimates of health indicators and children's experiences with the health care system.¹² The telephone survey includes questions about sociodemographics, physical and mental health status, health insurance coverage, and access to and use of health care services. The NSCH public use data set contains no information on the personal identity of participants, and this analysis was approved as exempt by the University of Michigan Human Subjects Review Board.

The NSCH used random-digit dialing to recruit and survey households with children younger than 18 years. One child in each household was randomly selected to be the subject of the survey, and the respondent for the interview was the parent or guardian (hereafter termed parent) who was most familiar with the child's health and health care. Interviews were conducted in English or Spanish. Estimates reported herein are based on 85 272 interviews completed from January 2003 through July 2004; the NSCH had with a weighted response of 55.3%.

Autism was ascertained through a question to the parent, "Has a doctor or health professional ever told you that your child has autism?" Inquiries about other medical and mental health conditions used the same question format. No questions were asked to help distinguish subtype or phenotype of ASD, so we use the terminology of the questionnaire and refer to autism henceforth throughout the article. The 483 affirmative answers produced the autism group for this analysis, and all other children in the survey sample composed the comparison group (N = 84 789).

Prevalence proportions of selected variables were calculated and adjusted using the stratified weighted sampling fractions provided in the NSCH public use data set.¹² Multivariable logistic regression techniques were used to estimate the relative odds of selected outcomes after adjusting for the potentially confounding effects of child's age and sex, the primary language spoken in the home (English or other), the highest level of educational attainment in the household, and insurance status (categorized as shown in **Table 1**). Missing data were assessed for their differential distribution in the autism and nonautism groups and for their potential influence on the measures of effect. Of the covariates examined, only race and poverty level had missing responses of more than 3%. Neither race nor household poverty level met the criteria as a confounder in this data set, so these variables were not included in our regression models and no information was lost because of missing data from them. Those with missing data for other variables of interest (Table 1) were excluded from the regression models under the untested assumption that they were missing at random.

As measures of health care use, parents were first asked whether during the past 12 months their child saw a doctor, nurse, or other health professional. If they answered yes, parents were queried about the number of preventive care visits,

Table 2. Parental Description of Health Status and Therapy and Services Use, From the National Survey of Children's Health

Variable	Children With Autism (n = 324 000)*	Children Without Autism (n = 61 100 000)*	OR (95% CI)†
Would you say your child's health is			
Excellent	33.7	60.2	1.0
Very good	22.8	23.5	1.8 (1.2-2.7)
Good	32.7	13.0	5.9 (3.9-9.1)
Fair	7.4	2.9	7.7 (4.3-13.8)
Poor	3.5	0.4	21.1 (9.3-47.9)
Does the child use more medical care, mental health or educational services than is usual for most children of the same age?	89.6	11.8	52.8 (34.7-80.4)
Is the child limited or prevented in the ability to do the things most children the same age can do?	68.5	5.7	36.2 (24.9-52.6)
Does the child get special therapy, such as physical, occupational, or speech therapy?	76.0	6.3	44.4 (31.9-61.8)
Does the child have any emotional, developmental, or behavioral problem for which she needs treatment or counseling?	75.4	7.0	36.9 (25.7-53.1)
Does the child currently need or use medicine prescribed by a doctor, other than vitamins?	54.7	21.1	3.5 (2.6-4.7)
If yes, is this for a condition expected to last 12 mo or longer?	51.4	14.5	11.0 (1.6-76.9)

Abbreviations: CI, confidence interval; OR, odds ratio.

*Data are given as the percentage of each group and are based on sampling fractions and weighted extrapolation from parent report of 483 children with autism and 84 789 children without autism.

†Data are adjusted for sex, primary language, age, insurance, and household educational attainment.

hospital emergency department visits, and nonemergency visits in that 12-month period. Where the answer to the initial question was no, we ascribed 0 visits in each category. We then used a 2-equation modeling technique¹³ to provide an adjusted mean number of visits for each type of physician visit. This model accounts for the strong right skewing of the data because of the high frequency of those with no visits and relatively few high users of health care services. Because variances are not directly produced in the 2-equation modeling method, we calculated 95% confidence intervals for the means after bootstrapping standard errors, drawing 1000 samples from the data.

