

Experience Matters: A View into the Health and Wellbeing of US Children and Families with Autism Spectrum Disorder (ASD)



Prepared by
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Introduction

Autism Spectrum Disorder (ASD) has received increasing attention from both researchers and media in the past decade. Seemingly increasing with every new release of national data, recent estimates from the 2011/12 National Survey of Children's Health suggests that more than 1.1 million children under the age of 18 in the United States may have ASD. The experiences of these children and their families are critical for understanding the needs of this vulnerable population.

This chartbook represents one of the first national portraits of children in the U.S.: how they receive their diagnoses, how their daily lives are impacted, and how their families are doing. This chartbook can be used by the following groups:

- **Families:** can learn how other families with ASD are doing, and advocate for issues important to them.
- **Advocates:** can reference the latest family-centered ASD data and disparities in outcomes for their advocacy efforts.
- **Policymakers:** can understand the scope of needs of their constituent families with ASD.
- **Researchers:** can learn about the scope of the impact of ASD on the family.

This chartbook can either be read in its entirety, or by topic-specific sections:

- **Prevalence of ASD:** this section details differing ASD prevalence rates and the key characteristics of families with ASD.
- **Diagnosing ASD:** this section describes parents' and health care providers' role in the early detection efforts and diagnosis of ASD.
- **The Child's Health:** this section provides an overview of the health problems experienced by children with ASD.
- **Health Care and Related Services:** this section explores how families with ASD engage in the health care system to meet their child's needs.
- **School and Social Wellbeing:** this section details the personal connections and educational services that meet the needs of children with ASD.
- **Coping with ASD:** this section explores parental wellbeing and points of view among families with ASD.

Readers will find expanded appendices at the end of this chartbook with additional information on the ASD data presented here, including a glossary, a crosswalk of the data sources used in this chartbook, methodological information, and guidance for accessing this data on the [Data Resource Center for Child and Adolescent Health \(DRC\)](#).

The [Child & Adolescent Health Measurement Initiative \(CAHMI\)](#) and [Autism Speaks](#) have produced this chartbook in the hope of expanding and expediting the actionable use of available national data on ASD. We encourage you to reach out with any questions, comments, or suggestions to info@cahmi.org.

Prevalence of Autism Spectrum Disorder in the US

A variety of studies have tried to pinpoint the prevalence of Autism Spectrum Disorder (ASD) in the United States. Population-based estimates of ASD can vary from survey to survey, but studies over the past 10 years have consistently shown increasing rates of ASD. Changes in the public's awareness, in the medical and diagnostic understanding of ASD, and its early detection may play a role in increasing rates. Finally, in population-based surveys, the way that parents are asked about their child's diagnosis is important to pay attention to, since slight changes in survey questions may elicit different responses. Having precise estimates of the number of children with ASD in the United States is important, as it will allow for more therapeutic and medical efforts aimed at identifying and treating ASD.

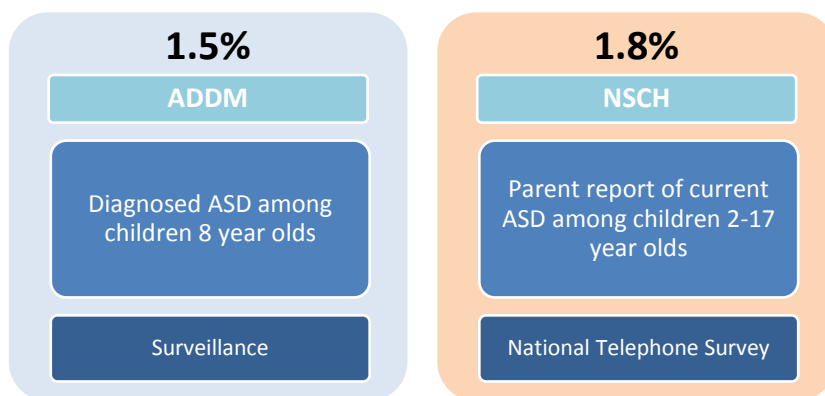
National Prevalence of ASD

An estimate for how many children in the U.S. have ASD is an important starting point for this chartbook. In this section, we present the prevalence rates from national surveys and a large surveillance monitoring system.

The National Survey of Children's Health (NSCH) provides one estimate of the prevalence of Autism Spectrum Disorder: the 2011/12 NSCH found that 1.8% of U.S. children currently have ASD. See Figure 1-1. This amounts to approximately 1.17 million children in the U.S. living with ASD. Additional information in this chartbook comes from the National Survey of Children with Special Health Care Needs (NS-CSHCN), where 7.9% of U.S. children identified *with special health care needs* have ASD.

Both rates from the NSCH and NS-CSHCN are not dissimilar from the Autism and Development Disabilities Monitoring Network (ADDM), a national public health surveillance program coordinated by the CDC, which monitors 8 year olds who have been diagnosed with ASD. The ADDM estimates that 1.5% of 8 year olds have ASD. See Figure 1-1.

Figure 1-A. Prevalence Estimates of ASD in the United States



Abbreviations: ADDM = Autism and Development Disabilities Monitoring Network; NSCH = the National Survey of Children's Health, 2011/12.

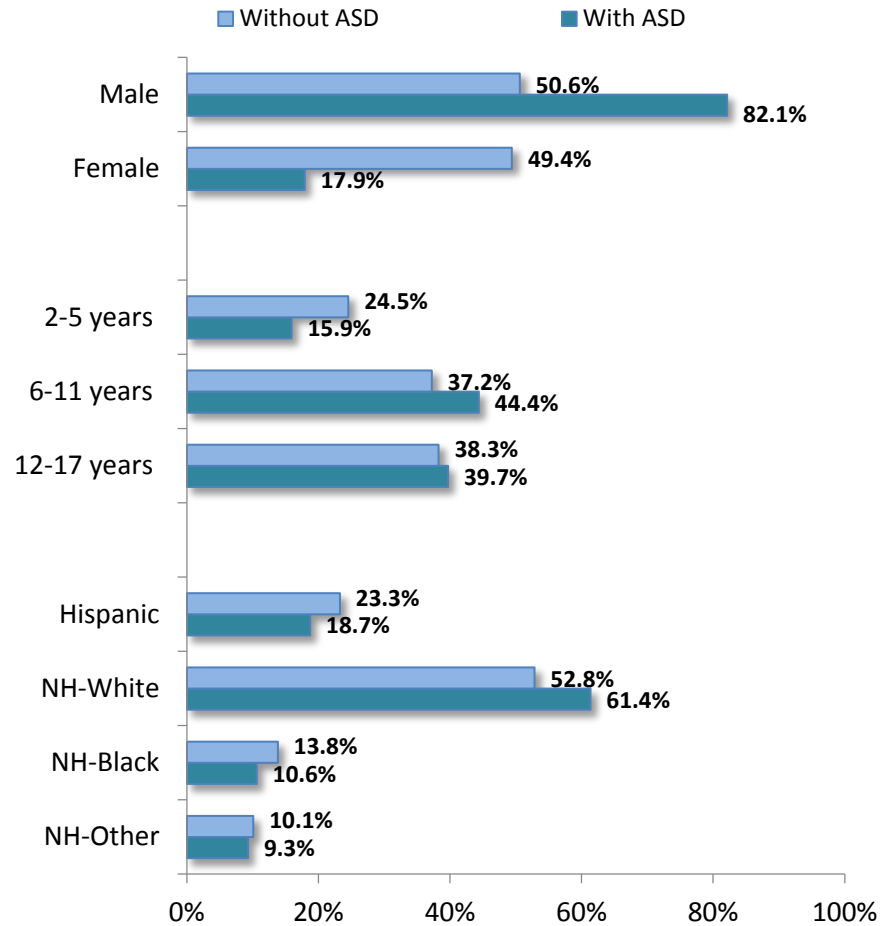
Scientific notes: Any prevalence estimates used in this chartbook are primarily based on the NSCH data.

Health and Demographic Characteristics of Children with ASD

The health and demographic characteristics of children with ASD help paint a picture to illustrate where and how services are needed.

Compared to children without ASD, more children with ASD are male. The prevalence of ASD in children 6 years or older is higher than in younger children, perhaps reflecting the later onset of ASD symptoms, or later recognition of those symptoms. As compared to children without ASD, more children with ASD are non-Hispanic white. See Figure 1-2.

Figure 1-2. Health and demographic characteristics of children, by ASD status, among children ages 2-17 years.



Data source: The National Survey of Children's Health, 2011-2012.
Abbreviations: NH = non-Hispanic.

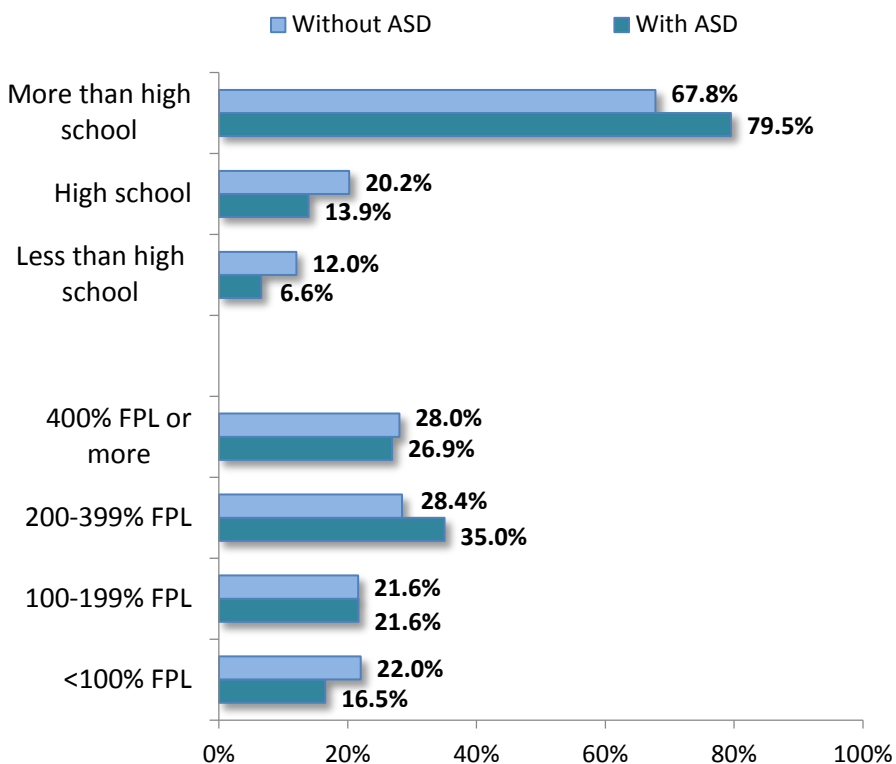
Parental and Familial Characteristics of Children with ASD

The familial characteristics of children with ASD provide interesting findings. As compared to children without ASD, a greater proportion of children with ASD come from a family where a parent has earned more than a high school degree.

Additionally, a greater proportion of children with ASD come from higher income homes. 62% live in a household earning 200% or more of the federal poverty level (FPL), and a fewer come from families living below the poverty level. See Figure 1-3.

Unlike other prevalent childhood conditions like asthma - which is more common in low income families - the predominant demographic picture of children with ASD is of a non-Hispanic white, school-age boy with educated parents in a middle or upper-middle-class homes. This population profile differs significantly from those typically affected by chronic conditions. This finding is important when identifying resources and strategies for providing services to children with ASD, and is most helpful for identifying children from less affluent households or who are not white - as they may be receiving delayed diagnoses and treatment.

Figure 1-3. Familial characteristics of children, by ASD status, among children ages 2-17 years.



Data source: The National Survey of Children's Health, 2011/12.

Abbreviations: FPL = Federal Poverty Level.

Scientific notes: Education information is for the member of the household with the highest level of completed education. Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011.

Key Takeaways

- ✓ Approximately 1.5-1.8% of children in the United States have Autism Spectrum Disorder (ASD).
- ✓ More children with ASD are boys than girls.
- ✓ As compared to children without ASD, a greater proportion of children with ASD are non-Hispanic white.
- ✓ A greater percentage of children with ASD come from homes where the parents have more than a high school education.

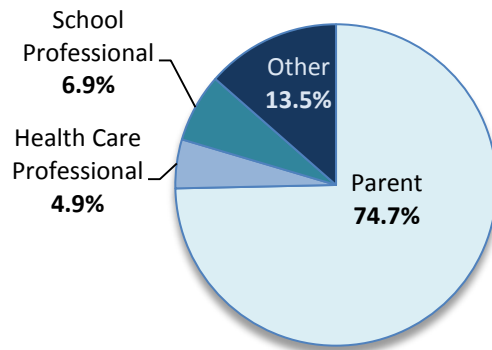
Parental Concern about Child's Condition

The age at which concerns with development or behavior are first noticed, and by whom, are important in the diagnostic experiences of those with Autism Spectrum Disorder (ASD). Parents may be the first to notice developmental concerns, but health care and school professionals also play an important role in identifying concerns or delays. Data from the 2011 Survey of Pathways to Diagnosis and Services (Pathways) are used to show which concerns were first noticed and who first noticed them, among school-aged children (ages 6-17) with special health care needs (CSHCN) and ASD. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Person First Concerned about Child's Development

Concerns about ASD typically come early in development, and most often from one or both parents. In the Pathways survey, three-quarters of initial concerns about ASD among school-aged CSHCN who have ASD came from parents. The remaining 25% came from health care professionals, school-based professionals, and other sources. See Figure 2-1. These figures did not vary greatly by the child's sex or race/ethnicity. (Data not shown.) However, other demographic differences are outlined below.

Figure 2-1. Person first concerned about child's development among CSHCN ages 6-17 years with ASD.

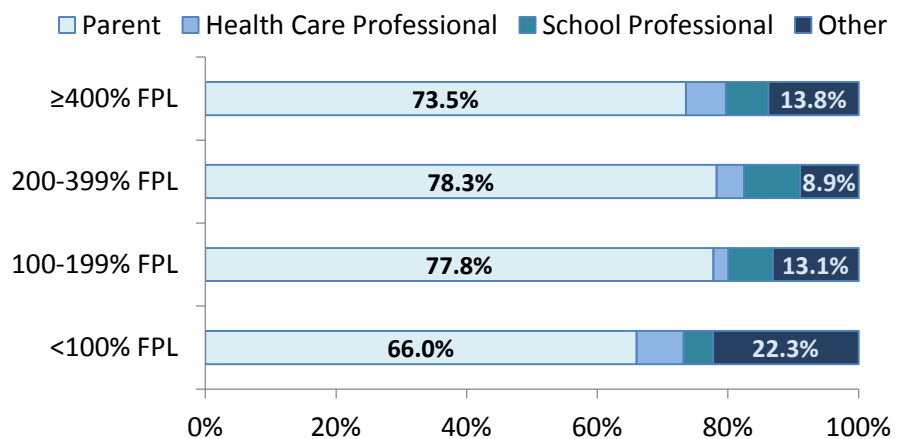


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Person First Concerned about Child's Development, by Income

Compared to middle and high-income households, fewer low-income children had a parent who was the first adult to express concerns about their child's development. See Figure 2-2.

Figure 2-2. Person first concerned about child's development, by income, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Abbreviations: FPL= Federal poverty level.

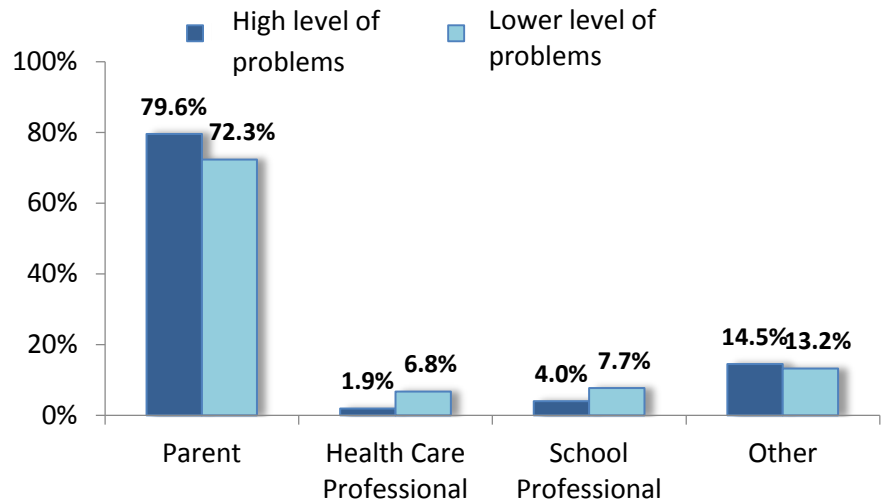
Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011.

Person First Concerned about Child's Development, by SDQ Score

The Pathways survey includes the brief Strength and Difficulties Questionnaire (SDQ). The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. As seen in Figure 2-3, parents appeared to express more concern about their child when the child exhibited a higher level of mental health problems.

The reverse appeared to be true among health care and school professionals, who may be able to pick up on non-behavioral symptoms that have gone unnoticed by parents.

Figure 2-3. Person who was first concerned about child's development, by Strength and Difficulties Questionnaire (SDQ) score, among CSHCN ages 6-17 years with ASD.



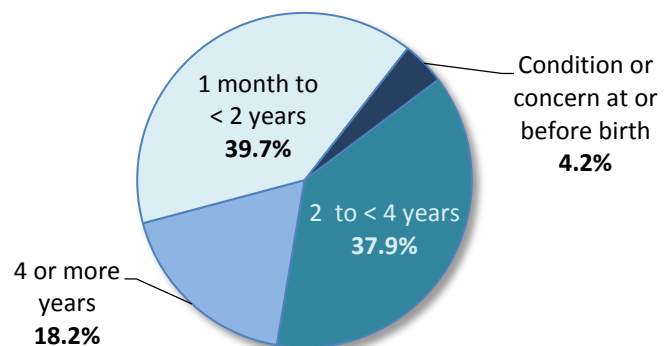
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Scientific notes: The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. Chi-square test $p < 0.05$.

Child's Age When Parent First Concerned

About 40% of developmental concerns first emerged when CSHCN with ASD aged 6-17 at the time of the survey were between birth and 2 years of age. Concerns emerged for another 38% of children between 2 and 4 years of age. However, for nearly two in ten children, concerns did not emerge until 4 years of age or older. See Figure 2-4.

Figure 2-4. Child's age when parent first concerned about development, among CSHCN ages 6-17 years with ASD.

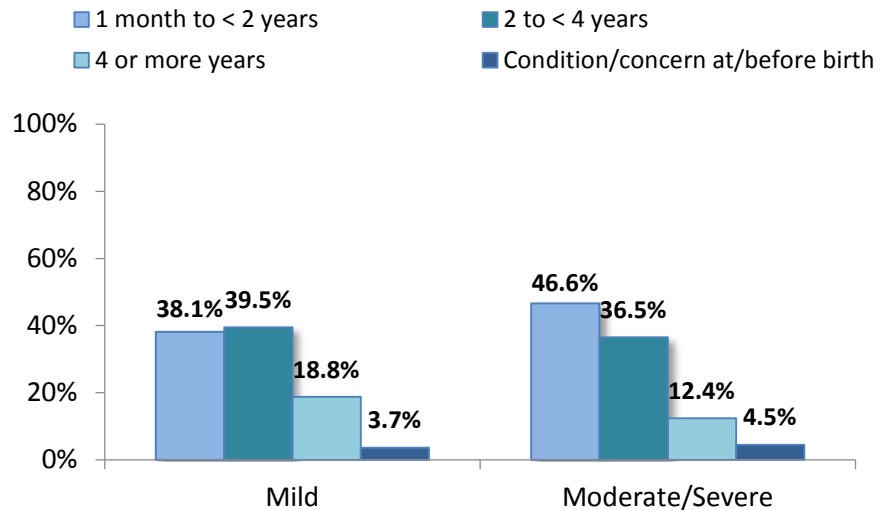


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Child's Age When Parent First Concerned, by ASD Severity

Among children with moderate or severe ASD, most parental concerns emerged when the child was between 1 month and less than 2 years old. A greater proportion of children with mild ASD had concerns that emerged after 4 years of age. See Figure 2-5

Figure 2-5. Child's age when parent first concerned, by ASD severity, among CSHCN ages 6-17 years with ASD.

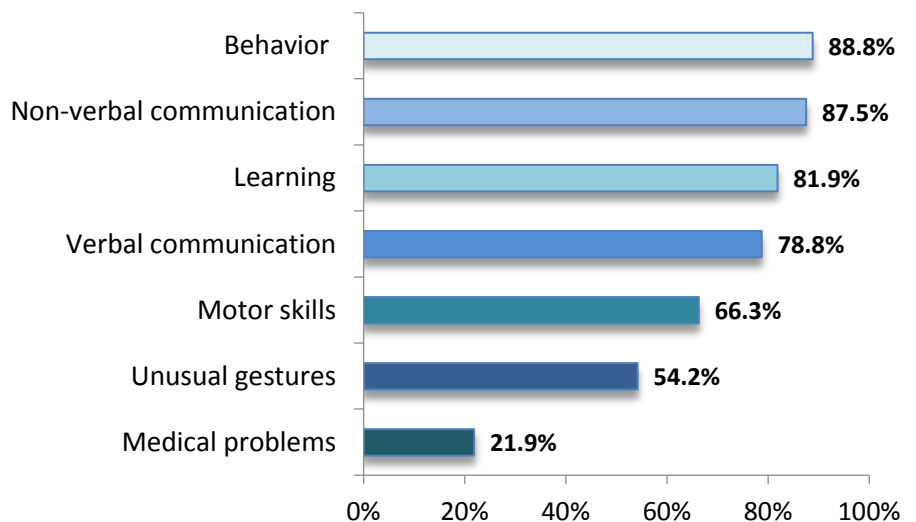


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Types of Developmental Concerns Parent First Notice

The types of issues that caused the most parental concern involved learning, communication (both verbal and non-verbal), and behavior. Over 80% of school-aged CSHCN with ASD had parents who were concerned about each of these areas. Only 22% of children's parents first developed concerns because of medical problems. See Figure 2-6.

Figure 2-6. Types of developmental concerns parent first noticed, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Scientific notes: *Medical* include issues such as seizures, lack of physical growth, stomach problems or other medical issues; *Unusual gestures* include movements such as hand-flapping, toe-walking, or self-spinning; *Learning* include problems understanding what others say or difficulty learning new things or skills; *Non-verbal communication* problems making eye contact, responding when called or to sounds, or with other forms of non-verbal communication; *Motor skills* include problems with coordination and gross or fine motor skills; *Behavior* problems include difficulty playing or with change, sleep-ing/eating, hyper activity, wandering, tantrums, aggression or being destructive; and *Verbal communication* problems include talking, communicating, or speech skills.

Key Takeaways

- ✓ Three-quarters of first concerns about ASD came from parents.
- ✓ Fewer low-income parents were the first adult to express concern about their child, as compared to parents in higher-income households (66% vs. > 74%).
- ✓ Fewer parents have concerns when the condition is mild or when a developmental delay threshold (such as that measured by the Strengths and Difficulties Questionnaire) is not met.
- ✓ Equal percentages of parents first expressed concern when their child was 1 month-<2 years old and 2-4 years old (40% each).
- ✓ Greater percentages of parents were first concerned with their child's learning, communication, and behavior.

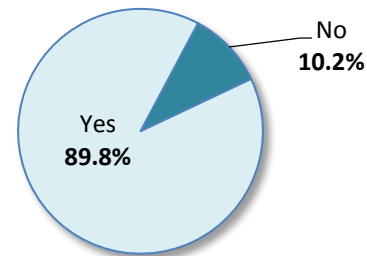
Addressing Parental Concerns

Even if a parent is not the first adult to express concern about their child’s development, parents who develop concerns will need these worries addressed. Concerned parents may choose to speak with their child’s health care provider or a school professional. Data from the 2011 Survey of Pathways to Diagnosis and Services (Pathways) are used to show if and when concerned parents of school-aged children (ages 6-17) with special health care needs (CSHCN) with Autism Spectrum Disorder (ASD) spoke with their child’s health care provider and how the provider responded. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Parent Spoke with a Doctor or Health Care Provider about Their Concerns

Almost 90% of school-aged CSHCN with ASD had a parent who shared their developmental concerns with a doctor or health care provider. See Figure 2-7. This figure did not differ between levels of current ASD severity. (Data not shown.)

Figure 2-7. Children whose parent spoke with a doctor or health care provider about their concerns, among CSHCN ages 6-17 years with ASD.



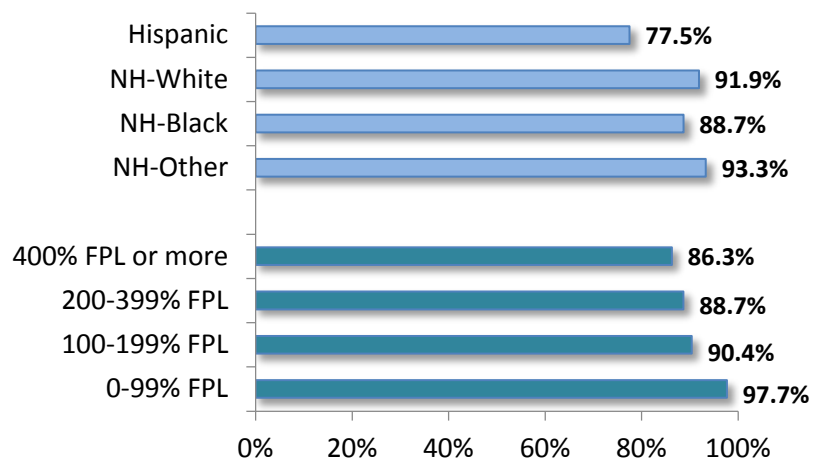
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Parent Spoke with a Provider about Their Concerns, by Race/Ethnicity and Income

Fewer Hispanic children had parents who spoke with a provider, as compared to children of other races/ethnicities. See Figure 2-8.

Variation also emerged based on household income level. A larger percentage of children in low-income households (<100% of the federal poverty level) had parents who spoke to a provider. See Figure 2-8. These findings suggest that low-income families were, in fact, able to express their concerns to a provider.

Figure 2-8. Children whose parent spoke to a doctor or health care provider about their concerns, by race/ethnicity and income, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Abbreviations: NH = non-Hispanic; FPL = Federal poverty level.

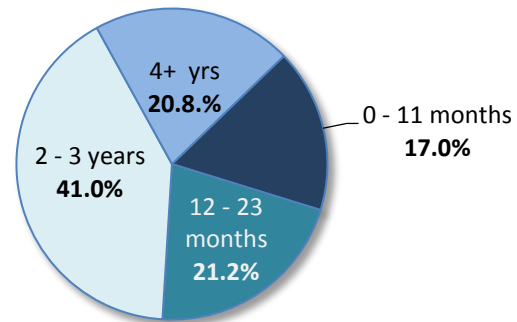
Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$ for race/ethnicity subgroup.

Child's Age When Parent First Spoke to Doctor or Health Care Provider about Concerns

Among school-aged CSHCN with ASD whose parent spoke with a health care provider, the majority of children were 2-3 years old at the time these concerns were shared (41%). See Figure 2-9. Equal percentages of children were 1-2 years old or over 4 years old when their parent first shared concerns (21%).

No large differences emerged by the child's sex. (Data not shown.) However, a greater percentage of children in two-parent step-families were over 4 years old when a parent first spoke to a provider (33%), as compared to children in single-mother or two-parent biological households (18-23%). (Data not shown.)

Figure 2-9. Child's age when parent first spoke to a doctor/health care provider about their concerns, among CSHCN ages 6-17 years with ASD.

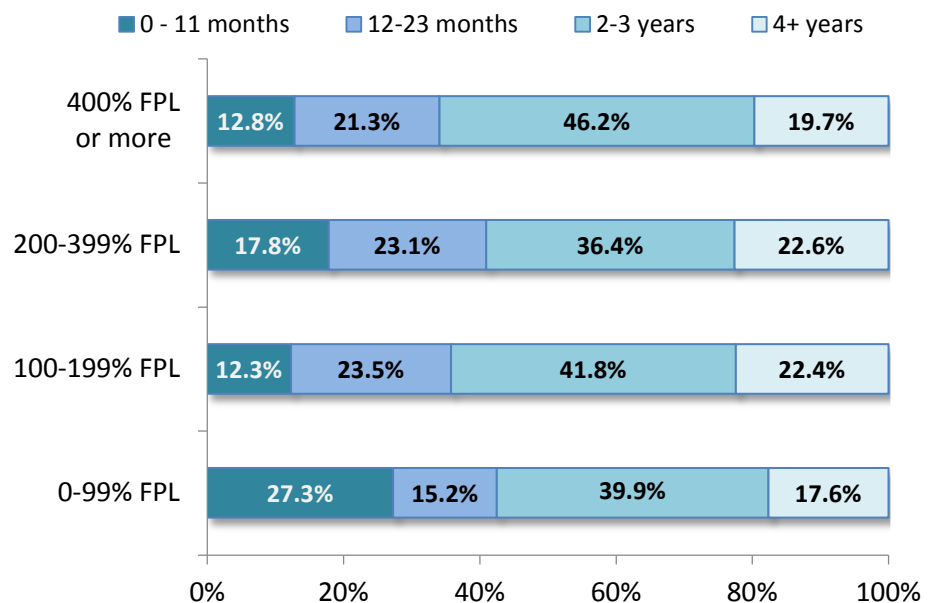


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Child's Age When Parent First Spoke to Provider about Concerns, by Income

As seen in Figure 2-10, a larger percentage of children living in households making <100% of the federal poverty level had a parent who spoke with a provider very early in their child's life (before 12 months old), as compared to children in higher income households.

Figure 2-10. Child's age when parent first spoke to a provider about their concerns, by income, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011.

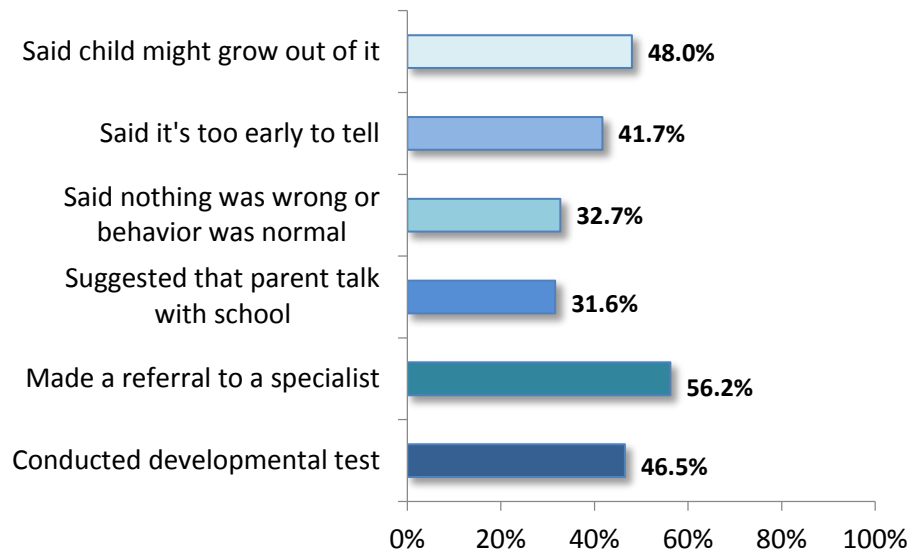
Doctor or Health Care Provider’s Response to Parental Concern

Doctors and health care providers can give a variety of responses when a parent expresses concern about their child’s development.

Just over half of school-aged CSHCN with ASD had providers who referred their parent to a specialist in response to parental concern (56%). A little less than half of children’s providers conducted a developmental test in response to parent’s concern (47%). About a third of providers suggested that the parent talk with their child’s school. See Figure 2-11.

Almost half of children’s providers told parents that their child “might grow out of it”. 42% felt it was too early to tell if there was a developmental concern, and one-third of children’s providers felt that the behavior parents described was normal. See Figure 2-11.

Figure 2-11. Doctor or health care provider's response to parental concern, among CSHCN ages 6-17 with ASD.



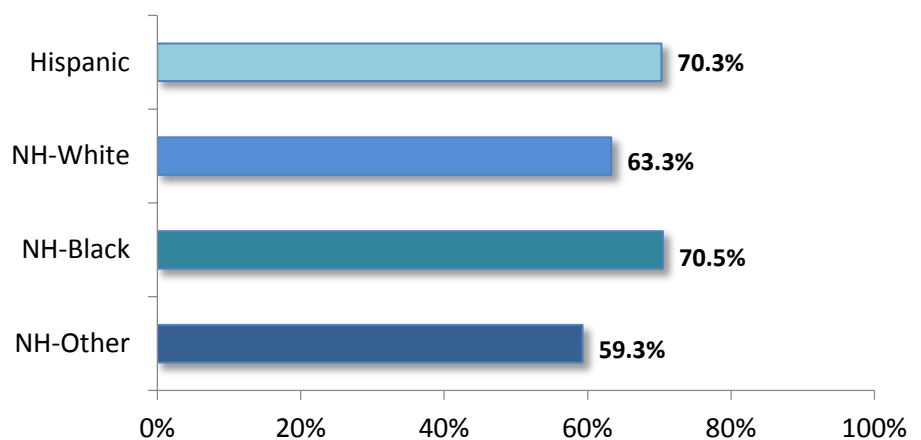
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Provider Conducted a Developmental Test and/or Provided a Referral in Response to Parental Concern, by Race/Ethnicity

64% of children had providers who conducted a developmental test and/or provided a referral when the child’s parents expressed concern.

This percentage did not differ greatly between current ASD severity or household income (data not shown), but did differ slightly among children of different races/ethnicities. As seen in Figure 2-12, a greater proportion of Hispanic or non-Hispanic black children received a developmental test or a referral in response to their parent’s concern, as compared to children of other races/ethnicities (70% vs. < 63%). This suggests that children in some of the most vulnerable racial/ethnic groups received positive provider responses in response to parental concern.

Figure 2-12. Provider conducted a developmental test and/or provided a referral when parent expressed concern, by race/ethnicity, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

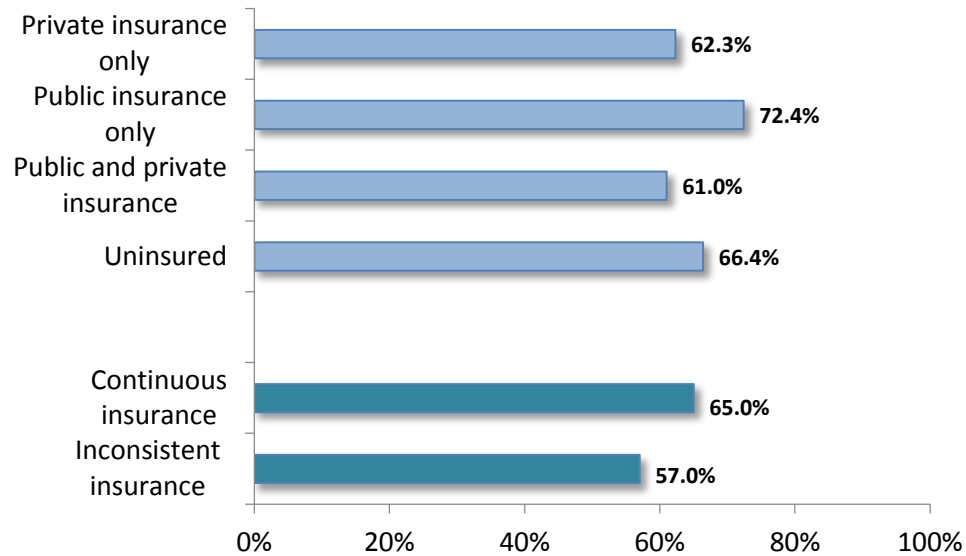
Abbreviations: NH = non-Hispanic.

Provider Conducted a Developmental Test and/or Provided a Referral in Response to Parental Concern, by Insurance Type and Insurance Continuity

The percentage of children whose providers gave them a developmental test or referral also differed by insurance type and insurance consistency. A greater percentage of children with public insurance received a developmental test or referral in response to their parent's concern than children with any other type of insurance. See Figure 2-13.

However, it is important to note the differences in provider response by insurance continuity. Fewer children who had at least one gap in their insurance in the past year received a developmental test or referral in response to parental concern, as compared to children with continuous insurance (57% vs. 65%). See Figure 2-13.

Figure 2-13. Provider conducted a developmental test and/or provided a referral in response to parental concern, by insurance type and insurance continuity, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Abbreviations: NH = non-Hispanic.

Scientific notes: No continuous insurance means that there was at least one gap in insurance coverage in the past 12 months.

Key Takeaways

- ✓ Almost 90% of children's parents spoke with a provider about their developmental concerns.
- ✓ Among the poorest households (<100% of the federal poverty level), almost 100% of children's parents spoke with a provider about their concern. This suggests that the lowest-income families are, in fact, able to connect with providers about these worries.
- ✓ A smaller proportion of Hispanic children's parents expressed their concern to a provider. This figure may result from language barriers, a need for increased cultural competence among providers, or increased awareness regarding ASD in this community.
- ✓ The majority of children were 2-3 years old when their parent first expressed their developmental concerns to a provider.
- ✓ When parents expressed concern, one-third of children's providers said nothing was wrong.
- ✓ 64% of children's health care providers gave a referral or conducted a developmental test when parents expressed concern.
- ✓ Higher proportions of children with continuous insurance, non-Hispanic black children, and Hispanic children received either a referral or a developmental test, compared to children of other races/ethnicities and children with non-continuous insurance.

Developmental Screening

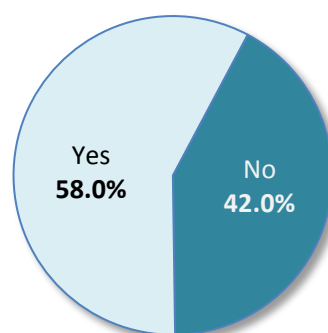
Screening for developmental concerns typically takes place during a well-child visit, and involves a health care provider asking questions or having the parent complete a brief questionnaire about developmentally-appropriate milestones. The goal is to assess whether a child is learning basic skills when they should, or if there are delays. Developmental screening is a crucial step in the journey to diagnosis for children with special health care needs (CSHCN) with Autism Spectrum Disorder (ASD). Data from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) are used to show if CSHCN with ASD ages 1-5 years old received screening in the past 12 months via a parent-reported tool. (Please see the [2009/10 NS-CSHCN questionnaire](#) for the complete wording of each survey question in this section.)

Child Received Developmental Screening via a Parent-Reported Tool

Almost 60% of young CSHCN with ASD received screening via a parent-based tool over the past year. See Figure 2-14. This figure did not differ greatly among boys and girls. (Data not shown.)

This figure is *higher* than the percentage of CSHCN without ASD who received screening via a parent-based tool in the past year (33%). (Data not shown.)

Figure 2-14. Child received developmental screening in the past 12 months, among CSHCN with ASD ages 1-5.

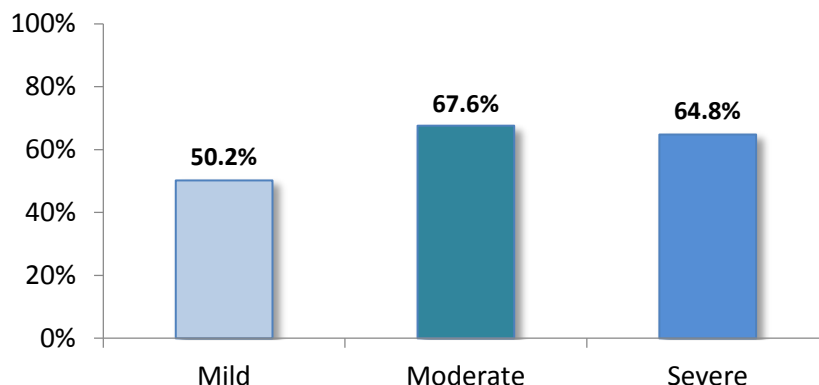


Data source: The National Survey of Children with Special Health Care Needs, 2009/10.

Child Received Developmental Screening, by ASD Severity

Fewer children with mild ASD received developmental screening in the past 12 months, compared to children with more severe ASD. See Figure 2-15. As compared to the 65-68% of 1-5 year-old children with moderate or severe ASD, only 50% of children with mild ASD received screening.

Figure 2-15. Child received developmental screening in the past 12 months, by ASD severity, among CSHCN with ASD ages 1-5.

