PEDIATRICS[®]

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Access to and Satisfaction With School and Community Health Services for US Children With ASD

Guillermo Montes, Jill S. Halterman and Caroline I. Magyar *Pediatrics* 2009;124;S407-S413 DOI: 10.1542/peds.2009-1255L

The online version of this article, along with updated information and services, is located on the World Wide Web at:

http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S407

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2009 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.



Access to and Satisfaction With School and Community Health Services for US Children With ASD

AUTHORS: Guillermo Montes, PhD, a,b,c Jill S. Halterman, MD, MPH, a,b and Caroline I. Magyar, PhDb

^aDepartment of Research, Children's Institute, Rochester, New York; bDepartment of Pediatrics, University of Rochester School of Medicine and Dentistry, Rochester, New York; and ^cSchool of Education, St John Fisher College, Rochester, New York

KEY WORDS

autism spectrum disorders, health survey, National Survey of Children With Special Health Care Needs, health services, access to health services, satisfaction, United States

ABBREVIATIONS

ASD—autism spectrum disorder

NS-CSHCN—National Survey of Children With Special Health Care

CSHCN—children with special health care needs

FPL—federal poverty level

OR-odds ratio

CI-confidence interval

Dr Montes had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

www.pediatrics.org/cgi/doi/10.1542/peds.2009-1255L

doi:10.1542/peds.2009-1255L

Accepted for publication Aug 3, 2009

Address correspondence to Guillermo Montes, PhD, Children's Institute, 271 N Goodman St, Suite D103, Rochester, NY 14607. E-mail: gmontes@childrensintitute.net

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2009 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

abstract

OBJECTIVE: Our objective was to compare access to and satisfaction with school and community health resources among families with a child with an autism spectrum disorder (ASD) and families of other children with special health care needs (CSHCN).

METHODS: Parents of 40 256 children aged 0 to 17 were surveyed by the 2005–2006 National Survey of Children With Special Health Care Needs. Autism was defined by the question, "To the best of your knowledge, does (child) currently have autism or autism spectrum disorder, that is, ASD?" We used χ^2 and multivariate regression analyses to compare access to and satisfaction with services for parents of children with ASDs and parents of other CSHCN.

RESULTS: Children with ASDs (n = 2123) comprise 5.4% of the CSHCN. More parents of children with ASDs reported difficulty using school and community services (27.6% vs 9.7%) and dissatisfaction (19.8% vs 7.9%) than parents of other CSHCN. Multivariate models determined that parents of children with ASDs were 3.39 times more likely to experience difficulty in obtaining services and 2.65 times more likely to be dissatisfied with services received than parents of other CSHCN, after controlling for household demographics and insurance status. Parents of children with ASDs reported a lack of available services and skilled providers.

CONCLUSIONS: Parents of children with ASDs reported less access to and more dissatisfaction with school and community health services than parents of other CSHCN. An increased supply of appropriate services with qualified providers for children with ASDs is needed in the United States. Pediatrics 2009;124:S407-S413

Autism spectrum disorders (ASDs) refers to a group of neurodevelopmental disorders characterized by difficulties in social communication and behavior.1 Children with this disorder often present with co-occurring conditions and comorbid disorders, including intellectual disability, deficits in adaptive and personal self-sufficiency skills, emotional and behavior disorders, and problems with feeding and sleeping. 1-6 In light of these developmental conditions and co-occurring disorders, children with ASDs often require comprehensive school and community-based services throughout childhood and receive more types of services than children with other disabilities in school.7 Some children with ASDs receive services initially through communitybased early intervention services, via an individualized family service plan. However, delays between diagnosis and referrals can create barriers to accessing services in a timely fashion.8 Moreover, under federal law, early intervention services end at age 3, and services are subsequently determined by the child's school district. Parents have reported difficulties with this transition because early intervention is family focused, whereas special education is education focused.8 Problems that are not directly related to education (eg, eating, sleeping, behavior at home) that may have been treated under early intervention typically receive little attention under special education.

