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Parent-Reported Severity and Health/Educational Services Use among U.S. Children with Autism: Results from a National Survey

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Abstract

Objective—Little national data exist regarding service use patterns for children with autism spectrum disorder (ASD) of varying severity. This study aimed to assess the relationship between parent-reported severity and use of educational and health care services.

Method—Data from the 2011 Survey of Pathways to Diagnosis and Services were used to examine a nationally-representative sample of 1420 US children aged 6–17 years with ASD, with or without developmental delay and intellectual disability. Weighted multivariable logistic regression assessed associations of parent-reported ASD severity and child sociodemographic characteristics with school-based therapy, non-school-based therapy, behavioral interventions, and specialty provider visits.

Results—Higher parent-reported ASD severity was associated with increased likelihood of current use of school-based therapy (Adjusted Odds Ratio [AOR] 4.08, 95% Confidence Interval 1.85–8.98), non-school-based therapy (AOR 3.60 [1.95–6.66]), and behavioral interventions (AOR 2.30 [1.22–4.34]), as well as regular specialty provider visits (AOR 2.99 [1.38–6.46]). Though rates of service use were generally highest among children with severe ASD, non-school-based therapy and behavioral interventions were only used by about half of children with severe ASD, and about 1 in 4 children with mild ASD were using none of the therapies asked about.

Conclusion—Parent-reported severity is associated with increased therapy and specialty provider service use among children with ASD. However, substantial variability exists in service use across levels of severity.

Keywords

autism spectrum disorder; severity; therapy service; site of care; specialty provider visit

Conflicts of Interest: None.

INTRODUCTION

Autism spectrum disorder (ASD) is a chronic neurodevelopmental condition which usually requires ongoing support in medical, educational, and vocational systems throughout the lifespan.¹ Data from the Centers for Disease Control and Prevention (CDC) classifies one in 68 school-aged children as having an ASD diagnosis, and comparisons of condition prevalence over time suggest a leveling off after rapid recent increases.^{2,3} This high prevalence is placing greater demands on already overburdened educational and health care systems.

Previous research shows that children with ASD are more likely to have trouble accessing and using health care and educational services compared to children with other developmental and/or mental health conditions.^{4,5} Additionally, among children with ASD, service use varies substantially, both by condition-specific factors (e.g., comorbid intellectual disability)⁶ and by child and family factors (e.g., race/ethnicity).^{7,8} As a result, there is a need to understand the drivers of ASD-related service use in both the health care and educational settings as an important first step toward guiding limited fiscal and personnel resources.

Interventions for ASD in the educational setting are provided through the Individuals with Disabilities Education Act (IDEA), Part B.⁹ Although coverage of services through IDEA incurs no cost to families, availability may be subject to federal and state budget limitations and local agency staffing; therefore, the type and supply of therapy may be limited. Interventions for ASD in the health care setting are typically paid for through medical insurance and/or out-of-pocket. Though insurance coverage of ASD-related therapies has expanded, families may experience coverage limits, funding caps, and cost-sharing that restrict use. As a result, families often confront complicated limits and choices in terms of accessing therapies for their children with ASD, and individual children may not receive all of the therapies that could benefit them.

Though the ideal complement of therapy modalities for a child with ASD is still unknown, guidelines provide evidence-based ratings of medical and non-medical interventions. While more evidence is needed for all types of ASD intervention, comprehensive behavioral intervention and modification programs, such as applied behavioral analysis, have the strongest evidence base, particularly for preschool and elementary-school age children (under age 12).^{10–13} There is less evidence for such therapies in adolescence.¹⁴ Moderate evidence exists for the effectiveness of social skills training, particularly for older children and young adults with higher-functioning autism or what was previously classified as Asperger's disorder, and for parent-training programs that foster younger children's (age <12 years) social skills and manage challenging behaviors.^{1,10,13,14} While there is little evidence to support educational interventions generally,¹³ specific educational interventions (e.g., joint attention interventions, Reciprocal Imitation Training, play skill programs) have a moderate evidence base.¹³ Other interventions, such as many complementary and alternative medicine therapies for ASD, lack evidence supporting their use for all age groups.¹⁵

As the severity of a child's ASD may influence which therapy modalities he or she receives, this investigation specifically focused on the relationship between parent-reported ASD severity and national ASD therapy use patterns. ASD severity has been defined in slightly different terms across studies.¹⁶ Some researchers have identified severity as the functional impairments caused by core ASD symptoms; others have identified severity as the presence of additional diagnoses, such as intellectual disability and emotional and behavioral problems.^{17–19} ASD severity may have a different meaning to parents than providers. In a 2015 study, Zablotsky and colleagues¹⁹ showed that child symptom ratings, child adverse impacts, and family adverse impacts differentiated children with parent-reported mild versus moderate ASD; however, only adverse family impacts differentiated children with parent-reported severe versus moderate ASD. As a result, parent severity ratings may represent complex interconnections between level of child impairment and child and family functioning.