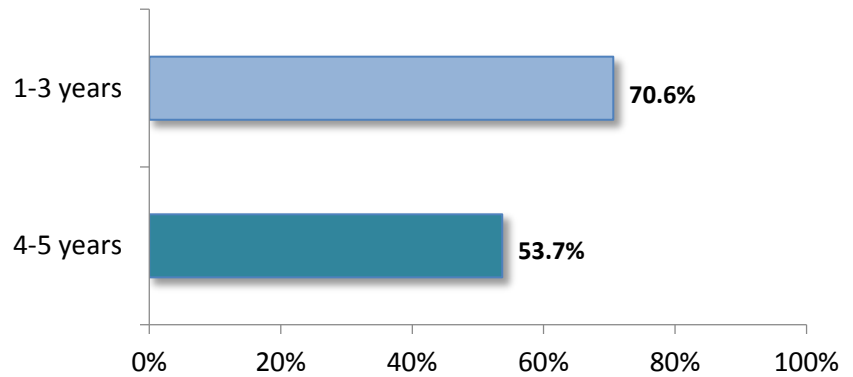


Data source: The National Survey of Children with Special Health Care Needs, 2009/10. Scientific notes: ASD severity is parent-observed.

Received Developmental Screening, by Age

A greater proportion of children with ASD ages 1-3 years old received developmental screening in the past year, as compared to children 4-5 years old (71% vs. 54%). See Figure 2-16. As may be expected, this suggests that regular screenings drop off as these children grow older.

Figure 2-16. Child received developmental screening in the past 12 months via a parent-reported tool, by age, among CSHCN with ASD ages 1-5.



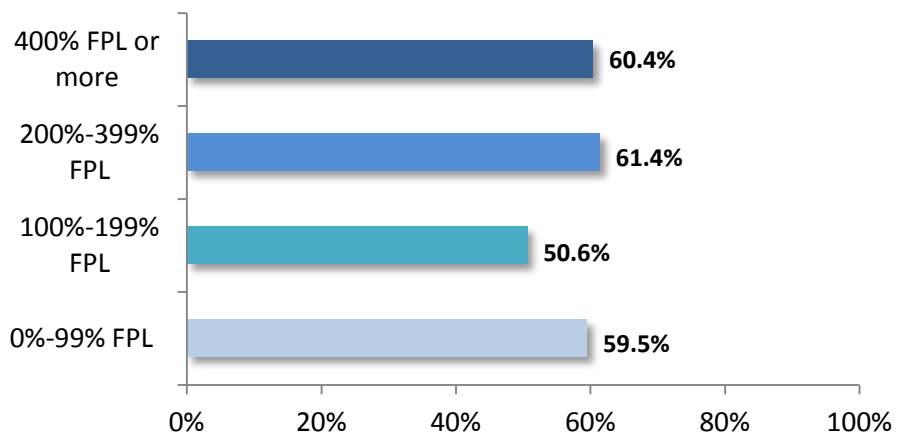
Data source: The National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: ASD severity is parent-observed.

Received Developmental Screening, by Income

Children in higher-income households did not necessarily receive more developmental screening. As seen in Figure 2-17, the proportion of young children with ASD who received screening in the past 12 months was similar between most household income levels (60-61%).

The exception was children living in households earning 100-199% of the federal poverty level. A smaller proportion of these children received screening via a parent-reported tool in the past year (51%). This suggests that children just above the lowest poverty bracket may require more attention to receive regular screening.

Figure 2-17. Child received developmental screening in the past 12 months, by income among CSHCN with ASD years 1-5.



Data source: The National Survey of Children with Special Health Care Needs, 2009/10.

Key Takeaways

- ✓ Almost 60% of CSHCN with ASD ages 1-5 years old received developmental screening via a parent-reported tool in the past year. CSHCN with ASD receive screening at almost two times the rate of CSHCN without ASD (33%).
- ✓ More children with moderate/severe ASD received screening in the past 12 months.
- ✓ Rates of screening were 25% higher among 1-3 years old than 4-5 year olds.
- ✓ Children just above the lowest poverty level received less screening than children in households earning <100% the federal poverty level. As income levels are related to public insurance availability and can vary by state, some children who miss the poverty cut-off may receive less than optimal medical care.

Getting a Diagnosis

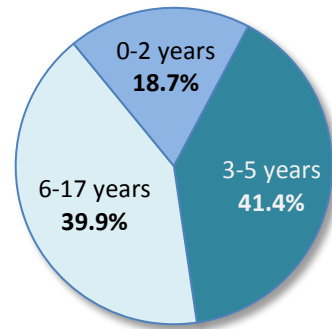
Getting a diagnosis of Autism Spectrum Disorder (ASD) can be a difficult but ultimately very helpful process for families of children with ASD. A formal identification of ASD can help families understand why their child experiences certain difficulties and what they can do to support their child. Additionally, it allows families to access services and resources they were not previously aware of or entitled to. The path to diagnosis can be difficult, confusing, and lengthy. Data from the 2011 Survey of Pathways to Diagnosis and Services (Pathways) are used to describe when school-aged children with special health care needs (CSHCN) with ASD first received an ASD diagnosis, by whom, and what this diagnosis entailed. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Age Child First Received ASD Diagnosis

About 40% school-aged CSHCN with ASD received their first ASD diagnosis when they were 3-5 years old or over 6 years old. Only 19% of children first received an ASD diagnosis before age 3. See Figure 2-18.

The age at which children received their first ASD diagnosis did not differ greatly by the child's sex, income, or type of insurance. (Data not shown.)

Figure 2-18. Age when child first received ASD diagnosis, among CSHCN ages 6-17 years with ASD.

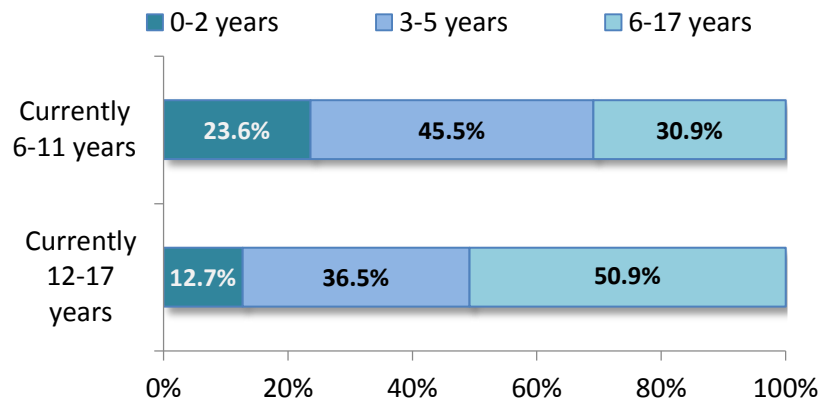


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Age Child First Received ASD Diagnosis, by Child's Current Age

Almost a quarter of children 6-11 years old received an ASD diagnoses before age 3, compared to only 13% of children ages 12-17 years old at the time of the Pathways survey. See Figure 2-19. This suggests that early ASD diagnoses may be increasing.

Figure 2-19. Age child first received ASD diagnosis, by child's current age, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

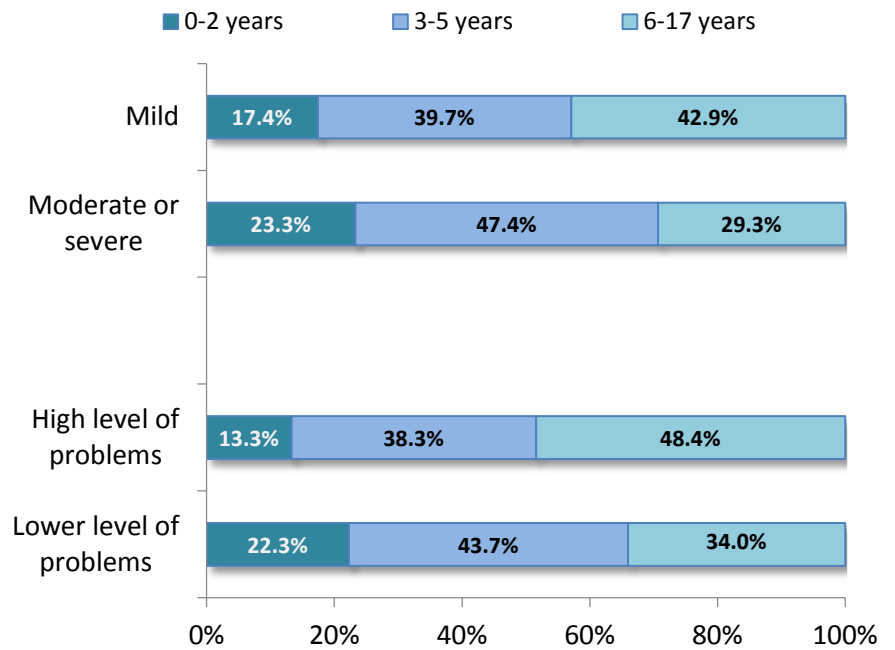
Scientific notes: "Current age" refers to the child's age at the time of the Pathways survey. Chi-square test $p < 0.05$.

Age Child First Received ASD Diagnosis, by Severity and SDQ Score

As may be expected, the age of a child’s first ASD diagnosis differed by the severity of their ASD condition. As seen in Figure 2-20, 71% of children with moderate or severe ASD received their ASD diagnosis before age 6. A smaller proportion of children with mild ASD received their diagnosis before age 6 (57%).

Perhaps less expected is the age of ASD diagnosis among children with high “brief Strengths and Difficulties Questionnaire (SDQ)” scores. The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. As seen in Figure 2-20, fewer children with a high level of mental health problems received their ASD diagnoses before age 6. This finding may result from the fact that the treatment of other mental health conditions may delay ASD diagnosis.

Figure 2-20. Age child first received ASD diagnosis, by ASD severity and Strengths and Difficulties Questionnaire (SDQ) score, among CSHCN ages 6-17 years with ASD.



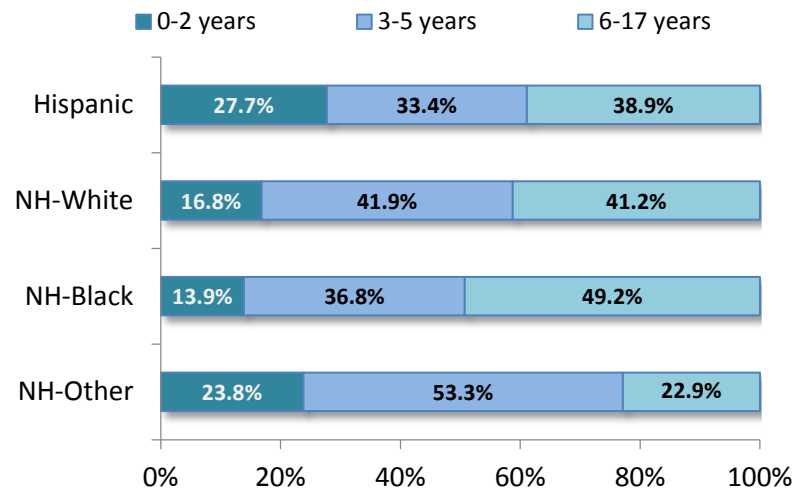
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Scientific notes: ASD severity is parent-reported. The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. Chi-square test $p < 0.05$.

Age Child First Received ASD Diagnosis, by Race/Ethnicity

Age of ASD diagnosis also differed by race/ethnicity. 14-17% of Non-Hispanic white and Non-Hispanic black children received their diagnosis before age 3. This can be compared to approximately one in five Hispanic children and children of “other” races/ethnicities with ASD who received their diagnosis before 3 years old (28% and 24%). Figure 2-21. This suggests that while Hispanic children with ASD require increased support in other areas, these children are receiving early diagnoses.

Figure 2-21. Age child first received ASD diagnosis, by race/ethnicity, among CSHCN ages 6-17 years with ASD.



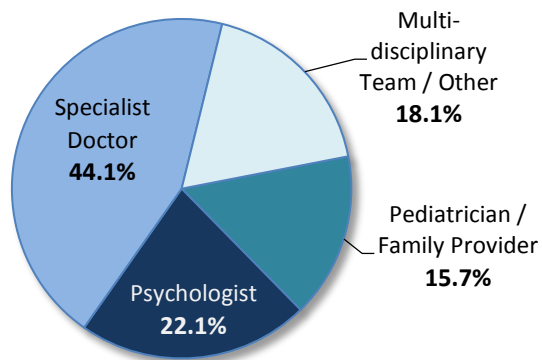
Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Definitions: NH = non-Hispanic.

Type of Doctor Who Made ASD Diagnosis

Almost half of school-aged CSHCN with ASD first received an ASD diagnosis from a specialist (44%). Just under a quarter of children received their first diagnosis from a psychologist. A multi-disciplinary team or other doctor provided 18% of first ASD diagnoses, followed by pediatricians and family providers (16%). See Figure 2-22.

Slightly more girls received their first ASD diagnosis from a psychologist (28% vs. 21%; data not shown.) More demographic differences are outlined in the sections below.

Figure 2-22. Type of doctor who made ASD diagnosis among CSHCN ages 6-17 years with ASD.

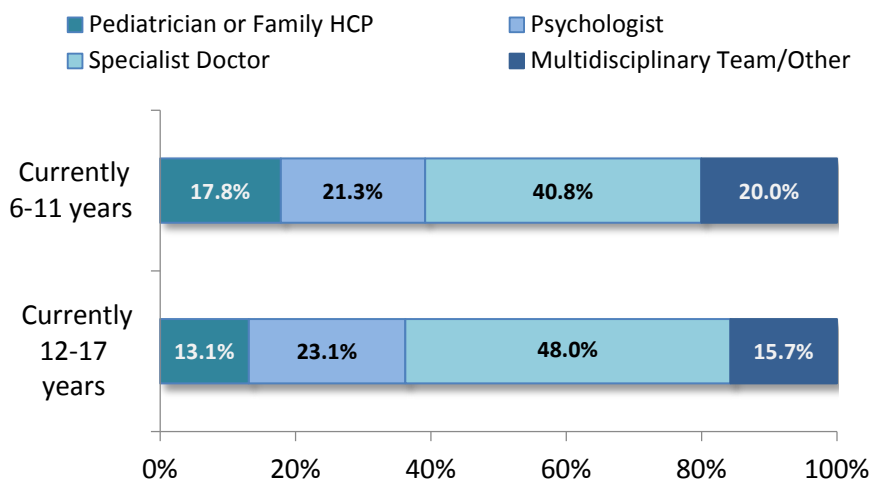


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Type of Doctor Who Made ASD Diagnosis, by Child's Current Age

As compared to older children, a slightly larger proportion of young children received their first ASD diagnosis from a pediatrician or family healthcare provider (HCP). See Figure 2-23. A larger percentage of older children received their first diagnosis from a specialist doctor.

Figure 2-23. Type of doctor who first made ASD diagnosis, by child's current age, among CSHCN ages 6-17 years with ASD.



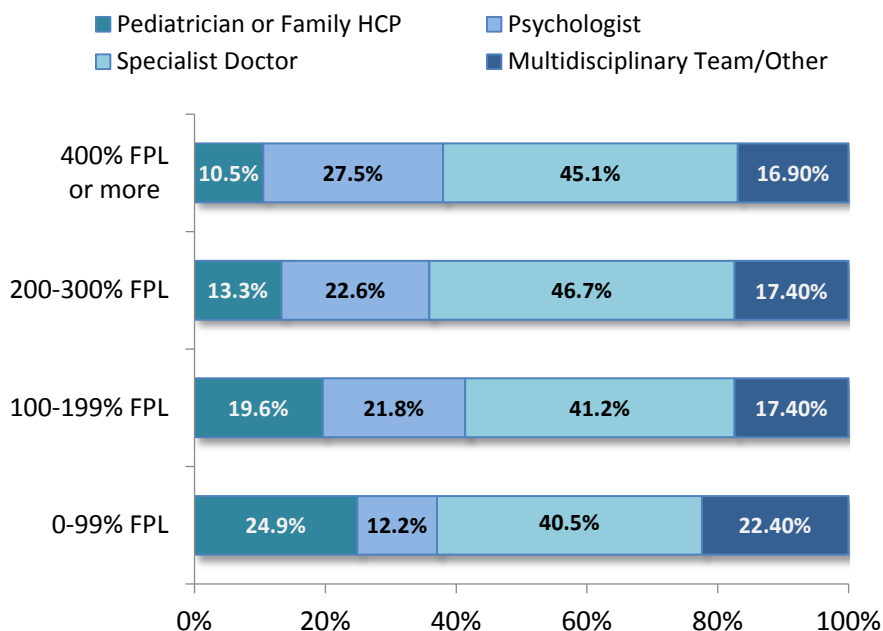
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Scientific notes: "Current age" refers to the child's age at the time of the Pathways survey.

Type of Doctor Who Made ASD Diagnosis, by Income

As seen in Figure 2-24, differences also emerged by income. A greater percentage of children living in lower-income households received their first ASD diagnosis from a pediatrician or family HCP, whereas more higher-income children received their first diagnosis from a psychologist. See Figure 2-24.

Figure 2-24. Type of doctor who first made ASD diagnosis, by income, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Abbreviations: FPL = Federal Poverty Level.

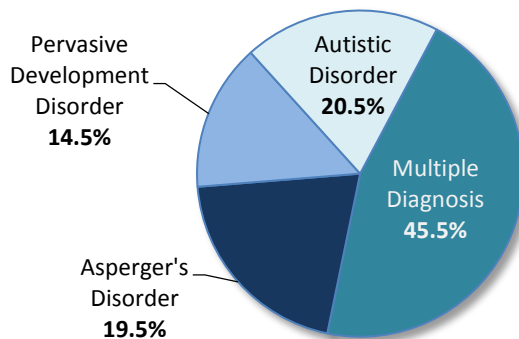
Scientific notes: Poverty threshold (<100% FPL) for a family of four is an annual income of \$22,350 in 2011.

Type of ASD Diagnosis

Just about half of school-aged CSHCN with ASD received multiple diagnoses under the umbrella of ASD. Among the other half of children who received only one diagnosis, equal percentages of children received only an [Asperger's Disorder](#) diagnosis or an [Autistic Disorder](#) diagnosis (~20%). 15% of children were diagnosed with [Pervasive Development Disorder](#). See Figure 2-25.

More girls than boys were given multiple ASD diagnoses (53% vs. 44%; data not shown). Additionally, compared to children with all other insurance types, a higher proportion of children with private insurance received [Asperger's Disorder](#) diagnoses (24% vs. <16%; data not shown).

Figure 2-25. Type of ASD diagnosis, among CSHCN ages 6-17 years with ASD.



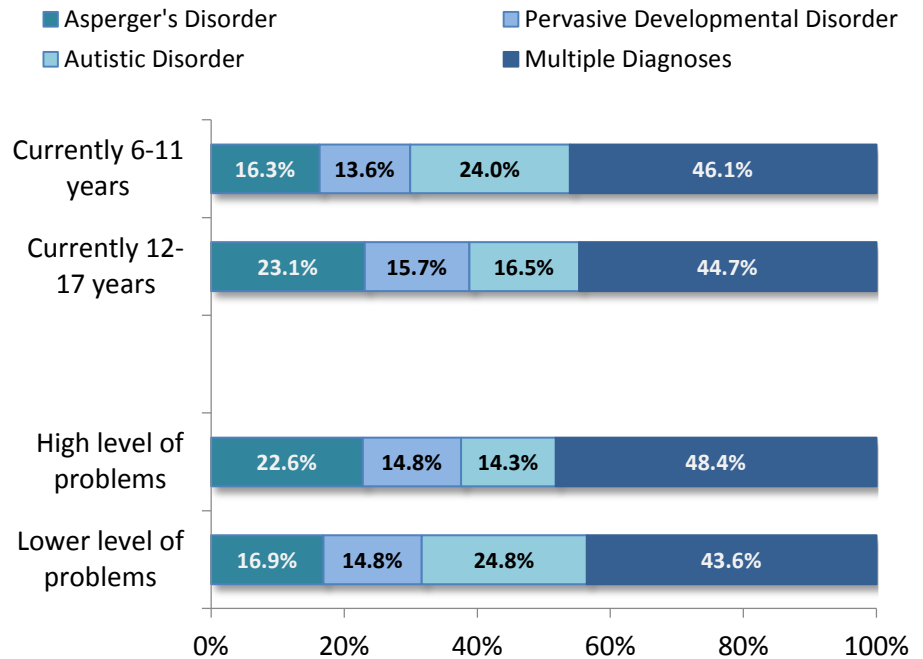
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Type of ASD Diagnosis, by Child's Current Age and SDQ score

As seen in Figure 2-26, a larger proportion of children who were younger at the time of the Pathways survey received an Autistic Disorder diagnoses, as compared to older children (24% vs. 17%). This can be compared to the slightly greater proportion of older children who received an [Asperger's Disorder](#) diagnosis (23% vs. 16%).

The Pathways survey also includes the brief [Strength and Difficulties Questionnaire \(SDQ\)](#). The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. Results indicate that children with a high level of mental health problems received fewer Autistic Disorder diagnoses. See Figure 2-26.

Figure 2-26. Type of ASD diagnosis, by child's current age and SDQ score, among CSHCN ages 6-17 years with ASD.

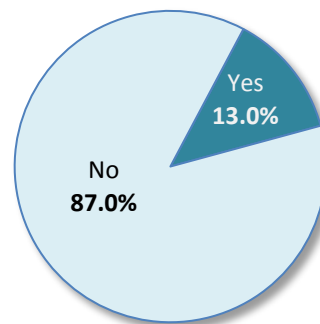


Data source: The Survey of Pathways to Diagnosis & Services, 2011.
 Scientific notes: "Current age" refers to the child's age at the time of the Pathways survey. The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems.

Child Told Does Not Have ASD after First ASD Diagnosis

Some parents of school-aged CSHCN with ASD received confusing and conflicting news after their child received his or her first ASD diagnosis. 13% of children who received a formal ASD diagnosis were afterwards told by a provider that they did not have ASD. See Figure 2-27. This conflicting news can lead to a prolonged diagnosis experience.

Figure 2-27. Child told does not have ASD after first ASD diagnosis, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Key Takeaways

- ✓ Equal percentages of school-aged CSHCN with ASD received their first ASD diagnosis at either 3-5 years old or 6-17 years old (~40%).
- ✓ 13% of children who originally received an ASD diagnosis were told by a provider at some point that they did not have ASD.
- ✓ More Hispanic children and children who were younger at the time of the Pathways survey received their ASD diagnosis very early in life (before 3 years old).
- ✓ Children with higher levels of mental health problems may be delayed in receiving an ASD diagnosis.
- ✓ Almost half of children with ASD first received their ASD diagnosis from a specialist. As household income decreases, more children in low-income households received their first ASD diagnosis from a pediatrician or family healthcare provider.
- ✓ Just about half of children with ASD received multiple types of ASD diagnoses.

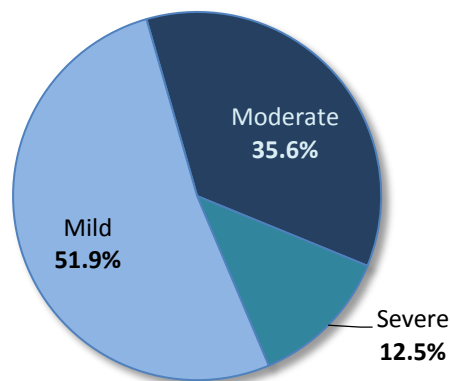
Severity of ASD and Comorbid Conditions

Children with Autism Spectrum Disorder (ASD) experience a broad range of functioning. Some children have mild cases of ASD, while others have more severe cases. Children with ASD often experience additional health conditions, also known as “[co-morbidities](#)”, which may interact with their ASD or require additional treatment and health-related services. Data from the 2011/12 National Survey of Children’s Health (NSCH) provides valuable information related to ASD severity and comorbidities among children with ASD. (Please see the [2011/12 NSCH questionnaire](#) for the complete wording of each survey question in this section.)

Severity of ASD

Half of children ages 2-17 years with ASD had a parent who reported their case as mild. More than one-third of children had moderate cases, and over one in ten children with ASD had severe cases. See Figure 3-1.

Figure 3-1. ASD was mild, moderate, or severe, among children with ASD ages 2-17 years old.

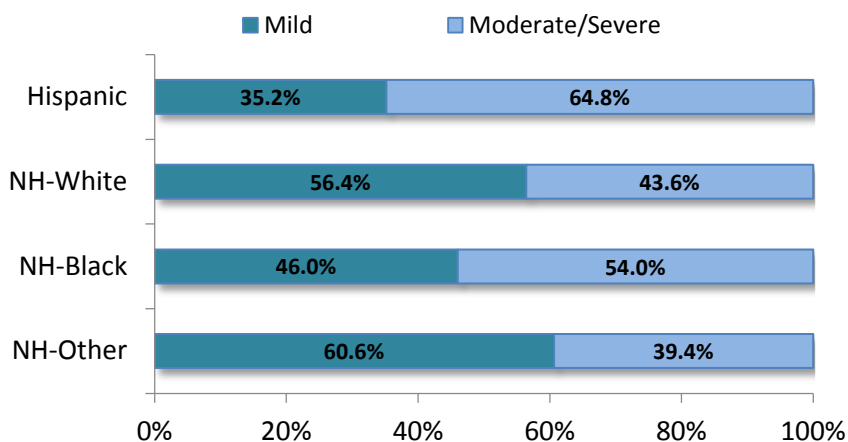


Data source: The National Survey of Children’s Health, 2011/12.
Scientific notes: ASD severity is parent-reported.

ASD Severity, by Race/Ethnicity

Variations in ASD severity were noticeable between children of different races and ethnicities. 64% of Hispanic children with ASD were reported as having moderate or severe ASD, followed by 54% of non-Hispanic black children. Fewer non-Hispanic white children and children of other races/ethnicities were reported to have moderate or severe ASD (39%-43%). See Figure 3-2.

Figure 3-2. ASD severity, by race/ethnicity, among children with ASD ages 2-17 years old.



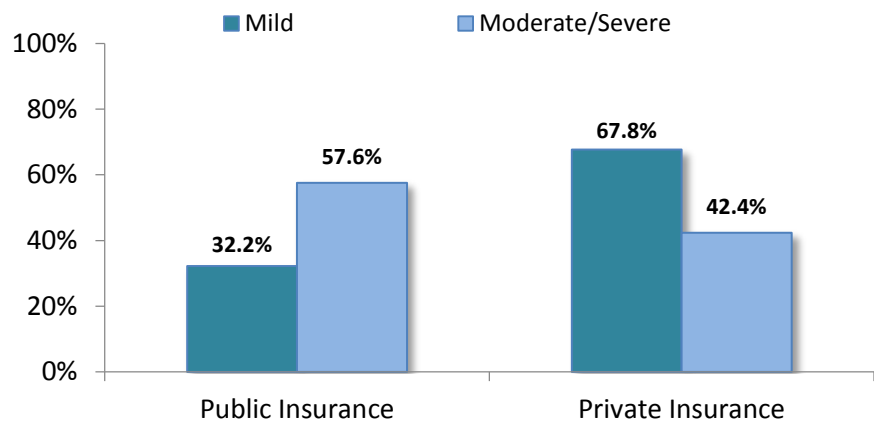
Data source: The National Survey of Children’s Health , 2011/12.
Abbreviations: NH = non-Hispanic.
Scientific notes: ASD severity is parent-reported. Chi-square test p < 0.05

ASD Severity, by Type of Insurance

Among children with ASD who had insurance, a greater proportion of publicly insured children were reported as having moderate/severe cases, compared to children with private insurance (56% vs. 42%). See Figure 3-3.

This finding may be an indicator of later diagnosis, less access to treatment, or less access to early intervention among publicly insured children.

Figure 3-3. ASD severity, by insurance type, among insured children with ASD ages 2-17 years old.



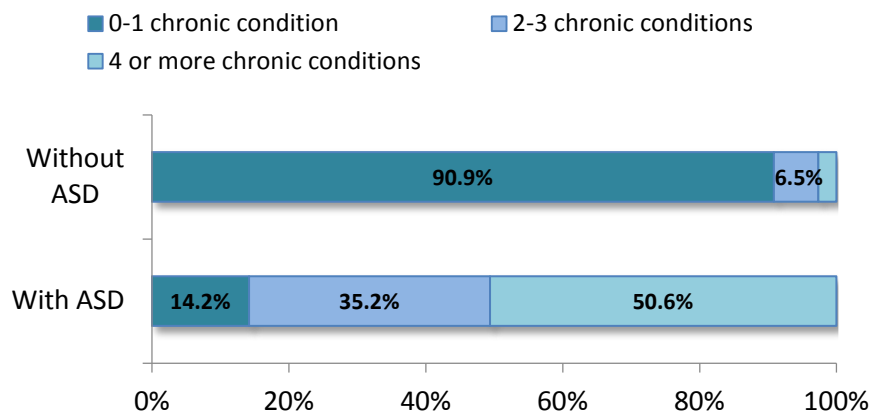
Data source: The National Survey of Children's Health , 2011/12.
 Scientific notes: ASD severity is parent-reported. Only 0.5% of children in the NSCH 2011-12 were uninsured AND had ASD. The sample is too small to reliably make statements about severity among the uninsured, and therefore is not included in this graphic. Chi-square test $p < 0.05$.

Other Conditions Experienced by Children with ASD

Children with ASD experience dramatically higher rates of [co-morbidity](#) compared to children without ASD. Specifically, over 90% of children without ASD experienced 0-1 other conditions. In contrast, 86% of children with ASD experienced *two or more* other conditions. Further, over 50% of children with ASD experienced four or more additional conditions. See Figure 3-4.

Knowing that children with ASD also experience multiple, simultaneous conditions is important in developing patient-centered care within a [medical home](#).

Figure 3-4. Number of co-morbidities, among children ages 2-17 years old.

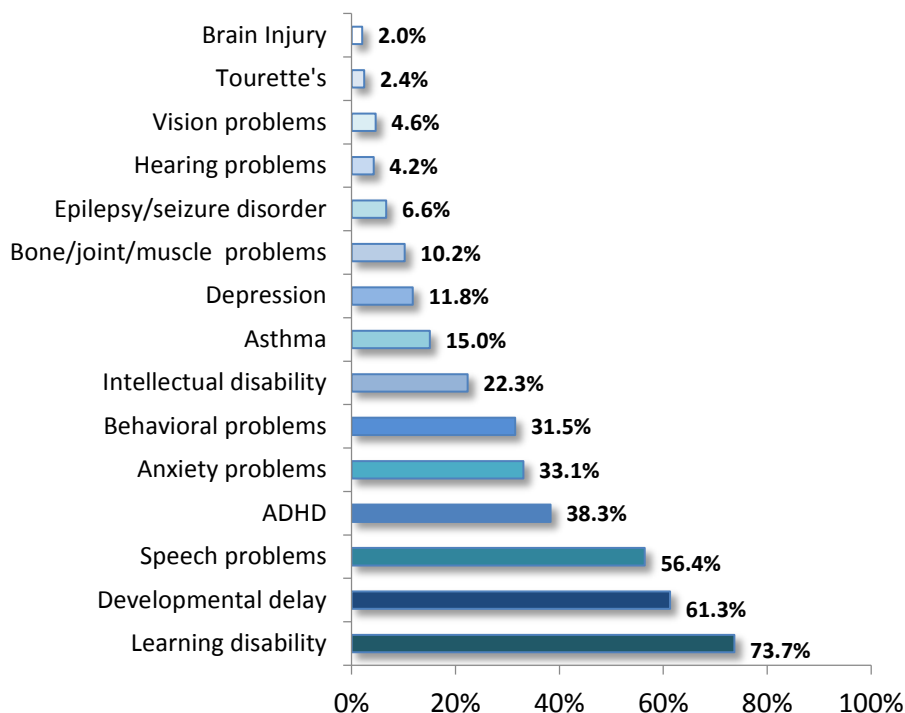


Data source: The National Survey of Children's Health, 2011/12.
 Scientific notes: Number of chronic conditions is based on a list of 17 conditions that were asked about in the survey, not including ASD. Chi-square test $p < 0.05$.

Most Common Other Conditions

As seen in Figure 3-4, other conditions are common among children with ASD. It is important to note the specific comorbid conditions experienced by this population, which include: learning disabilities (74%), developmental delays (61%), speech problems (56%), ADHD (38%), anxiety (33%), and/or behavioral problems (32%). See Figure 3-5.

Figure 3-5. Chronic conditions, among children with ASD ages 2-17 years.



Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Of the list of 17 chronic conditions, Cerebral Palsy and Diabetes were not included since the estimates did not meet standards of reliability and precision.

Key Takeaways

- ✓ Nearly half of all children with ASD had moderate or severe cases.
- ✓ A greater proportion of Hispanic children experienced moderate or severe cases of ASD, as compared to children of other races/ethnicities (65% vs. <54%).
- ✓ Moderate or severe cases of ASD were more common among children who had public insurance (58%).
- ✓ Children with ASD had drastically higher rates of comorbidity with two or more conditions than children without ASD (86% vs. 9%).
- ✓ More than 50% of children with ASD also experienced speech problems, developmental delays and/or learning disabilities.

Impact on Children’s Daily Lives

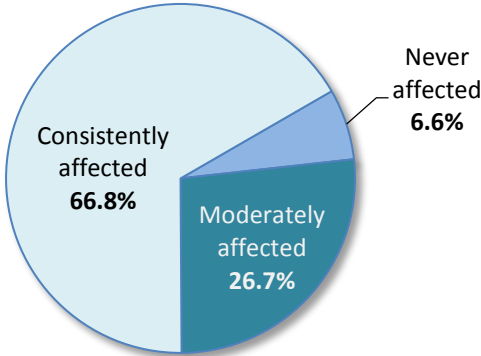
Children living with Autism Spectrum Disorder (ASD) are impacted in many ways as they live their daily lives. As detailed in the Severity section of this chartbook, the majority of children with ASD experience a number of other conditions in addition to ASD that may affect their lives, and ASD itself can affect how a child experiences school, play, and relationships with family and friends. Data from the 2011 Survey of Pathways to Diagnosis and Services (Pathways) explores the problems with daily functioning experienced by school-aged children (ages 6-17) with special health care needs (CSHCN) with ASD. It should be noted that the questions are asked about functioning generally, not specifically whether it is related to ASD. This includes the child’s ability to perform daily activities, their difficulty functioning, and their emotional and behavioral strengths and difficulties. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Child’s Condition(s) Affects Daily Activities

Another way of reporting the severity of a child’s condition is to assess how much their daily activities are affected by their condition. More than two in three school-aged CSHCN with ASD were greatly affected by their condition(s) on a daily basis (67%). See Figure 3-6. This figure is much greater than the 49% of children who do not have ASD and whose daily lives were affected by their condition. (Data not shown.)

It should be noted that a slightly higher percentage of female children with ASD were reported to be consistently affected by their condition(s), compared with boys (74% vs. 65%; data not shown).

Figure 3-6. Child’s condition(s) affects daily activities, among CSHCN with ASD ages 6-17 years.



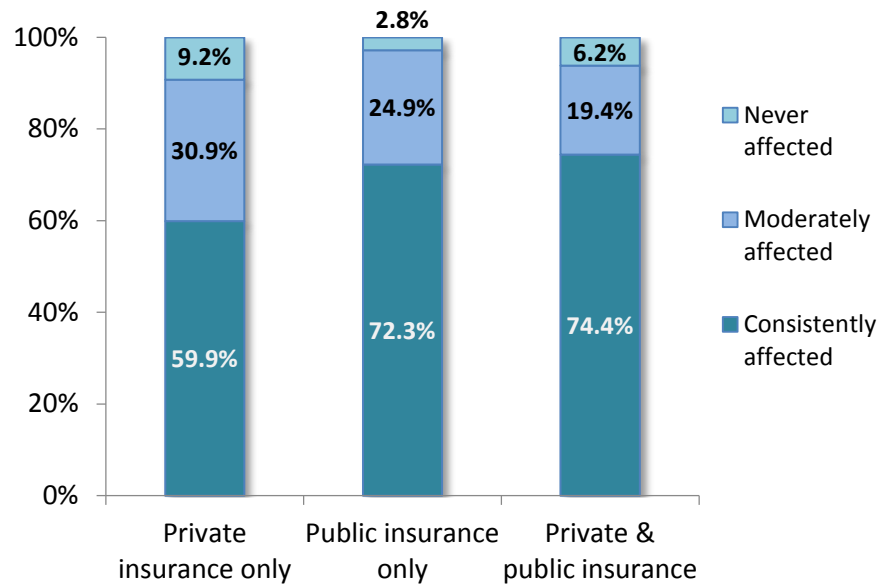
Data source: The Survey of Pathways to Diagnosis and Services, 2011.
Scientific notes: Conditions that affect daily activities can include other conditions besides ASD.

Child's Condition(s) Affects Daily Activities, by Insurance Type

A greater proportion of children with ASD with public insurance had a condition that consistently affected the child (72-74%), compared with children who only had private insurance (60%). See Figure 3-7.

This may indicate greater access to therapeutic services through private insurance, compared with other types of coverage. Additionally, it could indicate that most children with severe ASD may qualify for Supplemental Security Income (SSI), and thus have both public and private insurance.

Figure 3-7. Child's condition(s) affects daily activities, by insurance type, among CSHCN with ASD ages 6-17 years.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

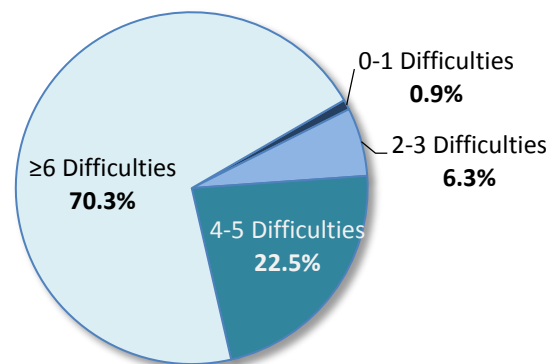
Scientific notes: Conditions that affect daily activities can include other conditions besides ASD. Chi-square $p < 0.05$.

Functional Difficulties

Children with ASD experience many [difficulties](#) with daily functioning. Parents were asked about whether or not their child experienced one or more of 14 difficulties with functioning on a day-to-day basis. The difficulties asked about included vision or hearing problems, difficulty with self-care, chronic pain, digestive problems, and anxiety or depression.

More than 70% of school-aged CSHCN with ASD experienced six or more of the difficulties asked about, which suggests the broad and multidimensional effect of ASD on functioning. See Figure 3-8.

Figure 3-8. Number of functional difficulties, among CSHCN with ASD ages 6-17 years.



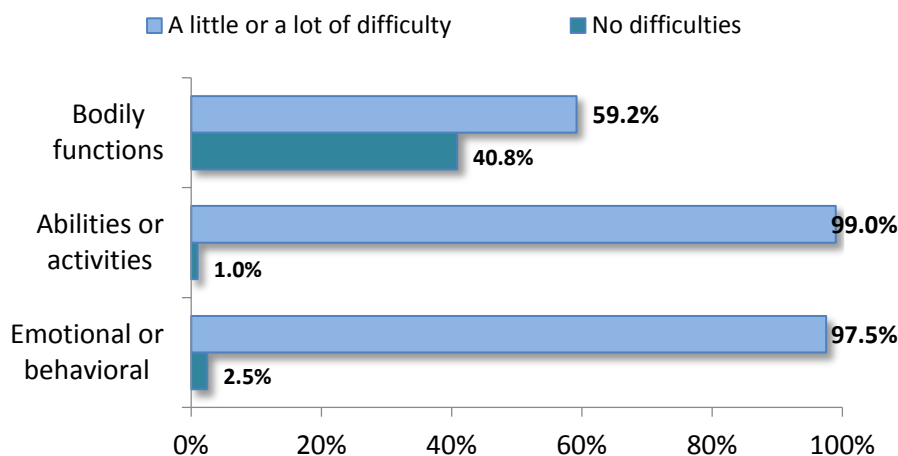
Data source: The Survey of Pathways to Diagnosis and Services, 2011.

Types of Functional Difficulties

Another way of thinking about children’s [functional difficulties](#) is to group them into domains: bodily functions, abilities or activities, and emotional or behavioral.

Almost 60% of children with ASD experienced bodily difficulties (such as breathing difficulties). However, nearly 100% of children with ASD experienced difficulties with their abilities and activities (such as self-care tasks like eating and dressing) and emotional or behavioral health (such as difficulties making and keeping friends). See Figure 3-9.

