

# Comparison of Indicators for a Primary Care Medical Home Between Children With Autism or Asthma and Other Special Health Care Needs

## *National Survey of Children's Health*

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**Objective:** To assess the extent to which parents of children with autism compared with parents of children with asthma or other special health care needs report receiving primary care for their child consistent with the American Academy of Pediatrics medical home model.

**Design:** Population-based cross-sectional study.

**Setting:** National Survey for Children's Health 2003-2004 telephone interview.

**Participants:** Parents of 495 children with autism, parents of 6716 children with asthma, and parents of 11 403 children with other special health care needs without asthma.

**Main Exposures:** Autism and other special health care needs including asthma.

**Main Outcome Measures:** Medical home score and components of care, as follows: personal provider and preventive; family-centered, compassionate, and cultur-

ally appropriate; accessible; comprehensive; and coordinated.

**Results:** The odds of parents reporting care consistent with that in a medical home were less likely for children with autism (odds ratio, 0.45; 95% confidence interval, 0.30-0.66) and more likely for children with asthma (odds ratio, 1.17; 95% confidence interval, 1.06-1.30) compared with children with other special health care needs (1 [reference]). These differences persisted even after controlling for condition severity, personal characteristics, and insurance status. Specific components of a medical home less prevalent among children with autism than among children with other special health care needs included family-centered, comprehensive, and coordinated care.

**Conclusion:** Although we could not evaluate the reasons why, a large percentage of children with autism do not receive primary care consistent with that in a medical home.

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**A**UTISM SPECTRUM DISORDERS (hereinafter called autism) are a heterogeneous class of neurodevelopmental disorders that include core qualitative impairments in reciprocal social interaction, communication, and language, as well as restricted, repetitive, and stereotypic behaviors, interests, and activities.<sup>1</sup> Because of the increase in autism diagnosis in the United States and elsewhere<sup>2-5</sup> and the often complex and varied medical and mental health difficulties that children with autism experience, interest is emerging for the medical home model for primary care of children with autism.<sup>6</sup>

In an average practice setting, general pediatricians provide medical care for at least 1 child with autism.<sup>6</sup> These children have multiple needs that bring them to the physician's office more frequently than other children,<sup>7</sup> including comorbid medi-

cal conditions,<sup>7-14</sup> mental health problems, and developmental delays.<sup>7,11,15,16</sup> Primary care providers are called on to guide parents through a growing and shifting array of specialty services, providers, and treatments.<sup>6</sup> Medical subspecialty care, psychopharmacologic and behavioral interventions, educational and rehabilitation therapies, and complementary and alternative medicines are frequently used in the treatment of children with autism.<sup>6,17-19</sup> The high demand for specialized medical and other services for these children requires extra time and energy, particularly if the primary care provider is unfamiliar with the treatments or believes they are not empirically supported.<sup>17</sup>

Primary medical care models are often not adequately structured to provide comprehensive care for children with complex health care needs, such as those with autism, potentially resulting in fragmented provision of care.<sup>20</sup> In response, the Ameri-

can Academy of Pediatrics (AAP) has advocated for the medical home model of primary pediatric care. The AAP defines medical home care as accessible, continuous, comprehensive, family-centered, compassionate, culturally effective, and coordinated with specialized services.<sup>21</sup> Patient needs are comprehensively addressed by incorporating and coordinating specialty services and referrals. The primary care provider discusses these services within a culturally appropriate context and ensures that the family clearly understands the child's care needs. There is some support for the benefits of this model. Parents of children with special health care needs who received care consistent with the medical home reported that their children had greater health care satisfaction and better health compared with parents of similar children without such care.<sup>22,23</sup>

Obtaining primary care that meets the criteria for medical home care may be particularly challenging for children with autism. Title V directors, who manage Maternal and Child Health Bureau services for children with special health care needs, reported that children with autism experienced greater problems in accessing comprehensive, continuous, coordinated care than did children with other special health care needs (COSHCHN).<sup>24</sup> Of parents of children with autism, 30% reported that they were offered no help with education, therapy, or parental support groups, and only 10% reported that their child's problems were clearly explained by a health care professional.<sup>25</sup> In another study, parents of children with autism were twice as likely to report difficulty in accessing subspecialty care compared with parents of COSHCN.<sup>26</sup> While these studies focused on individual components of the medical home, to our knowledge no study has evaluated all the components of the AAP medical home recommendations.