Despite the limitations of parent-reported severity ratings, these ratings are important as they represent how a parent thinks of his or her child in relation to other children with ASD and may also reflect the child's service needs. Furthermore, from a policy standpoint, it is important to understand typical health care and educational treatment profiles of children across the autism spectrum when forecasting services use. From a clinical perspective, providers may want to take typical treatment profiles into consideration when recommending services to an individual child or family.

No prior studies have addressed the relationship between ASD severity and setting of service use. However, two studies previously examined ASD service use patterns in a national sample. Magaña, Parish, and Son⁸ focused on disparities among Latino and white children with ASD. Their study revealed that children with severe ASD (as indicated by functional severity) were more likely to receive behavioral interventions (BI), social skills training, and occupational therapy than children with mild ASD. This study did not assess setting of care (school versus non-school), which might be an important marker of services accessibility. The other study that examined specific ASD treatment types did distinguish treatment settings, but did not account for ASD severity in most analyses. Bilaver, Cushing, and Cutler's²⁰ study was the first to detail educational service receipt among US children with ASD. The authors assessed rates of educational services (defined as behavioral therapy, speech or language therapy, occupational therapy, and mental health services) individually and by their location of receipt (school or elsewhere). The research indicated that a larger proportion of preschool-aged children with ASD received speech and occupational therapy at school, rather than behavioral therapy which has the strongest evidence base in ASD. Overall, children with ASD were more likely to receive any amount of services at school rather than outside of school.²⁰ The study only scrutinized the role of severity in that it found that children with severe ASD were more likely to receive any services than children with less severe ASD. However, it did not examine how severity impacted services in the educational versus medical setting.

Building on this prior research, the present study aimed to further delineate the relationship between ASD treatment modality (including setting of care), ASD severity, and child/family sociodemographics. We identified patterns of school-based and non-school-based therapy

utilization, as well as specialty provider visits among CSHCN with ASD by parent-reported severity levels. Given the results of Bilaver and colleagues' study,²⁰ we expected CSHCN with ASD would receive more treatments that were school-based than non-school-based and that there would generally be low rates of behavioral intervention across severity levels. We also predicted that therapy utilization and provider visits would vary by ASD severity. As frequent provider visits may be an indicator of more complicated medical needs, we hypothesized that children with higher severity would be more likely to have regular medical provider visits; however, a significant portion of children even with severe ASD would have no regular provider visits. Furthermore, a sizable minority of children, mostly with mild ASD and/or of low socio-economic status, would have no regular provider visits or regular therapies.

METHODS

Data Source and Study Sample

This was a secondary analysis of the 2011 Survey of Pathways to Diagnosis and Services ("Pathways") conducted by the CDC's National Center for Health Statistics (NCHS). Pathways was a follow-up survey to the 2009–10 National Survey of Children with Special Health Care Needs (NS-CSHCN). The participants in Pathways ($n = 4032$) were a random sample of households surveyed in the NS-CSHCN with children aged 6–17 years and who had ever been diagnosed with ASD, developmental delay, or intellectual disability (ID). Data for Pathways, including informed consent, was collected via telephone interviews and mail questionnaires in English, with the same parents or guardians ("parents") who had previously participated in the 2009–10 NS-CSHCN. Response rate for the 2009–10 NS-CSHCN was 35.5%. Pathways had a weighted completion rate of 62%. Detailed survey methodology has been previously documented.^{21,22} From the original Pathways sample, the present analysis exclusively examined the nationally-representative sample of CSHCN with current ASD, with or without developmental delay and ID, and a reported ASD severity level ($n=1269$).

Measures

Autism spectrum disorder diagnosis and severity—This analysis examined experiences of children who were reported to have current ASD in both the NS-CSHCN and Pathways. In NS-CSHCN, ASD status was assessed by the item, "Has a doctor or other health care provider ever told you that your child had autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder?" and "Does your child currently have autism or an autism spectrum disorder?" Parents who said "yes" to either item were recontacted to participate in Pathways, where they were again asked to confirm their child's current ASD status. Ratings of ASD severity were obtained from an item in the 2009–2010 NS-CSHCN survey: "Would you describe [your child's] autism or ASD as mild, moderate or severe?"

