

Differences in Perceived Need for Medical, Therapeutic, and Family Support Services Among Children With ASD

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abstract **OBJECTIVE:** Identifying racial and ethnic differences in perceived need for treatment among families of children with autism spectrum disorder (ASD) will improve understanding of disparities in care seeking. We described racial and ethnic differences in perceived need for services that children with ASD and their families frequently use.

METHODS: We conducted bivariate analyses of racial and ethnic categories and perceived need for 6 common services used by children with ASD as found in the 2005 to 2006 ($n = 2123$) and the 2009 to 2010 ($n = 3055$) National Survey of Children With Special Health Care Needs data sets. Multivariate logistic regressions within concatenated data sets were conducted to examine associations between racial and ethnic category and perceived service needs while controlling for predisposing, enabling, and child factors.

RESULTS: Compared with caregivers of white non-Hispanic children with ASD, caregivers of Hispanic children reported less need for prescription medications in adjusted multivariate analyses. Caregivers of black non-Hispanic children with ASD reported less need for prescription medications and for child and family mental health services than caregivers of white non-Hispanic children. Both English-speaking Hispanic caregivers and black non-Hispanic caregivers reported greater need for occupational, speech, and physical therapy than white non-Hispanic caregivers. No racial or ethnic differences were found in perceived need for specialty medical care or respite care.

CONCLUSIONS: Caregivers of children with ASD from different racial and ethnic backgrounds may differentially perceive need for different types of care. Their perceptions may in turn affect how they prioritize and seek care, independent of their child's specific needs.

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A diagnosis of autism spectrum disorder (ASD) should result in a cascade of medical, psychological, and educational evaluations and interventions for the child and family. Although evidence is still emerging regarding best practices, the American Academy of Pediatrics recommends that comprehensive treatments include educational, therapeutic, medical, and family support services.¹ The American Academy of Pediatrics clinical guideline¹ recommends behavioral interventions, such as applied behavioral analysis; habilitative therapies, such as occupational, speech, and physical therapy; comprehensive educational interventions; specialty care to manage comorbid conditions; prescription medications for comorbid conditions; and mental health and respite care services for the child and family. Peer-reviewed evidence and other clinical guidelines support these interventions.²⁻⁴ However, caregivers of children with ASD have reported that obtaining appropriate and timely care is often difficult and costly,⁵ and many are dissatisfied with the process of obtaining care.^{6,7}

Caregivers of children with ASD report more unmet needs for a variety of services than caregivers of children with other emotional, developmental, or behavioral difficulties.^{8,9} Caregivers of children with ASD who are from racial or ethnic minority groups experience even greater difficulty than nonminority caregivers obtaining care.¹⁰⁻¹⁴ Authors of these studies finding racial or ethnic differences in type and quality of care suggest that these differences may not result solely from health care system or provider factors (eg, availability of providers, sensitivity of providers) but also from parents' help-seeking behaviors.¹⁵⁻¹⁷

Perceived need for a service precedes help-seeking behaviors. At least 2

studies have examined caregiver perceived need for services for children with ASD^{9,18}; however, these studies recruited small samples and had little information about race or ethnicity. No quantitative research has explored racial or ethnic differences in perceived need for care among caregivers of people with ASD, although research on children with emotional, developmental, and behavioral conditions suggests that Spanish-speaking Hispanic caregivers report less perceived need for mental health services for their children than caregivers of children of other races or ethnicities.¹⁹

To address this question for children with ASD, we relied on the Andersen Behavioral Model of Health Care Use^{20,21} to frame our study questions and variables. Andersen and Davidson²¹ proposed that perceived need for health care and help-seeking behaviors are socially driven and reflect individual and contextual characteristics, including race and ethnicity. If there are racial and ethnic differences in perceived need, it suggests the need for interventions to increase awareness of the types of care from which children with ASD and their families would benefit, as well as for research about why certain groups do not perceive that these services will meet their needs. The purpose of this study was to identify differences in caregiver-reported perceived need for treatment services among children with ASD from 5 racial and ethnic groups in 2 cross-sectional population-based data sets.

METHODS

Data Sources and Sample

The 2005 to 2006 and the 2009 to 2010 National Survey of Children With Special Health Care Needs (NS-CSHCN) data sets, collected by the Centers for Disease Control and Prevention, National Center for

Health Statistics (NCHS), were used for this study.²² These cross-sectional surveys collected information about perceived need and health service use, child needs, satisfaction with services, insurance status, and other demographic information. This study used variables from the screening, household, and main interview data sets. The study was deemed exempt by the first author's institutional review board.

