

# Geographic Disparities in Treatment for Children with Autism Spectrum Disorder



Benjamin Zablotsky, PhD; Matthew J. Maenner, PhD; Stephen J. Blumberg, PhD

From the National Center on Birth Defects and Developmental Disabilities (MJ Maenner), Atlanta, Ga; and National Center for Health Statistics (B Zablotsky and SJ Blumberg), Hyattsville, Md

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Address correspondence to Benjamin Zablotsky, PhD, National Center for Health Statistics, Centers for Disease Control and Prevention, 3311 Toledo Rd, Hyattsville, MD 20782 (e-mail: [bzablotsky@cdc.gov](mailto:bzablotsky@cdc.gov)).

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## ABSTRACT

**OBJECTIVE:** Geographic differences may provide insight into what factors influence the likelihood that a child is diagnosed with autism spectrum disorder (ASD) in the United States; yet, there have been few nationally representative surveys that have explored this topic. The current study expands the limited literature by analyzing regional differences in ASD prevalence, service utilization, and the presence of unmet needs within a nationally representative sample of children.

**METHODS:** Data were drawn from the 2014–2016 National Health Interview Survey (NHIS), a nationally representative household survey of the noninstitutionalized US population. Children 3 to 17 years of age were included in the analytic sample. Prevalence estimates accounted for the complex survey design of the NHIS, and differences between geographic regions were compared using logistic/linear regressions with and without adjustment for child/family characteristics.

**RESULTS:** The prevalence of ASD was highest in the Northeast (3.0%), followed by the Midwest (2.4%), South (2.4%),

and West (2.3%). A significant difference was found between the Northeast and West ( $P < .05$ ); however, after accounting for child and family characteristics, this difference was no longer significant. Children with ASD in the Northeast were the most likely to have seen a specialist in the past year. Approximately 1 in 8 children with ASD experienced at least 1 unmet need, but there were no differences found by geographic region.

**CONCLUSIONS:** Although differences in prevalence were not significant after adjustment, service utilization differences remained. It appears that children with ASD in the Northeast utilize the greatest number of specialty services when compared to children with ASD from other parts of the country.

**KEYWORDS:** autism spectrum disorder; children; national survey; prevalence; treatment

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## WHAT'S NEW?

The current study expands the literature exploring geographic regions among children with autism spectrum disorder (ASD) using a nationally representative sample. Although children with ASD in the Northeast were found to have a greater utilization of specialized services, they were not less likely to have unmet needs when compared to children with ASD from other geographic regions.

AUTISM SPECTRUM DISORDER (ASD) refers to a group of neurodevelopmental disorders characterized by impairments in social communication and the presence of repetitive behaviors or restricted interests.<sup>1</sup> Over the past 2 decades, numerous studies have shown an overall trend of increasing ASD prevalence over time.<sup>2–5</sup> Previous studies have also consistently shown large geographic variation in the prevalence of ASD in the United States at a single time point.<sup>2,3,6</sup> Multiple factors are thought to contribute to regional variation in ASD prevalence, including

sociodemographic characteristics and availability of autism-related services.<sup>7–12</sup>

The most recent data from the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) Network yielded an overall prevalence of 1.7%, with surveillance sites in different states reporting ASD prevalence ranging from 1.3% to 2.9%.<sup>2</sup> ASD prevalence estimates based on administrative sources have also shown variability by geography.<sup>13,14</sup> These geographic differences in ASD prevalence are not fully understood, although the distribution of surveillance site estimates from ADDM may be the product of some sites relying on data from medical records alone while others utilized both medical records as well as educational records. Nonetheless, studies based exclusively on a review of existing records are usually not well suited to simultaneously explore the array of factors that might contribute to regional differences—especially for individual- or family-level characteristics.