Therapy service types—Pathways contained a number of survey items assessing current use of services, including behavior intervention or modification, sensory integration therapy, cognitive based therapy, occupational therapy, physical therapy, social skills training, and

speech or language therapy. The survey did not specify the setting in which the first three service types were received. For the latter four service types, however, participants were explicitly asked whether their CSHCN accessed these services in school and/or outside of school. For our analyses, we therefore examined three major therapy services groups: (1) behavioral intervention or modification (regardless of location), (2) school-based therapies (i.e., occupational therapy, physical therapy, social skills training, and speech or language therapy), and (3) non-school-based therapies (i.e., occupational therapy, physical therapy, social skills training, and speech or language therapy). In this analysis, a child was considered to be currently receiving the therapy modality if the parent reported receipt of the therapy “currently, on a regular basis.”

Regular provider visits—Pathways also had a series of items assessing whether CSHCN had ever or currently had a visit with the following provider types: developmental pediatrician, neurologist, psychiatrist, psychologist or psychotherapist, social worker, audiologist, nutritionist, and at-home or long-term nurse. Given our particular interest in interactions with specialists offering ongoing management of ASD-related issues, we focused on the first five of these provider types. In this analysis, a child was considered to be seeing the provider type if the parent reported the child “currently sees [the provider] on a regular basis.”

Sociodemographic factors—The following child and household characteristics were used to characterize the study sample and were controlled for in multivariable analyses: child’s age (in years), child’s sex, child’s race/ethnicity, insurance type (private, public, both types, or uninsured), parental education, household income relative to the federal poverty level (FPL), and US census region. Studies have posited these sociodemographic factors to be associated with health services access and needs among children with developmental disabilities.^{4,23,24}

Statistical Analyses

Descriptive statistics were initially computed to illustrate the sociodemographic makeup of the sample, both overall and according to ASD severity (Table 1). Descriptive statistics were also used to show the distribution of therapy types and provider visits by ASD severity (Table 2). Specific combinations of ASD therapy types were also examined (Table 3). Then multivariable logistic regression modeling was used to assess how service use in the school and non-school settings and provider visits varied by ASD severity. For each model, the service use outcome was the dependent variable of interest and ASD severity was the primary independent variable. All previously listed child and family sociodemographic characteristics were entered into the model as covariates. All analyses were weighted as per NCHS guidance, using SAS software version 9.4 of the SAS System for Windows. The SAS procedures SURVEYFREQ and SURVEYLOGISTIC were used to obtain weighted frequencies and model estimates.

RESULTS

Study Population

Table 1 provides the demographic data for the sample presented by the severity levels of mild ($n = 638$), moderate ($n = 481$), and severe ASD ($n = 150$). Consistent with current epidemiologic studies,²⁵ males made up 82.1% of the sample. Overall, most of the children in the sample identified as white/non-Hispanic (66.2%) and had a parent with more than a high school education (76.7%). A plurality had only private insurance (49.2%), lived in a household where income was between 200% and 399% of FPL (34.0%), and lived in the US South (33.8%). Only insurance ($p < 0.0001$) and household income ($p = 0.01$) differed significantly by reported ASD severity.

Prevalence of Therapy Types and Providers Visits Overall and by ASD Severity

Table 2 summarizes the use of therapies and provider visits overall and by ASD severity. School-based therapies were the most frequent type of therapies used. Among school-based therapies, the service types used were speech or language therapy (54.1%) and social skills training (48.9%). Children with severe ASD showed a non-significant trend toward more use of school-based services as compared to BI (88.2% versus 52.6%; $p = 0.06$). In general, as ASD severity increased, rates of all types of school-based therapy rose, with the exception of social skills therapy, which was used at similar rates by children with moderate and severe ASD ($p = 0.90$).

Overall, the prevalence of non-school-based therapies (35.7%) was lower than school-based therapies. The most widely used non-school-based therapy was social skills training (24.1% of total sample), followed by speech or language therapy (14.3%). Similar to school-based therapies, there was a general pattern of higher proportions of children using each therapy modality with increasing ASD severity. Behavioral intervention (in any setting) was used at similar rates to non-school-based therapies (38.8%). Children with severe ASD had the highest rates of use, with just over half receiving behavioral intervention.