Sampling methods for these surveys have been described elsewhere.^{23,24} Briefly, the sampling plan of both surveys included identifying ≥ 750 eligible households with children with special health care needs (CSHCN) in each of the 50 states and the District of Columbia. Both surveys were integrated within the State and Local Area Integrated Telephone Survey program.²² Cell phone users were included in the sampling frame for the 2009 to 2010 NS-CSHCN.

The NS-CSHCN screened 364 841 households in 2005 to 2006 and 372 698 households in 2009 to 2010 with children <18 years old.^{23,24} The screening process identified whether a CSHCN lived at the residence. CSHCN were defined as "those who have or are at increased risk for 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."²⁵ Caregivers of screened CSHCN were invited to participate in the longer main interview.

The main interview data set for children with ASD in each survey year was used to define the analytic sample; based on NCHS recommendations, all analyses used subpopulation adjustments to ensure that standard errors for children with ASD reflected the entire sample of CSHCN.²³ Children with ASD were identified by caregivers as having a diagnosis;

children were classified as having ASD if the caregiver answered affirmatively to the question, "To the best of your knowledge, does [child] currently have autism or autism spectrum disorder, that is, an ASD?" (2005–2006 survey, $n=2123$) or in the 2009 to 2010 survey, "Does [child] currently have autism, Asperger's disorder, pervasive developmental disorder (PDD), or other autism spectrum disorder?" ($n=3055$). In 2009 to 2010, the survey also asked whether a child *ever* had autism, Asperger's disorder, pervasive developmental disorder, or other ASD; in our study, 2009 to 2010 children were included only if they responded "yes" to "currently" having an ASD. Few children <3 years old were identified as having ASD ($n=65$), as is consistent with typical diagnostic patterns.²⁶ We included the full sample of children 0 to 17 years to capture caregiver-perceived service needs for young children with ASD. This method is consistent with previous research in this area.¹⁴

Variables

The wording for race and ethnicity and for perceived service needs remained the same for both survey years.

Perceived Service Need

Perceived need for services was operationalized as an affirmative response to yes/no questions: "During the past 12 months, was there any time when [child] needed [service]?" Six service types were included, which reflect commonly used interventions among children with ASD. Service types included those recommended for medical management of ASD symptoms, including specialty physician care and treatment with prescription medication; therapeutic and psychological treatment services, including specialized therapies (occupational therapy, speech therapy, physical therapy), and

child mental health care; and family support services including respite care and family mental health services.¹ Caregivers were asked whether the child "needed occupational, physical, or speech therapy"; the survey did not distinguish between these therapies.

The NS-CHSCN did not include questions about educational or behavioral services; the analyses in this article do not include information on these services.

Race and Ethnicity

Our primary independent variable was racial and ethnic category, which the survey categorized as white, black, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, and other. Ethnicity was based on 2 categories (non-Hispanic or Hispanic/Latino/Spanish origin). We collapsed several of these groups because of small sample sizes in some strata. Additionally, we created 2 Hispanic groups based on language spoken at home because differences in prevalence and functional needs of children have been found for primarily English-speaking Hispanic families versus primarily Spanish-speaking Hispanic families.²⁷ We used 5 categories to examine differences in perceived need: white non-Hispanic; any race, English-speaking Hispanic; any race, Spanish-speaking Hispanic; black non-Hispanic; and other race non-Hispanic.

Individual and Contextual Characteristics

Covariates were selected for multivariate analyses based on Andersen's Behavioral Model^{20,21} and included predisposing, enabling, and need characteristics that may affect the outcome variable of interest (perceived service need). Individual predisposing characteristics were defined as immutable sociodemographic