In the United States, sociodemographic characteristics have been observed to be associated with ASD prevalence; for example, data from ADDM show that ASD

prevalence is positively associated with increasing neighborhood-level socioeconomic status.<sup>15</sup> One hypothesis for this association is that children of families with higher socioeconomic status are more likely to have access to services that may lead to ASD identification.<sup>16,17</sup> It has also been posited that geographic differences in the availability of services might in themselves drive geographic differences in ASD prevalence,<sup>18</sup> as previous research has suggested that a greater availability of autism services in urban areas might contribute to higher ASD prevalence in urban versus rural areas.<sup>19,20</sup>

An investigation of regional service utilization patterns among children with ASD may also provide insight into factors that may contribute to a higher ASD prevalence. In fact, 2 administrative studies of health service utilization (one utilizing data from the Healthcare Cost and Utilization Project, the other from privately insured beneficiaries) have shown higher utilization of services in the Northeast than other regions of the country among children with ASD.<sup>21,22</sup>

As the observed prevalence of ASD continues to change over time, there is a need to investigate regional differences in ASD prevalence using recent and population-based information. Large national surveys such as the National Health Interview Survey (NHIS) from the National Center for Health Statistics are ideally suited for this type of investigation. The NHIS is designed to be nationally representative of the noninstitutionalized US population and collects timely, in-depth information on health conditions, health service utilization, and family sociodemographic characteristics. The primary goal of this study is to use recent NHIS data for children ages 3 to 17 years to examine 1) whether regional differences in ASD prevalence exist in the United States, and 2) whether health service utilization and unmet needs differ among children with ASD living in different regions of the United States. Given notable health and service disparities seen between children living in rural and urban settings,<sup>23,24</sup> a secondary analysis explores whether differential effects are seen by metropolitan statistical area (MSA) status within different regions of the United States.

## METHODS

### DATA SOURCE

The study used data from the 2014–2016 NHIS. The NHIS is generally an in-person interview conducted in the respondent's home, although some follow-up data collection may be conducted by telephone. The survey consists of 3 components: a family interview (collecting information about all members of the family), a sample adult interview (collecting detailed information about 1 randomly selected adult per family), and a sample child interview (collecting detailed information about 1 randomly selected child per family). The sample child interview is completed by a knowledgeable adult respondent, typically the child's parent (approximately 91% of cases). Data for the current analysis utilized data from both the child and family interview. Response rates for the 2014–2016 Sample Child component of the NHIS ranged from 61.9%

to 66.6%. For more information about NHIS, visit <https://www.cdc.gov/nchs/nhis.htm>.

### SAMPLE

A total of 30,530 children between the ages of 3 and 17 years were included in the analytic sample, of which 711 children were ever diagnosed as having autism spectrum disorder. Missing data on ASD occurred in approximately 0.9% of cases.

### MEASURES

#### AUTISM SPECTRUM DISORDER

An autism spectrum disorder case was defined based on an affirmative answer to the question “Has a doctor or other health professional ever told you that [child's name] had autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?”

#### GEOGRAPHIC REGION

States were grouped into 4 regions used by the US Census Bureau: *Northeast* (Maine, Vermont, New Hampshire, Massachusetts, Rhode Island, Connecticut, New York, New Jersey, Pennsylvania), *Midwest* (Ohio, Illinois, Indiana, Michigan, Wisconsin, Minnesota, Iowa, Missouri, North Dakota, South Dakota, Kansas, Nebraska), *South* (Delaware, Maryland, District of Columbia, West Virginia, Virginia, Kentucky, Tennessee, North Carolina, South Carolina, Georgia, Florida, Alabama, Mississippi, Louisiana, Oklahoma, Arkansas, Texas), and *West* (Washington, Oregon, California, Nevada, New Mexico, Arizona, Idaho, Utah, Colorado, Montana, Wyoming, Alaska, Hawaii).

#### SOCIODEMOGRAPHIC CHARACTERISTICS

The sociodemographic characteristics examined included the child's sex and age (broken into age groups of 3–7, 8–12, and 13–17 years of age); race/ethnicity (non-Hispanic white, non-Hispanic black, non-Hispanic other, or Hispanic); insurance status (any private, public only [Medicaid, Children's Health Insurance Program, and other state-sponsored coverage], or uninsured); family income recorded as a percentage of the federal poverty level (<100%, 100%–199%, 200%–399%, or ≥400%); educational attainment of the highest educated family member (less than high school education, high school education or General Education Diploma (GED), or greater than high school education); family structure (2 parents, single parent, or other); MSA status (large [county or group of counties including an urbanized area with a population of at least 50,000 and having a combined population total of 1 million or more], small [county or group of counties including an urbanized area with a population of at least 50,000 but having a combined population total of less than 1 million], or not in a MSA); and survey year.