In terms of regular provider visits, psychiatrists were the only provider type seen regularly by a majority of school-aged children with ASD (57.7%). Other providers who were commonly seen regularly included social workers (42.6%) and psychologists/psychotherapists (42.0%). Overall less than a third of children regularly saw a developmental pediatrician (33.2%). Generally as severity increased so too did the percentage of children reporting regular visits with a specialty provider. However, there were three exceptions to this pattern. For psychologists/psychotherapists, children with moderate ASD and those with severe ASD had the same percentage of provider visits (41.7%). For developmental pediatricians and neurologists, children with mild ASD reported a higher but not significantly different percentage of visits versus children with moderate ASD (32.4% versus 28.5%, $p = 0.53$ for developmental pediatricians and 30.9% versus 24.9%, $p = 0.38$ for neurologists).

Prevalence of Service Use Overall and by ASD Severity

Table 3 presents a summary of therapy service use categories and provider visits by ASD severity. Overall 17.2% of parents reported that their children did not use any of the therapy services asked about in the survey. The percentage of children with no therapy service use declined with increasing severity level (mild 24.0%, moderate 12.7%, and severe 2.5%). Of those accessing services, the most frequent type of therapy service received was school-based therapy only (28.9%). About 17.1% were using a combination of BI, school-based, and non-school-based therapies. A low percentage of children (2.8%) received BI exclusively, which comprised the smallest service use category, followed by non-school-based services only at 4.5%.

Nearly a third of families of children with ASD did not have regular visits with any of the specialty providers asked about in the survey (31.1%). About one in 10 children with severe ASD had no regular provider visits. The percentage of children with no regular provider visits decreased from the mild category (38.3%) to moderate (30.1%) to severe (9.3%).

Associations of Service Use and ASD Severity

Results from adjusted analyses revealed that receipt of any BI, any regular school-based therapy, any regular non-school-based therapy, and any regular provider visit was significantly positively associated with ASD severity (Table 4). Children who were younger or had public only or both public and private insurance had higher odds of reporting any BI compared to children who were older or had private insurance only, respectively. Children who were younger, uninsured, had parents with less than high school education, or lived in families above 400% FPL had higher odds of reporting any regular school-based therapy use compared to children who were older, had private insurance only, had parents with more than high school education, or lived in families at less than 100% of the FPL, respectively. Receipt of any regular non-school-based therapy was positively associated with younger age, having both private and public insurance compared to private only, and higher parental educational attainment compared to completing at most high school. Regular provider visits for ASD were also positively associated with public plus private insurance status compared to private only, as well as residing in the Northeast United States compared to any other region.

DISCUSSION

This analysis sought to investigate the relationship between ASD severity and rates of autism-related service use among US school-aged children with ASD. The study found that children with higher parent-reported severity were using more therapy services overall and were using more of nearly all of the therapy services types investigated in the Pathways survey. In addition, parent-reported severity was associated with higher rates of multi-modality therapy use and with more frequent regular provider visits. Nonetheless, substantial variability existed in this sample. For instance, 17.1% of children with ASD were not using any therapy services at home or at school, and were also not using BI in any setting. 25.8% of children with severe ASD were using school-based therapies only. Nearly 50% of children with severe ASD were not using BI, despite the fact that this latter type of

therapy has the strongest evidence base for improving outcomes in ASD. Among children with mild ASD, 24% were using no therapy services whatsoever, over 60% were not using BI, and 38% did not have regular specialty provider visits.

As this study used a population-based dataset, it is not possible to determine what types of medical and educational services would have been most appropriate for any individual child. The study, nevertheless, raises noteworthy clinical and policy-related issues for children on both ends of the severity spectrum. For children with a more severe ASD presentation, it is likely that therapy in multiple settings (e.g., both in school and outside of school) would be beneficial. The study's findings suggest that non-school-based therapy may be underused by children of all severity levels and particularly among those with severe ASD. Study results suggest that providers in the medical system (where most non-school-based services are authorized) may need to inform families of the non-school based treatments they can access and also advocate for better therapy availability.

Of the school-based therapies that were being received, the most common ones—speech or language therapy and social skills therapy—have only a moderate evidence base. Given the high rates of use of these services, further research should investigate their utility specifically for ASD. Similarly, a substantial portion of children with ASD would likely benefit from BI, which has shown particularly promising results for children on the mild end of the autism spectrum.¹³ In this sample, only a minority of children with mild ASD used it, which may reflect complex issues of awareness, desirability, cost, and accessibility of this therapy. Finally, given the lifetime developmental trajectory of ASD, the fact that significant numbers of children with mild ASD are not using any therapy services indicates that this population may be underserved by both the educational and medical systems. Findings suggest that providers should ask families of children with ASD about their therapy service use and not assume that therapies are being used; additionally, providers should proactively provide information about therapy modalities available for ASD and their evidence base.