characteristics, including child's age in years (continuous) and gender (dichotomous). Individual enabling characteristics were defined as variables that support an individual or family's ability to pay for, travel to, and use services; these included household income (<200% of the federal poverty level [FPL], 200%–400% FPL, >400% FPL), annual family out-of-pocket costs (<\$500, \$500–\$1000, \$1000–\$5000, >\$5000), child insurance status (private, public, both private and public, uninsured), and highest level of education of someone in the child's household (less than high school graduate, high school graduate, more than high school graduate). Individual need characteristics were defined as factors that reflect perception about the magnitude of the problem for which a person might seek care and included child functional needs (*Never has functional difficulty compared with same age peers, Sometimes, Usually, or Always*). Metropolitan statistical area (MSA) status was used to classify children as living in a metro area (urban) or a nonmetro area (nonurban) to examine the influence of contextual characteristics, which considers the influence of factors related to health care utilization rates based on where a person lives or receives care.^{23,24} MSA status was suppressed for children living in states with either few rural (<500 000 people) or few urban (>500 000 people) locations. To include all possible cases in the analysis, children living in states with few MSAs (Alaska, Idaho, Maine, Montana, North Dakota, South Dakota, Vermont, and Wyoming) were classified as nonurban. Children living in states with large numbers of MSAs (Connecticut, Delaware, Hawaii, Massachusetts, Maryland, New Hampshire, Nevada, and Rhode Island) were classified as urban. These procedures are considered

valid and appropriate for maximum inclusion of all potential children in the study.²⁸

Statistical Analysis

Data Cleaning and Management of Missing Data

Standard analytic public use files for both survey waves were downloaded from the NCHS/Centers for Disease Control and Prevention Web site and imported into Stata 12 (Stata Corp, College Station, TX).²⁹ Data files for both survey years were concatenated. All observations were retained to ensure adequate variance estimation,²²⁻²⁴ and an indicator for survey year was created. A new stratification variable was created by using state, year, and sample type (cell phone vs landline) to accommodate differences in the sample design by survey year.

Missing data were evaluated within the sample of interest, children with ASD, for the variables of interest, race and ethnicity and service type. Of 5178 children with ASD, 44 were missing race and ethnicity data because of nonresponse, 11 reported “don’t know,” and 8 refused, resulting in 63 children (1.2%) missing race or ethnicity data. Across the service types, no missing data occurred because of nonresponse; “don’t know” responses ranged from 0% to 0.4%, and “refused” responses occurred once for child mental health need (0.001%). No adjustments were made for missing data.

Analytic Approach

Pooled analyses on the combined data sets were conducted according to Stata’s survey procedures. As is recommended for analyses with NS-CSHCN data,^{23,24} subpopulation approaches were used during analysis to ensure appropriate variance estimation when we analyzed the ASD sample alone,²²⁻²⁴ as opposed to deleting non-ASD

cases. The provided interview sampling weights and strata were used in the data analysis to control for the complex sampling plan. The prevalence of perceived service need between racial and ethnic groups was examined with bivariate methods to examine row and column independence by using Rao–Scott design-based *F* statistics^{30,31} to correct for the complex sampling design. Evaluation of the estimates and overlap of the 95% confidence intervals (CIs) for each service type allowed descriptive comparisons between racial and ethnic groups. Multivariate logistic regressions were conducted to examine the relationship between race and ethnicity and perceived service need after we controlled for predisposing, enabling, and child need variables. All analyses used an α of $P \leq .05$ to minimize type I error. No adjustments were made for multiple statistical tests.

RESULTS

Description of the Sample

Consistent with the epidemiology of ASD,³² ~80% the sample was male, regardless of race or ethnicity. The majority of the sample was white non-Hispanic (71.8%). Both English-speaking and Spanish-speaking Hispanic children were younger, on average, than other groups. Racial and ethnic groups differed on several enabling characteristics, including income, parent or caregiver education, insurance status, and household out-of-pocket costs (Table 1). Most children were reported to always have functional difficulties, regardless of race or ethnic category.

Perceived Need for Services

Bivariate analyses of perceived need for therapeutic, medical, and family support services revealed

greater perceived needs for certain services regardless of racial or ethnic group, as well as perceived service needs that varied by race and ethnic group (Table 2). Overall differences were found for specialty physician services, prescription medication, therapy services, and respite care. No overall differences were found for child or family mental health services in bivariate analyses. Across all racial and ethnic groups, prescription medication and therapy services were identified as needed most frequently (76.7% and 75.3%, respectively). The service types identified as least needed across all race and ethnic groups were family support services of respite care (24.5%) and family mental health care (27.2%). Approximately half of caregivers reported their child needed mental health services (52.4%), regardless of race or ethnicity, which was less than reported need for specialty physician services (59.5%) but greater than for family support services.