RESULTS

The weighted prevalence of reported autism among children aged 3 to 17 years was 53 per 10 000 (95% confidence interval, 45-61 per 10 000), equating to a US national estimate of 324 000 children with autism (95% confidence interval, 274 000-375 000 children with autism). Table 1 compares the distribution of sociodemographic characteristics among those with and without autism in the study population. The male-female ratio was 3.8:1 among children with autism, compared with 1:1 in children without autism. The annual household income distribution, relative to the federal poverty level, showed little evidence of differences between the comparison groups. Similarly, any difference in race distribution was not statistically significant, and black children composed about 15% of those with and without autism in the study population. Non-English-speaking parents, however, were underrepresented in the autism group relative to the nonautism group, and the educational level of parents with children with autism was, on average, higher than that of the comparison parents.

Parental perceptions of their child's health status and need for therapies and services are shown in **Table 2**.

Parents with a child with autism were much more likely to report their child's health as fair or poor, rather than excellent, compared with other parents in the study. Strong differences in measures of reported use of or need for mental and physical health therapies were also observed between the study groups. During the preceding 12 months, children with autism were far more likely than children without autism to receive physical, occupational, or speech therapy; to need treatment or counseling for an emotional, developmental, or behavioral problem; and to be using medication. Among children using prescribed medication, many more parents of children with autism reported that the use was for a condition expected to last at least 12 months.

A variety of conditions were more frequently reported by parents of children with autism than parents of children without autism (**Table 3**), including depression or anxiety problems, behavioral or conduct problems, and ADHD or attention-deficit disorder. No differences between the study groups were observed for diabetes mellitus or asthma. Allergies, however, whether respiratory, food, or skin, were reported more often for children with autism, with food allergies having the strongest relative difference between the study groups.

The relative frequencies and adjusted means of physician visits for preventive care, nonemergency care, and hospital emergency care are shown in **Table 4**. On average, parents reported significantly more visits for their children with autism in the previous 12 months for each type of physician visit than did parents of children without autism. The largest differences were observed for visits involving preventive care and nonemergency care; for the latter, the adjusted mean number of visits was 2.80 for children with autism, compared with 1.56 for children without autism ($P < .001$).

Table 3. Parental Report of Clinical Conditions Among Children With and Without Autism, From the National Survey of Children's Health

Variable	Children With Autism (n = 324 000)*	Children Without Autism (n = 61 100 000)*	OR (95% CI)†
Has a doctor or health professional ever told you that he/she has			
Behavioral or conduct problems	58.9	5.2	23.4 (16.9-32.4)
Attention-deficit disorder or attention-deficit/hyperactive disorder, that is, ADD or ADHD	45.1	7.0	8.0 (5.6-11.4)
Stuttering, stammering, or other speech problems	40.1	3.3	16.7 (12.0-23.1)
Depression or anxiety problems	38.9	4.2	15.0 (10.1-22.3)
Bone, joint, or muscle problems	23.0	3.4	7.5 (4.7-12.1)
Three or more ear infections	13.2	4.8	3.1 (2.1-4.7)
Hearing problems or vision problems that cannot be corrected with glasses or contact lenses	10.7	2.8	3.7 (2.4-5.7)
Asthma	17.6	13.5	0.9 (0.6-1.4)
Diabetes	0.4	0.3	1.1 (0.4-3.1)
During the last 12 mo, have you been told by a doctor or other health professional that he/she has			
Hay fever or any kind of respiratory allergy	27.0	16.2	1.6 (1.1-2.4)
Any kind of food or digestive allergy	14.1	3.2	4.5 (3.0-7.0)
Frequent or severe headaches, including migraines	12.0	5.5	2.4 (1.2-5.0)
Eczema or any kind of skin allergy	14.9	9.2	1.4 (1.0-2.1)

Abbreviations: See Table 2.

*Data are given as the percentage of each group and are based on sampling fractions and weighted extrapolation from parent report of 483 children with autism and 84 789 children without autism.