#### SERVICE UTILIZATION CHARACTERISTICS

Respondents were asked a series of questions about the types of providers their child had seen in the past 12 months.

The providers included a generalist (pediatrician, family medicine doctor, internal medicine doctor); a specialist; a mental health professional (psychiatrist, psychologist, psychiatric nurse, clinical social worker); or a therapist (physical therapist, speech therapist, respiratory therapist, audiologist, occupational therapist). A composite measure of specialty care was defined as children who had seen a specialist, mental health professional, or therapist in the past 12 months. Respondents were also asked whether, and how many times, their child had received services at a series of locations, including a doctor's office or clinic, an emergency department, or their own home. It was not possible to ascertain what specific services were received at each location.

### UNMET NEEDS

Respondents were asked whether their child needed a series of services but was unable to get them because they could not be afforded, including 1) medical care, 2) seeing a specialist, 3) follow-up care, 4) prescription medicines, and 5) mental health care or counseling.

### STATISTICAL ANALYSIS

Demographic differences between regions among children with ASD were compared using Rao-Scott chi-square tests that accounted for the survey design (presented as *F* values); significant overall *F* tests were followed up with bivariate comparisons between regions and the demographic characteristic. Multivariate logistic regressions examined differences in ASD prevalence among geographic regions adjusted for child (age, sex, race/ethnicity, insurance status) and family (federal poverty level, family structure, highest adult education level, MSA status) characteristics and survey year. Additional multivariate logistic regressions examined service utilization differences and unmet needs among children with ASD by geographic regions both unadjusted and adjusted for child and family characteristics. As part of a secondary analysis, a series of interaction terms between region and MSA status were included in adjusted models to determine if geographic density had a differential effect in different parts of the country.

All analyses were conducted using Stata 14.0<sup>25</sup> and made use of the survey sampling weights and the appropriate procedures to account for the complex survey design of the NHIS, as well as the imputed income data provided by the National Center for Health Statistics. Weights accounted for nonresponse to the questionnaire and included a raking adjustment.

## RESULTS

### PREVALENCE

Between 2014 and 2016, the prevalence of ASD among children 3 to 17 years of age in the United States was 2.5% (95% confidence interval [CI], 2.2–2.7). The prevalence of ASD was 3.0% (95% CI, 2.4–3.8) in the Northeast, 2.4% (95% CI, 2.0–3.0) in the Midwest, 2.4% (95% CI, 1.9–2.9) in the South, and 2.3% (95% CI, 1.9–2.7) in

the West. A significant difference was found between the Northeast and West (odds ratio, 0.74; 95% CI, 0.55–0.99;  $P < .05$ ). However, after accounting for child and family characteristics, this difference was no longer significant (adjusted odds ratio, 0.88; 95% CI, 0.64–1.20;  $P = .42$ ). A series of regression sensitivity analyses was used to examine the impact of each covariate in this adjusted model, revealing that the inclusion of children's race and ethnicity (non-Hispanic white vs all other races) had the greatest impact in shifting the association from significant to non-significant.

### DEMOGRAPHICS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Basic demographics by geographic region among children diagnosed with autism spectrum disorder appear in Table 1. Children with ASD in the Northeast and Midwest were more likely to be non-Hispanic white than children with ASD from other regions; children with ASD from the West were more likely to be Hispanic than children with ASD from other regions. Children with ASD in the Midwest were most likely to be living in a single-parent household than children with ASD in other regions but were less likely to be living in a household where the highest educated member had less than a high school education when compared to children with ASD from the South and West. Children with ASD were distributed similarly by MSA status across the 4 geographic regions, with approximately 7 out of 8 children with ASD living in an MSA.

### SERVICE UTILIZATION AMONG CHILDREN WITH AUTISM SPECTRUM DISORDER

More than 9 out of 10 children with ASD had received care at a doctor's office or clinic, emergency department, or their own home in the past 12 months, and approximately 4 in 5 children with ASD had multiple visits at 1 of these locations (Table 2). Additionally, the vast majority of children with ASD had seen at least 1 of the 4 provider types within the past year (95.2%; standard error [SE], 1.2). In unadjusted models, children with ASD in the South were least likely to have received care at home over the past year, whereas children with ASD in the Northeast were more likely to have seen a therapist compared to children with ASD in the South and West. These differences remained significant in adjusted models accounting for child and family characteristics. There were no differences across regions in the proportion of children with ASD who received care multiple times in a given location.