After the age of 3, intervention for ASDs is provided via an individualized education plan, a document that is developed by school personnel in collaboration with parents and identifies the services and accommodations the child will receive. These plans are often unsatisfactory, however, because despite federal mandates to use evidence-based instructional methods in schools, school personnel often do

not use effective methods for children with ASDs. ¹⁰ Indeed, there is a long history of special education litigation documenting that, in many cases, schools have not complied with federal law. ^{11,12}

In the context of increased prevalence of ASDs in schools 13,14 and lack of adequate training, recruitment, and program development, 15 many parents of children with ASDs request additional, related services. In fact, the vast majority of parents of children with special needs who request additional services from schools have faced difficulties obtaining them. 16 A nationally representative study¹⁷ showed that parents of preschool-aged children with ASDs in the United States were equally satisfied with the quality of services but less satisfied with the quantity of services their children received, compared with parents of children with other disabilities. Smaller, local studies have shown that a majority of parents of children with ASDs are dissatisfied with the school's ability to meet their child's needs,18 with nearly half of the parents wanting their children moved to another school. 19 Much special education litigation has been related to the quantity of services received.20

Community-based health services face similar training, access, and satisfaction issues to those faced by school services. Community-based health services are often needed by children with ASDs to address medical, emotional, and behavioral disorders that are not addressed in the school or included in the individualized education plan. Despite published practice guidelines for quality of care for children with ASDs,²¹ services have not been provided as recommended.²²

Previous studies have focused on the preschool-aged population or have used small, nonrepresentative samples. For this study we used the 2005—2006 National Survey of Children With

Special Health Care Needs (NS-CSHCN) to describe access to and satisfaction with school and community health services for children with ASDs aged 0 to 17 to determine if families with a child with ASDs have less access to school and community health resources than families of other children with special health care needs (CSHCN) and whether they are more dissatisfied with the services.

METHODS

Sample

For a description of the survey, please see the introductory article of this supplemental issue of *Pediatrics*.²³ The analytic sample for this study was the full sample.

Measures

Autism Measure

Autism was measured with the following yes/no question: "To the best of your knowledge, does (child) currently have autism or autism spectrum disorder, that is, ASD?"

Health Care Services Screener

Parents were asked if their child currently needed prescription medication; had limitation of activity; had emotional, developmental, or behavioral problems; needed physical, occupational, or speech therapy; or needed more medical care, mental health services, or educational services than his or her peers.

Access to Community and School Health Services

The survey defined community and school health services broadly: "We have been talking primarily about medical services provided by your child's doctors. There are other types of services children may need or use because of their health. These services may be provided by early intervention

programs, schools, childcare facilities, vocational education and rehabilitation programs, and other community programs."

Access to these services was measured with a yes/no question: "Thinking about (child)'s health care needs and all the services that (he/she) needs, have you had any difficulties trying to use these services during the past 12 months (since his/her birth [if child is an infant1)?"

Those who responded in the affirmative were asked to identify reasons for the lack of access from a list of 12 options. The reasons included "could not get information you needed" (information), "too much paperwork required" (paperwork), "you did not have enough money" (money), "transportation was a problem" (transportation), "you couldn't get the services when (he/she) needed them" (timing), "long waiting lists" (long wait), "problems in communication between service providers" (communication), "could not find service providers who had the skills the (child) needed" (skills), "types of services (child) needed were not available in your area" (availability), "services were available but (he/she) was not eligible" (not eligible), services were available but "(he/she) had used up all eligible benefits" (eligibility used), and "did not have time to figure it all out" (time).

Dissatisfaction With Services Received

Dissatisfaction with services was measured with a dichotomous variable that grouped parents who answered "Thinking about (child)'s health needs and the services (he/she) receives, how satisfied or dissatisfied are you with services?" with "very dissatisfied" or "somewhat dissatisfied" versus those who responded "somewhat satisfied" or "very satisfied."