This population-based analysis enumerates the percentage of children with autism who have a medical home, per parental report. Because of the complex impairments and unique factors surrounding autism, our overarching research question is whether the care of children with autism is more or less characteristic of the medical home compared with the medical care of COSHCN.

## METHODS

### STUDY DESIGN AND PARTICIPANTS

Data for these analyses are from the National Survey for Children's Health (NSCH).<sup>27</sup> Participants in the NSCH were 102 353 parents or legal guardians (hereinafter referred to as parents) who were most knowledgeable about their child's health. From each participating household, 1 child aged 0 to 17 years was randomly selected for the survey evaluation. From this sample, 495 children with autism were identified based on the question, "Has a health professional ever told you that your child has autism?" No questions about phenotype or diagnostic classification across the spectrum of autistic disorders were included in the survey. The comparison group included 18 119 additional children with special health care needs who were identified using the Children With Special Health Care Needs Screener.<sup>28</sup> This screening tool identifies children who have "a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type

or amount beyond that required by children generally"<sup>29(p138)</sup> and in whom the condition is expected to last more than 12 months. In the COSHCN group other than those with autism (n=18 119), 37% had asthma; 16% had attention deficit disorder or attention-deficit/hyperactivity disorder; 13% had behavioral or conduct problems; 11% had depression or anxiety; 9% had a developmental delay or physical impairment; 7% had bone, joint, or muscle problems; 4% had hearing disorders or vision disorders that could not be corrected with glasses; 2% had other conditions; and 1% had diabetes mellitus. Because of the large percentage of children with asthma, we stratified our analysis into 3 groups: children with autism, children with asthma, and COSHCN. Of the original group of 18 119 COSHCN, 6716 had asthma.

## SURVEY DEVELOPMENT AND DATA COLLECTION

The NSCH was a cross-sectional, population-based study, conducted from January 29, 2003, to July 1, 2004, that was designed to evaluate children's health in the United States. The NSCH Medical Home Section questions were devised by professional consensus at an NSCH Data Use Advisory Committee meeting and based on the AAP medical home definition.<sup>21</sup>

Participants in the NSCH were recruited using a multicluster sampling scheme via random digit dialing. Eligible participants were selected from homes with children aged 0 to 17 years from all 50 states and the District of Columbia in the National Immunization Survey Cohort. Completed interviews totaled 102 353, with a weighted overall response rate of 55.3%. These weighted data yield prevalence estimates for noninstitutionalized children aged 0 to 17 years nationwide. Detailed information can be found at <http://www.cdc.gov/nsch/slaits.htm>.

## MEASURES

The overall Medical Home Section score<sup>30</sup> was a composite of 5 components, each containing 1 to 4 questions, as follows (**Figure**).

### Personal Provider and Preventive Care

- A personal provider is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician assistant. Do you have 1 or more persons you think of as your child's personal provider?
- Preventive care visits include things like a well-child checkup, a routine physical examination, immunizations, or health-screening tests. During the past 12 months or since birth, did your child see a personal provider for preventive care?

### Family-Centered, Compassionate, and Culturally Appropriate Care

- How often does your child's personal provider spend enough time with him or her?
- How often does your child's personal provider explain things in a way that you and your child can understand?
- An interpreter is someone who repeats what one person says in a language used by another person. During the past 12 months or since birth, did you or your child need an interpreter to help speak with his or her doctors or nurse practitioners?
- When you or your child needed an interpreter, how often were you able to get someone other than a family member to help you speak with the doctors or nurse practitioners?

## Accessible Care

- During the past 12 months, have you needed to call your child's personal provider for help or advice over the phone?
- When you have called your child's personal provider for help or advice over the phone, how often were you able to get the help or advice you needed for your child?
- During the past 12 months, has your child needed care right away from his or her personal provider for an illness or injury?
- When your child needed care right away for an illness or injury, how often did he or she get this care from the personal provider as soon as you wanted?