### SPECIALTY CARE

Approximately 4 in 5 children with ASD saw a specialist, mental health professional, or therapist in the past 12 months (78.6%; SE, 2.0) (Figure). In unadjusted models, children with ASD in the Northeast were the most likely to have seen at least 1 type of specialist. This difference remained significant after accounting for child and family characteristics. Although about half of the children with ASD in the Northeast (54.5%; SE, 5.5) and Midwest

**Table 1.** Demographic Characteristics of Children With Autism Spectrum Disorder, by Geographic Region

	Total (N = 711) % (SE)	Northeast (n = 145) % (SE)	Midwest (n = 148) % (SE)	South (n = 234) % (SE)	West (n = 184) % (SE)	F Value
<b>Child characteristics</b>						
Age						0.63
3–7 y	30.1 (2.4)	32.7 (5.3)	24.3 (4.0)	30.6 (4.6)	32.7 (4.9)	
8–12 y	38.6 (2.5)	40.6 (6.0)	37.7 (5.5)	36.9 (4.0)	40.5 (5.1)	
13–17 y	31.3 (2.5)	26.7 (5.5)	38.0 (5.5)	32.5 (4.5)	26.8 (4.6)	
Sex						0.02
Female	75.3 (2.3)	24.3 (5.2)	24.3 (4.3)	24.6 (3.8)	25.9 (4.9)	
Male	24.7 (2.3)	75.7 (5.2)	75.7 (4.3)	75.4 (3.8)	74.1 (4.9)	
Race and ethnicity						6.18***
Non-Hispanic white	60.7 (2.4)	69.8 (5.0)	75.5 (4.1)	54.3 <sup>†,‡</sup> (3.8)	48.2 <sup>†,‡</sup> (5.4)	
Non-Hispanic black	16.8 (2.1)	13.6 (4.1)	13.5 (3.4)	25.6 <sup>‡</sup> (4.3)	8.2 <sup>§</sup> (2.8)	
Non-Hispanic other and multiple race	4.6 (1.0)	0.6 (0.4)	4.0 <sup>†</sup> (1.8)	3.0 (1.6)	11.3 <sup>†,‡,§</sup> (2.9)	
Hispanic	18.0 (1.9)	16.0 (3.6)	7.0 <sup>†</sup> (2.1)	17.1 <sup>‡</sup> (3.2)	32.3 <sup>†,‡,§</sup> (5.2)	
Insurance type						3.15**
Any private	50.8 (2.6)	62.4 (5.4)	54.6 (4.8)	42.8 <sup>†</sup> (4.8)	49.2 (5.8)	
Public only <sup>  </sup>	46.4 (2.6)	36.1 (5.3)	44.8 (4.8)	51.4 <sup>†</sup> (4.5)	49.3 (5.9)	
Uninsured	2.8 (0.8)	1.5 (0.9)	0.6 (0.4)	5.7 <sup>‡</sup> (2.1)	1.6 <sup>§</sup> (0.7)	
<b>Family characteristics</b>						
Federal poverty level						1.38
<100%	21.4 (2.1)	15.3 (3.4)	24.8 (4.5)	23.2 (4.0)	20.7 (4.3)	
100%–199%	28.8 (2.2)	26.1 (5.6)	26.0 (4.4)	31.2 (3.4)	30.0 (5.1)	
200%–399%	25.9 (2.1)	23.2 (4.3)	30.7 (3.9)	21.8 (3.7)	30.4 (5.3)	
≥400%	23.8 (2.1)	35.4 (5.5)	18.6 (3.8)	23.8 (3.2)	18.8 (4.1)	
Family type						2.55*
Two parents	63.7 (2.4)	67.5 (4.8)	56.5 (4.4)	62.7 (4.5)	69.2 (5.3)	
Single parent	31.0 (2.3)	27.4 (4.5)	42.6 <sup>†</sup> (4.3)	28.6 <sup>‡</sup> (4.1)	26.5 <sup>‡</sup> (4.6)	
Other	5.3 (1.2)	5.1 (2.9)	0.8 <sup>†</sup> (0.5)	8.7 <sup>‡</sup> (2.5)	4.3 <sup>‡</sup> (1.8)	
Highest educated member						2.41*
Less than high school	8.9 (1.6)	4.8 (1.9)	3.3 (1.3)	14.1 <sup>†,‡</sup> (3.6)	9.8 <sup>‡</sup> (3.2)	
High school diploma or GED	19.0 (1.9)	19.9 (3.9)	24.7 (4.7)	18.1 (3.5)	13.9 (3.5)	
More than high school	72.1 (2.1)	75.3 (4.4)	71.9 (4.7)	67.8 (3.7)	76.3 (4.2)	
MSA status <sup>¶</sup>						2.07
In MSA	87.8 (1.7)	92.8 (2.7)	81.3 (5.0)	87.2 (2.9)	91.2 (2.5)	
Not in MSA	12.2 (1.7)	7.3 (2.7)	18.7 (5.0)	12.8 (2.9)	8.8 (2.5)	