Demographic Variables

Race of the child was measured with a derived race variable that categorized race as white, African American or black, other race, or multiple races. Similarly, we used derived variables for Hispanic or Latino ethnicity, child's gender, insurance status (insured according to the National Center for Health Statistics definition or not), urban, and highest level of education in the household (less than high school, high school, or more than high school). Poverty level was coded by recategorizing the poverty-guideline—derived variable that used income and family size to classify household's income into the 2005 US Department of Health and Human Services guidelines. We collapsed the variable into 3 categories: ≤200% federal poverty level (FPL), 200% to 400% FPL, and \geq 400% FPL. All participants consented to the study. We did not impute missing data. Additional information on the survey and consent procedures is available.24

Weights

We used Stata (Stata Corp, College Station, TX) to adjust for the complex sample design by using Taylor approximations that provide the correct SEs. following NS-CSHCN guidelines.24

Analysis

Demographic characteristics and access and satisfaction questions were analyzed by using univariate descriptive and χ^2 statistics by ASDs versus other CSHCN groups. Because of the number of bivariate comparisons, we set the significance level at 1% to minimize type 1 errors. We conducted multivariate logistic regressions on the outcomes, controlling for demographic variables (age, gender, race, Hispanic ethnicity, education, insurance status, urbanicity, and poverty). Age was entered as a continuous variable.

RESULTS

Sample Description

There were 2123 children with ASDs in the sample, comprising 5.4% of the population of CSHCN. Table 1 lists the demographic characteristics for the children with ASDs and other CSHCN. Children with ASDs were comparable to other CSHCN in terms of race, parental education, poverty level, urbanicity, Hispanic ethnicity, and insurance status. Compared with other CSHCN, children with ASDs were less likely to be infants or toddlers (1.6% vs 6.9%; P < .01) and more likely to be male (79.1% vs 58.2%; P < .01).

Comparison on the Special Health Care Needs Screener

Table 1 also lists responses to the special health care needs screener. Compared with other CSHCN, children with ASDs were less likely to take prescription medication (57.8% vs 82.3%; P <.01) and more likely to have limitation of activity (70.0% vs 20.6%; P < .01), have emotional, developmental, or behavioral problems (80.7% vs 26.5%; P < .01), need physical, occupational, or speech therapy (76.2% vs 18.1%; P < .01), and need more medical care, mental health services, and/or educational services than their peers (89.6% vs 41.1%; P < .01).

Access to and Satisfaction With Community and School Services: Univariate Results

Table 2 compares access to and satisfaction with community and school services for children with ASDs versus other CSHCN. Parents of children with ASDs reported more problems using services (27.6% vs 9.7%; P < .01) and were more likely to be dissatisfied with the services received (19.8% vs 7.9%; P < .01).

In considering reasons for poor access to services, parents of children with ASDs who had difficulty using ser-

TABLE 1 Demographic Characteristics and Health Care Needs of Children With and Without ASDs