## Comprehensive Care

- Specialists are doctors such as surgeons, heart doctors, allergy doctors, psychiatrists, skin doctors, and others who specialize in one area of health care. During the past 12 months, did you or your child's personal provider think that the child needed to see any specialists?
- How much of a problem, if any, was it to get care from the specialist doctor or doctors?
- Children sometimes need other special types of services that they cannot get from their personal provider. For example, children may need special services such as physical therapy, medical equipment such as wheelchairs, special education services, or counseling. During the past 12 months, did your child need any type of special services, equipment, or other care for his or her health?
- How much of a problem, if any, did you have in getting the special services, equipment, or other care that your child needed?

## Coordinated Care

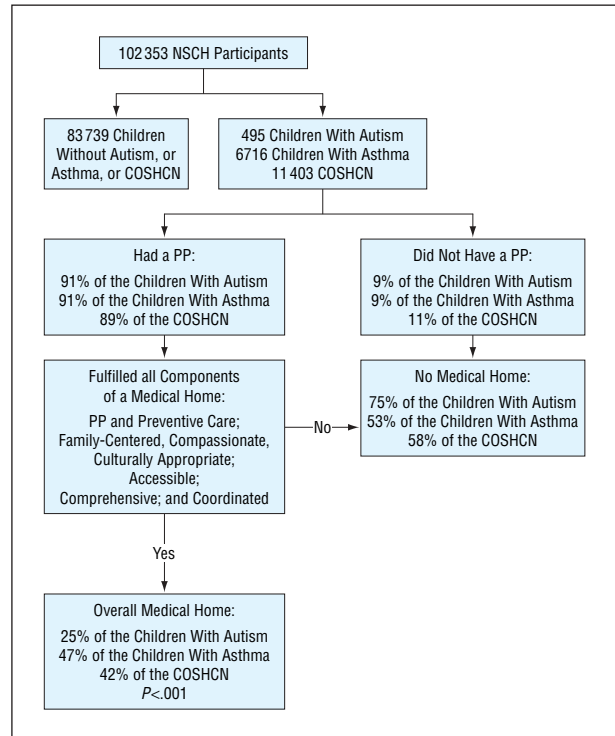
- How often did your child's personal provider talk with you about what happens during visits to a specialist doctor or doctors?
- How often did your child's personal provider talk with you about the special care or equipment that the child gets?

The personal provider and preventive care component was assigned a yes value if parents indicated that their child had both a personal doctor or nurse practitioner and visited them for preventive care during the past 12 months. Likert items for family-centered care, compassionate and culturally appropriate care, accessible care, comprehensive care, and coordinated care components were assigned numeric values of 0 for never, 25 for sometimes, 75 for usually, and 100 for always. These component scores were calculated by averaging the numeric values of the answers to questions composing each component. Scores of 75 or higher were then assigned a yes value. If a question was not applicable to a particular family (eg, English-speaking families were not asked about an interpreter), that question was not included in the calculations for the corresponding component. Overall, children whose parents' answers resulted in a yes value for all 5 components of the medical home score were classified as having a medical home.

The severity of a child's condition was characterized as mild, moderate, or severe according to the parent's response to the question, "Would you describe your child's condition as mild, moderate, or severe?" This variable was dichotomized into mild or moderate vs severe for analyses. Insurance status during the previous year included the following categories: no health insurance, state health insurance (Medicaid or State Children's Health Insurance Program), or private insurance.

## DATA ANALYSIS

Weighted proportions for demographic variables and medical home status were calculated separately for children with au-



**Figure.** Medical home status of children with autism, asthma, or other special health care needs. COSHNCN indicates children with other special health care needs; NSCH, National Survey for Children's Health; PP, personal provider (ie, personal doctor or nurse practitioner).

tism, asthma, and COSHNCN, and were compared using the  $\chi^2$  statistic. The Fisher exact test was used when cell counts were fewer than 5, which occurred with only 2 questions, both pertaining to an interpreter. Results are reported as odds ratios (ORs) with 95% confidence intervals (CIs) and *P* values. To evaluate the role of demographics and disease severity on the medical home outcome among the 3 special needs categories, a multivariable logistic regression model was used. Need category, sex, educational achievement, language, race, ethnicity, poverty level, and condition severity were included as predictors in the model. A separate logistic regression model was used to evaluate the effect of insurance status on the medical home outcome among the children in each of the 3 need categories. Sampling weights for probability, strata, and primary sampling units were provided with the NSCH data and applied to all analyses using STATA software (version 8.1; StataCorp LP, College Station, Tex). Missing data and "don't know" responses to the medical home questions were excluded from the analyses. These represented less than 1% of the responses.