Variation in perceived service needs was identified among the 5 racial and ethnic groups (Table 2). Fewer black non-Hispanic children were reported to need specialty care from a physician than white non-Hispanic children (51.0% vs 62.3%). Fewer Hispanic English-speaking children (64.0%), Hispanic Spanish-speaking children (62.3%), black non-Hispanic children (70.5%), or non-Hispanic children of other races (70.6%) were reported to need prescription medication compared with white non-Hispanic children (81.5%). More English-speaking Hispanic children were reported to need therapy services than white non-Hispanic children (83.3% vs 73.3%). Black non-Hispanic children were less likely to have a perceived need for child mental health services than white

TABLE 1 Characteristics of Children With ASD by Race and Ethnicity Category

	White Non-Hispanic (<i>n</i> = 3717), % (95% CI)	Any Race, Hispanic English Speaking (<i>n</i> = 408), % (95% CI)	Any Race, Hispanic Spanish Speaking (<i>n</i> = 130), % (95% CI)	Black Non-Hispanic (<i>n</i> = 418), % (95% CI)	Other Race Non- Hispanic (<i>n</i> = 442), % (95% CI)	<i>P</i>
Age, mean y	10.0 (9.8–10.2)	8.8 (8.2–9.6)	7.8 (6.7–9.0)	9.8 (9.2–10.4)	9.9 (9.4–10.5)	<.001
Male	80.0 (77.7–82.1)	81.1 (73.6–86.9)	78.8 (66.6–87.3)	76.4 (70.0–81.8)	81.8 (74.6–87.4)	.76
% Federal poverty level						<.001
<200% FPL	34.1 (31.4–36.8)	48.1 (39.8–56.5)	76.7 (60.8–87.5)	67.3 (60.6–73.3)	36.9 (27.7–47.3)	
200%–400% FPL	35.1 (32.4–38.0)	31.4 (24.2–39.6)	20.1 (10.0–36.5)	18.2 (13.8–23.7)	31.8 (20.1–46.3)	
>400% FPL	30.8 (28.4–33.3)	20.5 (14.5–28.2)	3.2 (0.8–11.6)	14.5 (10.3–19.9)	31.3 (21.6–43.1)	
Insurance status						<.001
Private	54.0 (51.2–56.7)	39.9 (32.4–47.8)	19.1 (11.2–30.7)	21.4 (16.7–26.9)	39.6 (30.3–49.6)	
Public	24.8 (22.5–27.3)	36.4 (29.0–44.4)	51.0 (38.5–63.3)	55.2 (48.4–61.7)	37.5 (26.3–50.1)	
Private and public	16.1 (14.1–18.3)	17.5 (11.8–25.1)	14.9 (7.8–26.7)	17.8 (13.2–23.6)	16.8 (9.3–28.5)	
Other insurance	2.9 (2.2–3.8)	3.0 (1.2–7.3)	5.5 (0.8–29.4)	2.3 (1.1–4.6)	1.7 (0.6–4.7)	
Uninsured	2.2 (1.7–2.9)	3.3 (1.6–6.7)	9.5 (4.5–19.1)	3.4 (1.7–6.7)	4.5 (2.0–9.6)	
MSA status						<.001
Urban	79.9 (77.7–81.9)	91.3 (87.4–94.0)	97.5 (94.8–98.8)	87.9 (82.8–91.6)	85.3 (78.2–90.3)	
Household education ^a						<.001
Less than high school	4.2 (3.0–6.0)	12.8 (7.5–21.0)	29.4 (19.7–41.3)	11.5 (7.8–16.5)	4.8 (2.6–8.7)	
High school graduate	16.8 (14.7–19.1)	22.5 (16.3–30.1)	33.8 (22.4–47.5)	27.8 (21.7–34.9)	13.1 (8.1–20.5)	
More than high school	79.0 (76.4–81.4)	64.7 (56.2–72.4)	36.8 (25.8–49.4)	60.7 (53.7–67.4)	82.1 (74.3–88.0)	
Annual out-of-pocket costs						<.001
<\$500	49.8 (47.1–52.5)	57.9 (49.6–65.8)	84.3 (73.9–91.0)	75.6 (69.1–81.1)	68.9 (60.3–76.4)	
\$500–1000	12.4 (10.7–14.2)	5.3 (3.28.7)	9.9 (4.6–19.9)	7.1 (4.5–11.1)	7.1 (4.5–11.1)	
\$1000–5000	26.1 (23.8–28.5)	24.2 (17.6–32.3)	4.0 (1.8–8.7)	15.9 (11.2–22.0)	16.6 (11.9–22.8)	
>\$5000	11.8 (10.1–13.6)	12.6 (7.8–19.7)	1.8 (0.3–11.9)	1.4 (0.5–4.0)	7.3 (4.7–11.2)	
Condition impact on function						.04
Never	5.5 (4.5–6.7)	6.1 (2.9–12.6)	1.9 (0.6–5.6)	8.2 (5.1–13.0)	5.7 (2.5–12.2)	
Sometimes	28.0 (25.5–30.6)	26.1 (20.2–32.9)	24.4 (15.6–36.0)	36.4 (30.2–43.1)	23.7 (16.9–32.2)	
Usually	19.9 (17.8–22.1)	19.5 (13.8–26.9)	14.8 (7.8–26.3)	9.3 (6.7–12.8)	19.5 (13.8–26.8)	
Always	46.7 (44.0–49.4)	48.3 (40.3–56.3)	58.9 (46.3–70.4)	46.1 (39.4–53.0)	51.1 (40.1–62.1)	