	Child Has an ASD		Child Has Other Special Health Care Needs		All		Design-Corrected F
	%	95% CI	%	95% CI	%	95% CI	
Age, y							17.94ª
0-2 (n = 2317)	1.6	1.0-2.7	6.9	6.5-7.4	6.6	6.2-7.1	
3-5 (n = 5001)	18.6	15.8-21.7	14.0	13.4-14.7	14.3	13.7-14.9	
6-12 (n = 17762)	49.3	45.8-52.8	43.6	42.8-44.5	43.9	43.1-44.8	
13-17 (n = 15 176)	30.5	27.4-33.8	35.4	34.6-36.3	35.2	34.4-36.0	
Gender							136.99a
Female ($n = 16353$)	20.9	18.3-23.9	41.8	41.0-42.7	40.7	39.9-41.5	
Male $(n = 23830)$	79.1	76.1-81.7	58.2	57.3-59.0	59.3	58.5-60.1	
Race							1.11
White $(n = 30 697)$	73.5	70.3-76.4	71.0	70.1-71.8	71.1	70.3-71.9	
Black ($n = 4319$)	15.2	12.9–17.9	16.8	16.1–17.5	16.7	16.0-17.4	
Multiple race ($n = 1798$)	3.3	2.4-4.4	4.1	3.8–4.5	4.1	3.7-4.4	
Other $(n = 3182)$	8.0	6.2-10.2	8.1	7.6–8.7	8.1	7.6–8.6	
Hispanic ethnicity	0.0	0.2 10.2	0	7.0 0.1	0	7.0 0.0	0.32
Not Hispanic ($n = 36\ 172$)	87.7	85.0-90.0	88.5	87.8-89.0	88.4	87.8-89.0	0.02
Hispanic ($n = 3925$)	12.3	10.0–15.0	11.5	11.0-12.2	11.6	11.0–12.2	
Highest level of education	12.0	10.0 10.0	11.0	11.0 12.2	11.0	11.0 12.2	0.16
Less than high school ($n = 1828$)	6.4	4.8-8.4	6.6	6.2-7.1	6.6	6.2-7.1	0.10
High school ($n = 6339$)	23.9	20.7–27.4	23.0	22.2–23.8	23.0	22.3–23.8	
More than high school ($n = 32013$)	69.8	66.2–73.1	70.4	69.6–71.2	70.4	69.5-71.2	
Poverty level, % FPL	0.00	00.2-70.1	70.4	00.0-11.2	70.4	03.0-11.2	2.81
$\leq 200 \ (n = 13\ 083)$	44.2	40.6-47.9	40.4	39.5-41.3	40 G	39.7-41.4	2.01
200-400 (n = 12430)			40.4		40.6	29.5–31.1	
>400 (n = 11130)	30.1 25.7	26.6-33.8	30.3 29.3	29.5-31.1	30.3 29.1		
	20.1	22.9–28.7	23.0	28.5–30.1	23.1	28.4–29.9	1.44
Urban	15.0	17.0 10.4	17 E	100 101	17 /	100 100	1.44
Not urban $(n = 6062)$	15.9	13.6–18.4	17.5	16.9–18.1	17.4	16.8–18.0	
Urban ($n = 21749$)	84.1	81.6–86.4	82.5	81.9–83.1	82.6	82.0-83.2	0.004
Insurance status	00.0	05.7.07.0	00.0	007 000	00.0	00.7.00.0	0.004
Insured ($n = 38767$)	96.6	95.3–97.6	96.6	96.3–96.9	96.6	96.3-96.9	
Uninsured ($n = 1407$)	3.4	2.4–4.7	3.4	3.1–3.7	3.4	3.1–3.7	000 700
Child currently needs prescription medications	40.0	70.0 45.7	177	17.0 10.7	10.0	107 107	288.78 ^a
No $(n = 7590)$	42.2	38.8–45.7	17.7	17.0–18.3	19.0	18.3–19.7	
Yes $(n = 32647)$	57.8	54.3-61.2	82.3	81.7–83.0	81.0	80.3-81.7	710.000
Child needs more medical care/mental health/education							718.02 ^a
than peers	10.4	0.5 10.7	F0.0	F0.0 F0.7	F0.0	FF 4 F7 1	
No (n = 22 043)	10.4	8.5–12.7	58.9	58.0-59.7	56.2	55.4-57.1	
Yes $(n = 17553)$	89.6	87.3–81.5	41.1	40.3-42.0	43.8	42.9-44.6	4000 700
Child is limited in ability to do things	700		70.4		=0.0		1020.36 ^a
No $(n = 30.864)$	30.0	26.9–33.3	79.4	78.7–80.1	76.8	76.1–77.5	
Yes $(n = 9257)$	70.0	66.7–73.1	20.6	19.9–21.3	23.2	22.5-23.9	
Child needs physical, occupational, and/or speech therapy	07.0	000 000	0.1.0	04.0.00=	70 -	700 70 1	1447.71 ^a
No $(n = 31.854)$	23.8	20.9–26.9	81.9	81.2-82.5	78.7	78.0-79.4	
Yes $(n = 8360)$	76.2	73.1–79.1	18.1	17.5–18.8	21.3	20.6–22.0	
Child has emotional, developmental, or behavioral							1206.96ª
problem					_		
No $(n = 28 \ 165)$	19.3	16.8–22.0	73.5	72.7–74.2	70.5	69.8–71.3	
Yes (n = 11 922)	80.7	78.0–83.2	26.5	25.8–27.3	29.5	28.7–30.2	

P < .01.

vices reported "no providers with skills child needed" (59.3% vs 39.5%; P < .01) and "services not available in my area" (56.3% vs 39.1%; P < .01) more frequently than parents of other CSHCN. "Long waiting lists" was significant at the 5% level (55.1% vs 44.5%). The majority of parents in both groups reported that informational barriers, such as "could not get information," "could not get what was needed," and "communication problems among providers," created difficulties to accessing services.