†Data are adjusted for sex, primary language, age, insurance, and household educational attainment.

Table 4. Data for Physician Visits in the Past 12 Months as a Measure of Health Care Use Among Children With and Without Autism, From the National Survey of Children's Health*

Variable	Children With Autism (n = 324 000)†	Children Without Autism (n = 61 100 000)†
No. of visits for preventive care		
0	16.4	25.0
1-2	56.3	60.9
3-5	19.4	12.2
≥6	7.9	1.9
Mean (95% CI)	3.89 (3.57-4.21)	2.51 (2.49-2.53)
No. of hospital emergency department visits		
0	70.3	83.4
1	19.7	11.7
≥2	10.0	4.9
Mean (95% CI)	0.18 (0.12-0.23)	0.10 (0.09-0.10)
No. of nonemergency visits		
0	29.5	42.0
1	16.3	19.8
≥2	54.2	38.2
Mean (95% CI)	2.80 (2.44-3.16)	1.56 (1.54-1.58)

Abbreviation: See Table 2.

*Data are adjusted for sex, primary language, age, insurance, and household educational attainment. $P < .001$ for the difference between the 2 groups for all variables.

†Data are given as the percentage of each group and are based on sampling fractions and weighted extrapolation from parent report of 483 children with autism and 84 789 children without autism.

COMMENT

Results from this large national survey of children's health suggest a consistent pattern of substantially higher health

care needs and use among children with autism, relative to other children. Parents of children with autism reported needing markedly more services for emotional or behavioral problems; for physical, occupational, or speech therapy; and for prescribed medications meant for long-term use. Internally consistent with these results for children with autism were the concordant parental reports of higher average numbers of hospital emergency department, preventive care, and nonemergency physician visits and higher prevalences of behavioral and conduct problems, ADHD, anxiety or depression, allergies, and several other conditions. Indeed, parents reported their children with autism to be in fair or poor health far more frequently on average than did other parents (10.9% vs 3.3%), despite the fact that autism is not considered a medical disorder per se.

This study serves to highlight the breadth of health care challenges that are faced by children with autism and their families. In addition to the conditions asked about in this survey, it is well documented that epilepsy is common in children with autism, perhaps occurring in up to 29%.¹⁴ Although more controversial,^{15,16} a high frequency of chronic gastrointestinal problems also has been reported in several autism studies.⁷ Molloy and Manning-Courtney⁸ estimated the prevalence of gastrointestinal symptoms in a clinic population of children with autism at 24%, with chronic diarrhea being the most common at 12%. In addition, several rare clinical conditions are associated with autism, including Rett disorder, fragile X syndrome, and tuberous sclerosis.^{17,18} Rutter et al¹⁹ suggest that 10% to 12% of individuals with autism have congenital conditions affecting the central nervous system. The prevalence of these conditions in children with autism seems to vary with IQ, with increased frequency among those with lower intellectual capacities.²⁰ Other

researchers^{20,21} also describe the association of concurrent conditions with IQ and, with broader definitions, note that between 24% and 37% of children with autism were associated with another medical condition. They included in their definition of a medical condition metabolic, immune-related, and other diseases beyond those that directly affect the central nervous system.³

Comparing the range of concurrent conditions across studies is difficult because studies differ in their inclusion criteria for autism subtypes and differ in methods for identifying and defining what constitutes a comorbid condition. The latter issue is important when considering the high prevalence of parent-reported concurrent ADHD with autism in our study. The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*,^{1(p78)} states in reference to ADHD, "The disturbance does not occur exclusively during the course of a Pervasive Developmental Disorder," suggesting that ADHD should not be diagnosed concurrently with autism. However, as discussed in detail by Ghaziuddin,²² this *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, instruction is based on untenable clinical assumptions about autism, and ADHD certainly is diagnosed in children with autism in current practice, particularly for Asperger disorder.²³⁻²⁷ Nevertheless, the frequency of parent-reported dual diagnoses of ADHD and autism in our study is high and should be interpreted cautiously. Also, given the rigorous testing required for a clinical diagnosis of food allergies and the scant evidence in the medical literature to support our finding that food allergies are more common among children with ASD, caution should be exercised when interpreting this finding as well.