Data sources: Centers for Disease Control and Prevention, National Center for Health Statistics, and National Survey of Children With Special Health Care Needs, 2005–2006 and 2009–2010.

^a Highest level of education of anyone in the child's household.

TABLE 2 Perceived Need for Medical, Therapeutic or Psychological, and Family Support Services Among Children With ASD Aged 0–17 in the 2005–2006 and 2009–2010 NS-CSHCN

	White Non-Hispanic (<i>n</i> = 3717), % (95% CI)	Any Race, Hispanic English Speaking (<i>n</i> = 408), % (95% CI)	Any Race, Hispanic Spanish Speaking (<i>n</i> = 130), % (95% CI)	Black Non- Hispanic (<i>n</i> = 418), % (95% CI)	Other Race Non- Hispanic (<i>n</i> = 442), % (95% CI)	Total (<i>n</i> = 5115), % (95% CI)	<i>P</i>
Medical management							
Specialty physician (<i>n</i> = 5109)	62.3 (59.7–64.9)	55.0 (46.9–62.8)	61.3 (49.2–72.1)	51.0 (44.2–57.7)	54.2 (43.1–64.9)	59.5 (57.1–61.8)	.04
Prescription medication (<i>n</i> = 5102)	81.5 (79.5–83.4)	64.0 (55.5–71.6)	62.3 (50.1–73.1)	70.5 (64.2–76.2)	70.6 (61.2–78.6)	76.7 (74.7–78.6)	<.001
Therapeutic and psychological							
Therapy (<i>n</i> = 5109)	73.3 (70.9–75.6)	83.3 (77.0–88.1)	85.0 (75.3–91.3)	76.9 (71.1–81.9)	74.7 (65.7–82.0)	75.3 (73.4–77.2)	.02
Child mental health care (<i>n</i> = 5091)	54.4 (51.7–57.1)	57.0 (49.0–64.7)	45.7 (33.8–58.2)	44.2 (37.6–51.0)	47.1 (36.0–58.5)	52.4 (50.1–54.8)	.06
Family support							
Respite care (<i>n</i> = 5115)	25.3 (22.9–27.8)	22.9 (17.3–29.7)	10.2 (5.4–18.4)	23.6 (18.4–29.9)	29.0 (18.1–42.9)	24.5 (22.4–26.8)	.05
Family mental health care (<i>n</i> = 5110)	28.5 (26.0–31.1)	32.5 (25.4–40.6)	21.6 (13.3–33.0)	20.8 (15.8–27.0)	23.5 (17.4–30.8)	27.2 (25.2–29.4)	.15

Data sources: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children With Special Health Care Needs, 2005–2006, and National Survey of Children With Special Health Care Needs, 2009–2010.

non-Hispanic children (44.2% vs 54.4%). Spanish-speaking Hispanic children were less likely to have

a reported need for respite care than non-Hispanic white children (10.2% vs 25.3%).