It is notable that many children with ASD, including about 1 in 3 children with mild ASD and 1 in 10 children with ASD had no regular provider visits. Of those who were seeing providers, psychiatrists were the only provider type regularly seen by a majority of children with ASD, followed by social workers and psychologists. Such findings may point to a high burden of psychiatric co-morbidity and behavioral issues requiring psychiatric care and therapeutic supports among children with ASD. Additionally, the high rates of psychiatrist visits over social worker and psychologist visits may be due to parents needing access to providers who can prescribe medication for their children's symptoms and behaviors. The findings may also reflect a lack of access to other provider types, such as developmental-behavioral pediatricians and neurologists—both of which are in short supply in the US.^{26,27} The lower rates of regular visits with developmental pediatricians and neurologists raises the question of who is providing ongoing developmental monitoring, offering recommendations for accessing optimal services, helping families navigate complex medical and educational systems, and coordinating care. These study findings indicate a need for further investigation of the role of specialty providers in ensuring holistic, comprehensive care, as well as how specialty provider workforce shortages mediate access to care. From a clinical perspective,

these results suggest that primary care providers should proactively assess children's use of specialists and not assume that specialty care is being accessed.

Sociodemographic correlates of therapy use in this study may also shed some light on the reasons behind certain therapy use patterns. School-based therapy use was relatively lower among low-income households, but relatively higher among children with low parental education or who were uninsured, regardless of severity. As school-based therapy is provided at no cost to families, it is surprising that income in particular is associated with lower school-based services use. This finding may reflect differential access to school-based therapy services for children in low-income school districts. Conversely, the high rates of school-based therapy use among uninsured children and children with low parental education may reflect a lack of other therapy options outside the school system or a lack of knowledge about non-school-based therapy resources.

A different pattern was found with non-school-based services: families of lower educational attainment were less likely to use non-school-based therapies compared to parents of higher educational attainment, but there was no significant income variability. This finding is interesting because such services often incur cost-sharing for families. This finding suggests that use of non-school-based therapies for ASD may be more a matter of health literacy and knowledge of the medical and educational systems than of financial means per se. This may be particularly the case since both public and private payers are expanding coverage for ASD services. Children with both public and private insurance had the highest odds of BI, non-school-based services, and regular provider visits, which may reflect the fact that this type of coverage may provide more robust treatment benefits; likewise, parents who are able to obtain such coverage may also have relatively strong knowledge of the medical and educational systems.

This study's limitations included its cross-sectional nature, which makes any causal inference less certain. In particular, in addition to child's severity modifying service use profiles, it is conceivable that use of ASD services modifies parents' perceptions of severity. Another significant limitation is that all ASD diagnoses were per parent report and not verified, so misclassification bias is a possibility. However, other national surveys using parent-reported ASD diagnoses have produced prevalence estimates comparable to studies that have employed more rigorous ASD case ascertainment strategies.²⁸ In the Pathways survey, all therapy services were parent reported and not verified. Some parents may not have been certain of all the services their children were receiving, particularly in the school setting. Additionally, the potential datedness of the data is worth noting as a limitation since policies around insurance coverage have expanded in most states since 2011,²⁹ the year the Pathways survey was conducted. Rates of service receipt identified in this analysis may thus be an under-estimation of current rates of service receipt.

The use of parent-reported severity as a marker, while common,^{5,20,23} has certain benefits and drawbacks. As previously noted, parent-reported severity may be a better proxy for child and family burden than for actual symptom severity.¹⁹ If that is the case, one interpretation of our study's findings may be that families who experience hardship are receiving higher rates of services than families who experience less hardship, but that substantial variability

exists in service receipt. In this interpretation, it is likely the case that many families experiencing the most significant hardship are not receiving the services for their children that might help mitigate their burden. It is difficult to know how well parents' perceptions of severity correlate with providers' perceptions or with clinical scales, since little research has addressed this topic. Nonetheless, we believe parent-reported severity is an important marker of burden on families as well as potentially on health care and educational systems.