Finally, additional barriers to services reported by fewer than 50% of parents of both groups included transportation problems, language or cultural problems, lack of eligibility, used-up eligibility benefits, too much paperwork, and not having enough time.

 TABLE 2
 Access to and Satisfaction With Community and School Services

	Child Has an ASD		Specia	l Has Other I Health Care Needs	All		Design-Corrected F
	%	95% CI	%	95% CI	%	95% CI	
Difficulty using services (previous 12 mo)	72.4	69.2-75.4	90.3	89.8–90.8	89.3	88.8–89.8	255.73a
No $(n = 35598)$	27.6	24.6-30.8	9.7	9.2-10.2	10.7	10.2-11.2	
Yes $(n = 4295)$							
Dissatisfied with services	80.2	77.2-82.9	92.1	91.6-92.5	91.4	90.9-91.9	126.73a
No $(n = 36018)$	19.8	17.1-22.8	7.9	7.5-8.4	8.6	8.1-9.1	
Yes $(n = 3261)$							
Could not get information	40.7	34.5-47.2	38.5	35.9-41.1	38.8	36.4-41.3	0.39
No $(n = 1758)$	59.3	52.8-65.5	61.5	58.9-64.1	61.2	58.7-63.6	
Yes $(n = 2519)$							
Too much paperwork	71.2	65.1-76.6	76.0	73.5-78.3	75.3	73.1-77.5	2.41
No $(n = 3267)$	28.8	23.4-34.9	24.0	21.7-26.5	24.7	22.5-26.9	
Yes $(n = 988)$							
Not enough money	56.5	50.0-62.8	61.1	58.4-63.8	60.5	58.0-62.9	1.7
No $(n = 2593)$	43.5	37.2-50.0	38.9	36.2-41.6	39.5	37.1-42.0	
Yes $(n = 1680)$							
Transportation problem							0.58
No $(n = 3431)$	77.6	71.3-82.8	79.9	77.5-82.1	79.6	77.4-81.6	
Yes $(n = 859)$	22.4	17.2-28.7	20.1	17.9-22.5	20.4	18.4-22.6	
Could not get what was needed							0.42
No $(n = 1468)$	31.4	25.8-37.6	33.6	31.0-36.2	33.3	30.9-35.7	
Yes $(n = 2791)$	68.6	62.4-74.2	66.4	63.8-69.0	66.7	64.3-69.1	
Long waiting lists							5.69 ^b
No $(n = 1543)$	44.9	37.1-52.9	55.5	52.0-58.9	53.9	50.7-57.1	
Yes $(n = 1196)$	55.1	47.1-62.9	44.5	41.1-48.0	46.1	42.9-49.3	
Communication problems							1.83
No $(n = 2076)$	44.6	38.2-51.1	49.5	46.7-52.2	48.8	46.3-51.3	
Yes $(n = 2181)$	55.4	48.9-61.8	50.5	47.8-53.3	51.2	48.7-53.7	
Language or cultural problems							0.94
No $(n = 3820)$	85.2	79.0-89.9	87.9	85.9-89.7	87.5	85.6-89.2	
Yes $(n = 462)$	14.8	10.1-21.0	12.1	10.3-14.1	12.5	10.8-14.4	
No providers with necessary skills							31.21a
No $(n = 2412)$	40.7	34.5-47.1	60.5	57.7-63.1	57.7	55.1-60.1	
Yes $(n = 1849)$	59.3	52.9-65.5	39.5	36.9-42.3	42.3	39.9-44.9	
Service not available in the area							22.43a
No $(n = 2410)$	43.7	37.3-50.4	60.9	58.1-63.6	58.5	55.9-61.0	
Yes $(n = 1797)$	56.3	49.6-62.7	39.1	36.4-41.9	41.5	39.0-44.1	
Not eligible							0.08
No $(n = 2402)$	54.2	47.6-60.6	55.2	52.4-58.0	55.0	52.5-57.6	
Yes $(n = 1782)$	45.8	39.4-52.4	44.8	42.0-47.6	45.0	42.4-47.5	
Used up eligibility benefits							2.43
No $(n = 3720)$	82.7	77.2-87.1	86.6	84.5-88.5	86.1	84.1-87.8	
Yes $(n = 515)$	17.3	12.9-22.8	13.4	11.5-15.5	13.9	12.2-15.9	
Not enough time							2.79
No $(n = 3227)$	71.4	65.0-77.1	76.7	74.3-78.9	76.0	73.7-78.1	
Yes $(n = 1032)$	28.6	22.9-35.0	23.3	21.1-25.7	24.0	21.9-26.3	

a P < 01

Access to and Satisfaction With Community and School Services: Multivariate Results