Multivariate Model of Service Need
After we controlled for survey year (2005, 2009), sample type

TABLE 3 Adjusted Odds Ratio and 95% CI of Multivariate Logistic Regression Models Associated With Perceived Need for ASD Services Among Children with ASD Aged 0–17 in the 2005–2006 and 2009–2010 NS-CSHCN

	Perceived Need for Medical Services		Perceived Need for Therapeutic or Psychological Services		Perceived Need for Family Support Services	
	Specialty Physician	Prescription Medication	Therapy	Child Mental Health Care	Family Mental Health Care	Respite Care
White non-Hispanic (<i>n</i> = 3717)	Reference	Reference	Reference	Reference	Reference	Reference
Any race, Hispanic English-speaking (<i>n</i> = 408)	0.81 (0.57–1.15)	0.44 ^a (0.30–0.64)	1.63 ^a (1.02–2.62)	1.15 (0.79–1.68)	1.24 (0.84–1.83)	0.88 (0.56–1.38)
Any race, Hispanic Spanish-speaking (<i>n</i> = 130)	1.54 (0.85–2.80)	0.53 ^a (0.29–1.00)	1.76 (0.85–3.67)	0.98 (0.54–1.78)	0.88 (0.45–1.75)	0.49 (0.23–1.03)
Black non-Hispanic (<i>n</i> = 418)	0.82 (0.58–1.16)	0.55 ^a (0.39–0.79)	1.68 ^a (1.09–2.59)	0.57 ^a (0.40–0.81)	0.67 ^a (0.45–0.99)	1.14 (0.75–1.74)
Other race non-Hispanic (<i>n</i> = 442)	0.82 (0.50–1.34)	0.57 ^a (0.37–0.86)	1.02 (0.65–1.58)	0.75 (0.47–1.22)	0.87 (0.58–1.29)	1.24 (0.70–2.19)

All multivariate logistic regressions adjusted for the following covariates: survey year (2005, 2009), sample type (cell phone vs landline), child gender, child age, household income, annual household out-of-pocket expenses, household urbanicity, child's insurance status, highest level of education in the child's household, and child functional status.

Data sources: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children With Special Health Care Needs, 2005–2006, and National Survey of Children With Special Health Care Needs, 2009–2010.

^a The odds ratio differs from 1.00 ($P \leq .05$).

(cell phone vs landline), gender, age, income, family out-of-pocket expenses, urbanicity, insurance status, household education, and child functional status, the association between race and ethnicity group and perceived need changed for specialty physician care, therapy services, family mental health care, and respite care (Table 3). As in the bivariate analyses, caregivers of minority children were significantly less likely than white non-Hispanic children to report a perceived need for prescription medication. Black non-Hispanic children were significantly less likely to report a need for child and family mental health care than white non-Hispanic children. English-speaking Hispanic children and black non-Hispanic children were significantly more likely than white non-Hispanic children to report need for therapy services.

DISCUSSION

This is the first study to our knowledge to identify racial and ethnic differences in perceived need for medical, mental health, and therapy services among a

large, nationally representative sample of children with ASD. Main findings regarding the entire sample and regarding racial and ethnic differences both warrant discussion.

Among the whole sample, the needs for prescription medication and therapy services were most frequently reported, and the needs for mental health and respite care services were least frequently reported. There are few published data on children with ASD with which to compare our results. Farmer et al⁹ found that $\geq 70\%$ of caregivers of children with ASD in a convenience sample survey reported a need for prescription medications, speech therapy, specialty physician care, occupational or physical therapy, and family mental health care; they did not report perceived need separately for different racial or ethnic groups. Similar to Farmer et al,⁹ we found that prescription medications and therapy services were identified as needed by $>70\%$ of the sample. In contrast, only about half of caregivers in our study reported that their child needed care from a specialist physician

or mental health care provider. These differences may result from sampling differences; our study includes a sample representative of the US population, whereas Farmer et al⁹ used an online ASD registry of families, whose respondents may differ on education, family income, and other important characteristics. Our findings on overall service needs also differ from literature on population-based studies of US children with special health care needs; specifically, estimates of therapy need nationally are 23.5% of all CSHCN.²⁸ Our study of children with ASD found greater specialty physician and therapy needs and lesser prescription medication and child mental health care needs than studies of children with a neurologic condition or CSHCN with a *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* condition.³³

The literature is mixed regarding perceived need for respite care among caregivers of children with ASD. Hodgetts et al¹⁸ found that the greatest identified need among 143 parents in Canada was for respite care (26% of sample). We

also found that ~25% of our sample reported a need for family support services, including respite care and family mental health treatment. These findings differ from those of Farmer et al,⁹ who found that nearly 60% of their sample needed respite care, and 68% of caregivers reported a need for family mental health care.