Figure 3-9. Types of functional difficulties, among CSHCN with ASD ages 6-17 years.



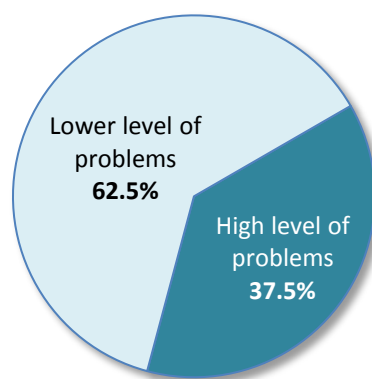
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Scientific notes: Bodily functions include breathing or respiration, swallowing, digestion, blood circulation, chronic physical pain, vision (even with glasses/contacts), and hearing (even with hearing aids). Daily abilities/activities include self care, coordination or moving around, using hands, learning, understanding or paying attention, speaking, communicating or being understood. Emotional difficulties include feeling anxious or depressed, acting out, fitting, bullying or arguing, making and keeping friends.

Emotional and Behavioral Strengths and Difficulties

Included in the 2011 Pathways survey, the brief [Strength and Difficulties Questionnaire \(SDQ\)](#) is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. Overall, 38% of school-aged CSHCN with ASD tend to experience a higher level of mental health problems. See Figure 3-10. Girls with ASD experienced higher levels of mental health problems as compared to boys with ASD (48% vs. 35%; data not shown).

Figure 3-10. Strength and Difficulties Questionnaire (SDQ) scores,



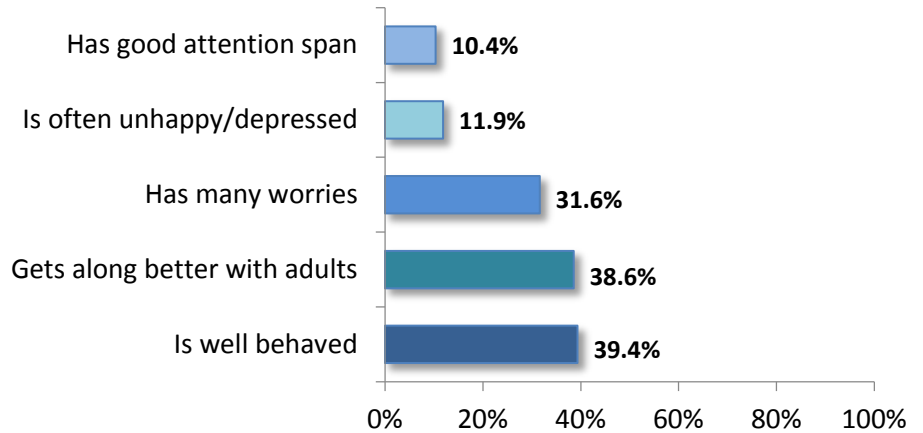
Data source: The Survey of Pathways to Diagnosis and Services, 2011.

Scientific notes: The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems.

Strength and Difficulties Questionnaire Items

The brief [SDQ](#) consists of five questions. As seen in Figure 3-11, a high proportion of parents of children with ASD reported that their child struggles with having a good attention span and being well behaved. (These items in the [SDQ](#) seek to reflect difficulties with hyperactivity and conduct problems.) A sizeable proportion (32-39%) of parents also reported that their child gets along better with adults than children, and that their child has many worries. Depression is not as prevalent among this population.

Figure 3-11. Parents who responded "certainly true" to Strength and Difficulties Questionnaire items, among CSHCN with ASD ages 6-17 years.



Data source: The Survey of Pathways to Diagnosis and Services, 2011.

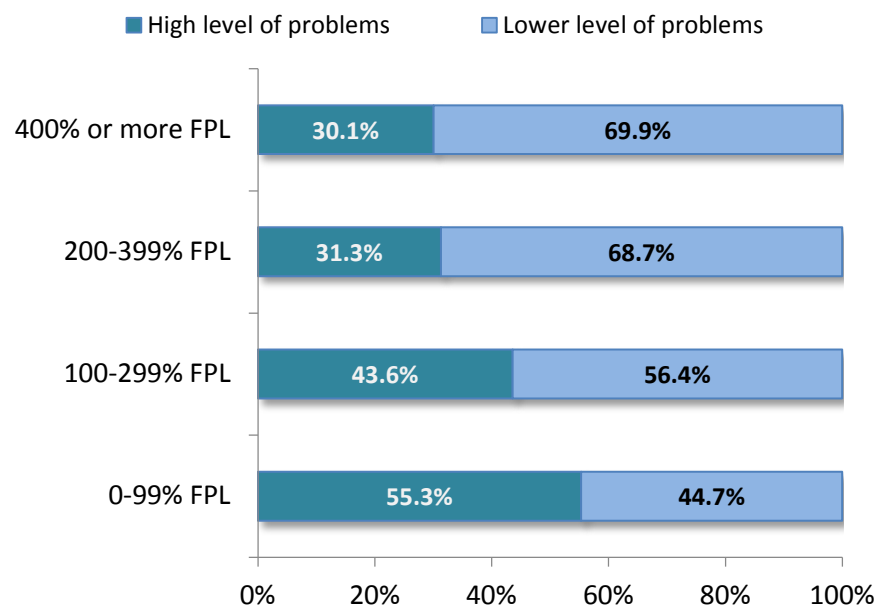
Scientific notes: Parent's responded not true, somewhat true, or certainly true to each of the SDQ items. Each item is a paraphrased version of the actual interview question.

SDQ Scores, by Income

The percent of children with ASD who exhibited higher levels of mental health problems increased as household income decreased. Over half (55%) of children with ASD from households earning less than 100% of the federal poverty level were found to have a high level of mental health problems (as measured by the brief [SDQ](#)). This can be contrasted with the 30% of children in higher income households with a high level of mental health problems. See Figure 3-12.

This finding may indicate that those families earning higher incomes have greater access to resources (such as private therapists or tutors) that can ameliorate some of the more difficult mental health problems that children with ASD face.

Figure 3-12. Strength and Difficulties Questionnaire (SDQ) scores, by income, among CSHCN with ASD ages 6-17 years.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Abbreviations: FPL= Federal poverty level.

Scientific Notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011. The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems.

Key Takeaways

- ✓ Almost all CSHCN with ASD had additional conditions. (See the Severity section of this chartbook.)
- ✓ Nearly 67% of children with ASD were impacted daily by their condition(s). 7 in 10 children with ASD experienced at least six daily functional difficulties from a list of 14 that were asked.
- ✓ Nearly 100% of children with ASD experienced functional difficulties in the domains of ability or activity limitations, or emotional or behavioral problems.
- ✓ Almost 40% of children with ASD have high levels of mental health problems, as measured by the brief Strengths and Difficulties Questionnaire (SDQ).
- ✓ 55% children with ASD living in poverty experience high levels of mental health problems, as compared to ~30% of their higher income peers.

Consistent & Adequate Insurance Coverage

Expanded health insurance coverage through the Children’s Health Insurance Program (CHIP) has greatly reduced the uninsured rate among children in recent years. However, challenges remain. Having consistent and [adequate insurance](#) coverage is important for all children and critical for children with Autism Spectrum Disorder (ASD). Any gaps in coverage (i.e. inconsistent insurance) or coverage that is inadequate to meet the child’s health needs can have a long-lasting impact on a child’s development and therapeutic trajectory.

In the 2011-12 National Survey of Children’s Health (NSCH), several questions ascertain the consistency and adequacy of insurance coverage. Children are said to have inconsistent insurance if they were uninsured at the time of the survey or had experienced any gaps in coverage in the prior 12 months. Gaps in coverage could be from a parent changing or losing a job, or from moving between public and private insurance. Whether or not insurance is adequate is measured by three items: 1) Whether the coverage meets the child’s needs; 2) Whether the child can see all needed providers; and 3) Whether the out of pocket costs are reasonable or not.

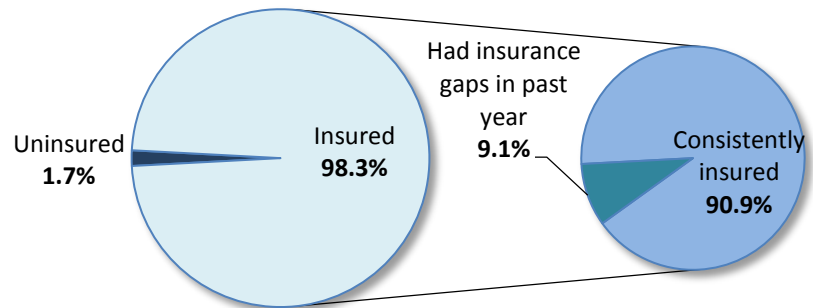
It should be noted that all surveys included in this chartbook were conducted prior to the implementation of the Patient Protection and Affordable Care Act (ACA). Presumably, the expansion of Medicaid (in states that have chosen to expand Medicaid) should have a positive impact on early detection and treatment accessibility among lower income children. It will be important to track these developments among children with ASD, particularly comparing accessibility and outcomes between children with ASD living in Medicaid expansion states versus those who have not expanded Medicaid. (Please see the [2011/12 NSCH questionnaire](#) for the complete wording of each survey question in this section.)

Insurance Status and Consistency of Insurance

About 6% of children without ASD were uninsured at the time of the 2011/12 NSCH (data not shown). In comparison, almost all children with ASD had insurance.

However, among children with ASD who had insurance at the time of the NSCH, about 1 in 10 (9%) had experienced gaps in coverage in the previous 12 months. See Figure 4-1. Any gaps in coverage can delay care or mean that children have to change providers when establishing new coverage. When comparing children who have ASD, children with special health care needs (but not ASD), and children with no special health care needs, no key differences in the consistency of coverage between the groups emerged. (Data not shown.)

Figure 4-1. Insurance status and any gaps in insurance, among children with ASD ages 2-17 years.



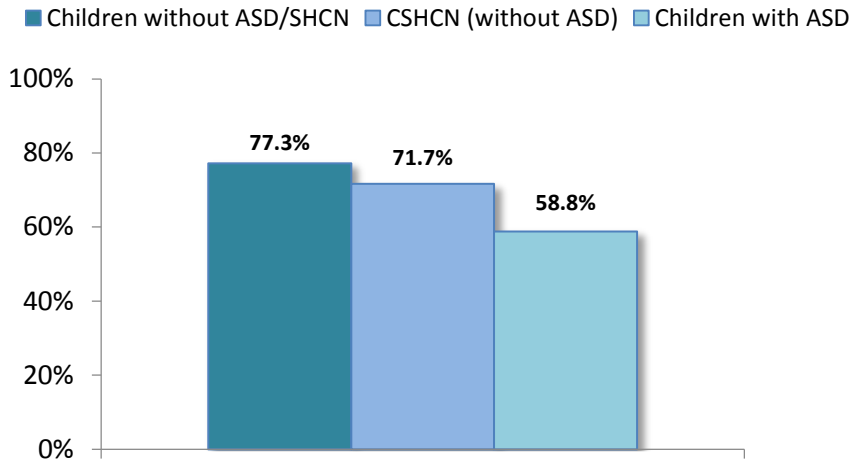
Data source: The National Survey of Children's Health, 2011/12.

Adequate Health Insurance Coverage

Among children with ASD with insurance, we find several differences regarding the adequacy of insurance coverage between children without special needs, CSHCN without ASD, and children with ASD. Fewer children with ASD had insurance coverage that is considered adequate (i.e. does *not* meet child's needs with reasonable out-of-pocket expenses), compared to children who have other special health care needs (59% vs. 72%, respectively). See Figure 4-2.

Despite having the same level of consistent insurance coverage compared to other children, children with ASD experience more problems with the adequacy of their insurance. This may reflect a lack of coverage for health care, providers, or other related services that meet the unique needs of children with ASD.

Figure 4-2. Adequate insurance coverage, among children with ASD, CSHCN without ASD, and children without either, ages 2-17 years.



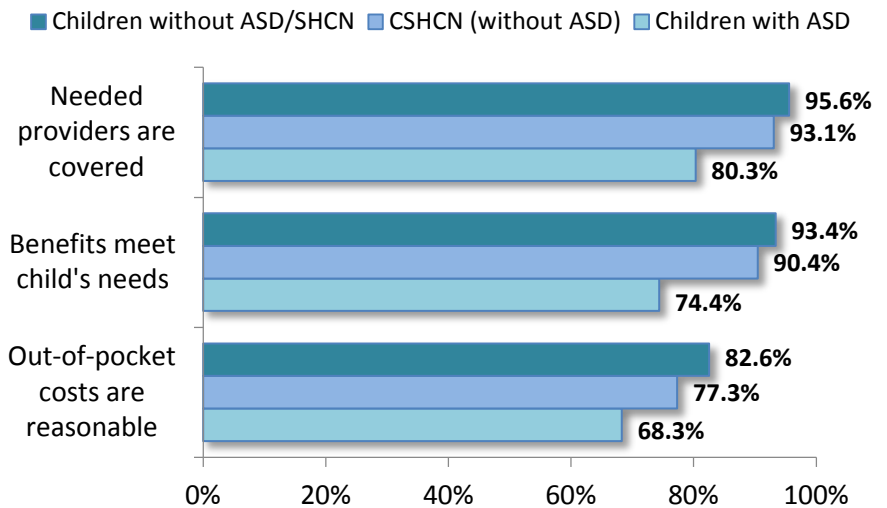
Data source: The National Survey of Children's Health, 2011/12.
 Scientific notes: Children without consistent insurance include uninsured children. Adequacy of insurance is asked among children with insurance coverage at the time of the survey. Chi-square test $p < 0.05$.

Detailed Components of Adequate Insurance Coverage

It is important to consider the specific inadequacies of insurance in order to understand the unique coverage needs of children with ASD.

Figure 4-3 demonstrates differences among children with regards to specific components of insurance coverage. In particular, fewer children with ASD had parents who reported that out-of-pocket expenses were reasonable. This perhaps reflects the use of specialized services which require higher co-pays or are not covered at all.

Figure 4-3. Adequate insurance components, among children with ASD, with SHCN without ASD, and children without either, ages 2-17 years.



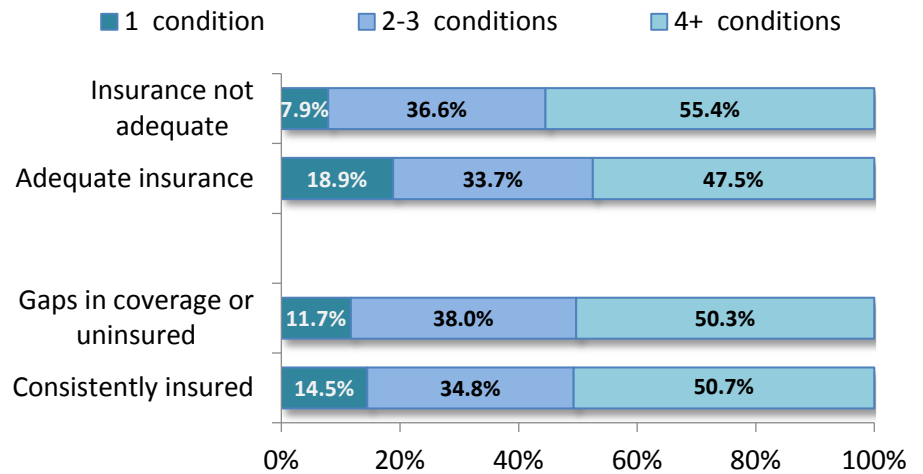
Data source: The National Survey of Children's Health, 2011/12.
 Scientific notes: Chi-square test $p < 0.05$.

Adequate and Consistent Coverage, by Number of Health Conditions

As seen in Figure 4-4, there does not appear to be a relationship between inconsistent insurance coverage and the child's number of conditions, including ASD.

However, a greater proportion of children with inadequate insurance had 4 or more conditions (other than ASD), as compared to children with [adequate insurance](#) (55% vs. 48%). As the number of conditions rises, a greater proportion of children (especially those with ASD) experienced inadequate insurance.

Figure 4-4. Adequate and consistent insurance coverage, by number of chronic conditions, among children with ASD ages 2-17 years.



Data source: The National Survey of Children's Health, 2011/12.

Scientific notes: Chi-square test $p < 0.05$ for insurance adequacy subgroup.

Key Takeaways

- ✓ Most children with ASD had insurance coverage, and most had consistent insurance coverage.
- ✓ Nearly 42% of children with ASD did not have *adequate* insurance coverage to meet their needs, which was higher than children with no conditions and even higher than children with other special health care needs.
- ✓ Fewer children with ASD have all three components of adequate insurance (benefits that meet their needs, reasonable out of pocket expenses, and the ability to see all providers needed), compared to children without ASD.
- ✓ A greater proportion of children with ASD with inadequate insurance experience 4+ additional health conditions, as compared to children with adequate insurance.

Health Care and Related Services Used

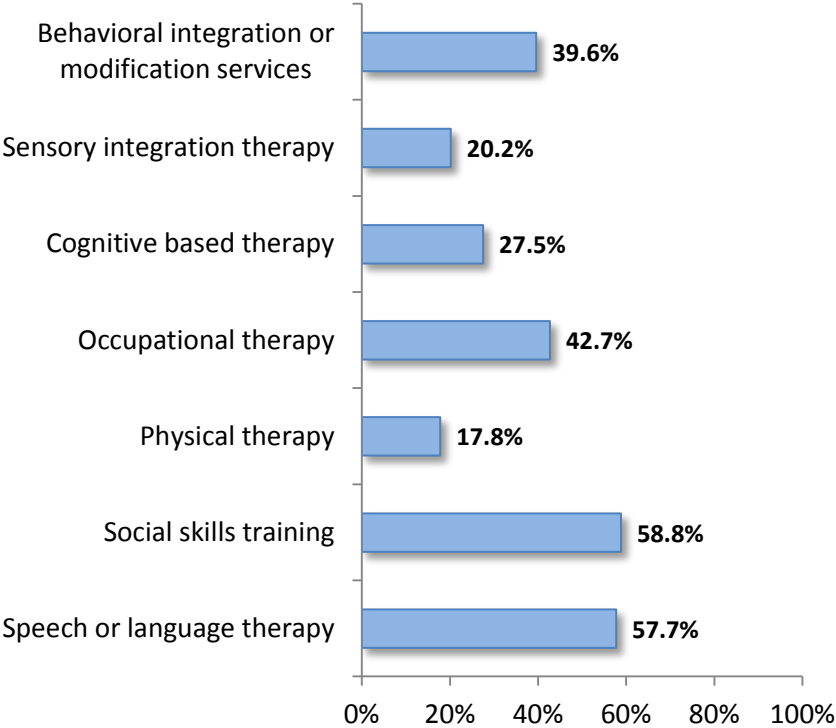
Many children with Autism Spectrum Disorder (ASD) rely on numerous health care and related services to manage their health conditions, address their unique developmental needs, and maintain their quality of life. The 2011 Survey of Pathways to Diagnosis and Services (Pathways) asked parents of school-aged children (ages 6-17) with special health care needs (CSHCN) with ASD questions about the health care and related services used by their children. Data collected includes types of services used, number of services used, and whether there are unmet needs for services. The last part of this section presents data on parental satisfaction with services, and the extent to which parents feel their child’s provider meets their needs. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Type of Health Care and Related Services Used

The Pathways Survey asked parents of school-aged CSHCN with ASD to review a list of seven services and indicate which services were currently used by their child on a regular basis. See Figure 4-5 for a list of services.

Social skills training was the service most commonly used by children with ASD (59%), closely followed by speech or language therapy (58%). Behavioral integration or modification services were utilized by about 40% of children with ASD.

Figure 4-5. Types of health care and related services used, among CSHCN ages 6-17 years with ASD.



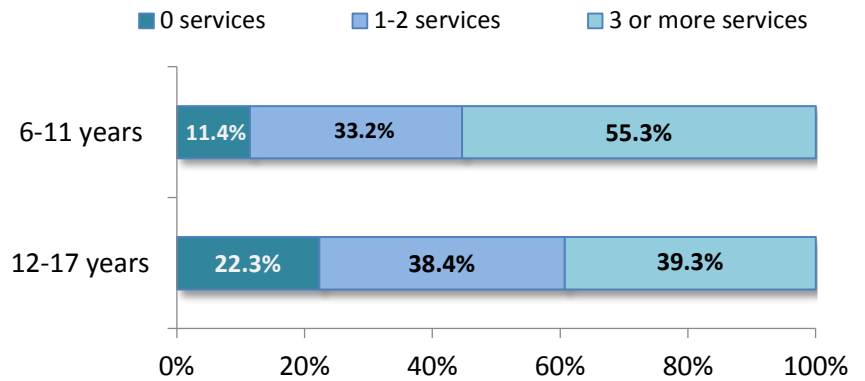
Data source: The Survey of Pathways to Diagnosis and Services, 2011.

Number of Health Care and Related Services Used

The Pathways Survey asked parents of school-aged CSHCN with ASD how many health and related services were used to meet their child's developmental needs. 48% of children with ASD used three or more services. (Data not shown.) Younger children with ASD (ages 6-11) were more likely to use three or more services than older children with ASD (55% vs. 39%). See Figure 4-6.

Additionally, children with moderate or severe cases of ASD used three or more services at almost twice the rate of children with mild cases of ASD (60% vs. 35%). (Data not shown.)

Figure 4-6. Number of health care and related services used, by age, among CSHCN ages 6-17 years with ASD.



Data Source: The Survey of Pathways to Diagnosis and Services, 2011.

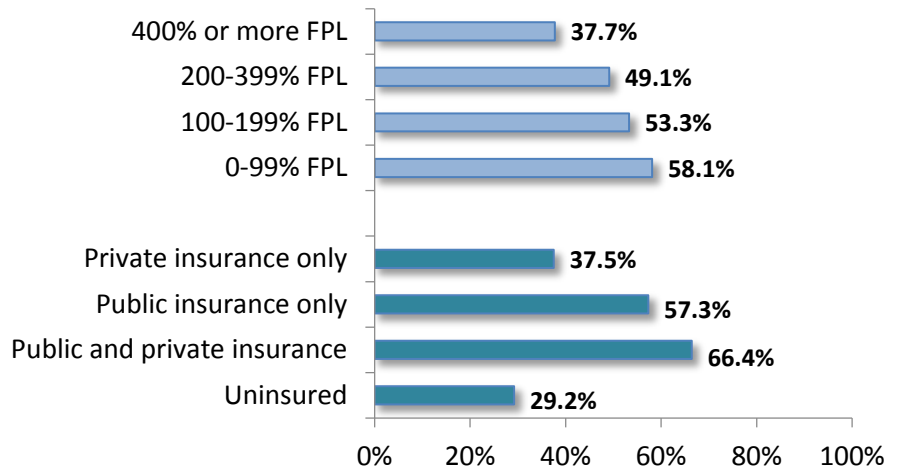
Scientific notes: Chi square test $p < 0.05$.

Number of Health Care and Related Services Used, by Income and Insurance Type

Children with ASD in lower-income households used more health care and related services than their higher-income peers. See Figure 4-7.

Additionally, children with public insurance utilized more services than children with private insurance only (57% vs. 38% used three or more services).

Figure 4-7. Child used 3 or more services, by income and insurance type, among CSHCN ages 6-17 with ASD.



Data source: The Survey of Pathways to Diagnosis and Services, 2011.

Abbreviations: FPL - Federal Poverty Level.

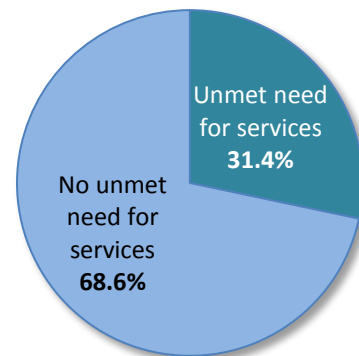
Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011.

Unmet Need for Treatments and Services during the Past Year

The Pathways Survey also asked parents of school-aged CSHCN with ASD if their child received all necessary treatments and services needed to care for the child's developmental needs during the past year. Children whose parents answered "no" were considered to have an unmet need. As seen in Figure 4-8, about 31% of children with ASD had unmet needs in the past year.

A greater proportion of children with moderate or severe ASD had unmet needs, (37%) as compared to children with mild cases of ASD (27%). (Data not shown.)

Figure 4-8. Unmet need for treatments and services during the past year, among CSHCN ages 6-17 with ASD.



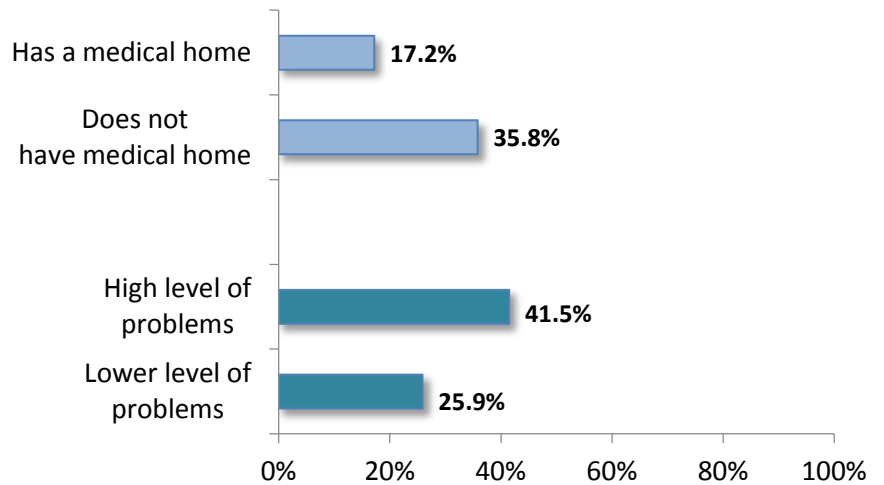
Data source: The Survey of Pathways to Diagnosis and Services, 2011.

Unmet Need for Treatments and Services, by Medical Home Status and SDQ Score

When children with ASD had a [medical home](#), they experienced fewer unmet needs. As seen in Figure 4-9, only 17% of children with ASD with a [medical home](#) experienced unmet needs, as compared to 36% of their peers without a [medical home](#).

A stark difference in unmet needs emerged by the child's level of mental health problems, as measured by the brief the Strengths and Difficulties Questionnaire ([SDQ](#)). The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. As seen in Figure 4-9, as children experienced higher levels of mental health problems, they also experienced higher levels of unmet need.

Figure 4-9. Unmet need for treatments and services during the past year, by medical home status and SDQ score, among CSHCN ages 6-17 with ASD.



Data source: The Survey of Pathways to Diagnosis and Services, 2011.

Abbreviations: SDQ - Strengths and Difficulties Questionnaire.

Scientific notes: The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. Chi square test $p < 0.05$.

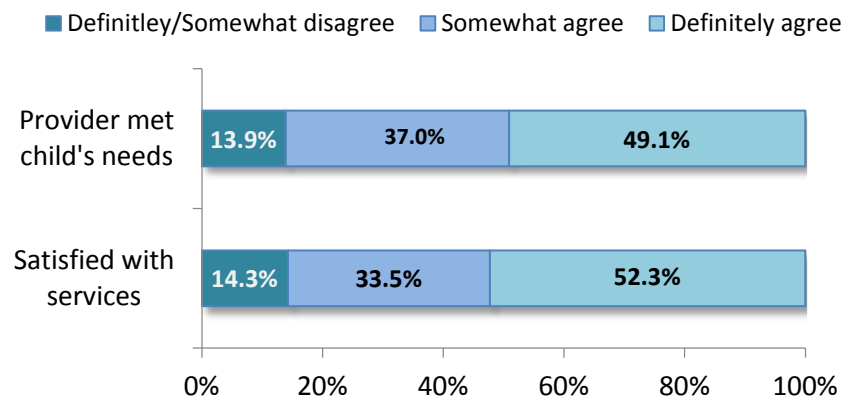
Parental Feelings about Health Care Providers and Services Received

The Pathways Survey asked parents to what extent they agreed with the following statements:

- 1) Doctors and other health care providers that my child sees are able to meet their needs.
- 2) I am satisfied with the services the child receives from doctors and other health care providers.

About half of school-aged CSHCN with ASD had a parent who “definitely agreed” that their child’s provider met the child’s needs. Similarly, about half “definitely agreed” that they were satisfied with the services provided to their child. See Figure 4-10.

Figure 4-10. Children whose parents definitely agreed that they were satisfied with their child's services and that providers met their child's needs, among CSHCN ages 6-17 with ASD.



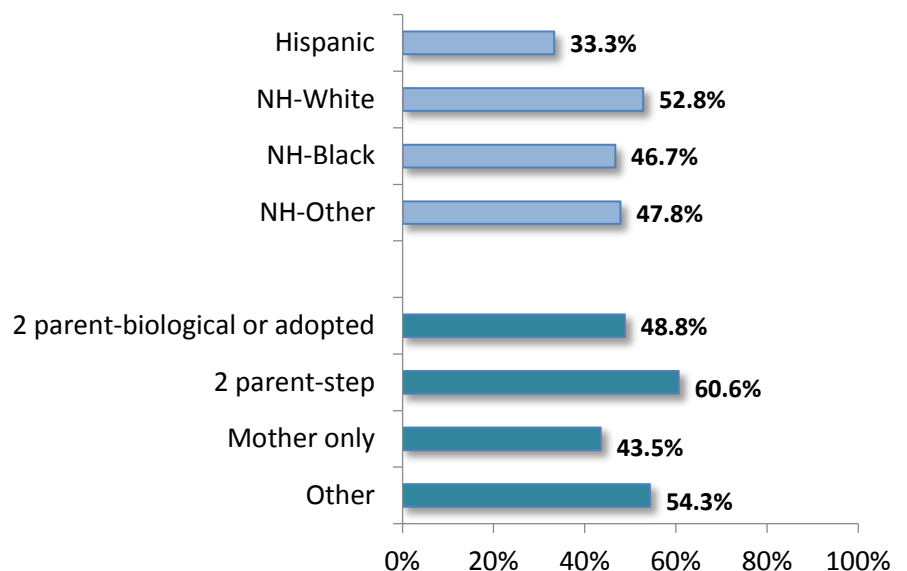
Data source: The Survey of Pathways to Diagnosis and Services, 2011.

Parent Agreed that Providers Met Their Child’s Needs, by Race/Ethnicity and Family Structure

Fewer Hispanic children had parents who felt their child’s needs were being met (33%), compared to children of other racial/ethnic groups (47% and higher). See Figure 4-11. Additionally, fewer Hispanic children had parents who felt satisfied with services received by their child, compared to parents of children in other racial/ethnic groups. (Data not shown).

Of all [family structures](#), fewer children in a single-mother home had a parent who felt their child’s needs were met (44%), or felt satisfied with services received (data not shown). See Figure 4-11.

Figure 4-11. Children whose parents definitely agreed that providers met their child's needs, by race/ethnicity and family structure, among CSHCN ages 6-17 with ASD.



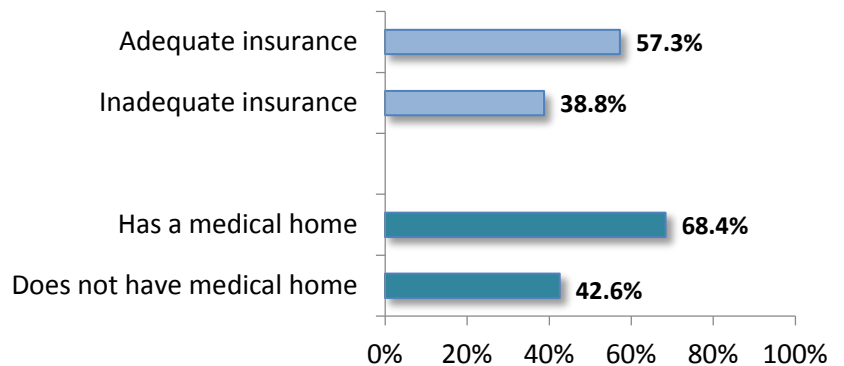
Data source: The Survey of Pathways to Diagnosis and Services, 2011.
Abbreviations: NH - Non-Hispanic.

Parent Agreed that Providers Met Their Child's Needs, by Insurance Adequacy and Medical Home Status

Perhaps unsurprisingly, fewer children with inadequate insurance had parents who felt their child's providers could meet their child's needs (39%), as compared to children with [adequate insurance](#) (57%). See Figure 4-12.

Similar findings emerged regarding the child's [medical home](#) status. A greater proportion of children with ASD with a [medical home](#) had parents who felt the child's providers could meet their needs (68%), compared to those children without a [medical home](#) (43%). See Figure 4-12.

Figure 4-12. Children whose parents definitely agreed that providers met their child's needs, by insurance adequacy and medical home status, among CSHCN ages 6-17 with ASD.



Data source: The Survey of Pathways to Diagnosis and Services, 2011.
Scientific notes: Chi square test $p < 0.05$.

Key Takeaways

- ✓ Social skills training and speech or language therapy are the most common types of services utilized by CSHCN with ASD.
- ✓ Younger children with ASD used 3 or more services at a higher rate than older children (55% vs. 39%).
- ✓ Lower income children, and those with public insurance, use more services than their higher income and privately insured peers.
- ✓ Almost one-third of all children with ASD had unmet health care and related needs in the past year.
- ✓ About 50% of children with ASD had parents that felt that their children's needs were being met by their service providers. Additionally, about the same proportion of children's parents felt satisfied with their children's services.
- ✓ Fewer Hispanic children had parents who felt providers met their child's needs, compared to parents of children in any other racial/ethnic group.
- ✓ Children with medical homes and adequate insurance had parents who felt providers met their children's needs more than those without medical homes or adequate insurance.

Transition to Adulthood

Population:
CSHCN, 12-17
years

Successful transition from the pediatric to the adult health care system is one of the six core outcomes established by the Maternal and Child Health Bureau (MCHB) for all children with special health care needs (CSHCN). Although transitioning systems can be challenging for all young people, it is particularly important for CSHCN due to their more complex health needs and their greater requirement for care coordination. The National Survey of Children with Special Health Care Needs (NS-CSHCN) measures this outcome for CSHCN ages 12-17 years old through two components:

- Part A: Child’s doctors provide necessary anticipatory guidance for transition to adult health care.
- Part B: Child’s doctors encourage age appropriate self-care skills.

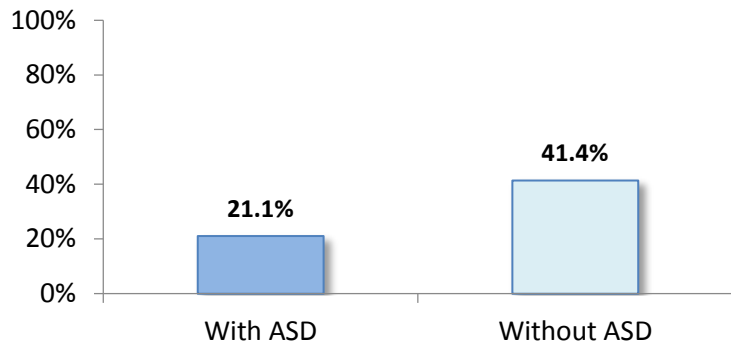
More information on these components can be found within their individual sections below. (Please see the [2009/10 NS-CSHCN questionnaire](#) for the complete wording of each survey question in this section.)

Child Received Necessary Services for Transition to Adult Health Care

As seen in Figure 4-13, only 21% of CSHCN with ASD 12-17 years old received the services necessary for transition to adult health care. Dramatically more children without ASD received these services (41%).

Fewer than 10% of children with ASD in the lowest income households (<100% of the Federal Poverty Level (FPL)) met the criteria for successful transition, as compared to children in higher income households (21-25%; data not shown). Additionally, a greater proportion of adequately insured children with ASD received the necessary services for transition, as compared to children with inadequate insurance (25% vs. 17%; data not shown).

Figure 4-13. Children who received necessary services for transition to adult health care, among CSHCN ages 12-17.

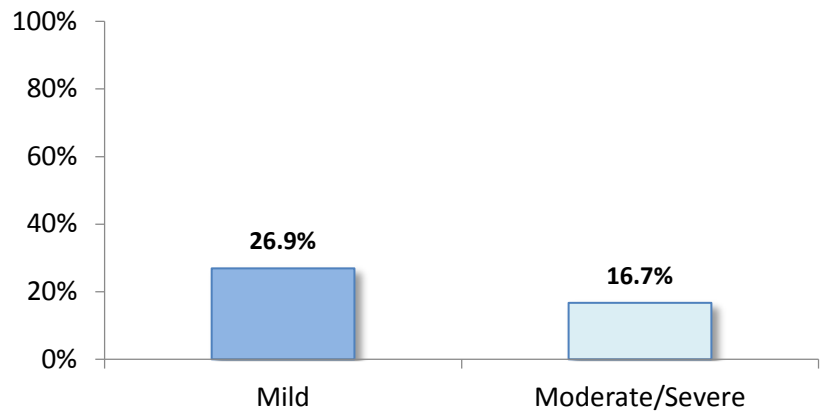


Data source: National Survey of Children with Special Health Care Needs, 2009/10. Scientific notes: Chi-square test $p < 0.05$.

Child Received Necessary Services for Transition to Adult Health Care, by ASD Severity

Just over a quarter of children with mild ASD met the criteria for successful transition, as compared to 17% of children with moderate to severe ASD. See Figure 4-14.

Figure 4-14. Children who received necessary services for transition to adult health care, by ASD severity, among CSHCN ages 12-17 with ASD.

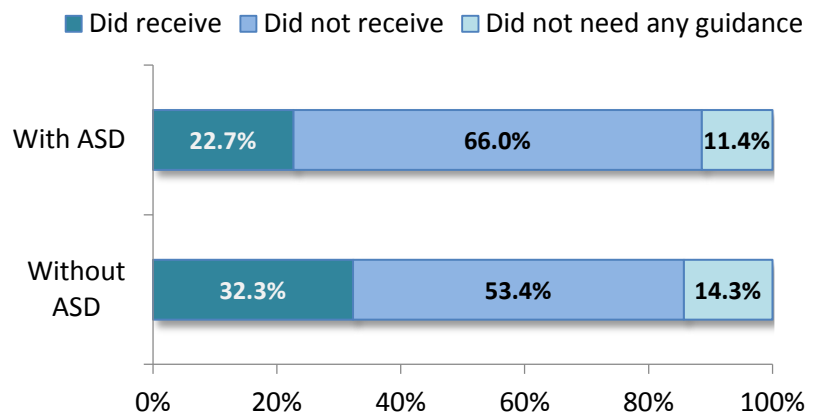


Data source: National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: ASD severity is parent-reported. Chi square test $p < 0.05$.

Child Received Necessary Anticipatory Guidance for Transition to Adult Health Care

A key component to successful transition services is the receipt of three types of anticipatory guidance, if needed. Those three pieces of guidance include discussing how to shift to an adult provider, the changing needs of adolescents becoming adults, and insurance coverage as an adult. Parents were asked if their child's doctors discussed any of these topics with their child. Some parents indicated that their child did not need guidance on any of these topics, as shown in Figure 4-15.

Figure 4-15. Children who received necessary anticipatory guidance for transition to adult health care, among CSHCN ages 12-17 years.



Data source: National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: Chi-square test $p < 0.05$.

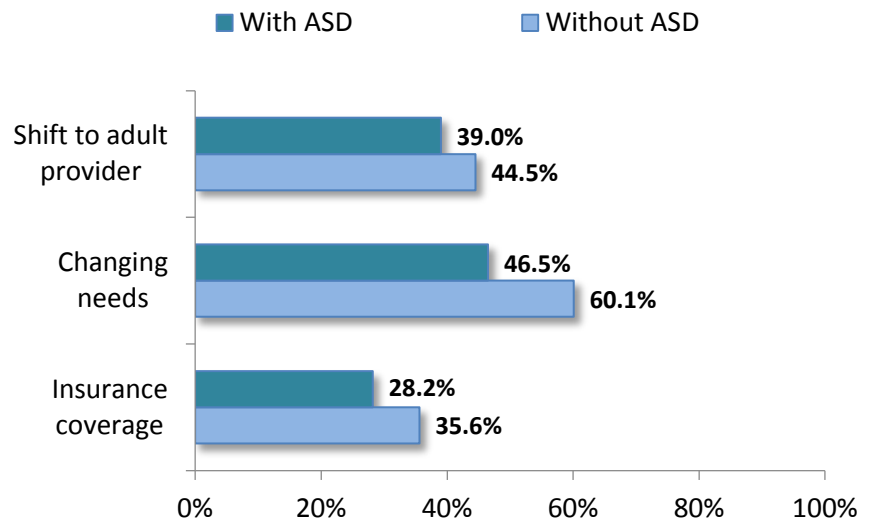
Only 23% of CSHCN ages 12-17 with ASD received guidance, leaving over 66% of children who needed guidance without it. These figures can be compared to the 33% of children without ASD who received guidance and the 53% who needed but did not receive it. See Figure 4-15.