Table 3 presents the results of multivariate analyses. For each outcome, the multivariate logistic model included age, gender, insurance status, parental education, race, Hispanic ethnicity, urbanicity, and poverty level as covariates. In these analyses, having a child with ASDs more than tripled the odds of reporting difficulty obtaining services (odds ratio [0R]: 3.39 [95% confidence interval (CI): 2.78—4.14]). In addition, lack of access was associated with living below 200% FPL (OR:

2.10 [1.77–2.50]), living between 200% and 400% FPL (OR: 1.33 [95% CI: 1.12–1.58]), and being uninsured (OR: 2.49 [95% CI: 1.94–3.19]). Parents of older children reported more difficulty accessing services (OR: 1.03 [95% CI: 1.02–1.04]), as did parents who lived in urban areas (OR: 1.36 [95% CI: 1.17–

b *P* < .05.

TABLE 3 Multivariate Logistic Regression Results

		ty Obtaining ervices	Dissatisfied With Services		
	OR	95% CI	OR	95% CI	
Child has an ASD	3.39a	2.78-4.14	2.65a	2.12-3.32	
Age	1.03a	1.02-1.04	1.04a	1.02-1.06	
Male	1.09	0.96-1.25	0.99	0.86-1.15	
Uninsured	2.49a	1.94-3.19	2.18a	1.66-2.86	
High school education	0.94	0.69-1.27	0.85	0.63-1.17	
More than high school education	1.21	0.92-1.60	0.98	0.74-1.31	
Black	0.87	0.71-1.06	1.10	0.90-1.35	
Multiple race	0.96	0.72-1.29	1.19	0.88-1.62	
Other race	1.09	0.84-1.42	1.36 ^b	1.01-1.84	
Hispanic	1.35 ^b	1.08-1.69	1.69a	1.32-2.16	
Urban	1.36a	1.17-1.59	1.21 ^b	1.02-1.43	
≤200% FPL	2.10 ^a	1.77-2.50	2.00a	1.64-2.44	
200%-400% FPL	1.33a	1.12-1.58	1.27a	1.04-1.54	

Default case is other CSHCN, female, insured, less than high school parental education, white, non-Hispanic, not urban, ≥400% FPI

1.59]) and parents of Hispanic children (OR: 1.35 [95% CI: 1.08–1.69]).

Multivariate logistic regression on dissatisfaction with services revealed a similar pattern. Controlling for demographics, having a child with ASDs more than doubled the odds of dissatisfaction with the community and school services received (OR: 2.65 [95% CI: 2.12-3.32]). Being uninsured (OR: 2.18 [95% CI: 1.66-2.86]) and poverty (OR: 2.00 [95% CI: 1.64-2.44], for below 200% FPL) had similarly sized ORs. Living in an urban area was associated with higher odds of dissatisfaction (OR: 1.21 [95% CI: 1.02-1.43]), as was being a parent of a Hispanic child (OR: 1.69 [1.32-2.16]), a child of "other race" (OR: 1.36 [95% CI: 1.01-1.84]), or an older child (OR: 1.04 [95% CI: 1.02-1.06]).

DISCUSSION

This is the first nationally representative study to investigate access to community and school health services and satisfaction with services received for parents of children aged 0 to 17 with ASDs. Parents of children with ASDs reported that their children required additional educational, mental health, or physical, occupational, or speech ther-

apy, consistent with previous research on health care and educational utilization for this subpopulation.^{7,25} We found that parents of children with ASDs were 3 times more likely to report difficulties accessing community and school health services their children needed, compared with parents of other CSHCN. This result was obtained after adjusting for demographic variables. It is interesting to note that, although the majority of parents of CSHCN, including parents of children with ASDs, reported serious informational and communication barriers to accessing services, parents of children with ASDs were more likely to identify lack of supply of qualified providers and available services as a problem (services not available or no skilled provider).