GED indicates General Education Diploma; SE, standard error; MSA, metropolitan statistical area.

<sup>†</sup>Significantly different from children in the Northeast ( $P < .05$ ) using bivariate logistic regression.

<sup>‡</sup>Significantly different from children in the Midwest ( $P < .05$ ) using bivariate logistic regression.

<sup>§</sup>Significantly different from children in the South ( $P < .05$ ) using bivariate logistic regression.

<sup>||</sup>Public insurance includes Medicaid, Children's Health Insurance Program, and other state-sponsored coverage.

<sup>¶</sup>A metropolitan statistical area consists of a county or group of counties that includes an urbanized area with a population of at least 50,000.

\* $P < .05$ .

\*\* $P < .01$ .

\*\*\* $P < .001$ .

(47.6%; SE, 5.5) had seen multiple types of specialists, only approximately 1 in 3 children with ASD from the South (36.2%; SE, 4.2) and West (34.6%; SE, 5.1) had seen multiple types of specialists.

## UNMET NEEDS

Overall, approximately 1 in 8 children with ASD (12.1%; SE, 2.0) experienced at least 1 unmet need in medical care, seeing a specialist, follow-up care, prescription medication, or mental health care or counseling due to cost—9.3% (SE, 3.6) of children with ASD in the Northeast, 8.5% (SE, 2.7) of children with ASD in the Midwest, 15.2% (SE, 4.0) of children with ASD in the South, and 13.4% (SE, 4.0) of children with ASD in the West (Table 3). Overall there was not a significant difference found by region either adjusted or unadjusted, although

children in the South with ASD were significantly more likely to have an unmet medical care need than children with ASD in the West after adjustment for child and family characteristics.

## DISCUSSION

### PREVALENCE

Based on data from the 2014–2016 NHIS, approximately 1 in 40 (2.5%) children ages 3 to 17 years had ever been diagnosed with ASD. Children in the Northeast had the highest prevalence compared to other geographic regions in the country. This is consistent with findings from the recent ADDM Network, where the New Jersey surveillance site reported the highest ASD prevalence,<sup>2</sup> and from the Nurses' Health Study II, where children in the "New England" area were more likely to be diagnosed