## RESULTS

### DEMOGRAPHIC DATA

No significant differences were found among children with autism or asthma or COSHNCN for language, ethnicity, or poverty level. Children with autism were more likely to be boys and were more likely to be in families where the highest educational achievement of anyone in the house was greater than high school compared with children with asthma or COSHNCN. Children with asthma were more likely to be black than children with either autism or COSHNCN (**Table 1**).

**Table 1. Demographic Characteristics of Children With Autism or Asthma and COSHCN**

Characteristic	Weighted Percentage (SE)			P Value
	Autism	Asthma	COSHCN	
Sex				<.001
Male	78 (2.7)	61 (1.0)	56 (0.8)	
Female	22 (2.7)	39 (1.0)	44 (0.8)	
Educational achievement*				.001
Less than high school	2 (0.7)	6 (0.5)	7 (0.5)	
High school	23 (3.7)	26 (1.0)	25 (0.8)	
More than high school	73 (3.9)	68 (1.0)	68 (0.8)	
Primary language				.37
English	98 (0.8)	94 (0.7)	94 (0.5)	
Not English	2 (0.8)	5 (0.7)	6 (0.5)	
Ethnicity				.06
Hispanic	10 (3.1)	12 (0.8)	11 (0.6)	
Other	89 (3.1)	87 (0.8)	88 (0.6)	
Race				<.001
Black	15 (3.7)	20 (0.9)	14 (0.7)	
Multiracial	2 (0.5)	5 (0.5)	4 (0.4)	
White	74 (4.2)	65 (1.1)	73 (0.9)	
Other	3 (0.9)	4 (0.6)	3 (0.4)	
Poverty level, %				0.34
0-99	17 (4.3)	19 (0.9)	17 (0.7)	
100-132	11 (2.3)	7 (0.7)	7 (0.5)	
133-149	1 (0.5)	4 (0.4)	3 (0.3)	
150-184	6 (1.9)	6 (0.5)	7 (0.5)	
185-199	2 (0.8)	3 (0.3)	3 (0.3)	
≥200	25 (2.8)	24 (0.8)	26 (0.7)	
Not reported	38 (3.3)	37 (0.9)	37 (0.7)	

Abbreviation: COSHCN, children with other special health care needs.  
\*Highest level of education of anyone in the household.

## MEDICAL HOME SCORE AND COMPONENTS

Parents of children with autism were 55% less likely to report medical care consistent with a medical home compared with parents of COSHCN. Conversely, the odds of medical home care were higher for children with asthma compared with COSHCN (**Table 2**).

### Medical Home Components

The parents of children with autism were just as likely as parents of COSHCN to report fulfilling the personal provider and preventive care component of the medical home; however, the parents of children with asthma were more likely to report fulfilling the personal provider and preventive care component of the medical home. Parents of children with autism were less likely to report that their child's care was family-centered than were parents of COSHCN. This difference was driven by the lower percentage of parents of children with autism reporting that a personal provider spent sufficient time with them compared with parents of COSHCN (Table 2).

Most parents of children in all 3 groups reported that their child's medical care was accessible. The odds of parents reporting that their child's care was comprehensive were lower for children with autism compared with COSHCN. Parents of children with autism were more likely to report problems in obtaining subspecialist care

compared with parents of COSHCN. Children with autism used special services (eg, physical therapy, medical equipment, special education, or counseling) more than COSHCN; however, the likelihood of reporting difficulty in obtaining such special services was similar. Coordinated services, as measured by discussing outside services with the personal provider, were less prevalent among children with autism and higher among children with asthma compared with COSHCN. Parents of children with autism were less likely and parents of children with asthma were more likely to report that their child's personal provider discussed special service care compared with parents of COSHCN (Table 2).