Other limitations of the study included the fact that the setting of care for BI was not ascertained in Pathways and that the survey did not assess the full variety of therapies that a child with ASD might need or use. Nonetheless, we do believe that the therapies evaluated in this study reflect the major therapy modalities utilized by US children with ASD. Finally, the sample in Pathways, though population-based, may not be representative of the diversity of US children with ASD. Aside from the survey's relatively low response and completion rate, Pathways was offered only in English, and the sample assessed was more white and affluent than the US population as a whole. We attempted to account for these limitations via statistical adjustment; however, it is likely that residual bias and confounding remained. Despite the survey's large sample size, it is also possible that some outcomes were under-powered, so that we were unable to detect significant findings when they existed.

With high prevalence rates of ASD and the increasing burden on educational and health care systems, it is imperative that we understand patterns of service receipt to guide policy, program development, and resource allocation. The findings of the present study suggest many children with ASD may not be receiving comprehensive care across settings, and that most children, even those with severe ASD, are receiving mainly therapies with low and moderate evidence bases. Further research should elucidate families' level of satisfaction with current services, factors driving their utilization of school-based and non-school-based therapies and regular provider visits, and barriers to access.

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Table 1
Sociodemographic Characteristics of Children with ASD, Age 6–17 Years, by Parent-Reported Severity (n = 1269)

	Overall % (n = 1269) ^a	Mild ASD % (n = 638) ^{ab}	Moderate ASD % (n = 481) ^{ab}	Severe ASD % (n = 150) ^{ab}	P-value ^c
Child Characteristics					
Age					
6–9yrs	33.7% (439)	34.5% (195)	32.1% (153)	25.3% (38)	0.27
10–13yrs	39.2% (570)	42.9% (274)	36.8% (177)	44.9% (67)	
14–17yrs	27.1% (411)	22.6% (169)	31.1% (151)	29.8% (45)	
Sex					
Male	82.1% (1155)	84.2% (527)	81.8% (388)	82.7% (120)	0.80
Female	17.9% (264)	15.8% (110)	18.3% (93)	17.4% (30)	
Race/Ethnicity					
Hispanic	13.0% (118)	12.8% (51)	9.5% (38)	13.5% (14)	0.23
Black/non-Hispanic	10.7% (89)	9.4% (29)	6.2% (28)	14.9% (13)	
Other/non-Hispanic	10.1% (145)	8.9% (58)	14.1% (56)	3.0% (14)	
White/non-Hispanic	66.2% (1056)	69.0% (494)	70.2% (356)	6.3% (108)	
Insurance Type					
Private only	49.2% (751)	59.8% (400)	45.7% (228)	22.4% (47)	<0.0001
Public only	31.4% (366)	19.9% (117)	38.6% (143)	41.0% (59)	
Both public and private	17.0% (231)	17.9% (88)	12.4% (85)	35.5% (38)	
Uninsured	2.4% (35)	2.3% (16)	3.3% (13)	1.1% (2)	
Household Characteristics					
Parental Education					
Less than high school	7.2% (43)	5.5% (16)	3.2% (10)	6.0% (4)	0.22
High school graduate	16.1% (156)	11.2% (49)	20.9% (71)	16.5% (16)	
More than high school	76.7% (1213)	83.4% (568)	75.9% (398)	77.5% (130)	
Household Income					
99% FPL	16.9% (185)	16.0% (68)	13.3% (61)	24.4% (27)	0.01
100%-199% FPL	19.5% (254)	12.3% (92)	22.9% (98)	6.3% (33)	

	Overall % (n = 1269) ^a	Mild ASD % (n = 638) ^{ab}	Moderate ASD % (n = 481) ^{ab}	Severe ASD % (n = 150) ^{ab}	P-value ^c
200%-399% FPL	34.0% (448)	35.4% (215)	39.9% (161)	6.4% (32)	
400% FPL	29.7% (429)	36.4% (225)	23.8% (118)	5.0% (45)	
Region					
Northeast	21.4% (277)	22.2% (137)	24.5% (88)	25.9% (32)	
Midwest	25.5% (338)	24.6% (155)	22.2% (112)	26.0% (38)	0.82
South	33.8% (388)	32.5% (151)	34.6% (144)	23.8% (38)	
West	20.3% (417)	20.6% (195)	18.8% (137)	24.3% (42)	

Abbreviations: ASD, Autism Spectrum Disorder; FPL, Federal Poverty Level; yrs, years

^aEstimates weighted to represent the non-institutionalized US child population

^bASD severity assessed via parent report

^cP-values from chi-square test, representing statistical significance across the three severity levels by each of the variables in the first column.