**Table 2.** Service Utilization of Children With Autism Spectrum Disorder, by Geographic Region

	Total (N = 711) % (SE)	Northeast (n = 145) % (SE)	Midwest (n = 148) % (SE)	South (n = 234) % (SE)	West (n = 184) % (SE)	F Value
<b>Locations received care in past 12 mo</b>						
Any office visits	93.1 (1.6)	97.2 (1.7)	91.4 (4.3)	90.7 (3.1)	95.3 (2.0)	1.17
Multiple office visits	80.9 (2.0)	86.7 (3.6)	78.5 (4.5)	77.3 (3.7)	84.0 (3.4)	1.36
Any emergency room visit	22.1 (2.2)	29.7 (5.3)	22.0 (4.3)	21.3 (3.8)	16.8 (4.1)	1.29
Multiple emergency room visits	8.5 (1.3)	10.4 (3.0)	11.5 (3.2)	7.3 (2.0)	5.9 (2.3)	0.95
Any home visit	6.8 (1.4)	11.6 (4.2)	9.7 (3.4)	2.0 <sup>†‡</sup> (0.8)	7.5 <sup>§</sup> (3.0)	3.09*
Multiple home visits	6.1 (1.4)	9.9 (4.1)	8.3 (3.4)	1.8 (0.8)	7.5 (3.0)	2.38
Any of these locations	94.0 (1.6)	97.8 (1.5)	91.9 (4.3)	92.2 (3.1)	95.4 (2.0)	0.95
Multiple visits at any of these locations	81.5 (2.0)	88.0 (3.5)	78.5 (4.5)	78.2 (3.7)	84.2 (3.4)	1.45
<b>Providers seen in past 12 mo</b>						
Generalist	88.3 (1.7)	94.3 (2.3)	83.9 (3.9)	88.1 (3.2)	87.6 (2.8)	1.56
Specialist	35.0 (2.5)	42.2 (5.6)	37.6 (4.8)	33.5 (4.4)	28.5 (4.8)	1.25
Mental health professional	50.4 (2.5)	56.1 (5.7)	54.7 (4.4)	45.7 (4.5)	48.6 (5.1)	1.07
Therapist	50.4 (2.6)	60.6 (5.3)	51.6 (5.2)	40.6 <sup>†‡</sup> (4.9)	41.0 <sup>†‡</sup> (4.7)	3.43*
Any of these providers	95.2 (1.2)	99.3 (0.6)	93.3 (2.3)	93.3 (2.8)	96.6 (1.3)	2.33

SE indicates standard error.

†Significantly different from children in Northeast after adjustment for child and family characteristics ( $P < .05$ ).

‡Significantly different from children in Midwest after adjustment for child and family characteristics ( $P < .05$ ).

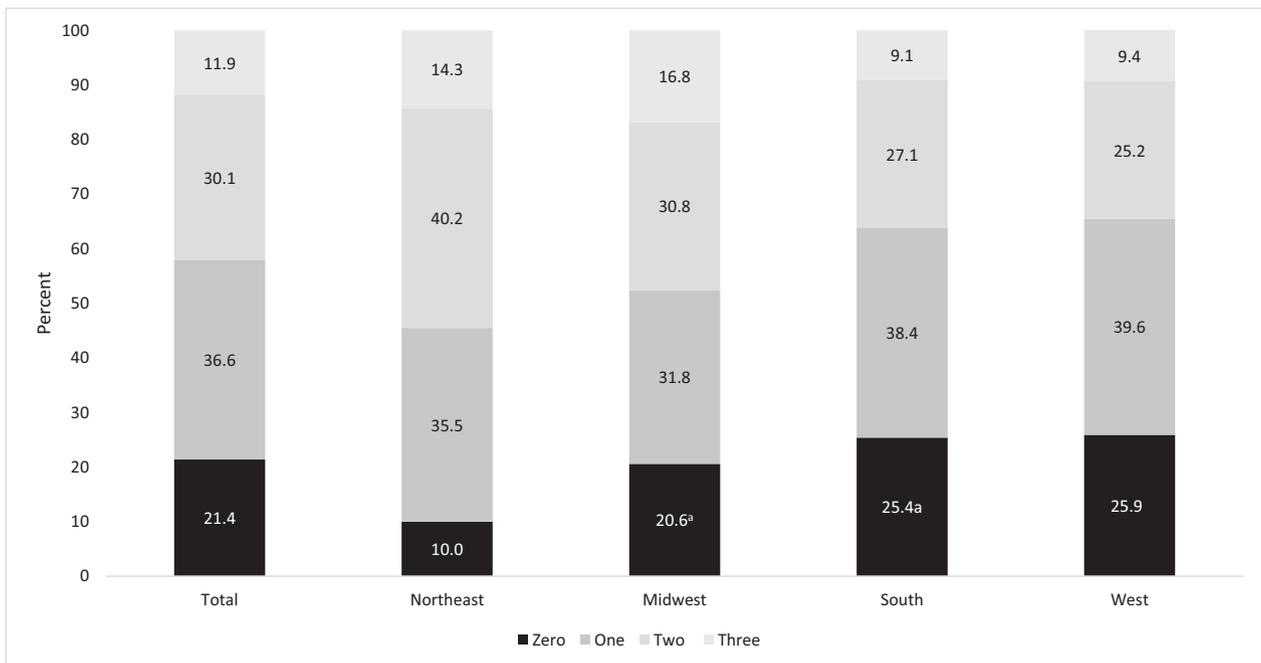
§Significantly different from children in South after adjustment for child and family characteristics ( $P < .05$ ).