Child Received Necessary Anticipatory Guidance, by Type of Guidance

Among children who needed and received guidance, the guidance received least was related to adult insurance coverage. The guidance provided the most frequently was related to changing needs in adulthood. See Figure 4-16.

In each category, fewer children with ASD received guidance as compared to children without ASD. The discussion of changing needs in adulthood had the largest disparity between children with and without ASD (47% vs. 60%). See Figure 4-16.

Figure 4-16. Children who needed and received each type of anticipatory guidance for transition to adult health care, among CSHCN ages 12-17 years.

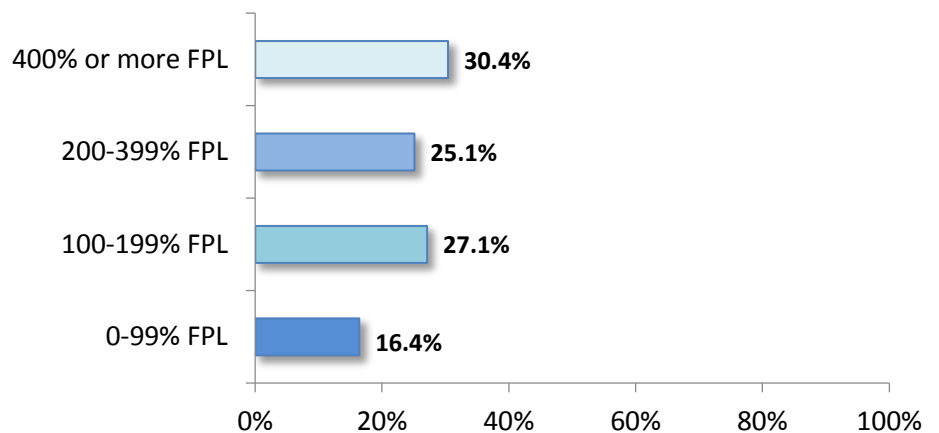


Data source: National Survey of Children with Special Health Care Needs, 2009/10.
 Scientific notes: Chi-square test $p < 0.05$.

Child Received Necessary Anticipatory Guidance, by Income

Among children with ASD who needed guidance, fewer children living in lower income households received the guidance they needed. See Figure 4-17.

Figure 4-17. Children who needed and received necessary anticipatory guidance for transition to adult health care, by income, among CSHCN ages 12-17 years with ASD.

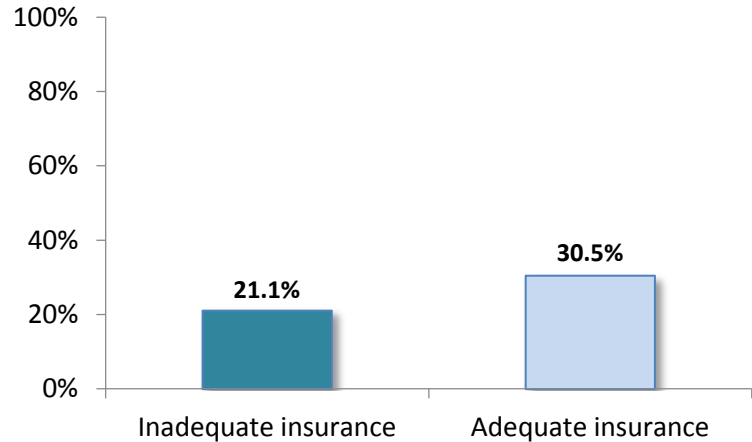


Data source: National Survey of Children with Special Health Care Needs, 2009/10.
 Abbreviations: FPL - Federal Poverty Level.
 Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,050 in 2010.

Child Received Necessary Anticipatory Guidance, by Insurance Adequacy

Among children with ASD who needed guidance, children with [adequate insurance](#) received more guidance. See Figure 4-18.

Figure 4-18. Children who needed and received necessary anticipatory guidance for transition to adult health care, by insurance adequacy, among CSHCN ages 12-17 years with ASD who had



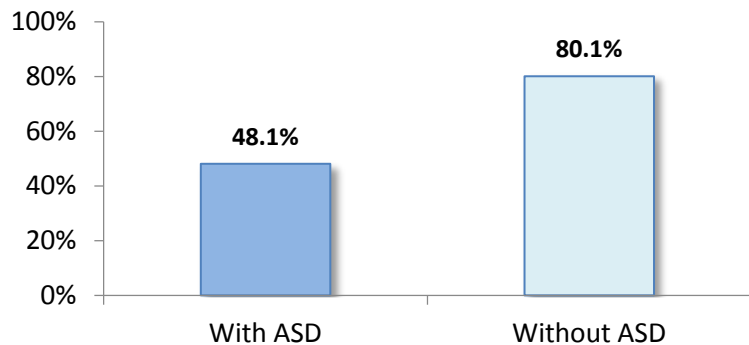
Data source: National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: Chi square test $p < 0.05$.

Provider Encouraged Child to Engage in Age-Appropriate Self-Care

As mentioned in the beginning of this section, the second component of successful transition services is the provider's encouragement of the child to engage in age-appropriate self-care. In the NS-CSHCN, parents were asked how often providers encouraged their 12-17 year old child to take responsibility for their health care needs, such as taking medication, understanding their diagnosis, or following medical advice.

A dramatically smaller proportion of children with ASD were "usually" or "always" encouraged to engage in age-appropriate self-care, as compared to children without ASD (48% vs. 80%). See Figure 4-19.

Figure 4-19. Children whose doctors usually or always encouraged them to engage in age-appropriate self care, among CSHCN ages 12-17.



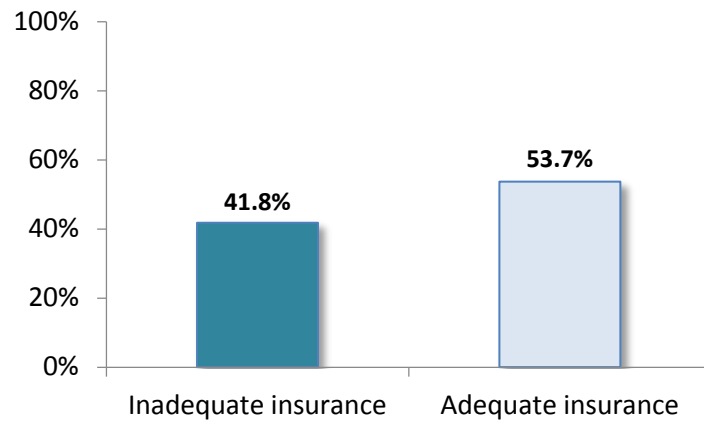
Data source: National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: Chi-square test $p < 0.05$.

Provider Encouraged Child to Engage in Age-Appropriate Self-Care, by Insurance Adequacy

Fewer inadequately insured children with ASD were encouraged to engage in self-care, versus those with [adequate insurance](#) (42% vs. 54%). See Figure 4-20.

Differences also emerged by ASD severity. 55% of children with mild ASD and 42% of those with moderate to severe ASD were encouraged to engage in age-appropriate self-care. (Data not shown.)

Figure 4-20. Children whose doctors usually or always encouraged them to engage in age-appropriate self-care, by insurance adequacy, among CSHCN ages 12-17 years with ASD.



Data source: National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: Chi square test $p < 0.05$.

Key Takeaways

- ✓ Just over one-fifth of CSHCN with ASD received all necessary services for their transition to adult health care. This can be compared to the 40% of CSHCN without ASD who received necessary transition services.
- ✓ Children with ASD in lower income households, with inadequate insurance, or with more severe ASD had a lower prevalence of receiving these necessary services.
- ✓ Among children who needed anticipatory guidance, children with ASD received it less often across all three types of guidance. In particular, children with ASD receive less guidance regarding their changing needs as they become adults.
- ✓ Far fewer children with ASD receive a key component of transition services: encouragement to engage in age-appropriate self-care. Only 48% of children with ASD receive this encouragement, as compared to 80% of children without ASD.

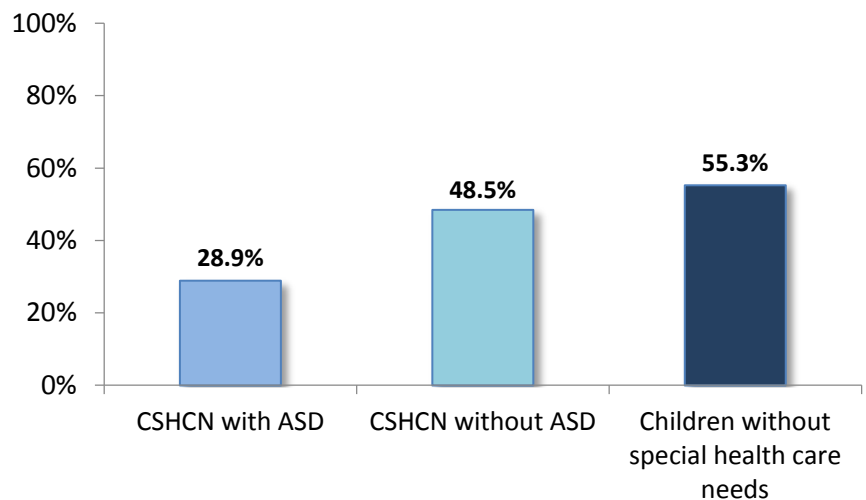
Medical Home

The American Academy of Pediatrics (AAP) believes all children deserve continuous, coordinated, and culturally-sensitive care from a personal doctor or nurse who knows the child well. The AAP calls this type of care delivery a “[medical home](#)”. The 2011/12 National Survey of Children’s Health (NSCH) asked parents about the receipt of care in five domains: 1) whether or not the child has a personal doctor or nurse; 2) whether the child has a usual source for their care; 3) whether the care received is family-centered and culturally sensitive; 4) whether the child receives referrals when needed; and 5) when needed, whether the child receives coordinated care between providers. If a child meets all five of these criteria, their care meets the criteria for the AAP’s definition of [medical home](#). In the 2011/12 NSCH, [medical home](#) care was assessed for three groups of children: 1) children with special health care needs (CSHCN) with Autism Spectrum Disorder (ASD), 2) CSHCN without ASD, and 3) children without special health care needs. (Please see the [2011/12 NSCH questionnaire](#) for the complete wording of each survey question in this section.)

Child Received Care within a Medical Home

As seen in Figure 4-21, less than one third of children with ASD received the type of care that the AAP deems essential. Dramatically fewer children with ASD received care within a [medical home](#), as compared to children without special health care needs (29% vs. 55%). Additionally, among the CSHCN population, we see that far fewer children with ASD received care within a [medical home](#) than CSHCN without ASD (29% vs. 49%).

Figure 4-21. Child received care within a medical home, among children ages 2-17 years.

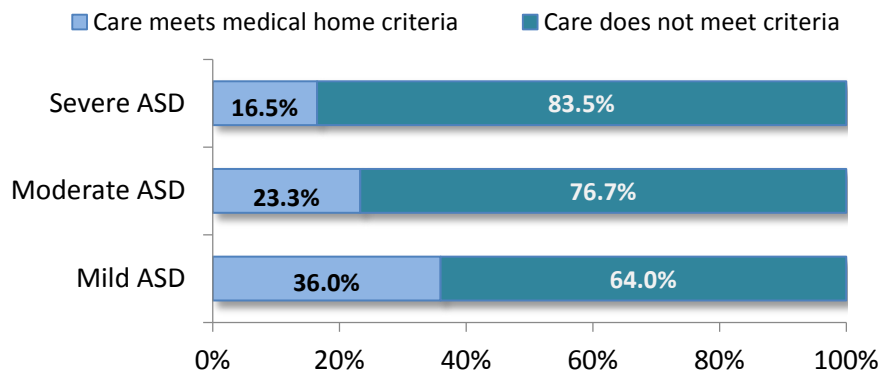


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Child Received Care within a Medical Home, by ASD Severity

Among children with mild cases of ASD, 36% received quality coordinated care within a [medical home](#). In contrast, only 17% of children with severe cases of ASD received care in a [medical home](#). This suggests that quality, coordinated care is not being received by children with ASD who need it most. See Figure 4-22.

Figure 4-22. Child received care within a medical home, by ASD severity, among children with ASD ages 2-17 years.



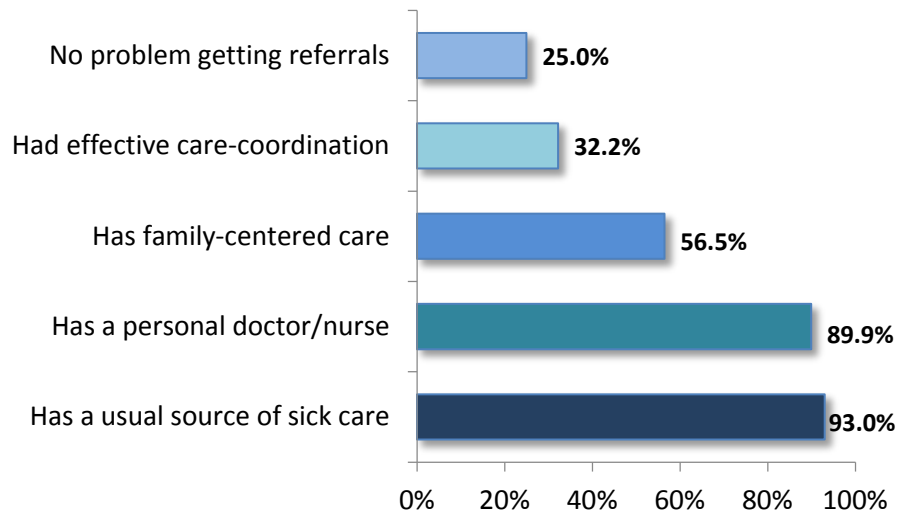
Data source: The National Survey of Children's Health, 2011/12.
 Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

Components of Medical Home Care

Each of the five subcomponents of the [medical home](#) are important pieces of quality care. Children with ASD who had a personal doctor or nurse (90%) and a usual source of care (93%) were relatively high, and did not differ substantially from children without ASD. (Data not shown.)

However, only 56% of children with ASD received family-centered care, and less than one-third received effective care coordination between services when needed. See Figure 4-23. Only 25% of children with ASD encountered no problems receiving needed referrals, meaning that 75% did encounter problems. For children with complex, multi-dimensional conditions such as ASD, effective care coordination and referrals are particularly important; yet, these are the components lacking most for those children. See Figure 4-23.

Figure 4-23. Child meeting the medical home subcomponents, among children with ASD ages 2-17 years.



Data source: The National Survey of Children's Health, 2011/12.

Key Takeaways

- ✓ Less than 3 in 10 children with ASD receive quality care within a medical home, nearly half the rate of children without ASD.
- ✓ Children with severe ASD are only half as likely to receive quality care within a medical home compared with children with mild ASD (17% vs. 36%).
- ✓ Less than one-third of children with ASD received effective care coordination for their services, and only 1 in 4 received all needed referrals for specialty care.

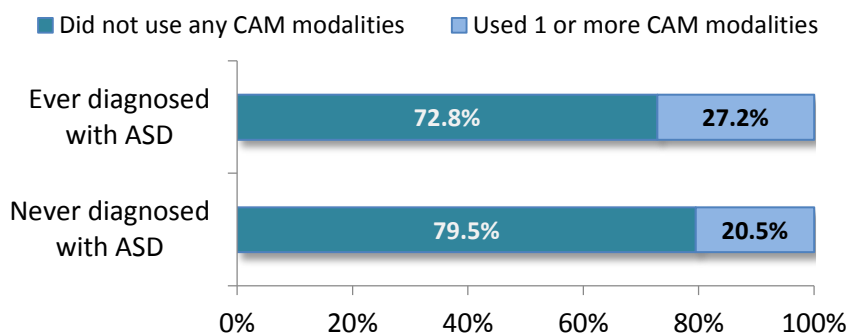
Complementary and Alternative Medicine

Many children with ASD rely on numerous services to manage their health conditions, address their developmental needs, and maintain their quality of life. Among these services are healing therapies that exist outside of conventional medical practices. The 2012 Complementary and Alternative Medicine (CAM) supplement of the National Health Interview Survey (NHIS) collected information about non-conventional health services, products, and practices commonly used in the United States. This includes data on biologically-based therapies such as vitamins and minerals, body-based therapies such as massage, alternative medical systems such as Traditional Chinese Medicine (which includes acupuncture), mind-body therapies such as yoga or tai chi, energy healing therapies, meditation, special diets, movement and exercise techniques, and others. The data presented in the following sections indicate the prevalence of CAM use among children ages 4-17 with ASD, in addition to parental beliefs about CAM. (Please see the [2012 NHIS-CAM supplement questionnaire](#) for the complete wording of each survey question in this section.)

Use of Complementary and Alternative Medicine (CAM)

About 27% of children ages 4-17 who ever received an ASD diagnosis used one or more [CAM modalities](#) during the past year. Slightly fewer children who were never diagnosed with ASD used CAM in the past year (21%). See Figure 4-24.

Figure 4-24. Child used CAM modalities in the past year, among children ages 4-17.

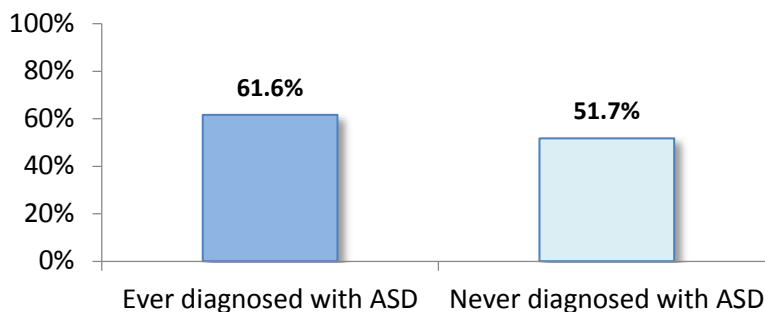


Data source: National Health Interview Survey, CAM Supplement, 2012.
Abbreviations: CAM - Complementary and Alternative Medicine.
Scientific notes: Modalities include a list of 34 CAM modalities, excluding vitamins/minerals.

Use of Vitamins or Minerals

A greater proportion of children ages 4-17 diagnosed with ASD took vitamins and/or minerals in the past year, compared to their peers never diagnosed with ASD (62% vs. 52%). See Figure 4-25.

Figure 4-25. Child took any vitamins or minerals in the past year, among children ages 4-17.



Data source: National Health Interview Survey, CAM Supplement, 2012.
Abbreviations: CAM - Complementary and Alternative Medicine.

Beliefs about CAM among Parents of Children Who Use CAM

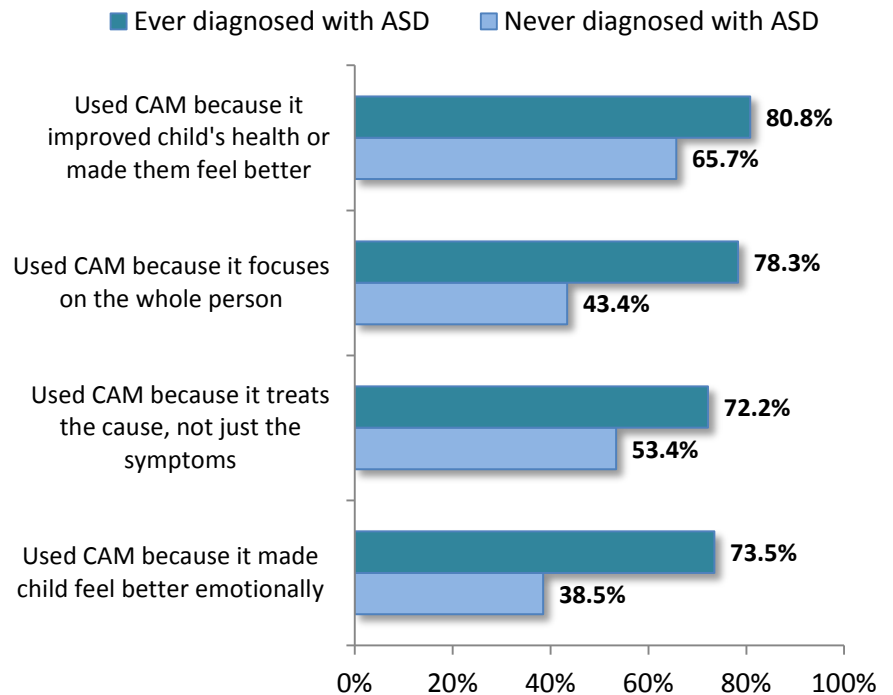
Parents of children ages 4-17 who received an ASD diagnosis had more positive beliefs about CAM's ability to improve their child's health and wellbeing, compared to parents of children who never received an ASD diagnosis.

74% of children who used CAM and received an ASD diagnosis had parents who felt that CAM "made the child feel better emotionally." In contrast, only 39% of children who used CAM but never received an ASD diagnosis had parents who felt this way about CAM.

Additionally, over 78% of children who used CAM and received an ASD diagnosis had parents who integrated CAM into their child's care because it "focuses on the whole person". In comparison, only 43% of children who used CAM without an ASD diagnosis had parents who felt similarly. See Figure 4-26.

These findings suggest that CAM is perceived as a highly valuable set of resources for children with ASD and their parents.

Figure 4-26. Parental beliefs about CAM, among children ages 4-17 who used 1+ CAM modalities.



Data source: National Health Interview Survey, CAM Supplement, 2012.

Abbreviations: CAM - Complementary and Alternative Medicine.

Scientific notes: Modalities include a list of 34 CAM modalities, excluding vitamins/minerals. Chi-square test $p < 0.05$ for: used CAM because it "improved child's health or made them feel better", "focuses on the whole person", and "made child feel better emotionally".

Key Takeaways

- ✓ CAM therapies were used slightly more among children who ever received an ASD diagnosis, as compared to children who never received this diagnosis (27% vs. 21%).
- ✓ Vitamins and/or minerals were used more among children who ever received an ASD diagnosis, as compared to children who were never diagnosed with ASD (62% vs. 52%).
- ✓ Children who ever received an ASD diagnosis had parents who possessed more positive beliefs about CAM's ability to improve and maintain their child's health and wellbeing, compared to children who never received a diagnosis.

Early Intervention Services

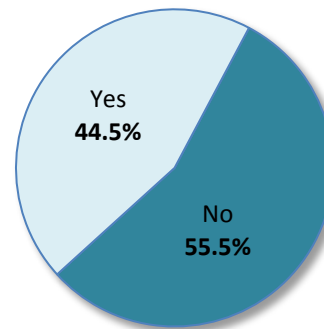
Early Intervention Services (EIS) are provided to young children who have or are at risk for disabilities or special needs. The Individuals with Disabilities Education Act (IDEA) allows any child younger than 3 years old who has a developmental delay or a physical or mental condition likely to result in a developmental delay to receive Early Intervention Services through federally-funded programs. However, the definitions of “developmental delay” and the types of services provided can vary state-to-state. Data from the 2011 Survey of Pathways to Diagnosis and Services (Pathways) are used to share the number of school-aged children with special health care needs (CSHCN) with Autism Spectrum Disorder (ASD) who received EIS in early childhood, as well as those children whose families were ever told they were ineligible for these services. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Child Received Early Intervention Services before Age 3

Less than half (45%) of school-aged CSHCN with ASD received EIS in their early childhood. See Figure 5-1.

The percentage of children who received EIS before the age of 3 varied notably among demographic groups. A greater proportion of children in households earning less than 100% of the federal poverty level received EIS, compared to households with higher income levels (56% vs. 41-45%; data not shown). More of these differences are described below.

Figure 5-1. Child received Early Intervention Services before age 3, among CSHCN ages 6-17 years with ASD.

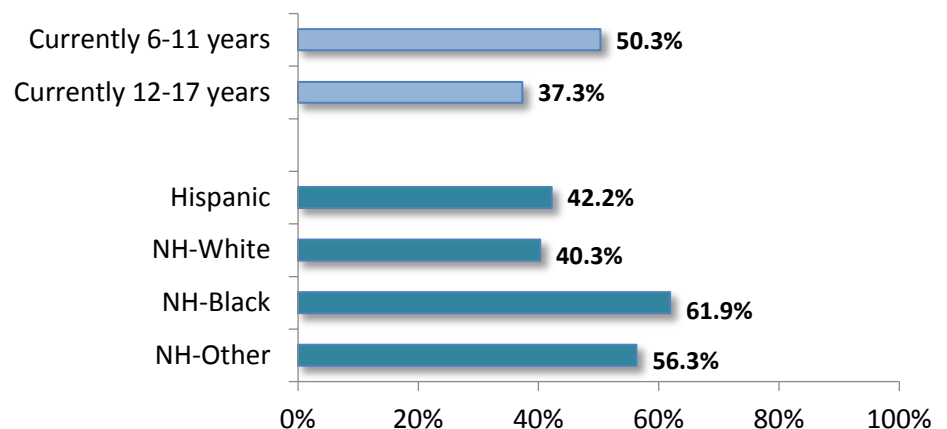


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Received EIS before Age 3, by Age and Race/Ethnicity

At the time of the Pathways survey (2011), a higher percentage of children 6-11 years old had received EIS in early childhood, compared to children 12-17 years old. See Figure 5-2. This figure suggests that overall receipt of EIS may have increased over time. Well over half of non-Hispanic black children and children of other races/ethnicities received EIS (62% and 56%, respectively). This figure can be compared to the <42% of Hispanic and non-Hispanic white children who received these services. See Figure 5-2.

Figure 5-2. Child received Early Intervention Services before age 3, by child's age and race/ethnicity, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

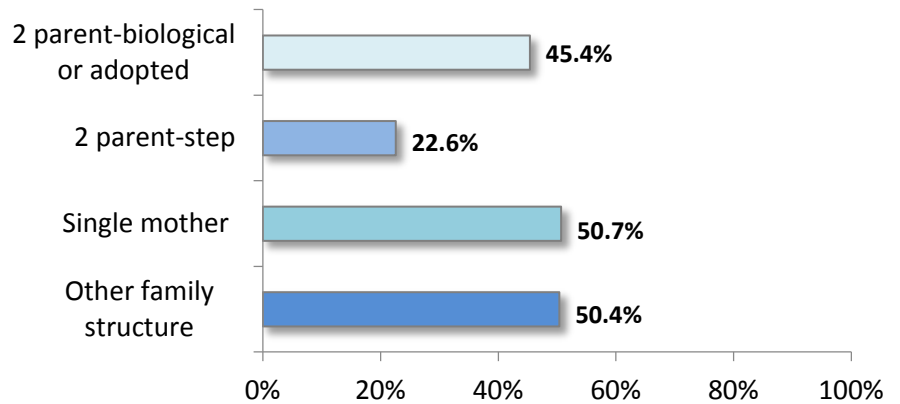
Abbreviations: NH = non-Hispanic.

Scientific notes: Chi-square test $p < 0.05$ for age . Race /ethnicity subgroup not significant.

Received EIS before Age 3, by Family Structure

Prominent differences in EIS receipt emerged by family structure. Less children living in two-parent stepfamilies received EIS, as compared to other family structures. See Figure 5-3. This suggests that children in this particular family structure may need increased attention in receipt of EIS services.

Figure 5-3. Child received Early Intervention Services before age 3, by family structure, among CSHCN ages 6-17 years with ASD.

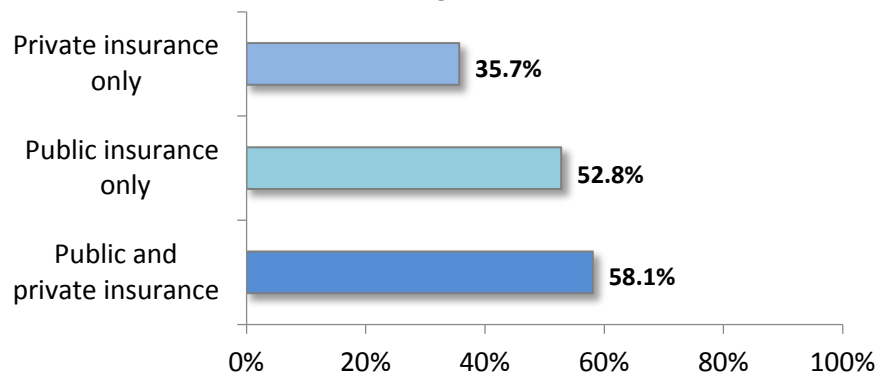


Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Scientific notes: Chi-square test $p < 0.05$.

Received EIS before Age 3, by Insurance Type

Among insured children, more children who had public health insurance received EIS in early childhood, as compared to children with private insurance only (>53% vs. 36%). See Figure 5-4.

Figure 5-4. Child received Early Intervention Services before age 3, by insurance type, among insured CSHCN ages 6-17 years with ASD.



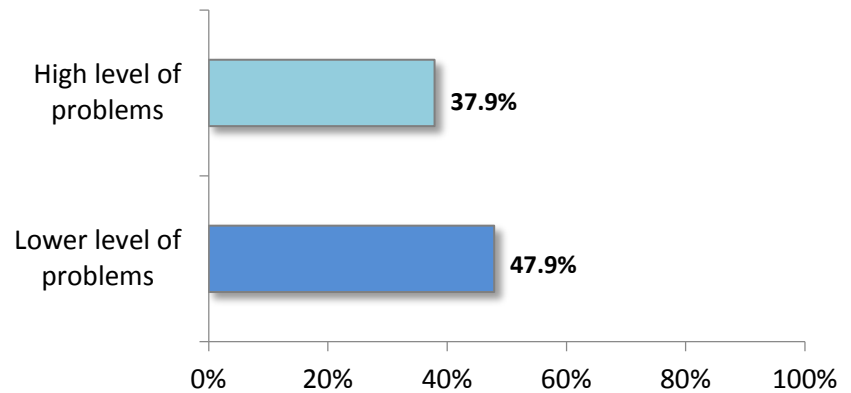
Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Scientific notes: Chi-square test $p < 0.05$.

Received EIS Before Age 3, by SDQ Score

The brief [SDQ](#) is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems.

As seen in Figure 5-5, fewer children with high levels of mental health problems received EIS (38% vs. 48%). This seemingly counter-intuitive finding may result from the fact that there are high levels of [co-morbidity](#) among children with ASD with other mental health problems. These [co-morbidities](#) may delay the diagnoses a child needs to qualify for EIS.

Figure 5-5. Child received Early Intervention Services before age 3, by strengths and difficulties questionnaire (SDQ) score, among CSHCN ages 6-17 years with ASD.

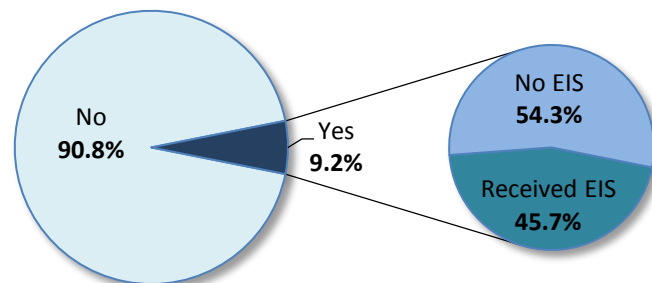


Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Scientific notes: The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems.

Family Told That Child Not Eligible for Early Intervention Services

About 9% of school-aged CSHCN with ASD were told at some point that they were not eligible for EIS. Among this subgroup, 46% of children eventually received EIS. See Figure 5-6.

Figure 5-6. Family told that child not eligible for Early Intervention Services, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Key Takeaways

- ✓ Less than half of school-aged CSHCN with ASD received EIS in early childhood.
- ✓ Almost half of the children who were ever told they were ineligible for EIS eventually received these services.
- ✓ Higher proportions of very low-income children and children receiving public insurance received EIS, suggesting that several vulnerable populations are gaining access to these services.
- ✓ Less than half of Hispanic children and non-Hispanic white children received EIS. More effort may be needed to reach children of these races/ethnicities to ensure their receipt of these services.
- ✓ Children who were younger at the time of the Pathways survey (6-11 years old) were more likely to have received EIS, suggesting EIS receipt may be increasing among CSHCN with ASD.
- ✓ Fewer children struggling behaviorally received EIS. This finding may suggest that emotional or behavioral comorbidities may delay the diagnosis necessary to receive EIS.
- ✓ Fewer children in two-parent stepfamilies households received EIS, as compared to other family structures. This finding suggests that children living in these households may need increased attention for these services.

Support at School

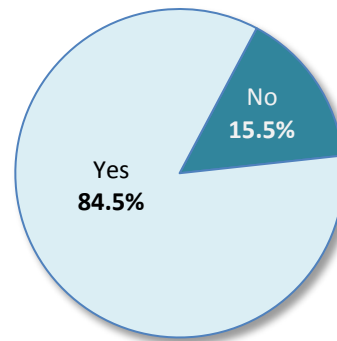
Children with Autism Spectrum Disorder (ASD) have individual needs which require attention throughout their education. Many children with ASD receive an Individualized Education Plan (IEP), which is a written document that tailors a child’s education program to their needs and strengths. These plans are intended to be highly individualized, and a plan that is appropriate for one child with ASD may not be appropriate for another. Data from the 2011 Survey of Pathways to Diagnosis and Services (Pathways) are used to describe the kinds of support school-aged children (ages 6-17) with special health care needs (CSHCN) with ASD receive at school. This includes whether the child received an IEP, if school professionals were able to meet their needs, and how satisfied parents were with their child’s school services. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Child Received Individualized Education Plan

84% of school-aged CSHCN with ASD received an Individualized Education Plan (IEP). Only 16% of children with ASD in school did not receive an IEP. See Figure 5-7.

Similar proportions of children with ASD in public and private school received IEPs. (Data not shown.)

Figure 5-7. Child enrolled in public or private school with an Individualized Education Plan, among CSHCN ages 6-17 years with ASD.

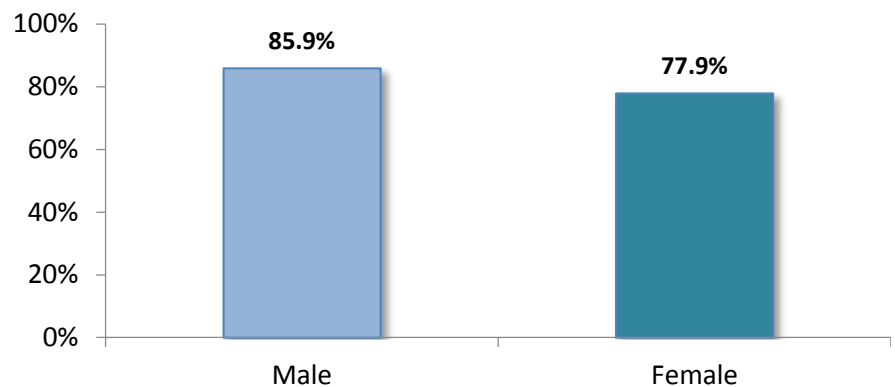


Data Source: The Survey of Pathways to Diagnosis & Services, 2011.
Scientific notes: Chi-square test $p < 0.05$.

Child Received IEP, by Sex

A greater proportion of boys with ASD received an IEP, as compared to girls with ASD (86% vs. 78%). See Figure 5-8.

Figure 5-8. Child enrolled in public or private school with an Individualized Education Plan, by sex, among CSHCN



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Parental Perception of School Services

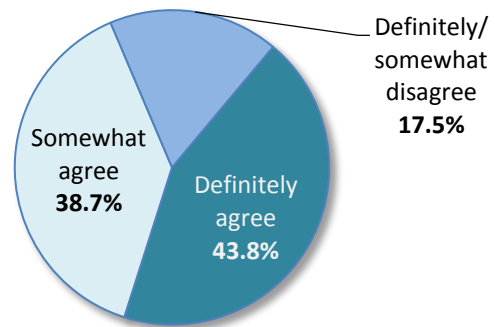
The Pathways survey asked parents of school-aged CSHCN if they thought their child’s school met their child’s needs. Less than half of children with ASD had parents who “definitely agreed” with the statement. See Figure 5-9.

Mirroring similar figures to Figure 5-9, just over 40% of children have parents who definitely expressed satisfaction with their child’s school services. See Figure 5-10.

Parental responses for both questions were fairly similar between children attending public school and private school. However, slightly fewer children in public school had parents who “definitely agreed” that they were satisfied with school services (42% vs. 48% of children in private school; data not shown).

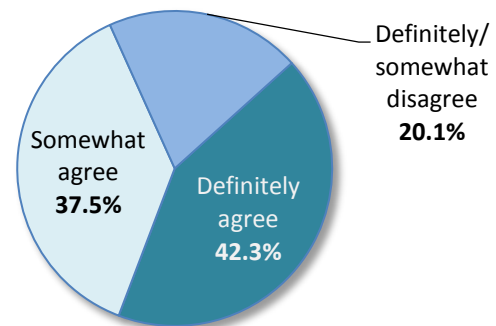
Additionally, slightly fewer children in two-parent stepfamilies or single-mother households have parents who “definitely agreed” with either statement, as compared to children in two-parent biological households. (Data not shown.)

Figure 5-9. Children whose parent feels school is able to meet child's needs, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Figure 5-10. Children whose parent is satisfied with school services, among CSHCN ages 6-17 years with ASD.

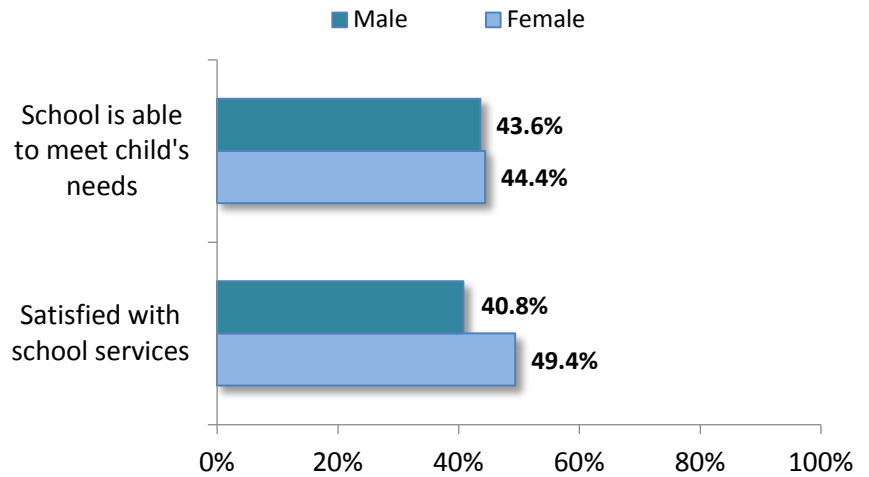


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Parent Definitely Agreed with School Services Statements, by Sex

Similar proportions of boys and girls had parents who “definitely agreed” that their child’s school met their child’s needs. See Figure 5-11. However, a larger proportion of girls’ parents “definitely agreed” that they were satisfied with school services.

Figure 5-11. Children whose parent definitely agreed with school services statements, by sex, among CSHCN ages 6-17 with ASD.



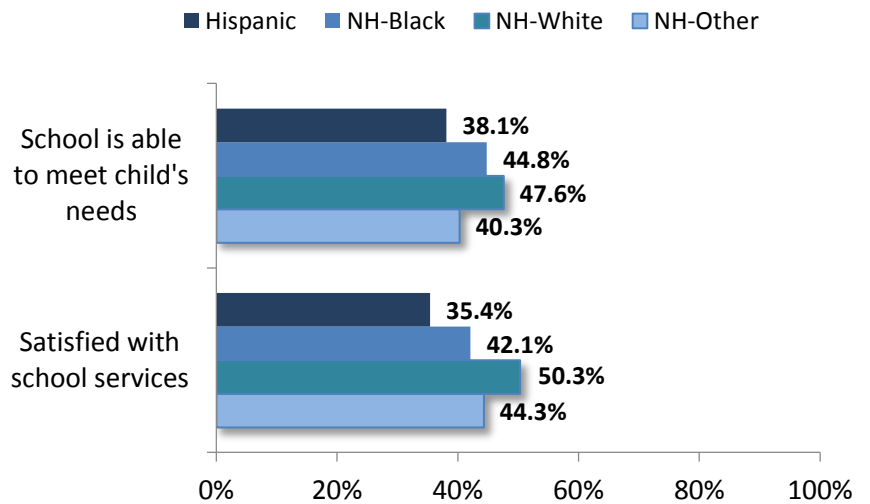
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Parental Definitely Agreed with School Services Statements, by Race/Ethnicity

Some differences emerged by race/ethnicity among children whose parents “definitely agreed” with school service statements. See Figure 5-12. These differences were even more pronounced when parents were asked if they were *satisfied* with services.