Table 2

Therapies and Provider Visits by ASD Severity

Therapy Type	ASD Severity ^a						P-value ^b
	Overall	Mild		Moderate		Severe	
	% (s.e.)	n	% (s.e.)	n	% (s.e.)	n	% (s.e.)
Behavioral intervention or modification	38.8% (2.3)	530	32.2% (3.4)	190	45.1% (3.8)	205	52.6% (6.6)
School-based therapies (any below)	72.0% (2.1)	1016	65.3% (3.2)	412	78.8% (3.6)	387	88.2% (4.1)
Occupational therapy	37.5% (2.3)	539	24.7% (2.8)	182	45.6% (3.8)	222	63.1% (6.1)
Physical therapy	14.5% (1.6)	220	7.8% (1.5)	63	18.5% (3.0)	89	27.9% (6.1)
Social skills	48.9% (2.3)	720	44.1% (3.4)	296	58.3% (3.8)	282	57.3% (6.7)
Speech or language therapy	54.1% (2.3)	732	48.5% (3.5)	283	59.4% (3.9)	284	75.4% (5.4)
Non-school-based therapies (any below)	35.7% (2.3)	512	22.6% (2.7)	185	42.0% (3.8)	200	49.2% (6.6)
Occupational therapy	10.8% (1.5)	165	4.4% (0.8)	53	12.6% (2.3)	62	17.7% (4.8)
Physical therapy	5.3% (1.1)	77	1.2% (0.4)	18	6.3% (1.5)	36	8.6% (3.4)
Social skills	24.1% (2.1)	339	16.8% (2.4)	133	26.1% (3.5)	124	36.1% (6.7)
Speech or language therapy	14.3% (1.7)	171	7.5% (1.6)	53	16.1% (2.8)	68	22.7% (5.4)
Regular provider visits							
Developmental pediatrician	33.2% (3.2)	201	32.4% (4.8)	76	28.5% (4.2)	73	58.1% (9.4)
Neurologist	29.3% (3.1)	175	30.9% (5.5)	64	24.9% (4.3)	59	37.9% (8.0)
Psychiatrist	57.7% (3.0)	424	48.4% (4.6)	162	54.9% (5.2)	144	66.8% (8.1)
Psychologist/psychotherapist	42.0% (2.9)	378	35.8% (4.3)	151	41.7% (4.5)	133	41.7% (8.0)
Social worker	42.6% (3.5)	247	41.2% (5.5)	84	42.3% (5.8)	100	61.0% (8.4)

Abbreviations: ASD, Autism Spectrum Disorder; s.e., Standard Error

^a ASD severity assessed via parent report^b p-values from chi-square test, representing statistical significance across the three severity levels by each of the variables in the first column

Service Use by ASD Severity

Table 3

Service Use Category	ASD Severity ^a						P-value ^b
	Overall	Mild		Moderate		Severe	
	% (s.e.)	n	% (s.e.)	n	% (s.e.)	n	% (s.e.)
Therapy Services							
Non-school-based only	4.5% (1.1)	64	2.9% (0.7)	32	2.4% (1.0)	11	6.5% (3.6)
School-based only	28.9% (2.1)	395	33.4% (3.3)	189	27.0% (3.3)	137	25.8% (5.6)
BI only	2.8% (0.8)	37	4.8% (1.8)	18	1.8% (0.9)	12	1.3% (0.9)
BI and school-based	15.3% (1.7)	217	15.2% (2.6)	90	16.4% (2.7)	75	21.3% (5.6)
BI and non-school based	3.5% (1.0)	46	3.0% (1.1)	20	4.2% (2.2)	15	1.6% (1.4)
School-based and non-school based	10.5% (1.4)	171	7.5% (1.3)	70	12.8% (2.2)	71	12.7% (4.4)
BI, school-based, and non-school based	17.1% (1.8)	230	9.2% (2.1)	62	22.7% (3.2)	103	28.4% (6.1)
No therapy services	17.2% (1.6)	256	24.0% (2.8)	155	12.7% (3.0)	56	2.5% (1.4)
Provider Visits							
Any regular provider visits	68.9% (2.2)	864	61.7% (3.5)	344	69.9% (3.7)	314	90.7% (2.6)
No regular provider visits	31.1% (2.2)	443	38.3% (3.5)	232	30.1% (3.7)	136	9.3% (2.6)
							<0.0001

Abbreviations: ASD, Autism Spectrum Disorder; BI, Behavioral Intervention; s.e., Standard Error

^aASD severity assessed via parent report^bp-values from chi-square test, representing statistical significance across the three severity levels by each of the variables in the first column

Table 4

ASD Severity and Sociodemographic Associations with Services Use Among US Children with ASD