### Multivariate Model

Personal, family, and disease characteristics did not affect the differences in prevalence of the medical home among the 3 special needs groups. After adjusting for condition severity, sex, educational achievement, language, race, ethnicity, and poverty level, the odds of reporting medical care consistent with a medical home remained lower for children with autism and higher for children with asthma compared with COSHCN (**Table 3**).

### Insurance Status

After adjusting for insurance type, the odds of reporting medical care consistent with a medical home remained lower for children with autism (OR, 0.38; 95% CI, 0.25-0.58) and higher for children with asthma (OR, 1.13; 95% CI, 1.00-1.28) compared with COSHCN. Independent of need category, the type of insurance had a significant effect on medical home status such that the odds of reporting medical care consistent with a medical home were lower for both those with state insurance (OR, 0.70; 95% CI, 0.60-0.82) and no insurance (OR, 0.40; 95% CI, 0.28-0.54) compared with those with private insurance.

## COMMENT

In this nationally representative sample, even after accounting for condition severity, personal and family characteristics, and insurance status, children with autism were half as likely as COSHCN to have medical care consistent with a medical home. Although most children reported having personal providers and accessible care, a greater percentage of children with autism lacked primary care related to the medical home components of family-centered care, comprehensive care, or coordinated care compared with children with either asthma or COSHCN. To our knowledge, this is the first study to compare children with autism with COSHCN (including asthma) within the context of the AAP recommendations for a comprehensive and coordinated delivery approach.

Our results for COSHCN are similar to those of the National Survey for Children With Special Health Care Needs, in which only half of the parents of children with all special health care needs indicated that their child had care consistent with a medical home.<sup>22</sup> Similar to our re-

**Table 2. Medical Home Care for Children With Autism or Asthma Compared With the COSHCN Reference Group**

Outcome Measure	OR (95% CI)	P Value	Weighted % (SE)
Overall medical home			
COSHCN	1 [Reference]		42 (0.8)
Asthma*	1.17 (1.06-1.30)	.003	47 (1.0)
Autism*	0.45 (0.30-0.66)	<.001	25 (3.7)
PP and preventive care component			
COSHCN	1 [Reference]		84 (0.6)
Asthma*	1.40 (1.21-1.63)	<.001	88 (0.7)
Autism	0.90 (0.57-1.43)	.66	83 (3.3)
PP			
COSHCN	1 [Reference]		89 (0.6)
Asthma*	1.27 (1.05-1.54)	.01	91 (0.6)
Autism	1.17 (0.64-2.13)	.61	91 (2.5)
Visited PP for preventive care			
COSHCN	1 [Reference]		82 (0.7)
Asthma*	1.37 (1.18-1.60)	<.001	86 (0.7)
Autism	1.01 (0.63-1.62)	.96	82 (3.5)
Family-centered, compassionate, culturally appropriate care component			
COSHCN	1 [Reference]		82 (0.7)
Asthma	1.05 (0.89-1.22)	.57	83 (0.9)
Autism*	0.64 (0.43-0.96)	.03	74 (3.8)
PP spends enough time with child			
COSHCN	1 [Reference]		84 (0.7)
Asthma	1.10 (0.93-1.29)	.28	85 (0.9)
Autism	0.66 (0.43-1.01)	.06	77 (3.7)
PP explains things in an understandable way			
COSHCN	1 [Reference]		94 (0.5)
Asthma	0.95 (0.70-1.29)	.74	94 (0.8)
Autism	0.74 (0.47-1.17)	.19	92 (1.6)
Needed an interpreter if English not the primary language			
COSHCN			36 (1.2)
Asthma	0.77 (0.53-1.12)	.17	30 (1.5)
Autism	1.06 (0.30-3.67)	.93	36 (7.0)
Able to access an interpreter, if needed			
COSHCN	1 [Reference]		59 (2.1)
Asthma	1.22 (0.65-2.31)	.54	63 (3.1)
Autism	2.00 (0.20-19.66)	.55	75 (9.4)
Accessible care component			
COSHCN	1 [Reference]		91 (0.7)
Asthma	0.83 (0.64-1.06)	.13	89 (1.0)
Autism	1.28 (0.77-2.12)	.34	92 (1.8)
In last 12 mo, needed to phone PP for help or advice			
COSHCN	1 [Reference]		53 (0.9)
Asthma*	1.34 (1.20-1.50)	<.001	60 (1.1)
Autism	1.11 (0.85-1.54)	.52	57 (4.0)
Able to obtain needed help or advice from PP when called			
COSHCN	1 [Reference]		93 (0.7)
Asthma	0.96 (0.71-1.31)	.82	93 (0.8)
Autism	1.10 (0.61-1.97)	.75	94 (1.7)
In last 12 mo, child needed immediate care from PP			
COSHCN	1 [Reference]		41 (0.9)
Asthma*	1.56 (1.40-1.75)	<.001	52 (1.1)
Autism	0.73 (0.52-1.03)	.07	35 (3.9)