Fewer Hispanic children have parents who “definitely agreed” that they were satisfied with school services (35%), as compared with parents of Non-Hispanic black children (50%) and children of other races/ethnicities (42-44%). This suggests that more effort could be made to reach Hispanic families in an effort to meet their needs in a satisfactory way.

Figure 5-12. Parent definitely agreed with school services statements, by race/ethnicity, among CSHCN ages 6-17 with ASD.



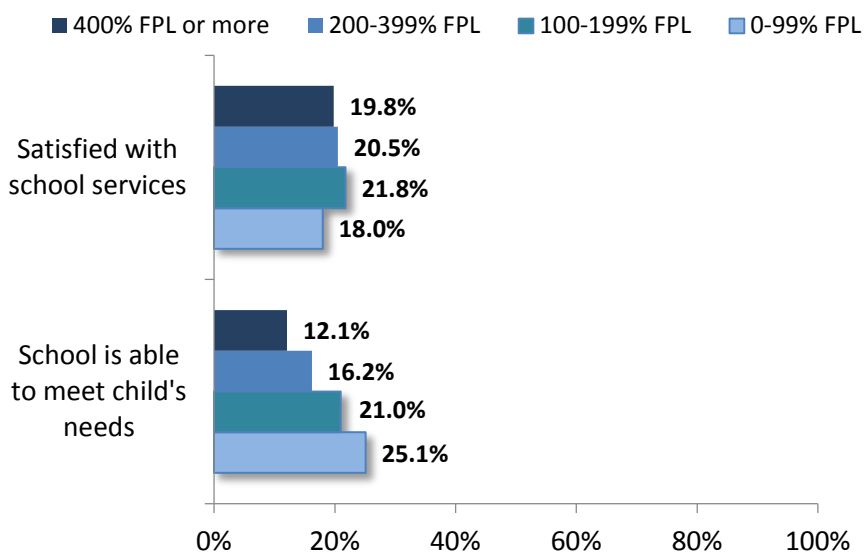
Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Abbreviations: NH = non-Hispanic.

Parent Disagreed with School Services Statements, by Income

Across income levels, similar proportions of children's parents *disagreed* with the satisfaction statement. See Figure 5-13.

However, as household income decreases, more children's parents disagreed with the statement: "The teachers and other professionals at my child's school are able to meet his/her needs". See Figure 5-13. These figures suggest higher dissatisfaction among the most economically vulnerable populations.

Figure 5-13. Parent *disagreed* with school services statements, by income, among CSHCN ages 6-17 with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Abbreviations: FPL - Federal Poverty Level

Scientific notes: Poverty threshold (<100% FPL) for a family of four is an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$. Income subgroup among satisfied with school services measure is not significant.

Key Takeaways

- ✓ Over 80% of CSHCN with ASD enrolled in school received an Individual Education Plan (IEP). This figure did not differ greatly between children in public or private schools.
- ✓ More boys with ASD received an IEP than girls with ASD (86% vs. 78%).
- ✓ Only 44% of children with ASD have parents who definitely agreed that their child's school met their child's needs. More research may be needed to understand how to improve child and parent needs.
- ✓ At lower income levels, fewer children have parents who feel that their child's school meets their needs.
- ✓ Only 42% of parents definitely agreed that they were satisfied with their child's school services. More research may be needed to understand how to improve parental satisfaction.
- ✓ Fewer boys and Hispanic children have parents who feel satisfied with school services.

School Experiences

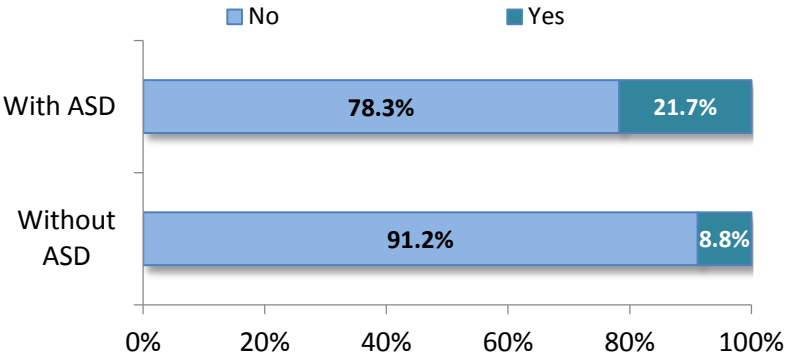
Children with Autism Spectrum Disorder (ASD) can have a range of experiences during their time at school, and often require additional support and resources to succeed. Data from the 2011/12 National Survey of Children’s Health (NSCH) are used to describe school experiences among school-aged children (ages 6-17) with ASD. Data are available on the number of missed days of school, times a school called home, and whether or not a child has ever repeated a grade. Additional data include parental perception of their child’s school engagement, and school success; concepts which are described in the following sections. (Please see the [2011/12 NSCH questionnaire](#) for the complete wording of each survey question in this section.)

Child Ever Repeated a Grade

As compared to school-aged children without ASD, over twice the number of children with ASD repeated a grade (22% vs. 9%). See Figure 5-14.

Among children with ASD, boys repeated a grade more than girls (23% vs. 16%; data not shown). Grade repetition of children with ASD did not differ by parental education level (data not shown).

Figure 5-14. Child ever repeated a grade, among children ages 6-17.

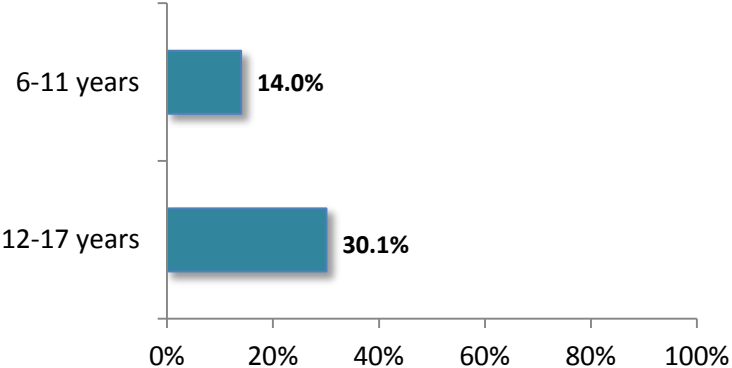


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test p < 0.05.

Child Ever Repeated a Grade, by Age

Older children with ASD repeated a grade more than younger children with ASD (30% vs. 14%). This suggests that children with ASD could face greater challenges once they reach higher grade levels. See Figure 5-15.

Figure 5-15. Child ever repeated a grade, by age, among children ages 6-17 years with ASD.

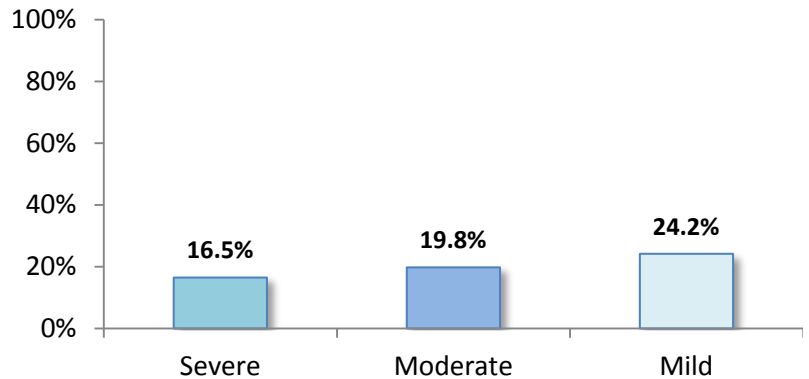


Data source: National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test p < 0.05 level.

Child Ever Repeated a Grade, by ASD Severity

A higher proportion of children with mild ASD repeated a grade (24%), as compared to children with severe ASD (17%). See Figure 5-16. These findings suggest that children with mild cases of ASD may not be receiving the same level of support in school as their peers with more severe ASD.

Figure 5-16. Child ever repeated a grade, by ASD severity, among children ages 6-17 years with ASD.



Data source: National Survey of Children's Health, 2011/12.
 Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

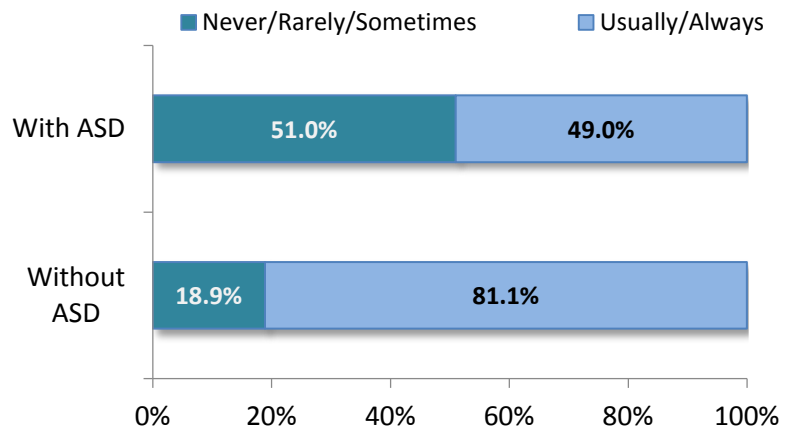
School Engagement

The 2011/12 NSCH included two questions which allow researchers to determine the extent to which a child is engaged in school:

- 1) In the past month, did the child care about doing well in school?
- 2) In the past month, did the child do all required homework?

School-aged children whose parents answer “usually” or “always” to both questions were considered to be engaged in school. 81% of children without ASD were usually or always engaged in school. Comparatively, only 49% of school-aged children with ASD were engaged in school. See Figure 5-17.

Figure 5-17. Child is engaged in school, among children ages 6-17.



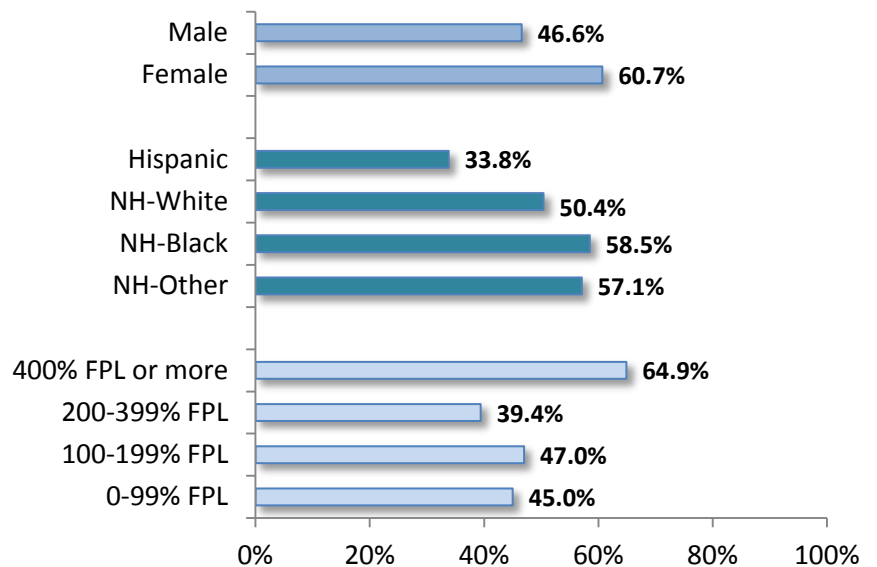
Data source: The National Survey of Children's Health, 2011/12.
 Scientific notes: Chi-square test $p < 0.05$.

Child Engaged in School, by Sex, Race/Ethnicity, and Income

More girls with ASD were engaged in school compared to boys with ASD (60% vs. 47%). Fewer school-aged Hispanic children with ASD were found to be engaged in school, compared to their peers of other races/ethnicities (34% vs. >50%). See Figure 5-18.

Additionally, children with ASD in households earning 400% or more of the Federal Poverty Level (FPL) were much more engaged in school than their lower-income peers. (65% vs. <47%). See Figure 5-18.

Figure 5-18. Child is engaged in school, by sex, race/ethnicity, and income level, among children ages 6-17 years with ASD.



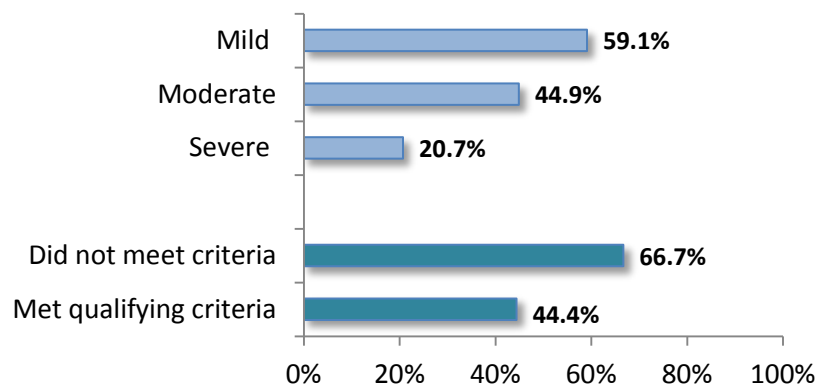
Data source: National Survey of Children's Health, 2011/12.
 Abbreviations: FPL= Federal Poverty Level, NH= non-Hispanic.
 Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$.

Child Engaged in School, by ASD Severity and EBD Criteria

Significant variations in school engagement emerged by ASD severity. A greater proportion of children with mild ASD were engaged in school (59%), followed by those with moderate (45%) and severe (21%) cases of ASD. See Figure 5-19.

Children with ASD who also had ongoing emotional, behavioral, or developmental (EBD) conditions were less engaged in school, compared to their peers without EBD conditions (44% vs. 67%). See Figure 5-19.

Figure 5-19. Child is engaged in school, by ASD severity and EBD criteria, among children ages 6-17 years with ASD.

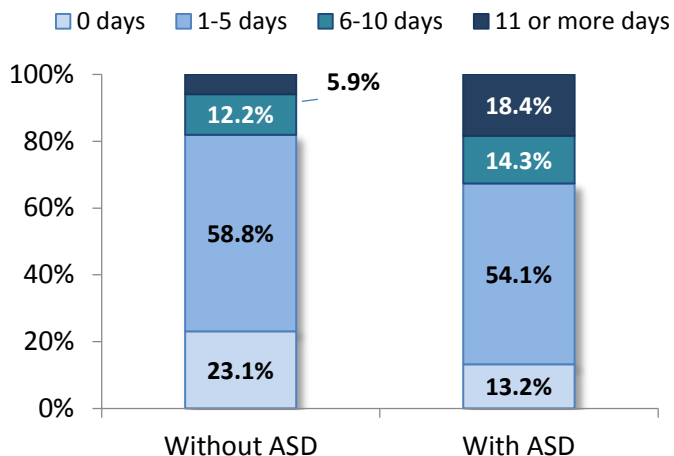


Data source: National Survey of Children's Health, 2011/12.
 Abbreviations: EBD = emotional, behavioral, or developmental conditions.
 Scientific notes: ASD severity is parent-reported. Children qualify as meeting EBD criteria if their parents answer yes to both of: "Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling?" and "Has this problem lasted or is it expected to last for at least 12 months?" Chi-square test $p < 0.05$.

Missed Days of School

It was most common for all school-aged children to miss between 1-5 school days in the past year. However, a greater proportion of children with ASD missed 11 or more days of school, compared to children without ASD (18% vs. 6%). See Figure 5-20.

Figure 5-20. Days of school child missed during the past year, among children ages 6-17 years.



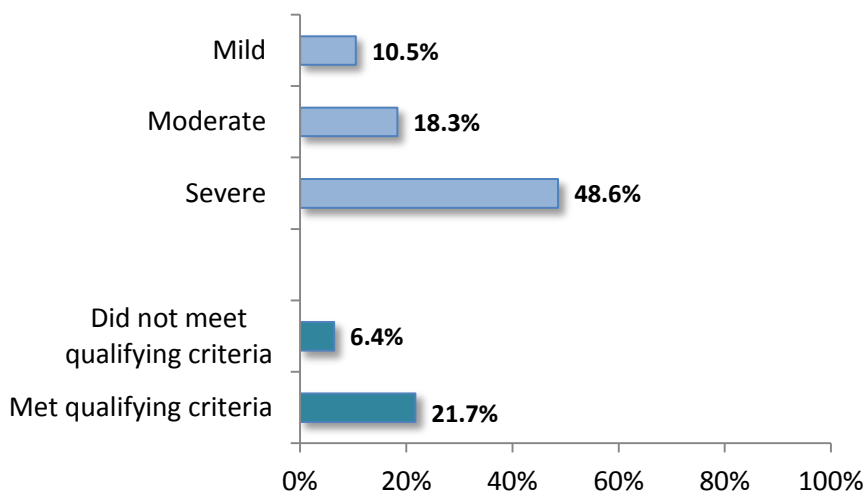
Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Days of School Child Missed, by ASD Severity and EBD Criteria

A much higher proportion of children with severe cases of ASD missed 11 or more days of school in the past year, compared to their peers with mild or moderate ASD (49% vs. 11-18%). See Figure 5-21.

Additionally, nearly 22% of children with both ASD and emotional, behavioral, or developmental conditions (EBD) missed 11 or more days of school in the past year, compared to 6% of children with ASD without EBD.

Figure 5-21. Child missed 11 or more days of school during the past year, by ASD severity and EBD criteria, among children ages 6-17 years with ASD.



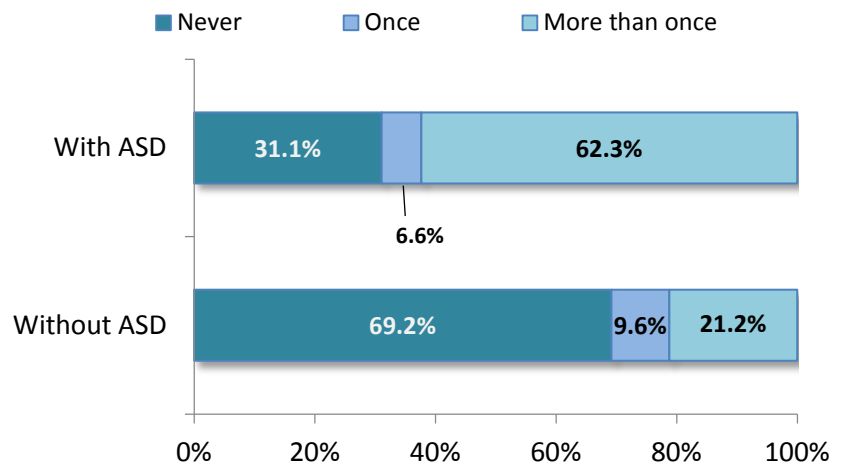
Data source: National Survey of Children's Health, 2011/12.
Abbreviations: EBD = emotional, behavioral, or developmental conditions.
Scientific notes: ASD severity is parent-reported. Children qualify as meeting EBD criteria if their parents answer yes to both of: "Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling?" and "Has this problem lasted or is it expected to last for at least 12 months?" Chi-square test $p < 0.05$.

School Called Home

About 62% of parents of school-aged children with ASD received more than one call home during the past year due to problems at school. In contrast, only 21% of parents of children without ASD received more than one call home. See Figure 5-22.

No difference was found by ASD severity or the child's sex with regards to receiving more than one call home in the past year. (Data not shown.) However, fewer Hispanic children with ASD received more than one call home in the past year, as compared to their peers of other races/ethnicities (49% vs. >61%; data not shown).

Figure 5-22. Number of times child's school called home in the past year, among children ages 6-17 years.

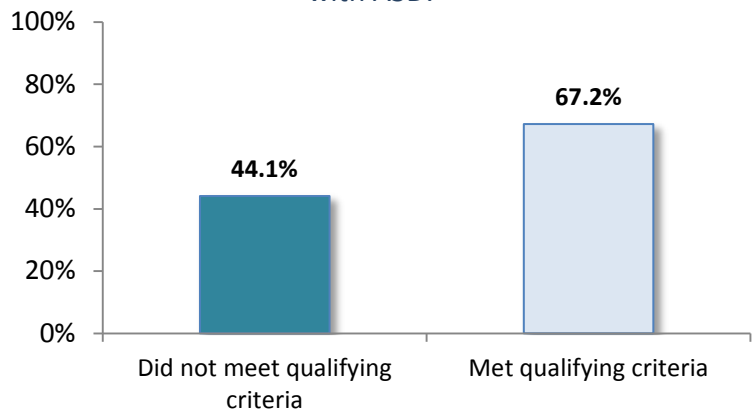


Data Source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Number of Times School Called Home, by EBD Criteria

A much higher percentage of children with ASD and emotional, behavioral, or developmental (EBD) conditions had their school call home more than once in the past year, as compared to children with ASD but no EBD. See Figure 5-23.

Figure 5-23. Child's school called home more than once in the past year, by EBD criteria, among children ages 6-17 years with ASD.



Data source: National Survey of Children's Health, 2011/12.
Abbreviations: EBD = emotional, behavioral, or developmental conditions.
Scientific notes: Children qualify as meeting EBD criteria if their parents answer yes to both of: "Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling?" and "Has this problem lasted or is it expected to last for at least 12 months?" Chi-square test $p < 0.05$.

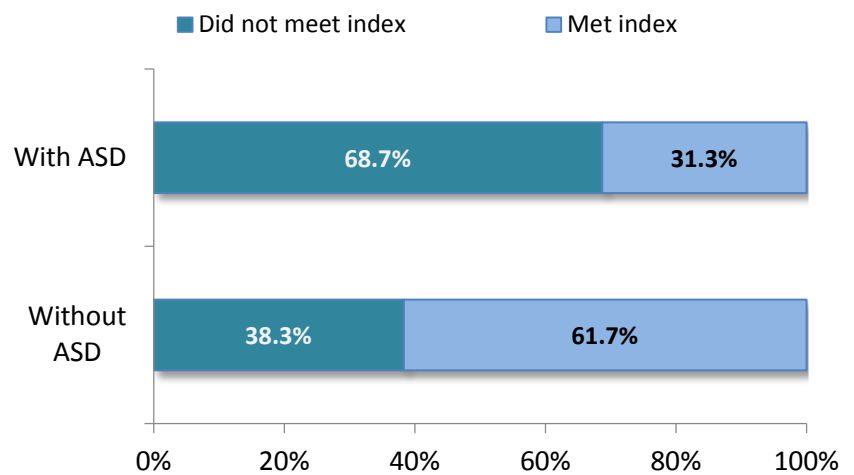
School Success Index

The 2011/12 National Survey of Children's Health asked parents of school-aged children a series of questions related to their child's school experiences. The Data Resource Center for Child and Adolescent Health (DRC) then compiled these answers into a School Success Index. In order to meet the School Success Index, children must have met the following criteria:

- 1) Child was engaged in school.
- 2) Child participated in extra-curricular activities during the past year.
- 3) Child usually or always felt safe at school.

Only 31% of children with ASD met the School Success Index, as compared to 62% of children without ASD. See Figure 5-24.

Figure 5-24. Child met School Success Index, among children ages 6-17 years.



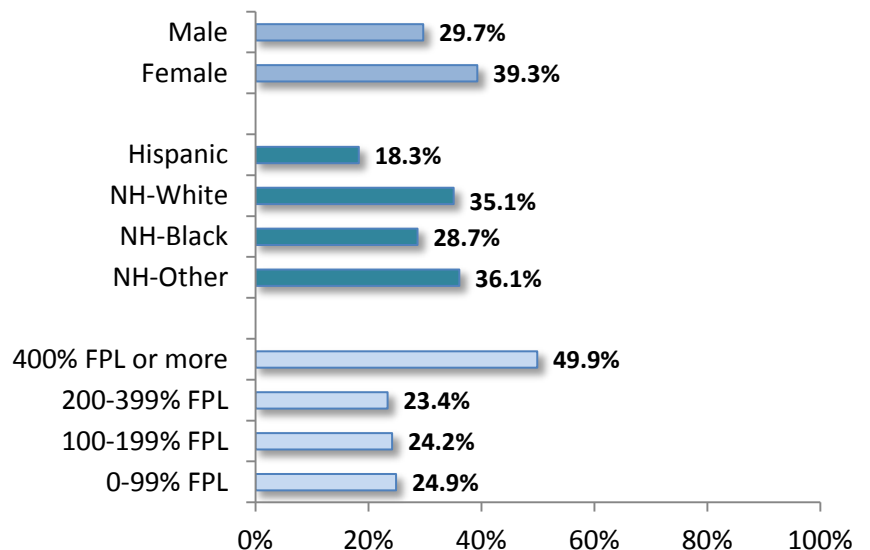
Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Child Met School Success Index, by Sex, Race/Ethnicity, and Income

Among children with ASD, fewer boys than girls met the School Success Index (30% vs. 39%). Additionally, only 18% of Hispanic school-age children with ASD met the School Success Index, compared to school-age children with ASD of other races/ethnicities (28-36%). See Figure 5-25.

Rates of school success also differed by income; two times the number of school-age children with ASD living in households making 400% or more of the Federal Poverty Level (FPL) met the School Success Index, as compared to their lower-income peers. See Figure 5-25.

Figure 5-25. Child met school success index, by sex, race/ethnicity, and income, among children ages 6-17 years with ASD.



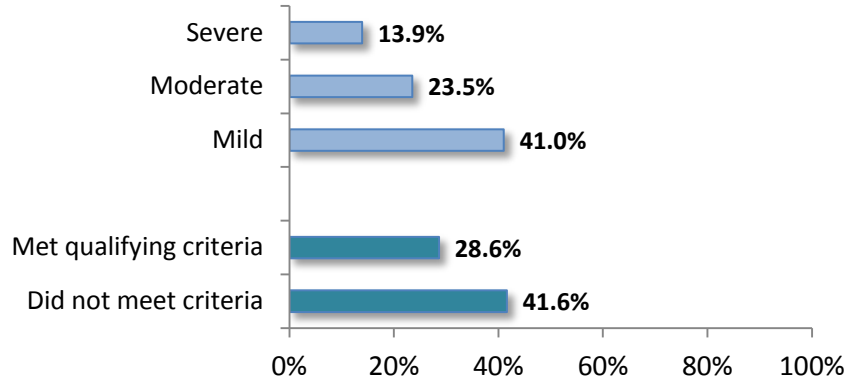
Data source: National Survey of Children's Health, 2011/12.
Abbreviations: FPL= Federal Poverty Level, NH= Non-Hispanic.
Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$ for poverty subgroup.

Child Met School Success Index, by ASD Severity by EBD Criteria

Fewer children with severe cases of ASD met the School Success Index (14%), followed by those with moderate (24%) and mild cases (41%).

A smaller proportion of children with both ASD and EBD also met the School Success Index, as compared to those with ASD but no EBD (29% vs. 49%). See Figure 5-26.

Figure 5-26. Child met school success index, by ASD severity and EBD criteria, among children ages 6-17 years with ASD.

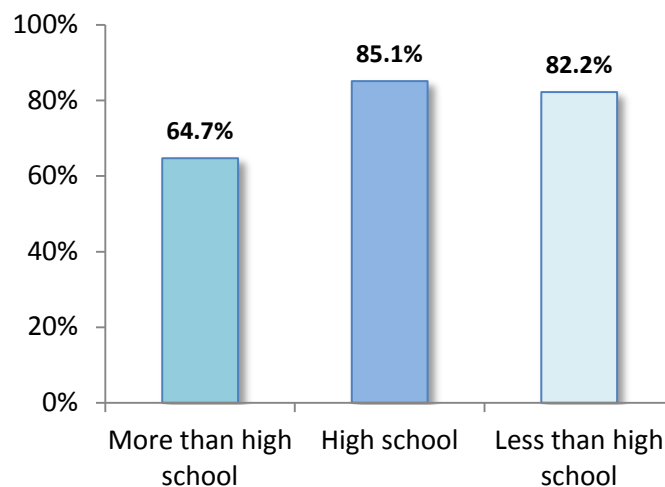


Data source: National Survey of Children's Health, 2011/12.
 Abbreviations: EBD= emotional, behavioral, and developmental difficulties.
 Scientific notes: ASD Severity is parent-reported. Children qualify as meeting EBD criteria if their parents answer yes to both of: Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling? and Has this problem lasted or is it expected to last for at least 12 months? Chi-square test $p < 0.05$.

Child Did Not Meet School Success Index, by Parental Education

As has been seen throughout this section, a fairly small percentage of children with ASD met the School Success Index. This is particularly true for children with ASD whose parents had a high school education or less - over 80% of those children did not meet the School Success Index, as compared to 65% of children whose parents had more than a high school education. See Figure 5-27.

Figure 5-27. Child did not meet school success index, by parental education, among children ages 6-17 years with ASD.



Data source: National Survey of Children's Health, 2011/12.
 Scientific notes: Chi-square test $p < 0.05$.

Key Takeaways

- ✓ Over double the proportion of children with ASD repeat a grade, as compared to their peers without ASD (22% vs. 9%). More children with ASD repeat a grade as they get older.
- ✓ A greater proportion of children with mild ASD repeated a grade, as compared to those with moderate or severe ASD (24% vs. 17%). This suggests that children with mild ASD may not be receiving the same level of support in school as peers with more severe ASD.
- ✓ Only half of children with ASD are considered engaged in school, as compared to 81% of children without ASD.
- ✓ More children with ASD from households earning 400% or more of the FPL were engaged in school, compared to children with ASD at lower income levels (65% vs. <47%).
- ✓ Hispanic children with ASD were less engaged in school than their peers with ASD of other races/ethnicities (34% vs. >50%).
- ✓ Nearly 3 times as many children with ASD missed 11 or more days of school in the last year, as compared to children without ASD. Missed days of school increased dramatically with increased ASD severity.
- ✓ As compared to children with ASD, almost two times the number of children without ASD met the criteria for the School Success Index (69% vs. 38%).
- ✓ Fewer children with severe ASD and who had emotional, behavioral, and developmental difficulties met the criteria for the School Success Index.

Relationships and Social Wellbeing

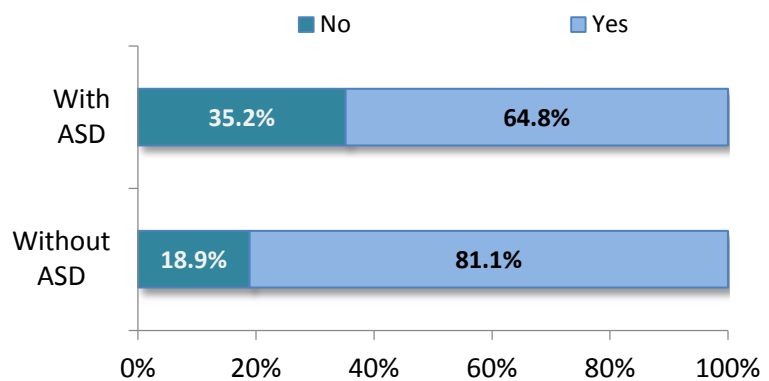
Population:
All children,
6-17 years

Challenges associated with the navigation of relationships and social living is common among children and adolescents with Autism Spectrum Disorder (ASD). The 2011/12 National Survey of Children’s Health (NSCH) and the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) collected information from parents of school-aged children (ages 6-17) related to their children’s social difficulties. Some of these difficulties include the child’s participation in activities outside of school, flourishing socially, staying calm and in control in the face of a challenge, and an ability to make and keep friends. While most of these difficulties differ between children with mild cases of ASD and those with more severe cases, additional differences can be observed between the sexes, age groups, income groups, and racial/ethnic groups. (Please see the [2011/12 NSCH questionnaire](#) and [2009/10 NS-CSHCN questionnaire](#) for the complete wording of each survey question in this section.)

Participation in Activities Outside of School

According to parental responses 65% of school-aged children with ASD participated in activities outside of school. This can be compared to the 81% of children without ASD who participated in activities. See Figure 5-28.

Figure 5-28. Participates in activities outside of school among children ages 6-17.

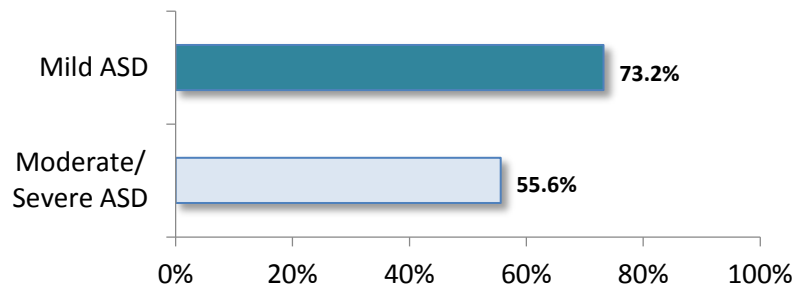


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Participation in Activities Outside of School, by ASD Severity

Children with mild cases of ASD were observed to be more socially active than those with moderate or severe cases. Specifically, 73% of children with mild ASD participated in activities outside of school, compared to 56% of children with moderate or severe ASD. See Figure 5-29.

Figure 5-29. Participates in activities outside of school, by ASD severity, among children ages 6-17 years with ASD.

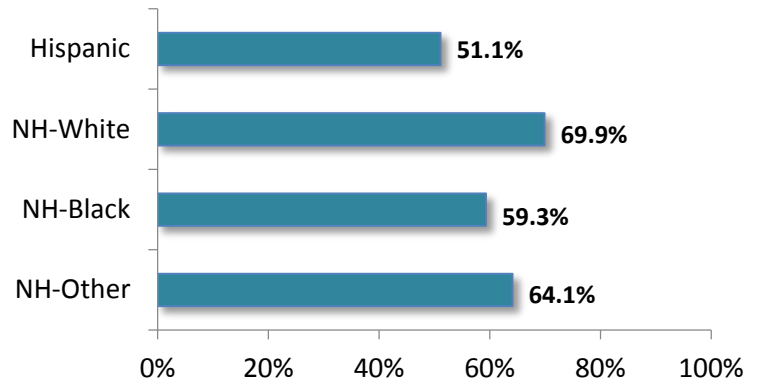


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

Participation in Activities Outside of School, by Race/Ethnicity

A larger percentage of non-Hispanic white children with ASD participated in activities outside of school (70%) compared to children with ASD in other racial/ethnic groups. See Figure 5-30.

Figure 5-30. Participates in one or more activities outside of school, by race/ethnicity, among children ages 6-17 years with



Data source: The National Survey of Children's Health, 2011/12.
Abbreviations: NH = non-Hispanic.

Flourishing

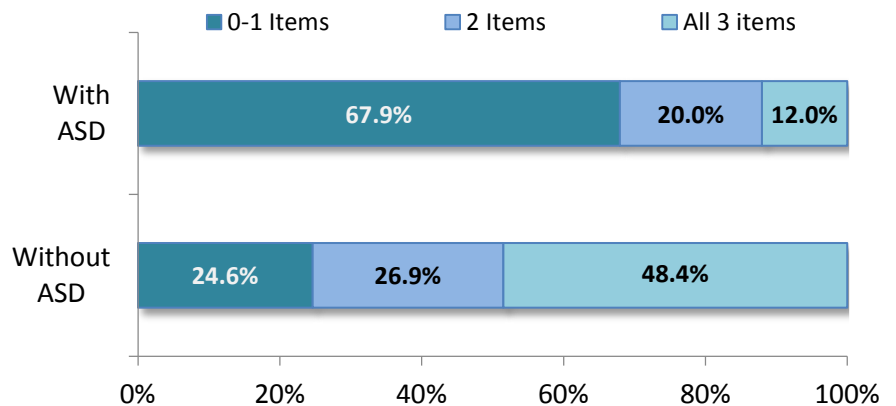
The 2011/12 NSCH asked parents of school-aged children three questions related to flourishing:

- 1) Does the child finish tasks and follow through with plans?
- 2) Does the child stay calm and in control when faced with a challenge?
- 3) Does the child show interest and curiosity in learning new things?

The Data Resource Center for Child and Adolescent Health (DRC) compiled answers to these questions to create the Flourishing Index. Children were thought to be “flourishing” when parents answered “usually” or “always” to all three of the questions above. Figure 5-31 demonstrates that dramatically fewer children with ASD fulfilled all 3 flourishing items, as compared to children without ASD (12% vs. 48%).

Older children with ASD (ages 12-17) showed slightly higher rates of flourishing compared to younger children (ages 6-11) with ASD (16% vs. 9%; data not shown).

Figure 5-31. Child meets flourishing items among children ages 6-17.

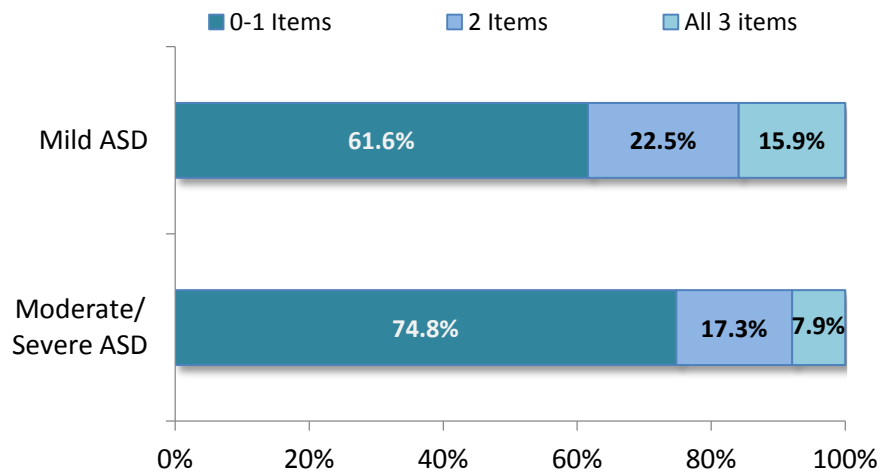


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Flourishing, by ASD Severity

Children with mild cases of ASD met all three flourishing items more often than children with moderate or severe cases of ASD (16% vs. 8%). However, the rate of flourishing among children of all levels of ASD severity was quite low. See Figure 5-32.

Figure 5-32. Child meets flourishing items, by ASD severity, among children ages 6-17 with ASD.



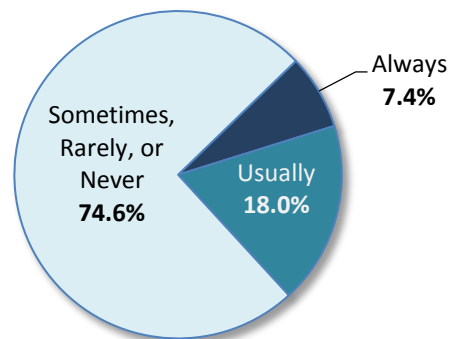
Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: ASD severity is parent reported.

Staying Calm and in Control in the Face of a Challenge

One of the NSCH survey questions in the Flourishing Index asked parents of school-aged children if their child “stays calm and in control when facing a challenge.”

Only 25% of parents of children with ASD indicated that their child “usually” or “always” stayed calm and in control when facing a challenge. See Figure 5-33. In contrast, over 65% of parents of children without ASD (data not shown) reported that their child “usually” or “always” stayed calm and in control when facing a challenge.

Figure 5-33. Child stays calm and in control when facing a challenge, among children ages 6-17 with ASD.

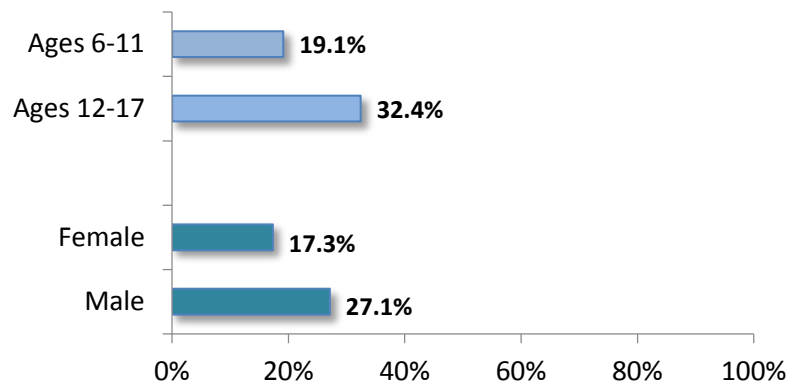


Data source: The National Survey of Children's Health, 2011/12.