	AOR (95% CI) Any behavioral intervention or modification (n = 530)	AOR (95% CI) Any regular school- based therapy (n = 1016)	AOR (95% CI) Any regular non-school based therapy (n = 512)	AOR (95% CI) Any regular provider visits (n = 864)
ASD Severity				
Mild	1.00	1.00	1.00	1.00
Moderate	2.03 (1.29–3.20)	2.13 (1.23 – 3.70)	3.05 (1.94 – 4.81)	1.27 (0.78 – 2.07)
Severe	2.30 (1.22–4.34)	4.08 (1.85 – 8.98)	3.60 (1.95 – 6.66)	2.99 (1.38 – 6.46)
Child Characteristics				
Age				
6–9yrs	2.77 (1.62–4.72)	6.26 (3.26 – 12.02)	1.93 (1.14 – 3.25)	0.95 (0.55 – 1.64)
10–13yrs	1.79 (1.07–3.01)	2.91 (1.69 – 5.00)	1.36 (0.82 – 2.24)	1.66 (0.97 – 2.85)
14–17yrs	1.00	1.00	1.00	1.00
Sex				
Male	1.00	1.00	1.00	1.00
Female	1.08 (0.63–1.83)	0.60 (0.33 – 1.10)	0.76 (0.48 – 1.22)	0.77 (0.45 – 1.31)
Race/Ethnicity				
Hispanic	0.55 (0.24–1.26)	1.76 (0.76 – 4.05)	0.79 (0.37 – 1.71)	2.23 (0.90 – 5.52)
Black/non-Hispanic	0.58 (0.25–1.33)	1.64 (0.63 – 4.28)	0.51 (0.22 – 1.14)	0.46 (0.21 – 1.05)
Other/non-Hispanic	0.70 (0.31–1.57)	2.05 (0.87 – 4.83)	0.86 (0.40 – 1.83)	1.68 (0.62 – 4.54)
White/non-Hispanic	1.00	1.00	1.00	1.00
Insurance Type				
Private only	1.00	1.00	1.00	1.00
Public only	1.89 (1.02–3.52)	1.78 (0.86 – 3.67)	1.55 (0.82 – 2.92)	1.54 (0.74 – 3.21)
Both public and private	2.99 (1.62–5.51)	2.02 (0.91 – 4.46)	2.68 (1.45 – 4.98)	2.62 (1.25 – 5.51)
Uninsured	1.68 (0.48–5.84)	4.85 (1.31 – 17.89)	2.30 (0.70 – 7.63)	2.26 (0.77 – 6.64)
Household Characteristics				
Parental Education				
Less than high school	0.89 (0.24–3.36)	8.31 (1.26 – 54.78)	0.28 (0.06 – 1.21)	0.82 (0.27 – 2.55)
High school graduate	0.75 (0.40–1.41)	1.46 (0.58 – 3.63)	0.47 (0.23 – 0.94)	0.73 (0.36 – 1.49)
More than high school	1.00	1.00	1.00	1.00
Household Income				
99% FPL	0.69 (0.31–1.54)	0.27 (0.10 – 0.70)	0.97 (0.45 – 2.10)	0.88 (0.36 – 2.14)
100%–199% FPL	0.62 (0.32–1.21)	1.02 (0.48 – 2.17)	0.68 (0.34 – 1.36)	1.15 (0.56 – 2.38)
200%–399% FPL	0.80 (0.47–1.36)	1.63 (0.93 – 2.85)	0.77 (0.46 – 1.29)	1.06 (0.61 – 1.87)
400% FPL	1.00	1.00	1.00	1.00
Region				
Northeast	1.00	1.00	1.00	1.00

	AOR (95% CI) Any behavioral intervention or modification (n = 530)	AOR (95% CI) Any regular school- based therapy (n = 1016)	AOR (95% CI) Any regular non-school based therapy (n = 512)	AOR (95% CI) Any regular provider visits (n = 864)
Midwest	0.75 (0.43–1.31)	0.81 (0.42 – 1.58)	0.77 (0.44 – 1.35)	0.27 (0.14 – 0.51)
South	0.73 (0.41–1.30)	0.56 (0.30 – 1.05)	0.89 (0.50 – 1.58)	0.23 (0.12 – 0.42)
West	0.53 (0.26–1.06)	0.65 (0.31 – 1.36)	0.70 (0.38 – 1.30)	0.19 (0.09 – 0.40)

Abbreviations: AOR, Adjusted Odds Ratio; CI, Confidence Interval; FPL, Federal Poverty Level; yrs, Years