This study corroborates findings from previous studies. Compared with a recent nationally representative study of satisfaction with school-based services for preschool-aged children with ASDs, our study found higher dissatisfaction but similar odds (\sim 2.5) between parents of children with ASDs and those of children with other disabilities.⁷ The dissatis-

faction levels we found were closer to those reported by smaller studies. We found that parents of older children were more likely to be dissatisfied, as were parents of children who lived in poverty or in the cities or who were uninsured. It is notable that the presence of ASDs was the largest predictor in the multivariate analyses, similar to the associations of being below 200% FPL or being uninsured.

Combined with results from a previous study²⁵ that showed that parents of children with ASDs were more likely to be dissatisfied with primary care services, our study suggests that parents with ASDs are more likely to be dissatisfied with services across all settings than parents of children with other conditions.

The multivariate logistic models revealed a compounded level of dissatisfaction and problems of access if the family, in addition to having a child with ASDs, was impoverished, uninsured, or both. This suggests that the likelihood that families of children with ASDs who have additional risk factors can secure services that satisfy them is very small.

In summary, although parents of children with ASDs face many of the same informational barriers to secure community and school services for their children faced by parents of other CSHCN, parents of children with ASDs face larger shortages in the supply of services appropriate for their children's needs. This lack of adequate supply seems amenable to public policy remedies that would fund additional training and services for children with ASDs in the United States.

Limitations of the Study

There are a few potential limitations in this study. First, all data were based on parental report. Although parent report of ASDs is viewed as fairly reli-

 $^{^{}a}P < .01.$

b *P* < .05.

able,13,16 we did not have access to medical records or diagnostic reports and were limited by the questions asked in the survey. In addition, some children may have been undiagnosed or improperly diagnosed. Finally, we did not control for comorbid conditions, because the majority of the children with ASDs had comorbidities.

Implications

In this study, we found that parents of children with ASDs have less access to and more dissatisfaction with school

and community health services than parents of other CSHCN. These findings highlight the need for increasing the supply of community and school services, staffed with qualified providers, available to children with ASDs in the United States.

REFERENCES

- 1. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 4th ed. Text revision. Washington, DC: American Psychiatric Association; 2000
- 2. Gadow KD, DeVincent CJ, Pomeroy J, Azizian A. Psychiatric symptoms in preschool children with PDD and clinical and comparison samples. J Autism Dev Disord. 2004;34(4): 379 - 393
- 3. Liu X, Hubbard JA, Fabes RA, Adam JB. Sleep disturbances and correlates of children with autism spectrum disorders. Child Psychiatry Hum Dev. 2006;37(2):179-191
- 4. Saemundsen E, Ludvigsson P, Hilmarsdottir I, Rafnsson V. Autism spectrum disorders in children with seizures in the first year of life: a population-based study. Epilepsia. 2007;48(9):1724-1730
- 5. Tonge BJ, Einfeld SL. Psychopathology and intellectual disability: the Australian child to adult longitudinal study. Int Rev Res Ment Retard. 2003;26:61-91
- 6. Volkmar FR, Sparrow SS, Goudreau D, Cichetti DV, Paul R, Cohen DJ. Social deficits in autism: an operational approach using the Vineland Adaptive Behavior Scales. J Am Acad Child Adolesc Psychiatry. 1987;26(2):156-161
- 7. Bitterman A, Daley TC, Misra S, Carlson E, Markowitz J. A national sample of preschoolers with autism spectrum disorders: special education services and parent satisfaction. J Autism Dev Disord. 2008;38(8): 1509-1517
- 8. Stoner JB, Bock SJ, Thompson JR, Angell ME. Hevl BS. Crowlev EP. Welcome to our world: parent perceptions of interactions between parents of young children with ASD and education professionals. Focus Autism Other Dev Disabl. 2005;20(1):39-51
- 9. No Child Left Behind Act of 2001. 20 U.S.C
- 10. Hess KL, Morrier MJ, Heflin LJ, Ivey ML. Au-