Staying Calm and in Control in the Face of a Challenge, by Age and Sex

The data suggest that older children with ASD stay calm and in control when facing a challenge more than younger children with ASD (32% vs. 19%). Additionally, more boys than girls were reported to have this strength (27% vs. 17%). See Figure 5-34.

Figure 5-34. Child usually or always stays calm and in control when facing a challenge, by age and sex, among children ages 6-17 with ASD.

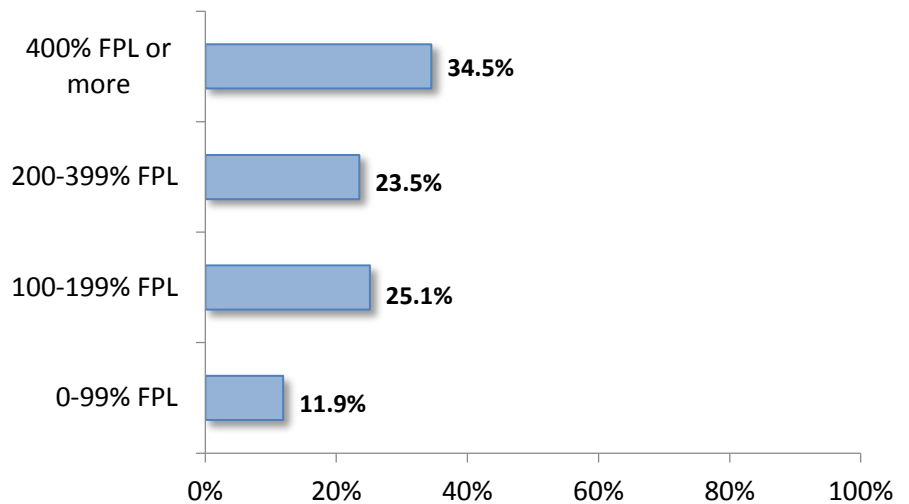


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Staying Calm and in Control in the Face of a Challenge, by Income

Fewer children living under the Federal Poverty Level (FPL) were reported to stay calm and in control in the face of a challenge (12%), compared to children living in higher income groups. The prevalence of this strength increased for the most part as household income increased. See Figure 5-35.

Figure 5-35. Child usually or always stays calm and in control when facing a challenge, by income, among children ages 6-17 with ASD.



Data source: The National Survey of Children's Health, 2011/12.
Abbreviations: FPL = Federal poverty level.
Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011.

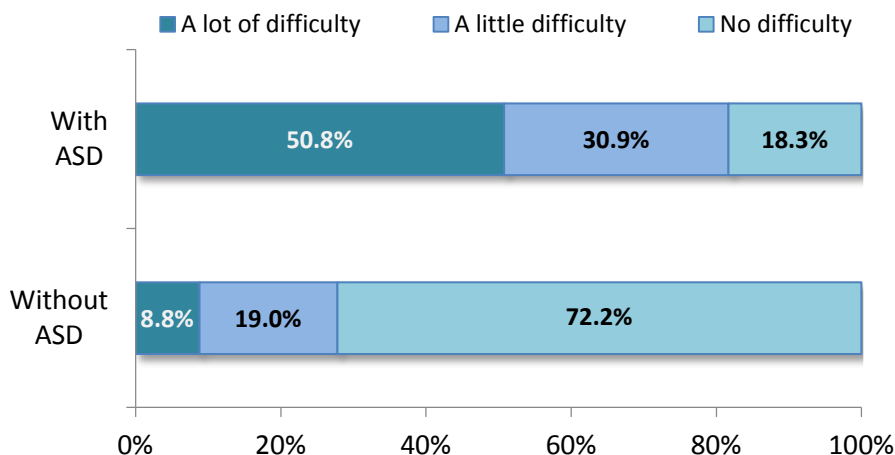
Difficulty Making and Keeping Friends

Data from the NS-CHSCN show large social differences between CSHCN ages 2-17 with and without ASD.

Children with ASD experience much greater difficulty keeping and making friends compared to CSHCN without ASD. Over 80% of parents of children with ASD reported that their child had at least some difficulty making and keeping friends, and over 50% reported “a lot” of difficulty. This figure is over five times greater than CSHCN without ASD. See Figure 5-36.

Further, children who have moderate or severe cases of ASD have greater difficulty making friends (85-87%; data not shown) compared to children with mild cases of ASD (77%; data not shown).

Figure 5-36. Child has difficulty making and keeping friends among children ages 2-17.



Data source: The National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: Chi-square test $p < 0.05$.

Key Takeaways

- ✓ Fewer children with ASD participate in activities outside of school, compared to children without ASD (65% vs 81%). Among children of different races/ethnicities, a larger proportion of white children with ASD participated in activities outside of school.
- ✓ Only 12% of children with ASD met all three flourishing items, compared to almost 50% of children without ASD.
- ✓ Only 25% of children with ASD are reported to stay calm and in control in the face of a challenge, as compared to 65% of children without ASD.
- ✓ Children with ASD living in higher income groups were reported to more frequently stay calm and in control in the face of a challenge, compared to children with ASD in lower income groups (>25% vs. 12%).
- ✓ Over 80% of children with ASD experience difficulty making and keeping friends.

Safety Concerns

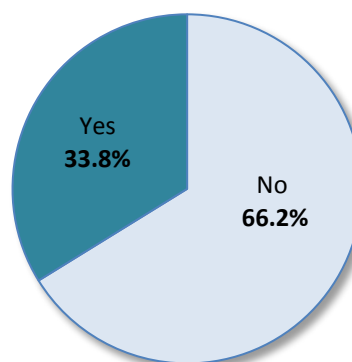
Many children with Autism Spectrum Disorder (ASD) are prone to wandering away from the safety of a responsible person’s care or safe environment. This could include wandering off or becoming lost from home, school, a public place such as a store or playground, or from someone else’s home such as a relative, neighbor, or babysitter. Wandering can sometimes result in harm or injury, and the likelihood of harm can increase due to unique challenges faced by children with ASD related to communication and safety awareness. Data from the 2011 Survey of Pathways to Diagnosis and Services (Pathways) are used to show the number of school-aged children (ages 6-17) with special health care needs (CSHCN) with ASD who wandered in the past year. Additionally, data is available regarding the percentage of children whose families erected barriers to keep their child from wandering, and the percentage of children who wore a tracking device. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Child Wandered Off in the Past Year

One-third of school-aged CSHCN with ASD wandered off from a safe area or from the care of a responsible adult in the past year. See Figure 6-1. 24% of children wandered off from a public place, 11% wandered off from home, 10% wandered off from school, day care, or summer camp, and 6% of children wandered off from someone else’s home. (Data not shown.)

Tendency to wander varied among different demographic groups. For example, boys wandered more than girls (35% vs. 27%; data not shown). Additionally, a greater proportion of Hispanic children wandered off compared to children of any other races/ethnicities (42% vs. 26-33%; data not shown). More differences by child and household characteristics are described below.

Figure 6-1. Child wandered off in the past year, among CSHCN ages 6-17 years with ASD.

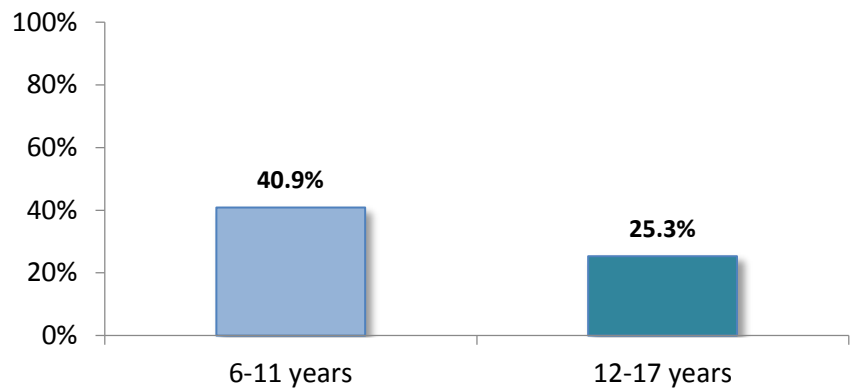


Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Child Wandered Off in the Past Year, by Age

As may be expected, younger children wandered off more frequently than older children (41% vs. 25%). However, wandering continued to be a problem among older youth; 1 in 5 youth and adolescents (ages 12-17 years) wandered from a safe environment. See Figure 6-2.

Figure 6-2. Child wandered off in the past year, by age, among CSHCN ages 6-17 years with ASD.



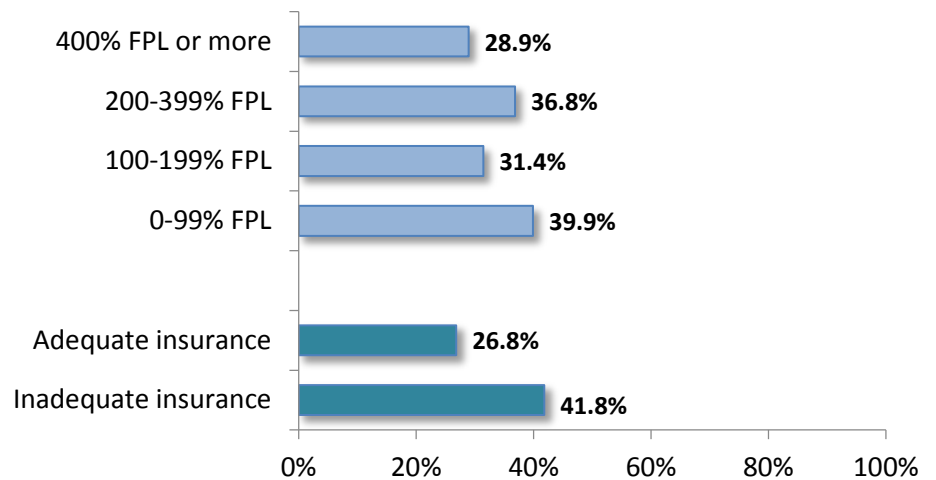
Data source: The Survey of Pathways to Diagnosis & Services, 2011.
 Scientific notes: Chi-square test $p < 0.05$.

Child Wandered Off in the Past Year, by Income and Insurance Adequacy

Children living under the Federal Poverty Level (FPL) wandered more than children in the higher income households. See Figure 6-3. However, children living in households earning 200-399% of the FPL also wandered more frequently than their higher-income peers.

Additionally, while 42% of children with inadequate insurance wandered in the past year, just over a quarter of children with [adequate insurance](#) did so. This suggests that families of children with inadequate insurance may not receive the information and resources they need to limit wandering behaviors.

Figure 6-3. Child wandered off in the past year, by income and insurance adequacy, among CSHCN ages 6-17 with ASD.



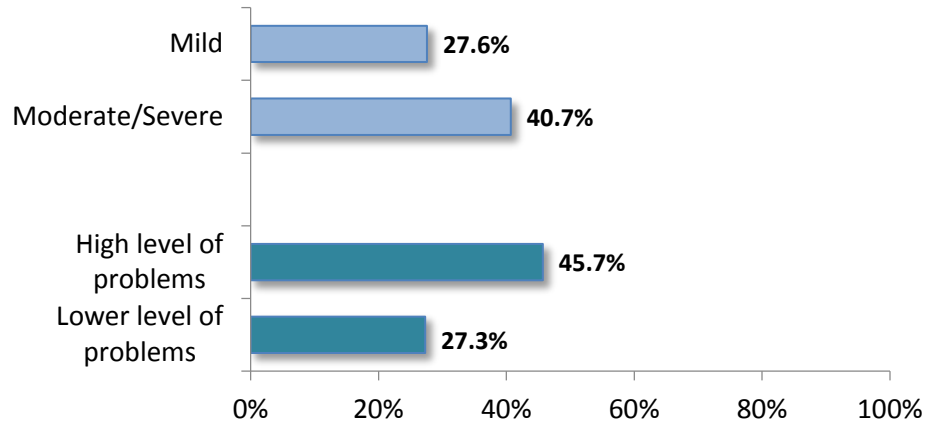
Data source: The Survey of Pathways to Diagnosis & Services, 2011.
 Abbreviations: FPL=Federal Poverty Level.
 Scientific notes: Poverty threshold (<100% FPL) for a family of four is an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$ for insurance adequacy subgroup.

Child Wandered Off in the Past Year, by ASD Severity and SDQ Score

Fewer children with mild ASD wandered off in the past year, compared to children with moderate or severe cases (28% vs. 41%). Figure 6-4.

However, a dramatic difference in wandering behavior emerged by the child's brief Strength and Difficulties Questionnaire (SDQ) score. The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. As seen in Figure 6-4, children with higher levels of mental health problems have a greater tendency to wander.

Figure 6-4. Child wandered off in the past year, by ASD severity and Strengths and Difficulties Questionnaire (SDQ) score, among CSHCN ages 6-17 with ASD.

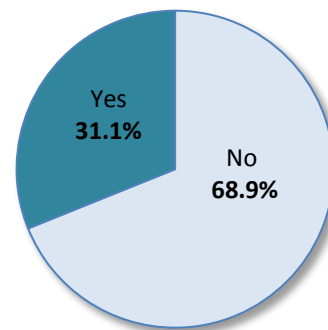


Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Abbreviations: SDQ = Strengths and Difficulties Questionnaire.
Scientific notes: The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. ASD severity is parent-reported. Chi-square test $p < 0.05$ for SDQ subgroup.

Child's Home Had Barriers Added in the Past Year

Just over 30% of CSHCN with ASD lived in homes that had barriers erected in the past year to discourage their child from wandering. See Figure 6-5. Barriers could include fences, gates, locks, alarms, or other structures to prevent a child from wandering off or becoming lost.

Figure 6-5. Child's home had barriers added in the past year, among CSHCN ages 6-17 years with ASD.



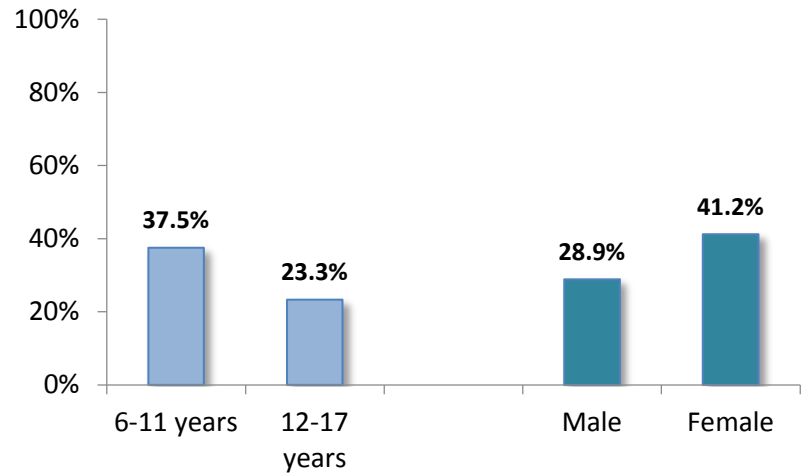
Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Child's Home Had Barriers Added in Past Year, by Age and Sex

At the time of the Pathways survey, a greater proportion of younger children lived in homes that had a barrier added in the past year, compared to older children. See Figure 6-6. Of note, almost a quarter of older youth and adolescents continued to need barriers added to their home for additional safety precautions.

Additionally, although rates of wandering were found to be slightly higher among boys than girls, a greater percentage of girls lived in homes that erected barriers to prevent their wandering compared to boys. See Figure 6-6.

Figure 6-6. Child's home had barriers added in the past year, by age and sex, among CSHCN ages 6-17 years with ASD.



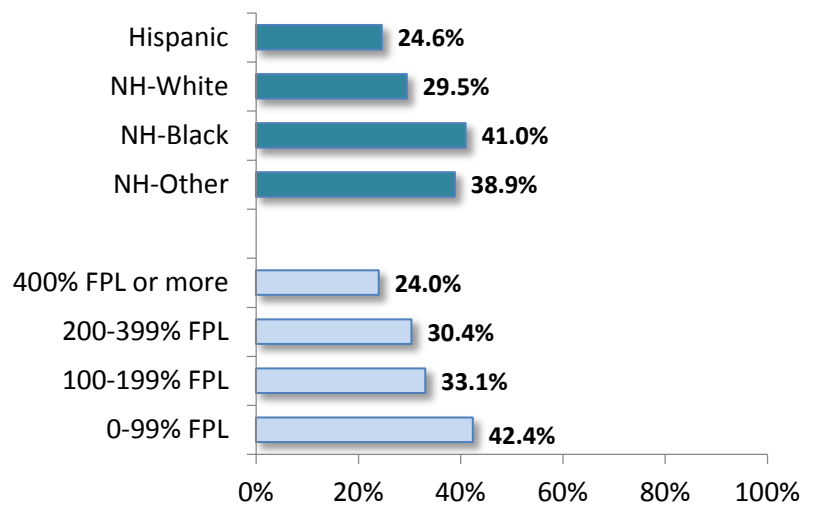
Data source: The Survey of Pathways to Diagnosis & Services, 2011.
 Scientific notes: Chi-square test $p < 0.05$.

Child's Home Had Barriers Added in Past Year, by Race/Ethnicity and Income

The proportion of children who lived in homes that erected barriers in the past year also differed by race/ethnicity and income. Despite the fact that the highest rates of wandering emerged among Hispanic children, fewer Hispanic children lived in households which erected barriers. See Figure 6-7.

Additionally, as household income decreased, barriers in the home appeared to increase. 42% of children in households living under the Federal Poverty Level (FPL) had a barrier erected in the past year, as compared to <25% of children in households in the highest income bracket. See Figure 6-7.

Figure 6-7. Child's home had barriers added in the past year, by race/ethnicity and income, among CSHCN ages 6-17 with ASD.

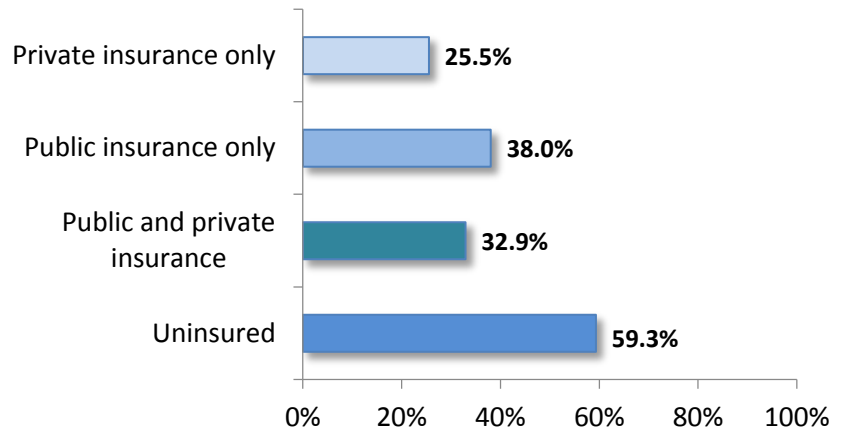


Data source: The Survey of Pathways to Diagnosis & Services, 2011.
 Abbreviations: FPL - Federal Poverty Level, NH - Non-Hispanic.
 Scientific notes: Poverty threshold (<100% FPL) for a family of four is an annual income of \$22,350 in 2011.

Child's Home Had Barriers Added in Past Year, by Insurance Type

Higher proportions of children with no health insurance or public health insurance only lived in homes that added a barrier within the past year. As compared to children with private insurance only (26%), almost 40% of children with public insurance only and almost 60% of uninsured children lived in homes which added this precaution. See Figure 6-8.

Figure 6-8. Child's home had barriers added in the past year, by insurance type, among CSHCN ages 6-17 with ASD.



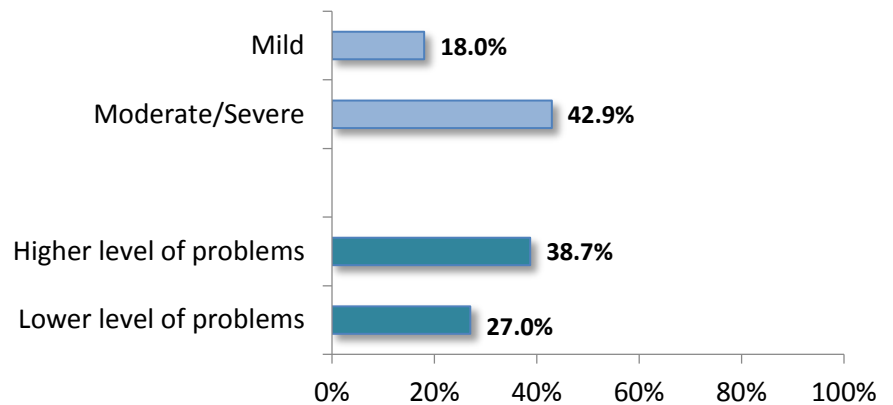
Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Scientific notes: Chi-square test $p < 0.05$.

Child's Home Had Barriers Added in Past Year, by ASD Severity and SDQ Score

Dramatically fewer children with mild cases of ASD lived in homes which had a barrier erected in the past year. See Figure 6-9. Compared to children with mild ASD, over two times the amount of children with more severe ASD had barriers added in their homes (18% vs. 43%).

Similar patterns can be observed by observing wandering behavior by children's brief Strengths and Difficulties Questionnaire (SDQ) score. A greater proportion of children with high levels of mental health problems had new barriers added to their home, indicating that children with greater mental health difficulties needed barriers added to their home as additional safety precautions. See Figure 6-9.

Figure 6-9. Child's home had barriers added in the past year, by ASD severity and Strengths and Difficulties Questionnaire (SDQ) score, among CSHCN ages 6-17 with ASD.

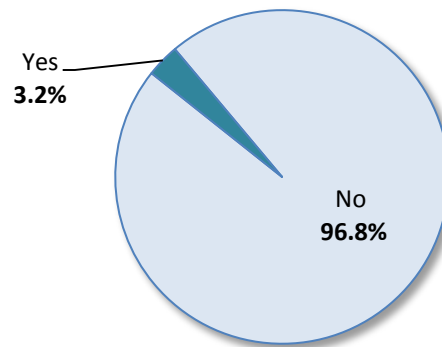


Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Abbreviations: SDQ - Strengths and Difficulties Questionnaire.
Scientific notes: The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. ASD severity is parent-reported. Chi-square test $p < 0.05$.

Child Wore a Tracking Device in Past Year

About 3% of CSHCN with ASD wore a tracking device in the past year to monitor their whereabouts. Most children in this population did not wear a tracking device.

Figure 6-10. Child wore a tracking device in the past year, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

Key Takeaways

- ✓ One-third of school-aged CSHCN with ASD wandered off from a safe environment in the past year, and wandering continued to be a problem in one of five older youth ages 12-17 years.
- ✓ A higher proportion of children without adequate insurance wandered off (42% vs. 27%). This suggests that families of children with inadequate insurance may not be receiving the information or resources they need to limit wandering behaviors.
- ✓ Children with high level of mental health problems exhibit more wandering away from a safe place.
- ✓ Just over 30% of children with ASD lived in homes which added a barrier to prevent their child from wandering in the past year.
- ✓ Although more boys wander, a greater percentage of girls lived in households which added barriers to prevent wandering.
- ✓ Despite the fact that the greatest proportion of children who wander are Hispanic, less than a quarter of Hispanic children lived in homes which erected barriers to control wandering in the past year.
- ✓ More physical barriers to prevent wandering were added amongst uninsured children and children with public insurance only.
- ✓ Only 3% of school-aged CSHCN with ASD wore a tracking device in the past year to monitor their whereabouts.

Parental Views about Condition & Prognosis

Population:
CSHCN with ASD,
6-17 years

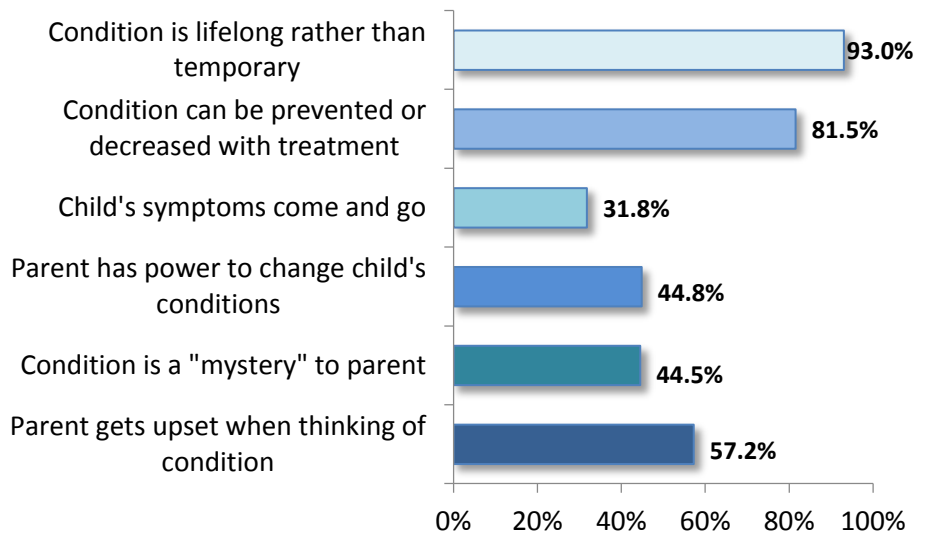
When parents learn that their child has Autism Spectrum Disorder (ASD), they may understandably feel a range of emotions regarding their child’s wellbeing. It is important for those working closely with families and children with ASD to understand familial concerns and worries, in order to assist families with their navigation of this unknown and sometimes frightening time. In the 2011 Survey of Pathways to Diagnosis and Services (Pathways), parents of school-aged children (ages 6-17) with special health care needs (CSHCN) were asked a series of questions to understand some of their thoughts and feelings about their child’s ASD. (Please see the [2011 Pathways Survey questionnaire](#) for the complete wording of each survey question in this section.)

Beliefs about ASD Condition & Prognosis

In the Pathways survey, parents of school-aged CSHCN with ASD were asked six questions about their beliefs about their child’s ASD condition and future prognosis. They were asked whether they “definitely agreed”, “somewhat agreed”, or “disagreed” with statements.

93% of CSHCN with ASD had parents who believed that the condition would be lifelong. However, 82% believed that ASD could be prevented or improved with treatment. 57% of CSHCN with ASD had parents who felt upset when they thought about their child’s condition. Less than half of children’s parents believed that they had the power to change the child’s condition. See Figure 6-11.

Figure 6-11 Child's parent definitely/somewhat agreed with statements about ASD condition and prognosis, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.

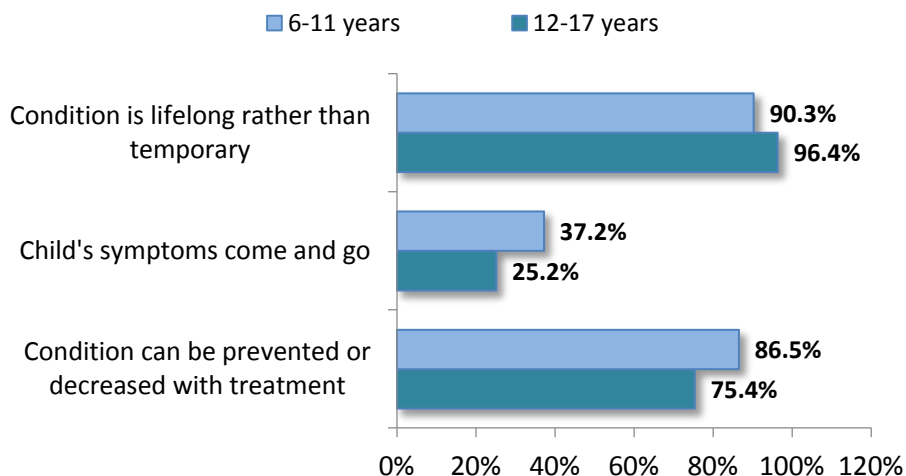
Beliefs about Condition and Prognosis, by Age

Some interesting differences in parental beliefs emerged depending on the child's age. Parents of older children with ASD (12-17 years old) were more cautious in their beliefs about their child's prognosis. These parents were more likely to see their child's condition as lifelong rather than temporary (96% vs. 90%), and fewer parents of older children believed that symptoms come and go (25% vs. 37%) and that their child's condition can be decreased with treatment (75% vs. 87%). See Figure 6-12.

Older children with ASD also had parents who were less likely to believe that they have the power to change the child's condition (36% vs. 52%). See Figure 6-13. Additionally, perhaps because they have known about their child's condition longer than the parents of younger children, these parents were also less likely to feel that the condition is a mystery (38% vs. 50%). See Figure 6-13.

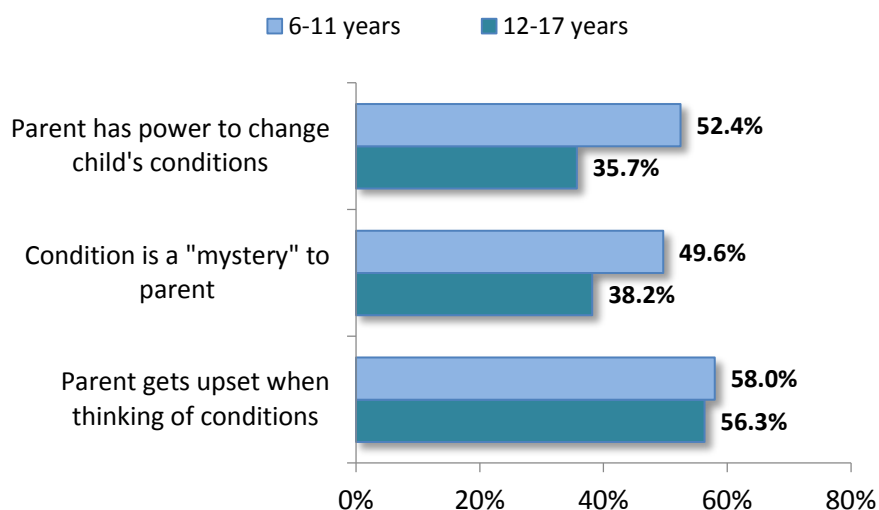
However, it is important to note that almost equal proportion of parents of older and younger children reported that they get upset when they think about their child's condition. See Figure 6-13.

Figure 6-12. Child's parent definitely/somewhat agreed with statements about ASD prognosis, by age, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Scientific notes: Chi-square test $p < 0.05$.

Figure 6-13. Child's parent definitely/ somewhat agreed with statements about ASD condition, by age, among CSHCN ages 6-17 years with ASD.



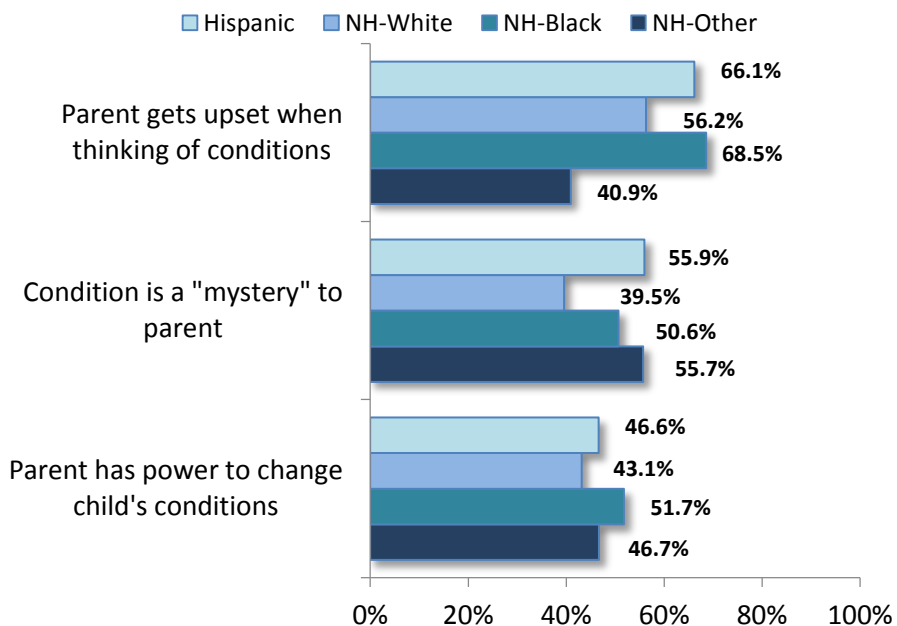
Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Scientific notes: Chi-square test $p < 0.05$ for "condition is a 'mystery' to parent" and "parent has power to change child's condition" subgroups.

Beliefs about Condition, by Race/Ethnicity

Compared to non-Hispanic white children, a greater proportion of non-Hispanic black and Hispanic children had parents who became upset when they thought about their child's ASD, and felt that their child's condition was a mystery. Fewer differences emerged among parents regarding their belief that they have the power to change their child's condition. See Figure 6-14. These findings may indicate that there is a need for public health awareness campaigns that reach out to minority communities about learning and other developmental conditions.

However, it is important to note that the percentage non-Hispanic white children whose parents became upset when they thought about their child's condition was still very high (56%). See Figure 6-14. These figures support efforts to provide increased resources for all parents of children of ASD.

Figure 6-14. Child's parent definitely/somewhat agreed with statements about ASD condition, by race/ethnicity, among CSHCN ages 6-17 years with ASD.



Data source: The Survey of Pathways to Diagnosis & Services, 2011.
Scientific notes: Chi-square test $p < 0.05$ for "parent gets upset when thinking of conditions" and "condition is a 'mystery' to parent" subgroups.

Key Takeaways

- ✓ 9 in 10 CSHCN with ASD had parents who believed that their child's condition is lifelong rather than temporary. However, more than 80% of children's parents believed that symptoms could be prevented or decreased with treatment.
- ✓ A greater proportion of younger children with ASD had parents who believed that their child's symptoms come and go, and that symptoms could be prevented or decreased with treatment.
- ✓ A larger percentage of older children had parents who neither felt that the condition was a mystery nor that they had the power to change it.
- ✓ More non-Hispanic black and Hispanic children had parents who became upset when they thought about their child's condition. Additionally, more non-Hispanic black and Hispanic children had parents who felt that their child's condition was a mystery.

Parental Wellbeing

Parental wellbeing is an important element for overall child health and wellbeing. Parents may already cope with stress, anxiety, or poor mental health, and raising a child with Autism Spectrum Disorder (ASD) may introduce new, stressful experiences. Data from the 2011/12 National Survey of Children’s Health (NSCH) provide several measures of parental stress, maternal physical and mental health, and a measure of how well a parent feels they are coping with the demands of parenthood. This section explores this data amongst parents of children 2-17 years old with and without ASD. (Please see the [2011/12 NSCH questionnaire](#) for the complete wording of each survey question in this section.)

Parental Stress Index

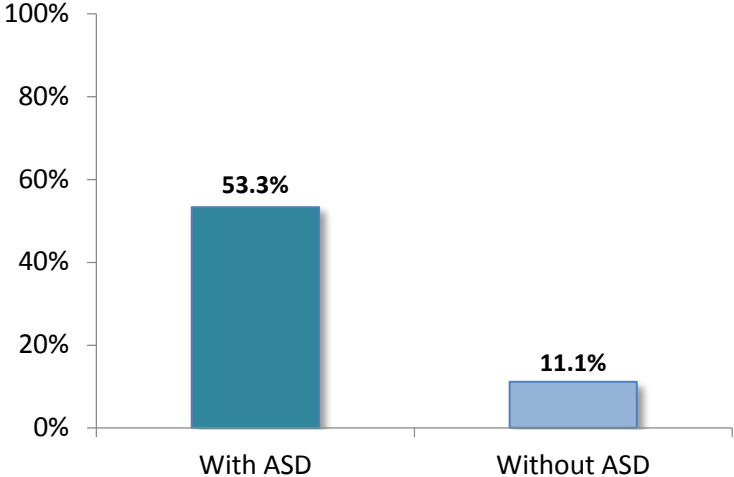
The 2011/12 National Survey of Children’s Health asked parents of children ages 2-17 a series of questions related to their stress. The Data Resource Center for Child and Adolescent Health (DRC) compiled the answers to create a Parental Stress Index measure. This measure consists of parents responding “usually” or “always” to feeling one of the following in the past 30 days:

- 1) Child is much harder to care for than other children
- 2) Parent is often bothered a lot by their child’s behavior
- 3) Parent is often angry with the child

Dramatically more children with ASD had parents who qualified on the Parental Stress Index, as compared to children without ASD (53% vs. 11%). See Figure 6-15.

Among children with ASD, the percentage of parents who met stress criteria did not differ greatly by sex, but did differ by age: 64% of young children 0-5 years old had parents who qualified on the Parental Stress Index, as compared to 51% of children 6-17 years old (data not shown). Other demographic differences in parental stress can be found in the following sections.

Figure 6-15. Children whose parents met one or more criteria on the Parental Stress Index, among children ages 2-17.



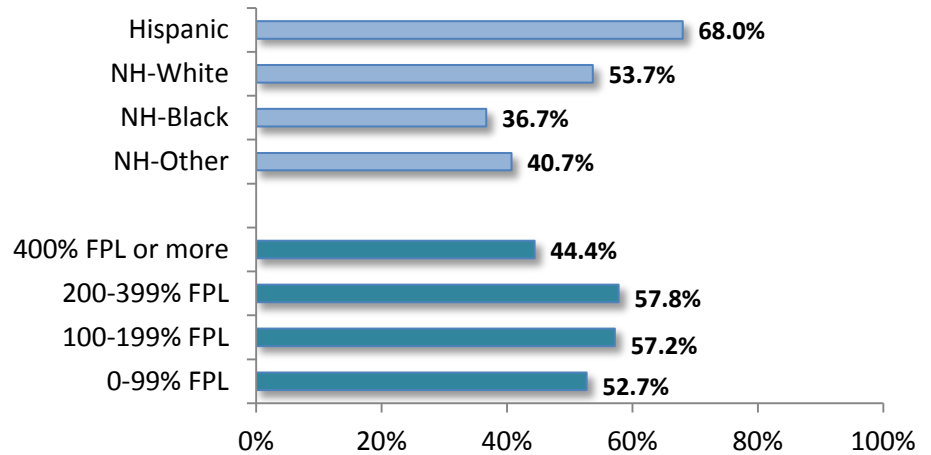
Data source: National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Parental Stress Index, by Race/Ethnicity and Income

Large disparities in parental stress emerged among children with ASD of different races/ethnicities. As seen in Figure 6-16, almost 70% of Hispanic children and 53% of non-Hispanic white children with ASD had parents who qualified on the Parental Stress Index. Fewer children of other races/ethnicities had parents who met stress criteria (<41%).

A smaller percentage of children living in the highest-earning households had parents who met stress criteria, as compared to lower-income households. See Figure 6-16.

Figure 6-16. Children whose parents who met one or more criteria on the Parental Stress Index, by race/ethnicity and income, among children ages 2-17 with ASD.

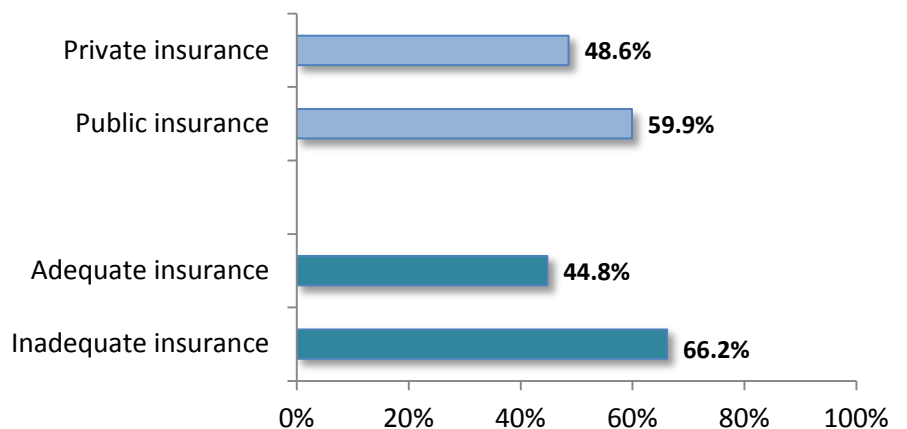


Data source: National Survey of Children's Health, 2011/12.
 Abbreviations: NH - Non-Hispanic; FPL - Federal Poverty Level.
 Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$ for race/ethnicity subgroup.