Our study found that perceived need for care differed by racial and ethnic group, even after we adjusted for many other variables. This finding raises questions about how parental beliefs about the perceived need for services affect their help-seeking behaviors and the interventions that their children with ASD receive. Parents prioritize care based on a variety of poorly understood factors that include beliefs about the etiology and course of ASD, lay referral networks and support networks, family structure and size, sociocultural values, and family finances.^{34,35} In a study of children with mental health conditions including autism, the majority of variables associated with perceived need were caregiver factors such as maternal and paternal education, parent stress, family support, and household income,³⁶ although child's race and ethnicity were also associated with need.

Research on children with other disorders has found that African American families identified stigma and "cultural mistrust" as common reasons for not seeking mental health care.³⁷ This finding is consistent with our finding that black non-Hispanic caregivers of children with ASD less frequently identified a need for child and family mental health services and prescription medications than white non-Hispanic caregivers of children with ASD. We also found that Hispanic caregivers less frequently reported a need for prescription

medications, a finding that has also been identified in studies of cultural differences in parent perception of medication treatment of attention-deficit/hyperactivity disorder (ADHD).^{38,39} Although children with ADHD and ASD differ in their needs for medications, the factors underlying Hispanic caregiver decisions regarding medications is a future area to be explored among parents of children with ASD.

Black non-Hispanic caregivers and English-speaking Hispanic caregivers perceived therapy services as needed more frequently than white non-Hispanic caregivers, suggesting that therapy services are more aligned with those parents' beliefs about the cause or course of ASD. The ADHD literature provides some support for this notion, including studies of African American parents, who were more likely than white families to explain their child's symptoms using non-medically based explanations,⁴⁰ use religious supports when treating their child,³⁸ and seek help from family members or respected professionals to treat their child.^{39,41} These families may be more likely to seek out treatment services that are more focused on functional outcomes⁴² such as communication skills or daily living skills rather than on curative approaches or medications that may be perceived as chemically restraining.

Limitations

Some study limitations should be noted. First, the NS-CHSCN is based on caregiver report, and therefore findings are subject to recall bias and to how well caregivers understood the questions. The NS-CSHCN was conducted in several languages to reduce language response bias. Second, diagnosis

and severity were not confirmed; however, the reported prevalence of children with ASD on this survey was close to the expected prevalence rate for the United States, suggesting that parents were not overreporting this diagnosis. Third, our study may underreport perceived need because NS-CSHCN skip patterns make it impossible to ascertain lack of a perceived need because a child is currently receiving a service. All NS-CSHCN service questions first inquire about a service need and then inquire about service receipt for those with an identified need. This approach to examining perceived need thus leaves out children who may need a service but whose caregiver does not report a need because they are currently receiving it.

CONCLUSIONS

Overall, caregivers of children with ASD may not perceive a need for certain services, including mental health services and family support services, both of which are frequently recommended in consensus guidelines. Families may not understand the importance of these treatments; health care practitioners should be aware of the system and family factors that may limit or prevent understanding of available treatments. Medical home models that emphasize family-centered communication, care coordination, and integration of technology to improve care quality across providers hold potential as a way to improve treatment of all children with ASD and their families.

Families of different racial and ethnic backgrounds may need additional communication and support in making treatment decisions for their children with ASD. Practitioners should recognize that caregivers of children with ASD may not pursue treatments

for a variety of reasons that have little to do with the child's clinical presentation. The greater salience of therapy services for different racial and ethnic groups should be explored more fully to elucidate perceived needs and their relationship to other, less understood phenomena explored in non-ASD literature, such as culture. Future research should explore sociocultural expectations closely related to race and ethnicity that guide caregiver selection of treatments to inform appropriate care models for providers and care recipients. Additionally, perceived

needs as reported by caregivers should be carefully considered in examining unmet need for service, which is often used as a marker for disparity.

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ABBREVIATIONS

ADHD: attention-deficit/hyperactivity disorder
ASD: autism spectrum disorder
CDC: Centers for Disease Control and Prevention
CI: confidence interval
CSHCN: children with special health care needs
FPL: federal poverty level
MSA: metropolitan statistical area
NCHS: National Center for Health Statistics
NS-CSHCN: National Survey of Children With Special Health Care Needs

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