Although the omission of survey questions related to medical and mental health conditions more specific to autism, such as epilepsy and mental retardation, is an important limitation of this analysis, these data illustrate the need for a comprehensive evaluation of the full spectrum of concurrent conditions among children with autism. The Council on Children With Disabilities of the American Academy of Pediatrics^{28(p1223)} stated that "although children with ASD have the same health care needs as children without disabilities, they are at greater risk of concurring psychiatric problems." Our data are consistent with the observation of higher rates of several psychiatric challenges, including depression, anxiety, and ADHD, but, in contrast to the American Academy of Pediatrics council statement, we also found a substantially higher proportion of a range of medical ailments than would be expected based on the comparison group. Presumably, the effects from epilepsy, gastrointestinal problems, mental retardation, and other medical and psychological conditions not asked about in this survey are reflected in our results through reported medication use, physician visits, need for therapies, and other measures of health care use. A formal investigation of economic and resource use related to autism would provide important information for future planning within health care systems.

The complex presentation of many children with autism, as suggested by the findings in our study, poses a potential dilemma in the pediatric primary care setting,

particularly when considering the characteristic sensory sensitivities that may be present in the child.^{29,30} Children with autism, along with their need for sameness and predictability, may be unusually reactive to the lighting, sounds, or odors of the clinic. They also may be very uncomfortable with being touched by instruments or by persons, including nurses and physicians, whom they do not know well. Given the relative infrequency of seeing autistic patients in most primary care practices, it may be unrealistic to design a clinical setting to specifically accommodate the special needs of these children. It might be possible, however, for large practices or health care systems to implement a coordinated care or case management plan (ie, a medical home model^{31,32}) for children with autism that would provide a knowledgeable central contact person who is familiar with the child's specific medical and psychological needs. Also, having office management procedures in place to alert staff, nurses, and physicians in anticipation of a visit and to minimize the social and sensory difficulties of the child with autism might improve the efficiency and effectiveness of the visit and of the patient/parent satisfaction level. Clinical research to evaluate these ideas could be informative.

The nature of the cross-sectional data in the survey (ie, unvalidated parental report with lack of specificity on type of ASD or method of diagnosis) is another limitation that needs to be considered when interpreting our findings. Although the possibility of false positives and false negatives for ASD is likely, the study's prevalence estimate of autism at 53 per 10 000 children aged 3 through 17 years is reasonably consistent with the range reported in recent studies.^{33,34} In addition, the weighted mean number of visits reported by parents for nonurgent care (preventive and nonemergency combined) of 3.46 among the children aged 3 through 17 years without autism in our study (data not shown) is also reasonably close to the 2.88 reported for children younger than 18 years in the National Ambulatory Medical Care Study.³⁵

In conclusion, the findings we report herein document an important pattern of high parent-reported rates of concurrent conditions and high health care use associated with childhood autism on a national scale that warrants systematic assessment in more specific detail, from the standpoint of health systems and effect on the family. The responsibilities that parents bear as they manage the diverse needs of their child with autism are likely to be enormous from economic, psychosocial, and caregiving perspectives. Likewise, an economic evaluation of health services related to ASD across health care systems would be valuable to understand and plan for present and future resource needs, perhaps including special training of primary care providers in the diverse management requirements of these pediatric patients. Given the striking trends of increasing prevalence of childhood ASD^{34,36} during the past decade, a more comprehensive understanding is needed on the impact of ASD on public and private health care systems.

Accepted for Publication: January 24, 2006.

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Author Contributions: *Study concept and design:* Gurney, McPheeters, and Davis. *Acquisition of data:* McPheeters. *Analysis and interpretation of data:* McPheeters. *Drafting of the manuscript:* Gurney and McPheeters. *Critical revision of the manuscript for important intellectual content:* Gurney, McPheeters, and Davis. *Statistical analysis:* Gurney and McPheeters. *Administrative, technical, and material support:* Gurney and Davis. *Study supervision:* Gurney. **Financial Disclosure:** None reported.

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