Parental Stress Index, by Insurance Type and Insurance Adequacy

Parental stress appeared to be greater amongst children with ASD who had public insurance or inadequate insurance coverage. See Figure 6-17. Two-thirds of children with public insurance had parents who met criteria on the Parental Stress Index, as compared to 49% of children with private insurance.

Figure 6-17. Children whose parents met one or more criteria on the Parental Stress Index, by insurance type and insurance adequacy, among children ages 2-17 with ASD.

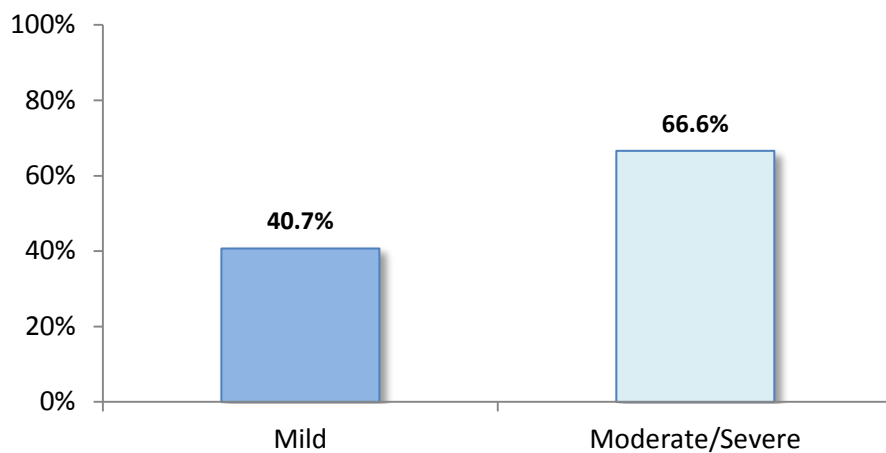


Data source: National Survey of Children's Health, 2011/12.
 Scientific notes: Chi-square test $p < 0.05$ for insurance adequacy subgroup.

Parental Stress Index, by ASD Severity

Parental stress appeared to be greater among families of children with more severe ASD. Over two-thirds of children with moderate or severe ASD had parents who met the Parental Stress Index criteria, compared to 41% of children with mild ASD. See Figure 6-18.

Figure 6-18. Children whose parents met one or more criteria on the Parental Stress Index, by ASD severity, among children ages 2-17 with ASD.



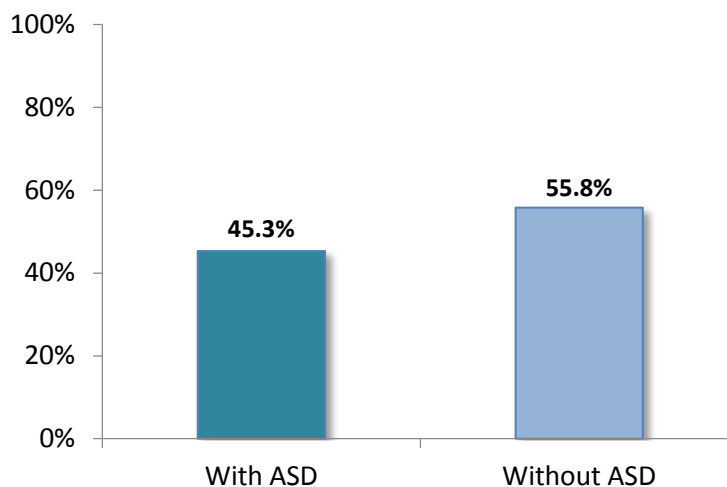
Data source: National Survey of Children's Health, 2011/12.
Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

Mother's Physical and Mental Health

The 2011/12 NSCH also asked about the mother's physical and mental health. 56% of children without ASD had mothers who were in "very good" or "excellent" physical and mental health. This can be compared to the 45% of children with ASD whose mothers are reported to be in the same state. See Figure 6-19.

Among children with ASD, the percentage of mothers in very good or excellent health did not differ greatly by the child's sex. Interestingly, this percentage also did not differ greatly by the severity of the child's ASD.

Figure 6-19. Children whose mother has very good or excellent physical and mental health, among children ages 2-17.



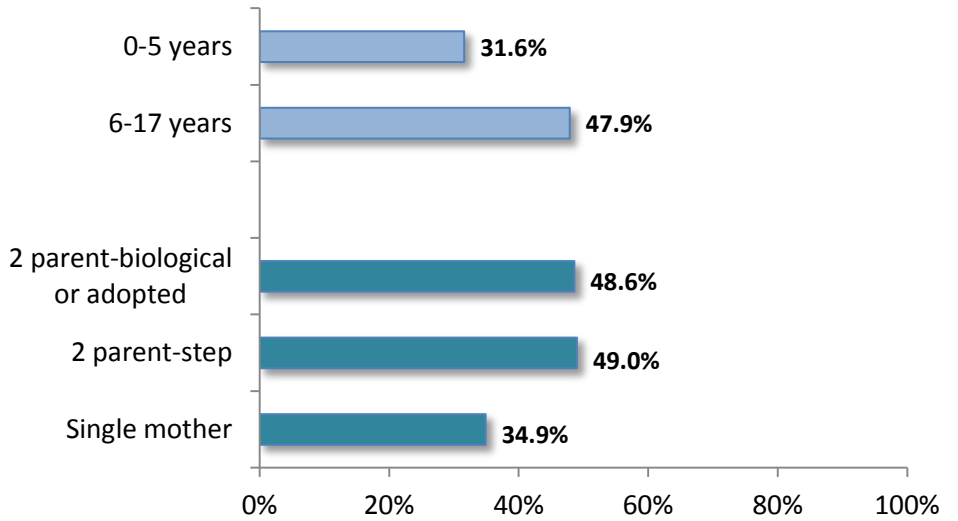
Data source: National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Mother's Physical and Mental Health, by Age and Family Structure

Maternal health differed by the child's age and household structure. Almost half of older children with ASD (6-17 years) had mothers in good health, as compared to only one-third of younger children with ASD (0-5 years). See Figure 6-20.

Fewer single mothers were reported to be in good health, compared to mothers in other household structures. See Figure 6-20.

Figure 6-20. Children whose mother has very good or excellent physical and mental health, by age and family structure, among children ages 2-17 with ASD.



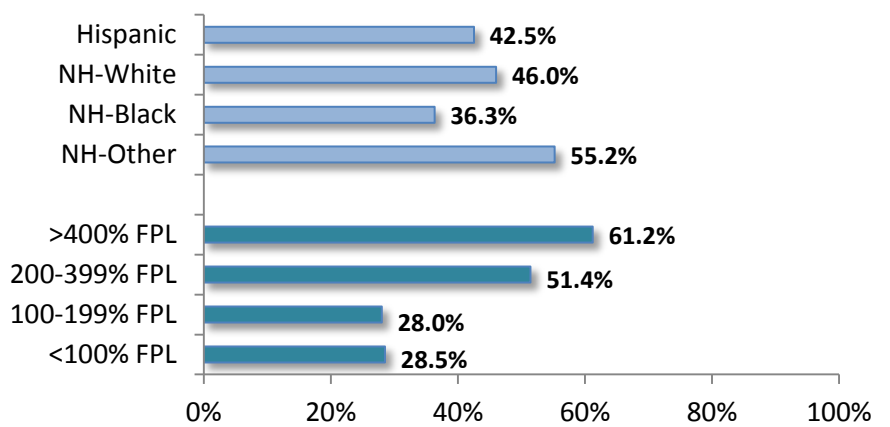
Data source: National Survey of Children's Health, 2011/12.
 Scientific notes: Chi-square test $p < 0.05$ for age subgroup.

Mother's Physical and Mental Health, by Race/Ethnicity and Income

Non-Hispanic black children and children living in the lowest income households were found to have mothers with the poorest physical and mental health. See Figure 6-21.

Fewer than 30% of children with ASD under the federal poverty level had mothers in very good or excellent health. Over two times this percentage of children lived in the highest income households and had mothers in very good or excellent health (61%). See Figure 6-21.

Figure 6-21. Children whose mother has very good or excellent physical and mental health, by race/ethnicity and income, among children ages 2-17 with ASD.



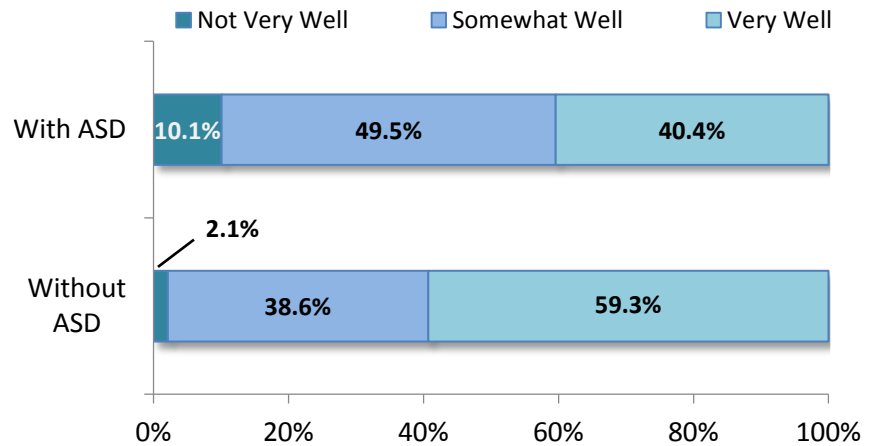
Data source: National Survey of Children's Health, 2011/12.
 Abbreviations: NH - Non-Hispanic; FPL - Federal Poverty Level.
 Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$ for income subgroup.

Parent Copes Well with the Demands of Parenthood

The NSCH 2011/12 asked parents to share how well they felt they were dealing with the demands of parenthood. As seen in Figure 6-22, almost 60% of children without ASD had parents who were coping “very well”, 39% were coping “somewhat well”, and only 2% were not coping well. In contrast, only 40% of parents of children with ASD felt they were coping “very well”, half felt they were coping “somewhat well” and 10% were not coping well.

Among children with ASD, a higher percentage of older children’s parents were coping “very well”, compared to younger children’s parents (42% vs. 34%; data not shown).

Figure 6-22. How child's parent copes with the demands of parenthood, among children ages 2-17.



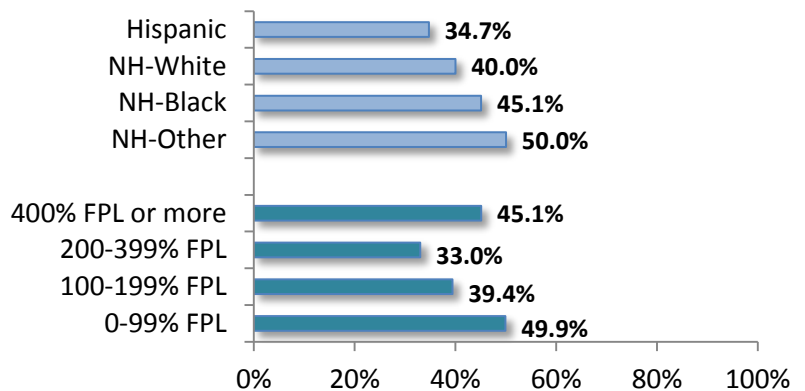
Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Parent Copes Very Well with the Demands of Parenthood, by Race/Ethnicity and Income

Non-Hispanic black children and children of “other” races/ethnicities had parents who appeared to be coping better with parenthood than Hispanic and non-Hispanic white children. See Figure 6-23.

Interestingly, compared to other income groups, more children living below the federal poverty level (0-99% FPL) and in the highest income households (400% FPL) had parents who reported that they were coping very well with parenthood. This finding may indicate that there is support provided to families earning below the federal poverty level that is less available to families earning between 100-399% FPL.

Figure 6-23. Child's parent copes very well with the demands of parenthood, by race/ethnicity and income, among children ages 2-17 with ASD.

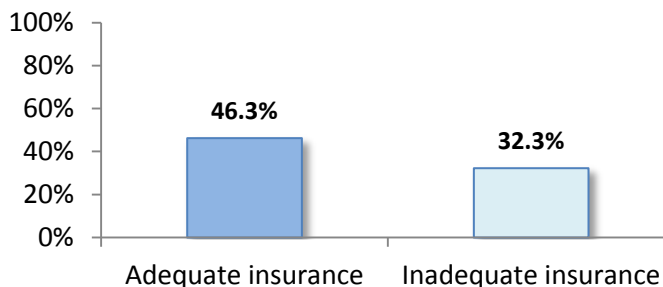


Data source: National Survey of Children's Health, 2011/12.
Abbreviations: NH - Non-Hispanic; FPL - Federal Poverty Level.
Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$.

Parent Copes Very Well with the Demands of Parenthood, by Insurance Adequacy

Almost half of adequately insured children with ASD had parents who felt that they were coping very well with parenthood. This can be compared to the less than one-third of inadequately insured children who had parents who felt similarly. See Figure 6-24. This finding may be attributable to the limited support services received by families without [adequate insurance](#).

Figure 6-24. Child's parent copes very well with the demands of parenthood, by insurance adequacy, among children ages 2-17 with ASD.

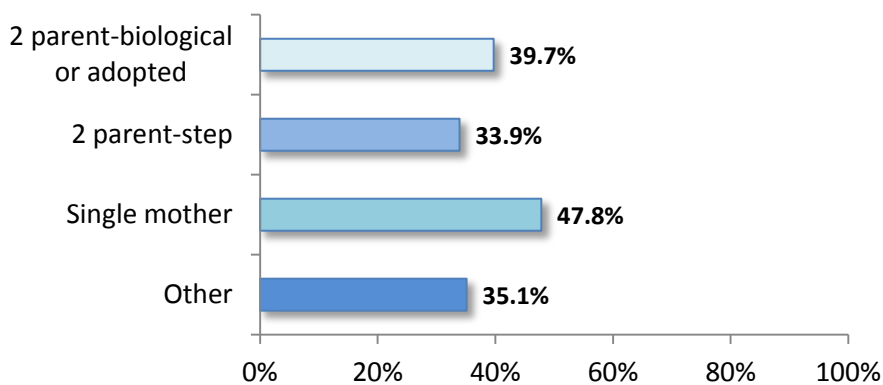


Data source: National Survey of Children's Health, 2011/12.

Parent Copes Very Well with the Demands of Parenthood, by Family Structure

Interestingly, among all [family structures](#) of children with ASD, single mothers reported that they were coping best with the demands of parenthood (50%). See Figure 6-25. This figure was lower amongst children with ASD from other [family structures](#).

Figure 6-25. Child's parent copes very well with the demands of parenthood, among children ages 2-17 with ASD.



Data source: National Survey of Children's Health, 2011/12.

Key Takeaways

- ✓ Significantly more children with ASD had parents who qualified on the Parental Stress Index, as compared to children without ASD (53% vs. 11%). Parents qualified on the Index if they were usually or always angry with their child, usually or always feeling like their child was harder to care for than other children, or usually or always bothered by their child's behavior.
- ✓ A much higher percentage of Hispanic children's parents met the stress criteria, as compared to children of other race/ethnicities (68% vs. <54%).
- ✓ Fewer children in the highest-income bracket had parents who met the stress criteria.
- ✓ Parental stress appeared to be greater amongst children with ASD who had inadequate insurance or public insurance.
- ✓ Fewer children with ASD had mothers in "very good" or "excellent" physical and mental health, compared children without ASD (45% vs. 56%).
- ✓ Low-income children, non-Hispanic black children, and younger children with ASD had mothers in poorer health.
- ✓ Far fewer children with ASD had parents who felt they were coping very well with parenthood, compared to children without ASD (40% vs. 59%).
- ✓ Fewer Hispanic children and inadequately insured children had parents who reported coping very well.

Home Environment

Population:
All children,
2-17 years

A child's home environment contains factors that shape their daily experiences. These factors, both positive and negative, can influence a child's ability to develop social and emotional skills and, ultimately, their lifelong health and happiness. As noted in previous sections, children with Autism Spectrum Disorder (ASD) experience more health problems and greater difficulty developing social and emotional skills compared to children without ASD. The 2011/12 National Survey of Children's Health (NSCH) includes several measures that attempt to capture psychosocial risk or protective factors present in the home and family lives of children ages 2-17 with ASD. (Please see the [2011/12 NSCH questionnaire](#) for the complete wording of each survey question in this section.)

Positive Home Environment

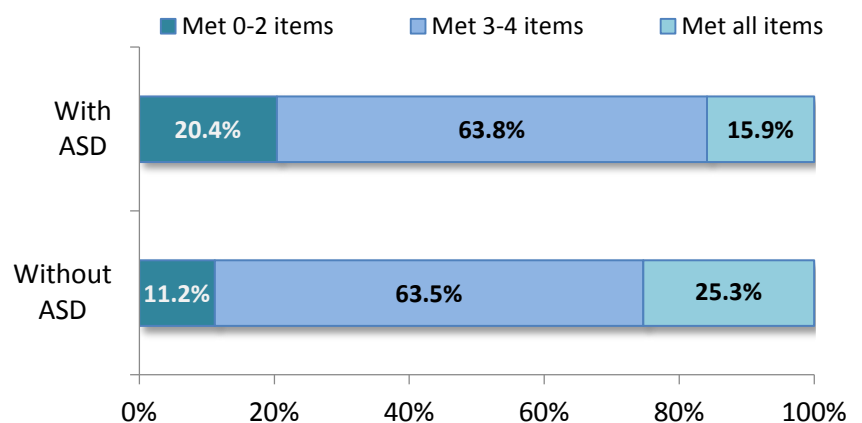
The 2011/12 National Survey of Children's Health asked parents a series of questions related to their child's home environment. The Data Resource Center for Child and Adolescent Health (DRC) then compiled these answers into a Positive Home Environment Index measure. This measure consists of the following items:

- 1) Young children are read/sung to every day (among children ages 0-5)
- 2) Young children were ever breastfed (among children ages 0-5)
- 3) Child has no TV in their bedroom (among children ages 6-17)
- 4) Child usually/always does required homework (among children ages 6-17)
- 5) Parent has met most/all of child's friends (among children ages 6-17)
- 6) Child has no exposure to household smoking (among children ages 0-17)
- 7) Family shares a meal on 4 or more days per week (among children ages 0-17)
- 8) Child watches less than 2 hours of TV per day (among children ages 1-17)

Children who met all of the age-appropriate items above were considered to be living in a positive home environment. The accompanying graphs are designed to display the proportion of children who met 0-2 items, 3-4 items, or all age-appropriate items.

As indicated in Figure 6-26, fewer children with ASD met all of the criteria for a positive home environment, compared to children without ASD (16% vs. 25%).

Figure 6-26. Child's home met Positive Home Environment Index, among children ages 2-17.

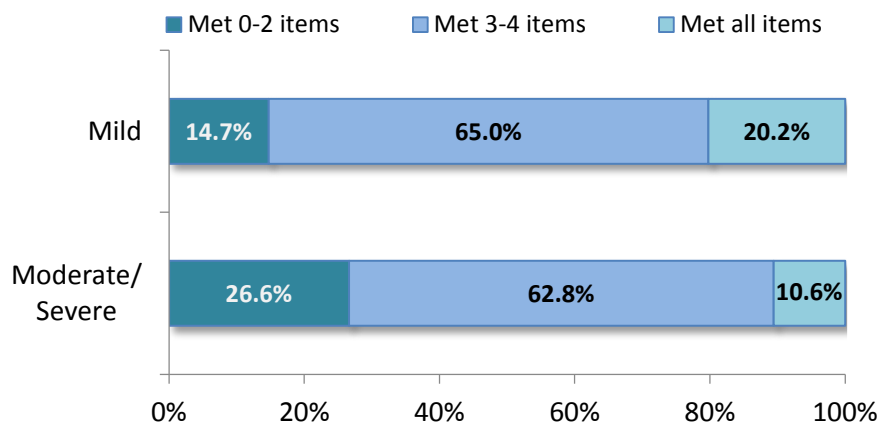


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Positive Home Environment, by ASD Severity

Children with mild cases of ASD met all positive home environment criteria more frequently than children with moderate or severe cases of ASD (20% vs. 11%). See Figure 6-27.

Figure 6-27. Child's home met Positive Home Environment Index, by ASD severity, among children ages 2-17 with ASD.

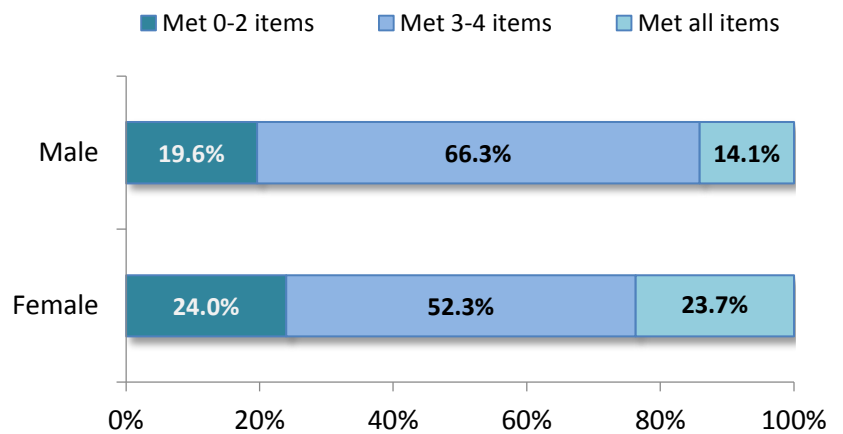


Data source: The National Survey of Children's Health, 2011/12.
 Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

Positive Home Environment, by Sex

About 14% of boys with ASD met all of the criteria for a positive home environment. In contrast, almost a quarter of girls with ASD met the criteria. See Figure 6-28.

Figure 6-28. Child's home met Positive Home Environment Index, by sex, among children ages 2-17 with ASD.



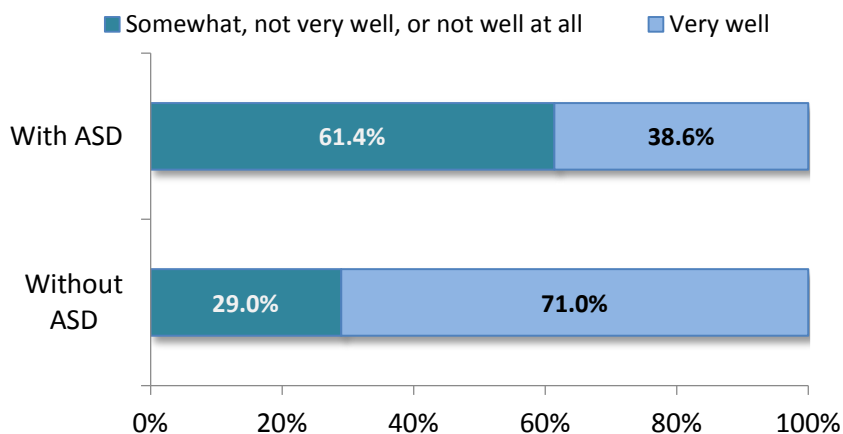
Data source: The National Survey of Children's Health, 2011/12.

Parent and Child Can Share Ideas

The 2011/12 National Survey of Children's Health (NSCH) asks parents, "How well can you and your child share ideas or talk about things that really matter?"

Far fewer children with ASD have parents who responded "very well" to this question, as compared to children without ASD. (39% vs. 71%). See Figure 6-29. These figures did not differ notably by the child's sex. (Data not shown.)

Figure 6-29. Parent and child can share ideas and talk about things that really matter, among children ages 2-17.

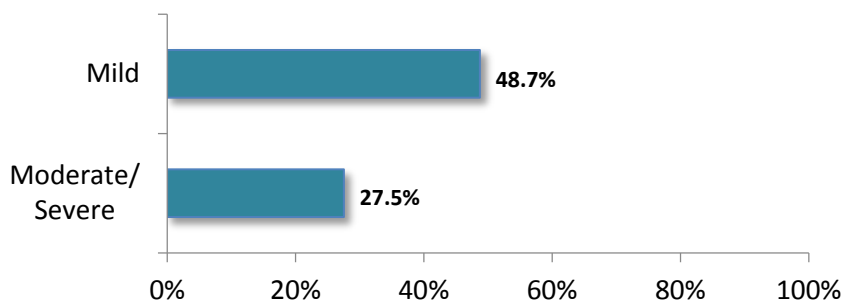


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Parent and Child Can Share Ideas, by ASD Severity

Children with mild ASD were able to share ideas and talk about things that really matter with their parents more frequently than children with moderate or severe cases of ASD (49% vs. 28%). See Figure 6-30.

Figure 6-30. Parent and child can share ideas "very well", by ASD severity, among children ages 2-17 with ASD.



Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

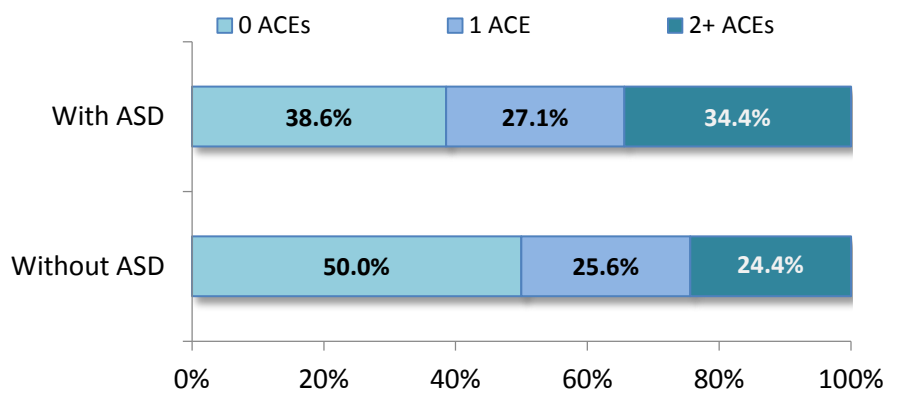
Adverse Childhood Experiences (ACEs)

Adverse Childhood Experiences (ACEs) can result in trauma and chronic/toxic stress, which have the ability to impact lifelong health. A growing body of research links ACEs to negative health outcomes later in life, making ACEs a topic of great interest to doctors, researchers, advocates, and parents alike.¹ The 2011/12 National Survey of Children’s Health included an ACEs Index, which attempts to capture these psychosocial risk factors that affect children’s health and wellbeing. Parents were asked to identify experiences faced by their children from the list of nine items below.

- (1) How often has it been very hard to get by on family’s income?
- (2) Child lived with a parent who got divorced or separated
- (3) Child lived with a parent who died
- (4) Child lived with a parent who served time in jail or prison
- (5) Child has witnessed domestic violence
- (6) Child ever victim/witness of neighborhood violence
- (7) Child ever lived with anyone who was mentally ill or suicidal
- (8) Child lived with anyone who had problems with alcohol or drugs
- (9) Child treated or judged unfairly because of his/her race or ethnic group

Children with ASD experienced more ACEs than children without ASD. Specifically, 34% of children with ASD had faced two or more ACEs. In contrast, 24% of children without ASD had encountered two or more ACEs. See Figure 6-31.

Figure 6-31. Adverse Childhood Experiences (ACEs) among children ages 2-17.



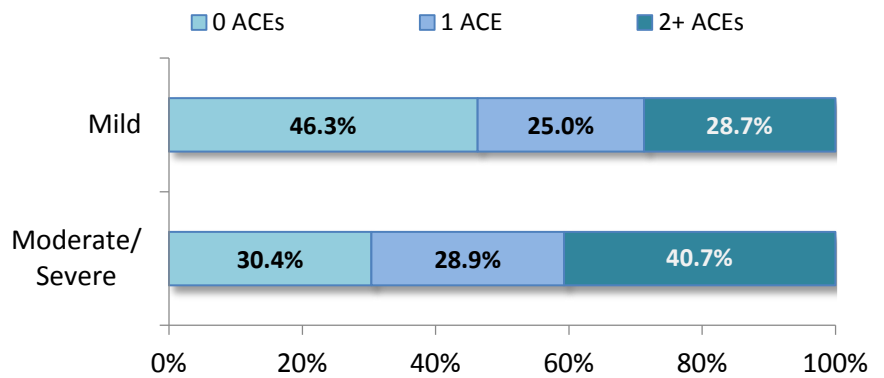
Data source: The National Survey of Children's Health, 2011/12.
 Scientific notes: Chi-square test $p < 0.05$.

¹ Bethell, Christina D., Paul Newacheck, Eva Hawes, and Neal Halfon. "Adverse childhood experiences: assessing the impact on health and school engagement and the mitigating role of resilience." *Health Affairs* 33, no. 12 (2014): 2106-2115.

Adverse Childhood Experiences (ACEs), by ASD Severity

Children with moderate or severe cases of ASD faced more Adverse Childhood Experiences (ACEs) than children with mild cases of ASD. See Figure 6-32.

Figure 6-32. Adverse Childhood Experiences, by ASD severity, among children with ASD ages 2-17.

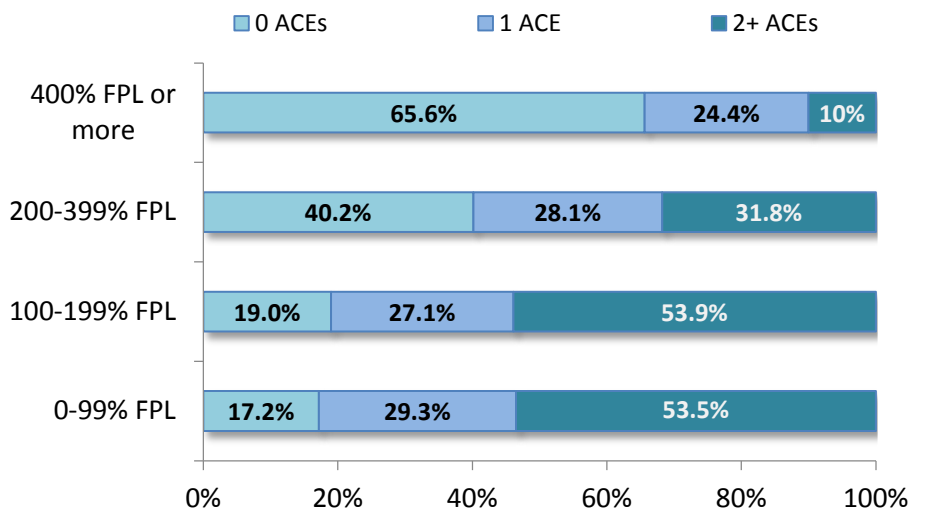


Data source: The National Survey of Children's Health, 2011/12.
 Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

Adverse Childhood Experiences (ACEs), by Income

Children with ASD in lower income households experienced dramatically more ACEs compared to their higher-income peers. Specifically, about 54% of children with ASD in household earning under 200% of the Federal Poverty Level (FPL) faced at least two ACEs. In contrast, only 10% of children with ASD in households earning 400% or more of the FPL had experienced at least two ACEs. See Figure 6-33.

Figure 6-33. Adverse Childhood Experiences, by income, among children with ASD ages 2-17.



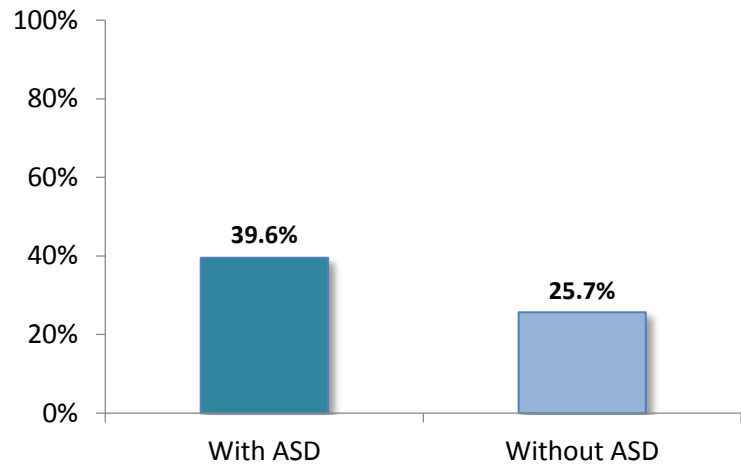
Data source: The National Survey of Children's Health, 2011/12.
 Abbreviations: FPL = Federal poverty level.
 Scientific notes: Poverty threshold (<100% FPL) for a family of four was an annual income of \$22,350 in 2011. Chi-square test $p < 0.05$.

Child's Household Experienced Economic Hardship

One of the items in the ACEs Index asked parents how often it has been hard to get by on their family's income. Answers were grouped into "never" or "rarely", and "somewhat often" or "very often". The accompanying graphs reflect the proportion of parents who answered either "somewhat often" or "very often", both of which indicate economic hardship.

As seen in Figure 6-34, families of children with ASD experienced more economic hardship than families of children without ASD (40% vs. 26%).

Figure 6-34. Child's household experienced economic hardship, among children ages 2-17.

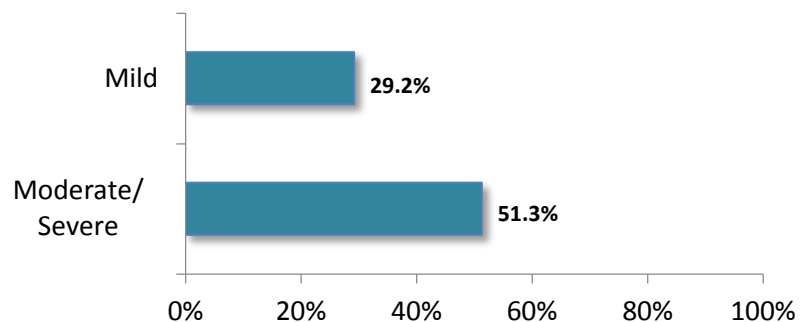


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Child's Household Experienced Economic Hardship, by ASD Severity

Families of children with moderate or severe cases of ASD experienced more economic hardship (51%) than families of children with mild cases of ASD (29%). See Figure 6-35.

Figure 6-35. Child's household experienced economic hardship, by ASD severity, among children ages 2-17 with ASD.

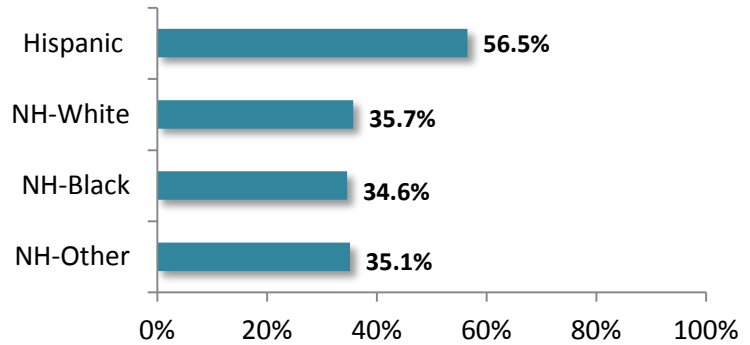


Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

Child's Household Experienced Economic Hardship, by Race/Ethnicity

Compared to all other racial/ethnic groups, Hispanic children with ASD experienced more economic hardship than their peers (57% vs. ~35%). See Figure 6-36.

Figure 6-36. Child's household experienced economic hardship, by race/ethnicity, among children ages 2-17 with ASD.

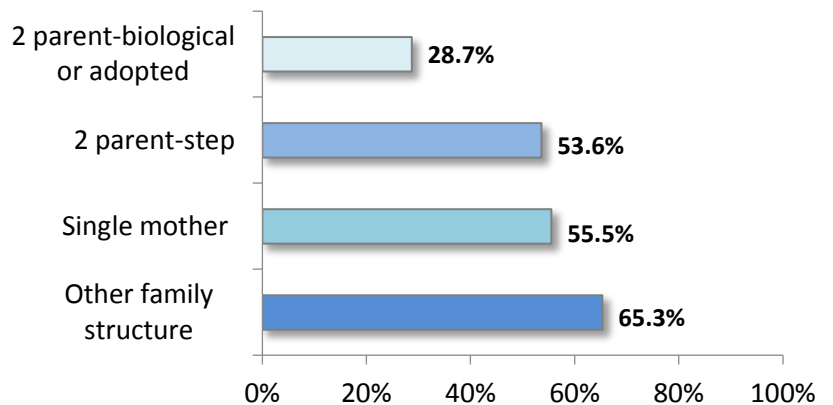


Data source: The National Survey of Children's Health, 2011/12.
Abbreviations: NH: non-Hispanic.

Child's Household Experienced Economic Hardship, by Family Structure

Children living with 2 biological or adopted parents experienced less economic hardship (29%) compared to children with ASD living in all other [family structures](#). See Figure 6-37.

Figure 6-37. Child's household experienced economic hardship, by family structure, among children ages 2-17 with ASD.



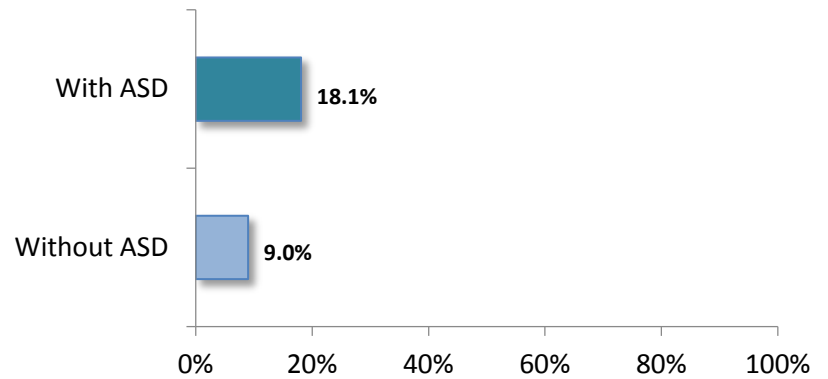
Data source: The National Survey of Children's Health, 2011/12.
Scientific notes: Chi-square test $p < 0.05$.

Child Lived with Someone who is Mentally Ill, Suicidal, or Severely Depressed

Another ACEs Index question asked parents if their child has ever lived with someone who was mentally ill, suicidal, or severely depressed for more than a couple of weeks. 18% of children with ASD lived with someone who was mentally ill, suicidal, or severely depressed. In contrast, only 9% of children without ASD lived with someone who was mentally ill, suicidal, or severely depressed for more than a couple of weeks. See Figure 6-38.

Additionally, more children with ASD in lower income groups lived with someone who was mentally ill, suicidal, or severely depressed than children with ASD in higher income groups (data not shown).

Figure 6-38. Child has lived with someone who is mentally ill, suicidal, or severely depressed for more than a couple of weeks, among children ages 2-17 with ASD.



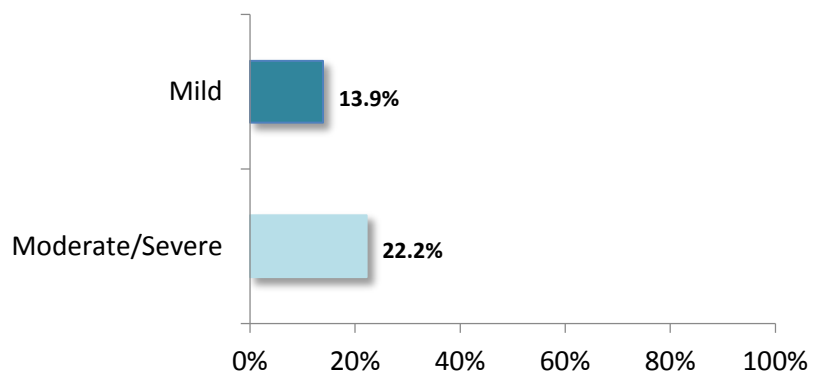
Data source: The National Survey of Children's Health, 2011/12.

Scientific notes: Chi-square test $p < 0.05$.

Child Lived with Someone who is Mentally Ill, Suicidal, or Severely Depressed, by ASD Severity

As seen in Figure 6-39, a greater proportion of children with moderate or severe cases of ASD lived with someone who was mentally ill, suicidal, or severely depressed, compared to children with mild cases of ASD (22% vs. 14%).

Figure 6-39. Child lived with someone who is mentally ill, suicidal, or severely depressed for more than a couple of weeks, by ASD severity, among children ages 2-17 with ASD.



Data source: The National Survey of Children's Health, 2011/12.

Scientific Notes: ASD severity is parent-reported.