- tism treatment survey: services received by children with autism spectrum disorders in public school classrooms. J Autism Dev Disord. 2008;38(5):961-971
- 11. Mandlawitz MR. The impact of the legal system on educational programming for young children with autism spectrum disorder. J Autism Dev Disord. 2002;32(5):495-508
- 12. Yell ML, Drasgow E. Litigating a free appropriate education: the Lovaas hearings and cases. J Spec Educ. 2000;33(4):205-214
- 13. 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
- 14. US Department of Education. Individuals With Disabilities Education Act (IDEA) data. Available at: www.ideadata.org. Accessed July 27, 2007
- 15. Simpson RL, Smith Myles B. Understanding and responding to the needs of students with autism. In: Simpson RL, Smith-Myles B, eds. Educating Children and Youth With Autism. Austin, TX: Pro-ed; 1998:1-23
- 16. Leiter V, Krauss W. Claims, barriers, and satisfaction: parents' requests for additional special education services. J Disabil Policy Stud. 2004;15(3):135-146
- 17. Bitterman A, Daley TC, Misra S, Carlson E, Markowitz J. A national sample of preschoolers with autism spectrum disorders: special education services and parent satisfaction. J Autism Dev Disord. 2008;38(8): 1509 - 1517
- 18. Spann SJ, Kohler FW, Soenksen D. Examining parents' involvement in and perceptions of special education services: an interview with families in a parent support group. Focus Autism Other Dev Disabl. 2003;18(4): 228 - 237

- 19. Kasari C, Freeman SFN, Bauminger N, Alkin MC. Parental perspectives on inclusion: effects of autism and down syndrome. J Autism Dev Disord. 1999;29(4):297-305
- 20. Etscheidt S. An analysis of legal hearings and cases related to individualized education programs for children with autism. Res Pract Persons Severe Disabl. 2003;28(2):
- 21. Volkmar F, Cook EH Jr, Pomeroy J, Realmuto G, Tanguay P. Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. American Academy of Child and Adolescent Psychiatry Working Group on Quality Issues [published correction appears in J Am Acad Child Adolesc Psychiatry. 2000;39(7):938]. J Am Acad Child Adolesc Psychiatry. 1999; 38(12 suppl):32S-54S
- 22. McLennan JD, Huculak S, Sheehan D. Brief report: pilot investigation of service receipt by young children with autistic spectrum disorders. J Autism Dev Disord. 2008;38(6): 1192-1196
- 23. Kogan MD, Strickland BB, Newacheck PW. Building systems of care: findings from the National Survey of Children With Special Health Care Needs. Pediatrics. 2009; 124(suppl 4):S333-S336
- 24. Blumberg SJ, Welch EM, Chowdhury SR, Upchurch HL, Parker EK, Skalland BJ. Design and operation of the National Survey of Children With Special Health Care Needs, 2005-2006. Vital Health Stat 1. 2008;(45):
- 25. Liptak GS, Orlando M, Yingling JT, et al. Satisfaction with primary health care received by families of children with developmental disabilities. J Pediatr Health Care. 2006; 20(4):245-252

Access to and Satisfaction With School and Community Health Services for US Children With ASD

Guillermo Montes, Jill S. Halterman and Caroline I. Magyar *Pediatrics* 2009;124;S407-S413

DOI: 10.1542/peds.2009-1255L

Updated Information including high-resolution figures, can be found at:

& Services http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S4

07

References This article cites 19 articles, 3 of which you can access for free

at:

 $http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S4$

07#BIBL

Citations This article has been cited by 1 HighWire-hosted articles:

http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S4

07#otherarticles

Subspecialty Collections This article, along with others on similar topics, appears in the

following collection(s): **Developmental/Behavior**

http://www.pediatrics.org/cgi/collection/developmental:behavior

Permissions & Licensing Information about reproducing this article in parts (figures,

tables) or in its entirety can be found online at: http://www.pediatrics.org/misc/Permissions.shtml

Reprints Information about ordering reprints can be found online:

http://www.pediatrics.org/misc/reprints.shtml