(continued)

**Table 2. Medical Home Care for Children With Autism or Asthma Compared With the COSHCN Reference Group (cont)**

Outcome Measure	OR (95% CI)	P Value	Weighted % (SE)
Care received from PP as soon as parent wanted			
COSHCN	1 [Reference]		91 (0.7)
Asthma	0.82 (0.60-1.13)	.23	90 (1.2)
Autism	1.28 (0.64-2.59)	.49	93 (2.3)
Comprehensive care component			
COSHCN	1 [Reference]		79 (0.9)
Asthma	1.00 (0.84-1.21)	.96	79 (1.3)
Autism*	0.54 (0.38-0.77)	.001	67 (3.9)
In past 12 mo, parent or PP suggested subspecialist care			
COSHCN	1 [Reference]		53 (0.9)
Asthma*	0.87 (0.78-0.97)	.01	49 (1.1)
Autism	1.13 (0.81-1.58)	.48	55 (4.1)
Had difficulty in obtaining subspecialist care			
COSHCN	1 [Reference]		16 (0.9)
Asthma	0.98 (0.79-1.22)	.85	16 (1.2)
Autism*	0.60 (0.39-0.92)	.02	24 (3.8)
In past 12 mo, child needed special services, equipment, or other care (eg, physical therapy or special education)			
COSHCN	1 [Reference]		32 (0.8)
Asthma*	0.84 (0.74-0.94)	.003	28 (1.0)
Autism*	5.80 (3.97-8.50)	<.001	72 (3.8)
Had difficulty in obtaining special services, equipment, or other care			
COSHCN	1 [Reference]		21 (1.3)
Asthma	1.05 (0.81-1.37)	.70	20 (1.9)
Autism	0.74 (0.50-1.12)	.16	26 (3.8)
Coordinated care component			
COSHCN	1 [Reference]		54 (1.1)
Asthma*	1.20 (1.05-1.38)	.009	58 (1.4)
Autism*	0.70 (0.49-1.00)	.051	45 (4.5)
PP discussed subspecialist visits with a parent			
COSHCN	1 [Reference]		60 (1.1)
Asthma	1.31 (0.97-1.32)	.12	63 (1.5)
Autism	0.75 (0.52-1.09)	.13	54 (4.5)
PP discussed special care or equipment with a parent			
COSHCN	1 [Reference]		54 (1.5)
Asthma*	1.32 (1.18-1.49)	<.001	59 (2.1)
Autism*	0.63 (0.50-0.78)	<.001	49 (4.6)

Abbreviations: CI, confidence interval; COSHCN, children with other special health care needs; OR, odds ratio; PP, personal provider (ie, personal doctor or nurse practitioner).

\*Indicates significantly different compared with COSHCN reference group at  $P < .05$ .

sults, parents of children with autism in previous studies expressed difficulty in obtaining family education and support.<sup>25</sup> In our study, children with autism had particular difficulty in obtaining comprehensive subspecialty care. Similar difficulties in obtaining subspecialist care were observed by Filipek et al,<sup>25</sup> who studied 1300 families of children with autism, almost 20% of whom reported having to exert considerable pressure or pay privately to receive a referral outside of the primary care provider. Krauss et al<sup>26</sup> reported that 36.8% of children with