Key Takeaways

- ✓ Fewer children with ASD met all of the criteria for a positive home environment, as compared to children without ASD (16% vs 25%).
- ✓ Children with moderate or severe cases of ASD met the criteria for a positive home environment less often than children with mild cases of ASD.
- ✓ Children with ASD faced more Adverse Childhood Experiences (ACEs) than children without ASD (34% vs. 24%). Children with moderate or severe cases of ASD experienced more ACEs than children with mild cases of ASD.
- ✓ Children with ASD had families who experienced greater economic hardship than children without ASD. Far more Hispanic children with ASD lived in households which experienced economic hardship compared to children with ASD in all other racial/ethnic groups (57% vs. ~35%).
- ✓ Children with ASD living with 2 parents (biological or adopted) experienced less economic hardship than children living with a single mom, step parents, or any other [family structure](#).
- ✓ A greater proportion of children with ASD have lived with someone who was mentally ill, suicidal, or severely depressed, compared to children without ASD (18% vs. 9%).

Family Impact

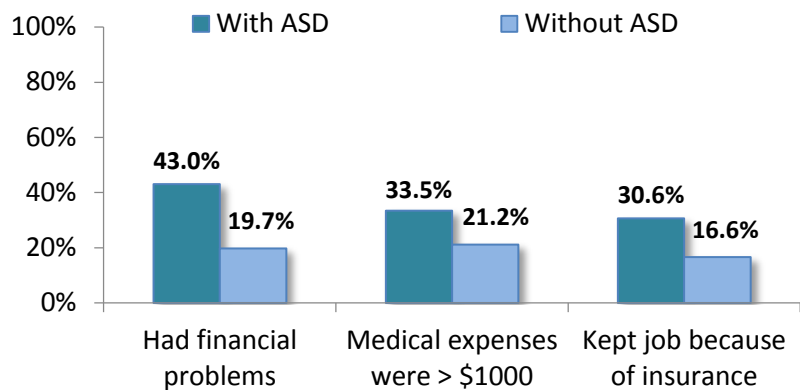
All families want to provide the best care for their children, regardless of whether they are developing typically or have mild or severe conditions. However, the toll on families who care for children with more difficult conditions, including Autism Spectrum Disorder (ASD), can be quite considerable. In the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN), a number of questions assess the extent to which caring for children with a range of conditions can impact families. It is critical to understand the impact on the financial health of families, the ability of parents to work, and the amount of time it takes to coordinate care and provide care for children with chronic conditions, including ASD. Knowing the extent to which families are impacted makes the case for stronger interventions which consider not only the child, but the child's family. (Please see the [2009/10 NS-CSHCN questionnaire](#) for the complete wording of each survey question in this section.)

Impact of ASD on Family Finances and Employment

Compared to CSHCN with conditions *other* than ASD, CSHCN with ASD had families who experienced greater financial problems and more medical expenses over \$1,000 in the past 12 months. Additionally, more children with ASD had families who kept a job so as not to disrupt insurance coverage. See Figure 6-40.

Fear of changing jobs for fear of losing insurance coverage, high medical expenses, and financial problems are strong indicators of the impact that ASD can place on families.

Figure 6-40. Family had financial problems because of child's condition, family had high medical expenditures, and parent kept employment to maintain insurance, among CSHCN ages 2-17 years.

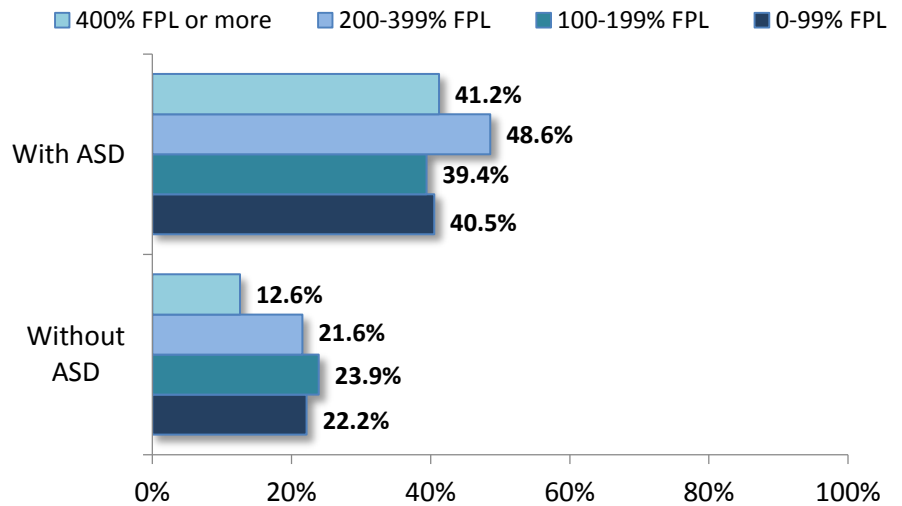


Data source: The National Survey of Children with Special Health Care Needs , 2009/10.
Scientific notes: Chi-square test $p < 0.05$.

Family Had Financial Problems because of Child's Condition, by Income

The financial problems associated with caring for a child's condition causes different impact across income levels. However, for children with ASD, *all* income levels experienced a fairly high impact of financial strain. See Figure 6-41.

Figure 6-41. Family had financial problems because of child's condition, by income, among CSHCN ages 2-17 years.



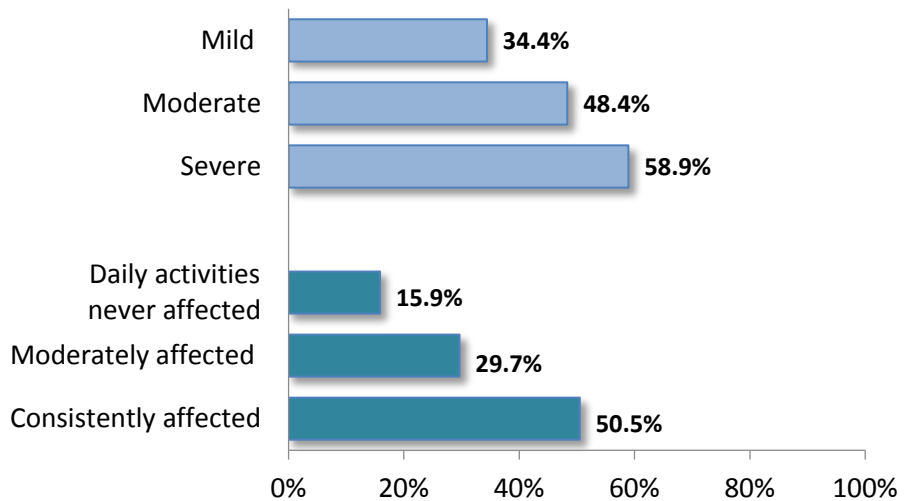
Data source: The National Survey of Children with Special Health Care Needs, 2009/10.
 Abbreviations: FPL = Federal Poverty Level.
 Scientific notes: Chi-square test $p < 0.05$ for "without ASD" subgroup.

Family Had Financial Problems because of Child's Condition, by ASD Severity and Daily Impact of Condition on Activities

Not surprisingly, the financial impact of ASD was more serious for families where the child's ASD was severe or the child was consistently affected by their condition. See Figure 6-42.

As compared to children with ASD whose daily activities were not affected by their condition, three times the number of children consistently affected by their condition lived in families that experienced financial problems. See Figure 6-42.

Figure 6-42. Family had financial problems because of child's condition, by ASD severity and daily impact of condition on activities, among CSHCN with ASD ages 2-17 years.



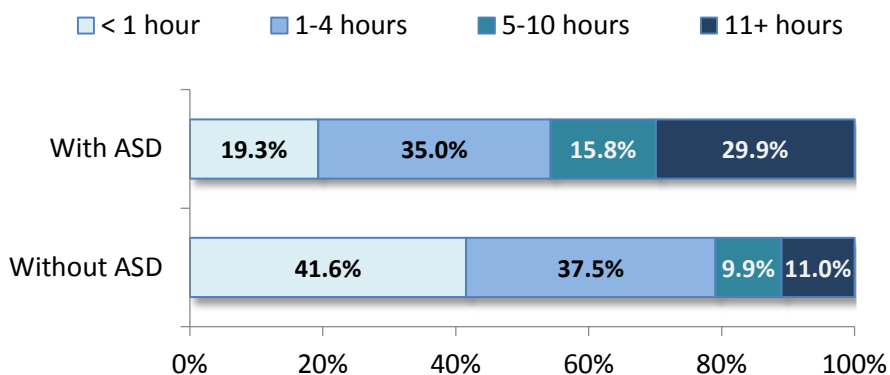
Data source: The National Survey of Children with Special Health Care Needs, 2009/10.
 Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

Time Spent Providing or Coordinating Care

Caring for children with ASD can be complex. There are many different types of therapies—behavioral, occupational—and other forms of therapeutic intervention. Coordinating or providing that care can take a lot of time.

30% of children with ASD had families who spent 11 or more hours a week coordinating or providing care, almost three times the rate of families who cared for CSHCN without ASD. See Figure 6-43.

Figure 6-43. Hours per week spent providing or coordinating care, among CSHCN ages 2-17 years.



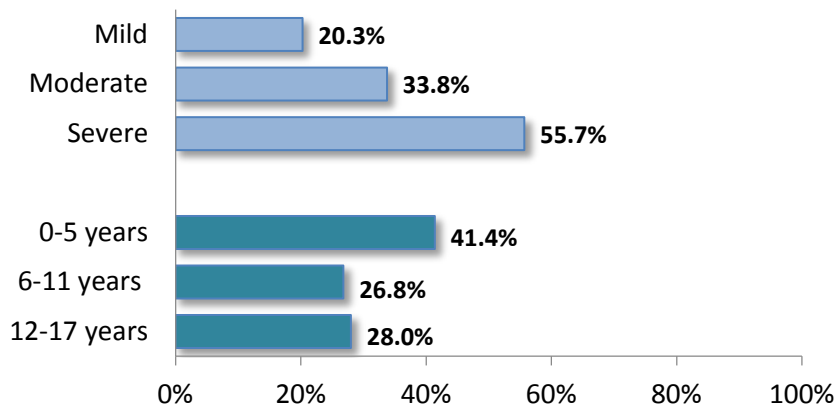
Data source: The National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: Chi-square test $p < 0.05$.

Time Spent Providing or Coordinating Care, by Age and ASD Severity

It is perhaps unsurprising that compared to children with mild ASD, more children with severe ASD had families who spent 11 or more hours a week providing or coordinating care. See Figure 6-44.

However, it is also important to note that a large proportion of very young children with ASD had families who spent a significant amount of time providing care. See Figure 6-44. 41% of children 0-5 years old had parents spent 11 hours or more per week on this task.

Figure 6-44. Family spent 11 or more hours per week providing or coordinating care, by age and ASD severity, among CSHCN with ASD ages 2-17 years.



Data source: The National Survey of Children with Special Health Care Needs, 2009/10.
Scientific notes: ASD severity is parent-reported. Chi-square test $p < 0.05$.

Key Takeaways

- ✓ The burdens of financial problems, high medical expenses, and avoiding changing jobs to keep insurance coverage were higher among families of CSHCN with ASD, compared to families whose children had other conditions.
- ✓ Financial impact was felt by roughly 40% of families of CSHCN with ASD at every income level.
- ✓ A greater proportion of children severely impacted by their ASD had families that experienced financial problems.
- ✓ Caring for children with ASD takes time. The more severe the condition or the younger the child, the greater amount of time it requires to coordinate care, especially compared to CSHCN without ASD.

Appendix: Glossary

Abbreviations

ACEs= Adverse Childhood Experiences

ADDM = Autism and Developmental Disabilities Monitoring Network

ASD = Autism Spectrum Disorder

AAP = American Academy of Pediatrics

CAHMI = Child and Adolescent Health Measurement Initiative

CAM = Complementary and Alternative Medicine

CHIP= Children's Health Insurance Program

CSHCN = Children with Special Health Care Needs

DRC = Data Resource Center for Child and Adolescent Health

EBD = Emotional and Behavioral Disorders

EIS = Early Intervention Services

FPL = Federal Poverty Level

HCP = Health Care Provider

IDEA = Individuals with Disabilities Education Act

MCHB = Maternal and Child Health Bureau

NH = Non-Hispanic

NHIS = National Health Interview Survey

NSCH = National Survey of Children's Health

NS-CSHCN = National Survey of Children with Special Health Care Needs

Pathways = The Survey of Pathways to Diagnosis and Services

SDQ = Brief Strength and Difficulties Questionnaire

SHCN= Special Health Care Needs

SSI = Supplemental Security Income

Definitions

Adequate insurance: For the purposes of this chartbook, insurance adequacy is based on parents' responses to three questions. Among children who are currently insured, children are considered adequately insured if the parents answer "usually" or "always" to the following criteria: 1) insurance coverage allows the child to see all needed providers, 2) insurance offers benefits or covers services which meets the child's needs, and 3) parents consider out-of-pocket costs for child's health care reasonable (or there were no out-of-pocket expenses).

ASD severity: References to ASD severity in this chartbook refer to parent-reported severity levels, and are not based on medical records or other source of official diagnosis. Parents of children who currently have ASD were asked to describe their child's ASD as mild, moderate, or severe.

Asperger's Disorder: See [Pervasive Development Disorder](#).

CAM modalities: In the NHIS-CAM supplement, parents were asked about 34 complementary and alternative medicine (CAM) modalities. These included biologically-based therapies such as vitamins and minerals, body-based/manipulation therapies such as massage, alternative medical systems such as Traditional Chinese Medicine, mind-body therapies such as yoga or tai chi, energy healing therapy meditation, special diets, and movement or exercise techniques. For the full list, see: http://childhealthdata.org/docs/cam-2012/fast-facts_2012-nhis-child-cam-supplement_7-29-13.pdf?sfvrsn=3.

Children with Special Health Care Needs (CSHCN): For the purposes of this chartbook, CSHCN are considered to be any children who qualify on the [CSHCN Screener](#). The screener seeks to operationalize an inclusive, non-condition-specific method of identifying CSHCN. The screener has five components, each with a base question and two follow-up questions. In order to qualify, a child's parents must answer "yes" to all parts (base and follow-up) of one component. The five components of the CSHCN Screener include: 1) child currently needs or uses medicine prescribed by a doctor (other than vitamins); 2) child needs or uses more medical care, mental health, or educational services than is usual for most children of the same age; 3) child is limited or prevented in any way in their ability to do things that most children of the same age can do; 4) child needs or gets special therapy, such as physical, occupational, or speech therapy; and 5) child has an emotional, developmental, or behavioral problem for which they need or get treatment or counseling. The follow-up questions include: 1) is this because of any medical, behavioral, or other health condition? and 2) is this a condition that has lasted or is expected to last for at least 12 months? (Please note: the fifth component only uses the second follow-up question.) At times, the term "children" is used in place of "CSHCN" if the population has already been introduced as CSHCN.

Co-morbidity: Comorbidity refers to additional chronic health conditions which may interact with ASD and/or require additional treatment and services. The NSCH asked parents if their child had 17 other chronic conditions; the NS-CSHCN asked parents if their child had 19 other chronic conditions, including various mental and emotional disorders, vision and hearing problems, developmental delay, and physical illnesses. For the full lists of these conditions, see: <http://childhealthdata.org/docs/nsch-docs/2011-12-list-of-conditions.pdf?sfvrsn=1> (NSCH) and <http://childhealthdata.org/docs/cshcn/2009-cshcn-conds-func-diff.pdf?sfvrsn=4> (NS-CSHCN).

Family structure: Family structure is characterized by number of parental figures present in the household and the relationships among adults living in the household (biological/adoptive parents, step-parents, or other family structure). A composite measure of family structure was created by the National Center for Health Statistics (NCHS) with four categories: 1) two-parent biological/adoptive, 2) two-parent step-family, 3) single mother, and 4) "other" family structure. Any of the four family structure categories may include other people who act as parents, such as grandparents, aunts, uncles, or unmarried partners of the parents. Legal guardians were not considered to be mothers or fathers. Households identified as having two mothers of the same type (biological, step, foster, or adoptive) were classified as "other family structure." However, because of this ambiguity about whether the respondent was also counted as another parent in the household, these households may actually be

“single mother” households. Other households with ambiguous structure (e.g., where a father refused to indicate whether he was the biological father) were also coded as “other family structure.”

Functional difficulties: Parents were asked about 14 functional difficulties in the NS-CSHCN, including emotional and behavioral conditions, vision and hearing difficulties, physical activity limitations, and more. Parents were asked if their child had no, a little, or a lot of difficulty for each item. For the full list, see: <http://childhealthdata.org/docs/cshcn/2009-cshcn-conds-func-diff.pdf?sfvrsn=4>. Additionally, see the “Daily Activities” section in this chartbook for more information on this topic.

Medical home: The American Academy of Pediatrics (AAP) defines a medical home as an approach to providing comprehensive and high quality primary care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective (<https://medicalhomeinfo.aap.org/overview/Pages/Whatisthemedicalhome.aspx>). Within the NSCH, NS-CSHCN, and Pathways, medical home is measured by five components (three that must be met for everyone, and two more that must be met if they are needed). The components are: 1) child has a personal doctor or nurse; 2) child has a usual source of sick care (that is not the emergency room); 3) child receives family-centered care (which includes sub-components such as: child’s doctors spend enough time with them, child’s doctors listen carefully to their parents, doctors are sensitive to family culture and values, doctors provide information specific to child’s health, and parents feel like partners in child’s care); 4) child has no problems getting referrals, if needed; and 5) child gets effective care coordination, if needed (which includes subcomponents such as: family gets help coordinating child’s health care, if needed, parents are satisfied with communication among child’s doctors, and parents are satisfied with communication of child’s doctors with their school).

Parent: Throughout this chartbook, the word “parent” is used to refer to the adult who answered questions about the child; it is typically the parent (which includes biological, adoptive, foster, and step-parents) but across surveys approximately 6% to 8% are other relatives or guardians.

Pervasive Development Disorder: Previously, the American Psychiatric Association (in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV)) used Pervasive Development Disorder (PDD) as an umbrella term under which specific diagnoses of ASD and related disorders were contained. These included Autistic Disorder, Asperger’s Disorder, Childhood Disintegrative Disorder, and PDD-NOS (Not Otherwise Specified). (See <http://www.autism-society.org/dsm-iv-diagnostic-classifications/> for more information on diagnostic criteria.) In the DSM-V, these diagnoses are all combined into one diagnosis: Autism Spectrum Disorder. Researchers found that these separate diagnoses were not consistently applied across different clinics and treatment centers. The Neurodevelopmental Work Group, which recommended the new criteria, believes a single umbrella disorder will improve the diagnosis of ASD without limiting the sensitivity of the criteria, or substantially changing the number of children being diagnosed. More information can be found here: <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf>.

Poverty Levels: The Federal Poverty Guidelines are put out every year by the U.S. Department of Health and Human Services (HHS). The guidelines provide a simplification of the poverty thresholds created for administrative use, such as determining financial eligibility for certain federal programs. The guidelines are adjusted for families of different sizes and by geographic location (with different guidelines for the 48 contiguous states and the District of Columbia; Alaska; and Hawaii). Information on past and current guidelines can be found here: <http://aspe.hhs.gov/prior-hhs-poverty-guidelines-and-federal-register-references>. For purposes of this chartbook, income levels reported by the respondents were translated into % FPL for their reported family size and geographic location, and then combined into four levels: 0-99% FPL, 100-199% FPL, 200-399% FPL, and 400% or more FPL.

Provider: This term includes any health care professional who could provide care for a child, such as doctors, nurses, physician’s assistants, and nurse practitioners. In the Pathways survey, parents were asked about the types

of providers with which their child works, including: audiologists, developmental pediatricians, neurologists, nutritionists, at home/long-term nurses, psychiatrists, psychologist/psychotherapists, and social workers.

Public and private insurance: Public insurance refers to government plans such as Medicaid and the Children’s Health Insurance Program (CHIP). Private insurance refers to any other type of insurance, such as that provided by an employer or one purchased independently.

Race/ethnicity: The NSCH, NS-CSHCN, NHIS, and Pathways surveys ask a series of questions about the child’s race and Hispanic or Latino ethnicity. Respondents are allowed to answer affirmatively to one or more categories of race. For the purposes of this chartbook, children were assigned to one of four mutually exclusive categories according to the following criteria:

- Hispanic: Children identified as having Hispanic or Latino ethnicity, regardless of reported race.
- White: Non-Hispanic children with “white” as the only reported race category.
- Black: Non-Hispanic children with “black” as the only reported race category.
- Other: Non-Hispanic children identified by a single one of the following categories: Asian, American Indian, Alaska Native, or Native Hawaiian/Pacific Islander, or Non-Hispanic children with two or more race categories reported.

School-aged children: For the purposes of this chartbook, school-aged children are those ages 6-17 years.

School professional: For the purposes of this chartbook, a school professional means a teacher, counselor, or a nurse at the child’s school.

Strength and Difficulties Questionnaire (SDQ): The brief SDQ is a shorter version of a 25-item tool intended to screen for the presence of mental health problems. The brief SDQ’s five measures include: 1) child is generally well behaved; 2) child has many worries or often seems worried; 3) child is often unhappy, depressed, or tearful; 4) child gets along better with adults than other children/youth; and 5) child has good attention span. Out of a total score of 10, a score of 6+ indicates a high level of problems, and a score of <6 indicates a lower level of problems. For more information on the SDQ, see: <http://www.sdqinfo.com/py/sdqinfo/c0.py> or <http://www.cdc.gov/nchs/data/nhsr/nhsr048.pdf>.

With/without ASD: In the NSCH, NS-CSHCN, and Pathways surveys, parents were asked if: 1) their child currently had ASD, 2) had previously been diagnosed with ASD but no longer had the condition, or 3) never had ASD. When this chartbook uses the terms “with ASD”, this refers to children who *currently* have ASD. When this chartbook uses the term “without ASD”, this refers to children who do not *currently* have ASD (even if they previously had ASD and do not any longer).

Appendix: Survey Design and Analytic Notes

The notes below provide additional information about the national surveys represented in this chartbook.

Background on the Surveys

- The [National Survey of Children's Health](#) (NSCH) was last conducted in 2011/2012. It was conducted by telephone in English and Spanish. 95,677 surveys were completed in 2011/12, approximately 1,800 per state. It is currently undergoing major revisions and new data will be available in 2017.
- The [National Survey of Children with Special Health Care Needs](#) (NS-CSHCN) was last conducted in 2009-2010. It was conducted by telephone in English, Spanish, Mandarin, Cantonese, Vietnamese and Korean. 40,242 surveys for children with special health care needs were completed in 2009-10, approximately 750 per state. It is currently being revised and will be conducted as part of the National Survey of Children's Health.
- The [Survey of Pathways to Diagnosis and Services \(Pathways\)](#) was conducted in 2011. This survey was a follow-back survey of the 2009-10 NS-CSHCN and was conducted only in English. The parent or guardian of children 6-17 years old with special health care needs (CSHCN) who reported in the NS-CSHCN survey that they had ever been told that their child had Autism Spectrum Disorder (ASD), intellectual disability (ID) and/or developmental delays (DD) were re-contacted for a more in-depth conversation about these conditions. 4,032 surveys were completed. Most of the Pathways survey was completed via telephone interview, and a follow-up portion of the survey was completed via a mailed questionnaire.
- The [National Health Interview Survey \(NHIS\)](#) is an annual health survey of the civilian, non-institutionalized household population including adults and children. The NHIS' annual Sample Child Core obtains information for a randomly selected child from each family. The Child Complementary and Alternative Medicine (CAM) Supplement is one of the NHIS Supplements, and was last conducted in 2012. The 2012 Child CAM Supplement collected information about 10,218 sample children aged 4-17 years.
- All four surveys have a national Technical Expert Panel which oversees their content development and revisions.
- All four surveys provide national level estimates for all data. The NSCH and NS-CSHCN also provide state level estimates for most data. The NHIS and Pathways survey provides national level estimates; researchers interested in state level data may request permission from the [Research Data Center](#).

Data Collection Methods

- The sampling and data collection for the 2011/12 National Survey of Children's Health were conducted using the SLAITS program. SLAITS is an acronym for the "State and Local Area

Integrated Telephone Survey,” an approach developed by the [National Center for Health Statistics](#) to quickly and consistently collect information on a variety of health topics at the state and local levels. Telephone numbers, both landline and cell phones, were called at random to identify households with one or more children under 18 years old. Cell-phone numbers were only used if the respondent either did not own a landline or the respondent stated that they were unlikely to answer the landline.

- For the NSCH, one child was randomly selected to be the subject of the interview. For the NS-CSHCN survey, households were first screened to identify those with special health care needs. Children were identified as having special health care needs by using the validated [Children with Special Health Care Needs Screener](#). The parent or guardian of CSHCN 6-17 years old from the 2009-2010 NS-CSHCN who had Autism Spectrum Disorder, intellectual disability and/or developmental delays were re-contacted for the Pathways survey.
- The NHIS is a cross-sectional household interview survey. Sampling and interviewing are continuous throughout each year. The sampling plan follows a multistage area probability design that permits the representative sampling of households and non-institutional group quarters (e.g., college dormitories). The NHIS uses computer-assisted personal interviewing and collects information about health and health care of every family member. One sample child age 17 years or younger is randomly selected from each family for additional questions for the Sample Child Core. The 2012 Child CAM Supplement interviewed sample children aged 4-17 years for information about non-conventional health services, products, and practices commonly used in US.
- Survey results are weighted to represent the population of non-institutionalized children (NSCH and NHIS) and CSHCN (NS-CSHCN) ages 0-17 nationally and in each state. Pathways survey results are weighted to represent the non-institutionalized CSHCN population, ages 6-17 years old, with ASD, DD, and ID nationally.

The Survey Sponsors

- The Maternal and Child Health Bureau, U.S. Department of Health and Human Services provided the primary funding for the NSCH and NS-CSHCN surveys; additional funding for the Pathways survey was provided by the National Institute of Mental Health with funds supplied by the American Recovery and Reinvestment Act of 2009 (ARRA) (Public Law 111-5).
- The NHIS is sponsored by the Centers for Disease Control and Prevention’s National Center for Health Statistics (NCHS). The National Center for Complementary and Integrative Health (NCCIH) of the National Institutes of Health provided the primary funding for the NHIS Child CAM Supplement.
- The National Center for Health Statistics of the Centers for Disease Control and Prevention oversaw the sampling and telephone interviews for the surveys.

Datasets for Public Use

- The [Data Resource Center for Child and Adolescent Health](#) (DRC) offers free cleaned and coded datasets for all four surveys in SAS and/or SPSS formats. For more information or to request a dataset, contact info@cahmi.org.

Additional Resources

The [Data Resource Center for Child and Adolescent Health](#) provides hands-on access to the data and resources for all four surveys. The DRC allows users to learn more about the content and methodology of the surveys (see below). Additionally the DRC provides quick access to data findings from all four surveys, allowing users to compare national and state-level findings for children of different ages, race/ethnicity, income levels, health status, etc. For a step-by-step walk-tutorial of how to access data in this chartbook on the DRC, see the “Accessing ASD Data on the DRC” section of this appendix.

- Learn more about the [National Survey of Children’s Health](#)
 - [Fast Facts about the survey](#)
 - [Guide to topics and questions asked](#)
 - [Sampling procedures](#)
- Learn more about the [National Survey of Children with Special Health Care Needs](#)
 - [Fast Facts about the survey](#)
 - [Guide to topics and questions asked](#)
 - [Sampling procedures](#)
- Learn more about [the Survey of Pathways to Diagnosis and Services](#)
 - [Fast Facts about the survey](#)
 - [Guide to topics and questions asked](#)
 - [Sampling procedures](#)
- Learn more about the [National Health Interview Survey Child Core](#)
 - [Fast Facts about the survey](#)
 - [Guide to topics and questions asked](#)
 - [Sampling procedures](#)
- Learn more about the [National Health Interview Survey Child CAM Supplement](#)
 - [Fast Facts about the survey](#)
 - [Guide to topics and questions asked](#)
 - [Sampling procedures](#)

Appendix: Survey Crosswalk

Overall survey information	Overall survey topics	Sample size of children with ASD	Prevalence of children with ASD	How is child's ASD condition identified in survey?	Questions asked specifically about ASD
2011 Survey of Pathways to Diagnosis and Services (Pathways)					
<p>Sample size: 4,032</p> <p>Geographic area: National & regional-level data</p> <p>Population: Non-institutionalized children with special health care needs (CSHCN) ages 6-17 years who were ever diagnosed with ASD, intellectual disability, or developmental delay in the 2009/10 NS-CSHCN. (See more about the 2009/10 NS-CSHCN below.)</p> <p>More information: http://childhealthdata.org/learn/Pathways</p>	<ul style="list-style-type: none"> ▪ Emergence of symptoms and context of the diagnoses ▪ Providers who made the diagnoses ▪ Child's current diagnostic status ▪ Types of clinical treatments, Interventions, and educational services used to address developmental delays ▪ Parental concerns and perspectives 	<p>Sample size: 1,420</p>	<p>Cannot calculate from this survey</p>	<p>1) 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?</p> <p>If yes to #1:</p> <p>2) To the best of your knowledge, does your child currently have the condition?</p>	<ul style="list-style-type: none"> ▪ Current or ever diagnosed with ASD* ▪ Whether parents were ever told child did not have ASD ▪ Age parent was told child had ASD ▪ Type of doctor who diagnosed <p>To note: All questions in the Pathways Survey can be observed by the ASD subpopulation.</p>

Overall survey information	Overall survey topics	Sample size of children with ASD	Prevalence of children with ASD	How is child's ASD condition identified in survey?	Questions asked specifically about ASD
2011/12 National Survey of Children's Health (NSCH)					
<p>Sample size: 95,677</p> <p>Geographic area: National, regional, & state-level data</p> <p>Population: Non-institutionalized children in the US ages 0-17 years</p> <p>More information: http://childhealthdata.org/learn/NSCH</p>	<ul style="list-style-type: none"> ▪ Physical and emotional health ▪ Factors that may relate to wellbeing of children, including: <ul style="list-style-type: none"> - Medical home - Family interactions - Parental health - School experiences - Safe neighborhoods 	<p>Sample size: 1,624</p>	<p>National prevalence of children with current ASD: 1.8%</p>	<p>1) Has a doctor or health professional ever told you that your child has Autism, Asperger's Disorder, Pervasive Developmental Disorder, or other Autism Spectrum Disorder?</p> <p>If yes to #1:</p> <p>2) Does your child currently have the condition?</p>	<ul style="list-style-type: none"> ▪ Current or ever diagnosed with ASD* ▪ Parent-rated severity of ASD ▪ Age of diagnosis <p>To note: Many questions (with sufficient sample size) can be observed by ASD subpopulation.</p>
2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN)					
<p>Sample size: 40,242</p> <p>Geographic area: National, regional, & state-level data</p> <p>Population: Non-institutionalized children with special health care needs (CSHCN) in</p>	<p>Overall health and health status of CSHCN, including:</p> <ul style="list-style-type: none"> ▪ Medical home ▪ Adequate health insurance ▪ Access to needed 	<p>Sample size: 3,055</p>	<p>National prevalence of children with current ASD among children with</p>	<p>1) Has a doctor or other health care provider ever told you that your child had Autism, Asperger's Disorder, Pervasive Developmental Disorder,</p>	<ul style="list-style-type: none"> ▪ Current or ever diagnosed with ASD ▪ Parent-rated severity of ASD <p>To note: Many</p>

Overall survey information	Overall survey topics	Sample size of children with ASD	Prevalence of children with ASD	How is child's ASD condition identified in survey?	Questions asked specifically about ASD
<p>the US ages 0-17 years</p> <p>More information: http://childhealthdata.org/learn/NS-CSHCN</p>	<ul style="list-style-type: none"> ▪ services ▪ Adequate care coordination ▪ Functional difficulties ▪ Transition services 		<p>special health care needs (CSHCN): 7.99%</p>	<p>or other Autism Spectrum Disorder, even if [he/she] does not have the condition now?</p>	<p>questions (with sufficient sample size) can be observed by ASD subpopulation.</p>
<p>2012 National Health Interview Survey (NHIS) with Child Complementary and Alternative Medicine (CAM) Supplement</p>					
<p>Sample size: 13,275 sample children (10,218 sample children, 4-17 years, for CAM Supplement)</p> <p>Geographic area: National, regional, & state-level data (state-level data only available from NCHS Research Data Center)</p> <p>Population: One randomly selected child age 0-17 years from each family is chosen from the Sample Child Core (and of those, 4-17 year-olds were included in the CAM Supplement). The NHIS covers the non-institutionalized US household population.</p> <p>More information: http://childhealthdata.org/learn/NHIS-Child http://childhealthdata.org/learn/NHIS-CAM</p>	<ul style="list-style-type: none"> ▪ The <i>Sample Child Core</i> obtains additional information on health status, health care services, and behavior for a randomly selected child, ages 0 to 17 years old, from each family. ▪ The <i>CAM Supplement</i> has questions on use of 34 specific CAM modalities, insurance coverage and out-of-pocket costs for visits to CAM practitioners, providers, classes, or trainings, and reasons for and benefits of CAM use. 	<p>Sample size: 156 (144 ages 4-17 years in NHIS linked file with CAM Supplement)</p>	<p>National prevalence of children who were <i>ever</i> told they had ASD (current and past): 1.2% (1.4% in CAM). Please interpret these figures with caution, given the small sample size.</p>	<p>Has a doctor or health professional ever told you that your child had Autism or Autism Spectrum Disorder?</p>	<ul style="list-style-type: none"> ▪ Ever diagnosed with ASD <p>To note: Many questions (with sufficient sample size) can be looked at by ASD subpopulation.</p>

*Both the NSCH & Pathways include follow-up questions for children who were ever diagnosed but do not currently have the condition (and/or were later told they didn't have the condition). Data from these questions are not included in the data query due to very small sample size.

Appendix: Accessing ASD Data on the DRC

The [Data Resource Center for Child and Adolescent Health \(DRC\)](#) has a wealth of data and resources available about children and families with ASD. Users interested in exploring the data in this chartbook (and much more) can access the data three ways:

The DRC's Interactive Data Query

- 1) Go directly to the DRC data query at:
<http://childhealthdata.org/browse/survey>.
- 2) You'll be presented with the option to select a particular **survey**, **year**, and if interested, **state or region** (not all surveys have data available at the state level).

All five surveys hosted on the DRC contain data on children with ASD. To see the content of each of these surveys, [see the survey content maps on the DRC's overview page](#). For example, if you're interested in health services received by children with ASD, selecting the Pathways survey is a good choice, since we see this topic mentioned in the Pathways content map, and know that the Pathways survey has a wealth of information on children with ASD.

Once you select "Pathways" in Step 2, you can then choose to view topics by all children or *just by those with ASD*. To only look at children with ASD, click to expand "Child Health Measures among CSHCN with ASD".

The screenshot shows the 'Browse by Survey & Topic' section of the DRC website. It includes a breadcrumb trail: 'Explore the Data > Data by Survey and Topic'. There are social media icons for Twitter, Facebook, and Email. Below the title, there is a brief instruction: 'To begin your interactive data search: 1) Select a Survey, Survey Year, and State or Region. 2) Select your desired Topic/Starting Point. 3) Select your indicator or measure.' A note states: 'This will direct you to a results page where you can compare across states, regions and by numerous subgroups.'

1. Select a Survey, Year, and Geographic Area

Select a Survey: A dropdown menu with 'Select a Survey' and a downward arrow.

Select a Year: A dropdown menu with a downward arrow.

Select a State/Region: A dropdown menu with 'Nationwide' and a downward arrow.

2. Select a Starting Point/Topic

- Child Health Measures among CSHCN with ASD, DD and/or ID (Content Map)
CSHCN with autism, developmental delay and/or intellectual disability
- Child Health Measures among CSHCN with ASD (Content Map)
CSHCN with autism spectrum disorder
 - Developmental Concerns
 - Diagnostic Experiences
 - Health and Education Services
 - Unmet Needs and Insurance Adequacy
 - Functioning, Strengths, and Difficulties
 - Parental Views and Safety Concerns

3. Select a Survey Question (click the ⓘ for more information on the question)

- Number of health and related services used ⓘ
- Type of health and related services - list of 7 services
- Number of providers children currently work with ⓘ
- Type of providers child currently works with -- list of 8 providers
- Number of medications children currently use ⓘ
- Type of medications child currently uses -- list of 6 medications
- Type of school child currently enrolled in ⓘ
- Received an Individualized Education Program ⓘ
- Adequacy of Individualized Education Program ⓘ
- Received services from an Early Intervention Services ⓘ
- Ever told that child was not eligible for Early Intervention Services ⓘ

- 3) Next, click “Health and Education Services” to display all questions in that topic area. You’ll see a question titled “Number of health and related services used”.
- 4) Once you click on “Number of health and related services used,” you’ll see the data results, including a chart and graph. The data results include the percent of children in each category, the sample size, and the population estimate. You can also subgroup by groups such as race/ethnicity, age, gender, region, etc. from the drop-down menu in the upper-right-hand corner.

Current Search Criteria

Survey: 2011 Survey of Pathways to Diagnosis and Services
Starting Point: Child Health Measures among CSHCN with ASD
Region: Nationwide
Topic: Health and Education Services
Question: Number of health and related services used ([details](#))

Edit Search Criteria

Compare Regions:

 Compare Subgroups:

[Change question, topic or survey](#)

How many CSHCN currently use two or more health care services on regular basis to meet their developmental needs, out of 7 types of health services? ([details](#))

	0-1 health care service used	2 health care services used	3+ health care services used	Total %
%	33.3	18.7	48.0	100.0
C.I.	(29.1 - 37.5)	(15.0 - 22.3)	(43.5 - 52.6)	
n	477	264	679	
Pop. Est.	217,374	121,881	313,786	

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics. n = Cell size. Use caution in interpreting Cell sizes less than 50.

- 5) In a second example, you may be interested in comparing outcomes among children with ASD to children without ASD. Since we know the National Survey of Children’s Health (NSCH) asks questions among all children (including a sizeable number of children with ASD), we’ll look at data from this survey.

Current Search Criteria

Survey: 2011/12 National Survey of Children’s Health
Starting Point: Survey Sections
State/Region: Nationwide
Topic: Middle Childhood and Adolescence, 6-17 years (Survey Section 7)
Question: Indicator 2.4: Flourishing for children and adolescents age 6-17 years ([details](#))
Sub Group: Current autism (2-17 years)

Edit Search Criteria

Compare Subgroups:

[Change question, topic or survey](#)

Indicator 2.4: Measure of flourishing for children and adolescents age 6-17 years ([details](#))

		Child met 0-1 flourishing items	Child met 2 flourishing items	Child met all 3 flourishing items	Total %
Do not currently have condition	%	24.6	26.9	48.4	100.0
	C.I.	(23.9 - 25.4)	(26.1 - 27.7)	(47.6 - 49.3)	
	n	14,623	16,841	32,672	
	Pop. Est.	11,936,545	13,045,834	23,477,272	
Currently have condition	%	67.9	20.0	12.0	100.0
	C.I.	(62.6 - 73.2)	(15.6 - 24.5)	(8.5 - 15.6)	
	n	898	325	170	
	Pop. Est.	670,834	197,861	118,974	

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics. n = Cell size. Use caution in interpreting Cell sizes less than 50.

To get to the NSCH data, click on the link under the drop down menu that says “Change question, topic or survey.” Then, scroll up to the top to select the NSCH.

- 6) You can look at the different topics in the NSCH in a variety of ways. If you wanted to look at the percent of school-aged children who are considered to be “flourishing”, choose “Emotional and Mental Health” under “Child Health Measures”. From here, click on “Flourishing for children and adolescents age 6-17 years.”

- 7) One of the subgroups for the NSCH is “Current autism (2-17 years).” You can select this subgroup from the drop-down menu in the upper-right-hand corner. You will then see flourishing findings among both children with and without ASD.

The DRC’s ASD Portal

Users can fast-track to much of the data in this chartbook on the Data Resource Center’s [ASD portal](#). The portal provides [easy access to data on the health and wellbeing of children and families with ASD](#), highlighting many of the topics covered in this chartbook. The portal also invites users to explore the variety of ways ASD data is being put into action, learn more about the surveys, and access a variety of other resources for families, advocates, and researchers.

Request Cleaned and Coded Datasets from the DRC

All topics covered in this chartbook can be viewed in the [DRC’s interactive data query](#). However, the chartbook sometimes displays data findings in two subgroups simultaneously, which is not possible on the DRC’s data query. To conduct this level of analysis with the data, you can [request free access](#) to cleaned and coded datasets and accompanying codebooks to assist with your analyses.