\* $P < .05$ .

with ASD.<sup>18</sup> Although the Nurses' Health Study II found that race and ethnicity could not fully explain geographic differences, it is important to note that neither of these studies recruited a representative sample of children, particularly as it relates to race and ethnicity.

The present study, however, did find that regional differences could be explained by the inclusion of child and family characteristics. A sensitivity analysis revealed that the child's race and ethnicity had the greatest impact in

attenuating the magnitude of the association and also resulted in a shift from significant to non-significant. More specifically, because non-Hispanic white children were more likely to be diagnosed with ASD and children in the Northeast were more likely to be non-Hispanic white relative to other regions,<sup>26</sup> controlling for regional differences in the prevalence of non-Hispanic white children was sufficient to reduce the regional differences from statistically significant to non-significant.



<sup>a</sup>Significantly different from children in Northeast after adjustment for child and family characteristics ( $P < .05$ ).

**Figure.** Number of types of specialists seen in the past year among children with autism spectrum disorder, by geographic region.

**Table 3.** Unmet Medical Needs Due to Cost in Past Year Among Children with Autism Spectrum Disorder, by Geographic Region

	Total % (SE)	Northeast % (SE)	Midwest % (SE)	South % (SE)	West % (SE)	F Value
Medical care	1.8 (0.7)	0.8 (0.6)	1.1 (1.1)	3.8 (1.8)	0.2 <sup>†</sup> (0.2)	3.07*
Seeing a specialist	6.3 (1.4)	2.9 (2.3)	6.7 (2.5)	8.9 (2.8)	4.9 (2.6)	0.92
Follow-up care	4.2 (1.2)	2.9 (2.3)	3.9 (1.8)	7.2 (2.8)	0.7 (0.6)	2.19
Prescription medicine	4.4 (1.0)	4.2 (2.8)	4.5 (2.0)	4.5 (1.6)	4.1 (2.1)	0.01
Mental health care or counseling	4.2 (1.0)	2.3 (1.4)	3.9 (2.0)	3.9 (1.5)	6.6 (2.6)	0.80
Any unmet need	12.1 (2.0)	9.3 (3.6)	8.5 (2.7)	15.2 (4.0)	13.4 (4.0)	0.85

SE indicates standard error.

<sup>†</sup>Significantly different from children in the South after adjustment for child and family characteristics ( $P < .05$ ).

\* $P < .05$ .

It is also worth noting that MSA status was not significantly associated with prevalence nor was there a significant difference found by MSA distribution across regions among children with ASD, which are intriguing findings given that previous research has found such a relationship.<sup>19,20</sup> In addition, the secondary analysis, designed to explore whether geographic density may have a differential effect in the 4 geographic regions, did not produce any significant interactions between MSA status and region, after adjustment for child and family characteristics. A previous US study reported that urban areas were more likely to be geographically closer to autism-related service providers and diagnosticians and that geographic proximity to these providers was associated with an earlier age of ASD diagnosis.<sup>10</sup> These studies differ from the present study in several important ways, as they covered time periods at least 10 years older than NHIS data used in this study, used different measures of “urbanicity,” and covered portions of a single US state or Denmark; also, the data were obtained—at least in part—from existing registries or from health care providers.

### SERVICE UTILIZATION AND SPECIALTY CARE

The vast majority of children with ASD had seen a health care provider in the past year (95.2%), with approximately half of all children receiving care from a mental health professional (50.4%) or a therapist (50.4%). Yet, children with ASD in the Northeast were the most likely to have received any specialty care (specialist, mental health professional, or therapist) in the past year. In the South and West, approximately 1 in 4 children with ASD had not received any specialty care, and less than half had seen multiple specialists, significantly lower proportions than children with ASD in the Northeast and Midwest. Children with ASD in the South and West were also less likely to have seen a therapist than children with ASD in the Northeast and Midwest.