**Table 3. Adjusted Medical Home Status for Children With Autism or Asthma Compared With the COSHCN Reference Group\***

Characteristic	OR (95% CI)	P Value
Need category (reference: COSHCN)		
Asthma†	1.20 (1.07-1.34)	.001
Autism†	0.47 (0.31-0.70)	<.001
Sex (reference: female)		
Male	0.95 (0.85-1.06)	.36
Educational achievement (reference: better than high school)		
Less than high school†	0.70 (0.51-0.96)	.03
High school	1.00 (0.86-1.13)	.87
Language (reference: not English)		
English†	2.0 (1.32-3.05)	.001
Ethnicity (reference: other)		
Hispanic	0.99 (0.77-1.25)	.90
Race (reference: white)		
Black†	0.81 (0.68-0.96)	.02
Multiracial	0.80 (0.61-1.06)	.12
Other	0.95 (0.65-1.40)	.78
Poverty level, % (reference: ≥150%)		
<150†	0.76 (0.65-0.87)	<.001
Condition severity (reference: mild to moderate)		
Severe†	0.74 (0.61-0.91)	.004

Abbreviations: CI, confidence interval; COSHCN, children with other special health care needs; OR, odds ratio.

\*Adjusted for condition, sex, educational achievement, language, ethnicity race, and poverty level.

†Indicates significantly different compared with COSHCN reference group at  $P < .05$ .

autism encountered a problem in accessing subspecialist care, compared with 21% of COSHCN. In another study, Title V directors reported that children with autism faced greater access barriers to pediatric specialists and mental health providers compared with COSHCN.<sup>24</sup>

Coordinated care was a challenge for children with autism in our study. In particular, families of children with autism were much more likely to use special services and also report that their personal physician or nurse did not discuss special services with them. Primary care providers have been noted to lack training and knowledge about therapies (eg, occupational and speech) and devices.<sup>31-33</sup> Furthermore, primary care providers are often unaware of concurrent use of complementary and alternative medicine,<sup>17</sup> used by 32% to 95% of children with autism.<sup>17-19</sup>

Primary care providers reported limited time and lack of medical staff as challenges to care coordination.<sup>34</sup> Clinics may not have the resources to hire a social worker or case manager, and most managed care organizations employ primary care providers as gatekeepers rather than care coordinators.<sup>35</sup> According to the AAP medical home model, primary care providers are accountable to deliver or direct and “help to manage and facilitate essentially all aspects of pediatric care.”<sup>21(p184)</sup> Challenges for a primary care provider are likely to be exacerbated when treating a patient with complex problems, particularly a child with the unique issues of autism.

Our results should be considered in the context of several methodologic limitations. Because of the nature of our questionnaire, we could not characterize the phenotype of autism, asthma, or other special health care needs. To the extent possible, we minimized the effect of condition severity by ensuring that asthma and other special health care needs were present for more than 12 months by analyzing asthma individually and by adjusting for parent-reported condition severity. The standard errors for the autism sample were greater than those for children with asthma and COSHCN because the number of children with autism (the denominator in the standard error) was smaller; thus, the autism sample estimates were less precise than one would wish. We were also unable to validate self-reported autism diagnoses or other medical data provided by the parents. Additional information from the primary care providers would add a more comprehensive perspective to the issue of medical home care and enable greater insight into the medical and administrative barriers to implementing such care. This is an important area for further research. Access to care for children with special health care needs has been found to differ by race and ethnicity.<sup>22</sup> In our study, parents of nonwhite children were more likely to report not having a personal provider compared with parents of white children and, thus, to skip the Medical Home Section of the survey (16% of nonwhites vs 8% of whites). These survey results should be interpreted with caution for underrepresented racial and ethnic minorities.

Despite these limitations, our analysis of this population-based national sample adds important data to the literature on medical care for children with autism. This report is timely because of national support of medical homes for all children, including *Healthy People 2010*,<sup>21</sup> and because of the increase in autism diagnosis.<sup>2-5</sup> Children with autism have intense and unique medical needs that challenge the national medical home care goal. Identifying the specific deficits in care for children with autism, that is, the lack of family-centered, comprehensive, and coordinated care, may allow health plans and health care providers an opportunity to use specific efforts to ensure that optimal care is provided. As conceptualized by the AAP, a model of care with incorporation of community resources, appropriate referrals, and family coordination may improve short- and long-term outcomes in children with special health care needs. Additional research is needed to explore the feasibility and limitations of applying the medical home model to the complex medical care of children with autism.

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