Children with ASD in the South were the least likely to have received care at home compared to children with ASD throughout the country. Overall, however, children with ASD were not more likely to have received care multiple times at any 1 location over the past 12 months, nor were any of the interaction terms significant as part of the secondary analysis. Previous research utilizing Medicaid claim data found that, although the proportion of children with ASD receiving services in urban versus rural settings did not differ significantly, the number of services used was higher in urban areas.<sup>27</sup>

Service availability could affect the likelihood of a child receiving an ASD diagnosis. For example, Hoffman and colleagues<sup>18</sup> found differing odds of ASD diagnosis depending on where the child was located, with children living in New England having the greatest odds of being diagnosed with ASD and children living in central and southern US having lower odds of receiving a diagnosis. The authors hypothesized that available diagnostic resources and services (such as those provided by the school under a child’s Individualized Education Program) may explain these differences, assuming that increased use of specialists reflects greater availability of specialists. The hypothesis that service availability influences ASD diagnosis and ASD prevalence (see also Hill and colleagues<sup>28</sup>) is consistent with the present study’s unadjusted prevalence estimates and service utilization patterns. The exact mechanisms that may lead to these regional differences are not entirely clear. For example, Mazumdar and colleagues<sup>12</sup> analyzed smaller “clusters” of ASD in California neighborhoods and concluded that neither “institutional diagnostic dynamics” nor families moving to areas with greater services explained differences seen in ASD prevalence.

### UNMET NEEDS

Although children in the Northeast had the highest ASD prevalence and children with ASD in the Northeast had the greatest service utilization and most specialty care encounters, children with ASD in the Northeast were not less likely to have unmet needs regardless of geographic region. In contrast, a previous analysis of data on children with special health care needs (CSHCN) (defined broadly) from the 2009–2010 National Survey of Children with Special Health Care Needs did identify regional differences in unmet need; in general, it reported lower unmet need in the Northeast or Midwest compared to the West and the South.<sup>29</sup> Similarly, data from the 2005–2006 National Survey of Children with Special Health Care Needs showed regional differences in unmet need for health services among children with ASD; for example, there was more unmet need in the West than the Northeast.<sup>8,30</sup>

It is unknown if differences between the current study and these previous findings are a reflection of changes in service availability for children with ASD over the past decade or perhaps differences between children with ASD with or without special health care needs. Given that children with ASD require additional services and experience greater levels of impairment than children with other

special health care needs,<sup>31</sup> findings for CSHCN may not be generalizable to children with ASD. However, it is worth noting that the secondary analysis did not find differential effects of MSA status and region, nor MSA status alone, allowing for the possibility that some of the previously identified barriers to accessing care in rural settings for children with ASD<sup>32,33</sup> may have resolved. Additional research into the impact of efforts to train practitioners to work in rural environments, such as those recommended by the American Medical Association,<sup>34</sup> may provide insight into changes seen.

### LIMITATIONS

The NHIS has notable strengths in its large sample size and high response rate; however, caution regarding estimates is warranted because of several survey-related limitations. The reliance on parent reports could result in misreporting of child's ASD diagnosis; such reports may also be subject to recall biases. Additionally, parents' reports were not validated through clinical evaluation or educational records, and parents were only asked to reflect on lifetime diagnoses of ASD rather than current diagnoses; therefore, children who have lost their original diagnosis would be included in the sample of children with ASD and the reported prevalence. Previous research has found that most ASD diagnoses persist, but there are reasons children who received a diagnosis in the past may no longer meet the criteria for a diagnosis, including, but not limited to, maturation, misdiagnosis, and effective treatment.<sup>35</sup> Some children may also be less likely to meet diagnostic criteria for ASD after the introduction of revised diagnostic criteria with the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition, in 2013.<sup>36</sup> Additionally, although data were pooled over 3 years of NHIS interviews, there is still the potential for the small sample size of children with ASD to impact the interpretability of some findings; namely, there may not be sufficient power to rule out a true difference between regions when the prevalence of an outcome for children with ASD was low. Finally, as the NHIS is a survey of the non-institutionalized population, children living in places other than the household (eg, long-term care facilities) are not included in the estimates.

### CONCLUSIONS

Although differences seen in the prevalence of ASD could be explained by child and family characteristics, such was not the case for differences seen in the receipt of specialized services by region. Additional research is warranted to further explore how child and family characteristics may lead to a disproportionate receipt of services or the ability to receive an ASD diagnosis.

### DISCLAIMER

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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