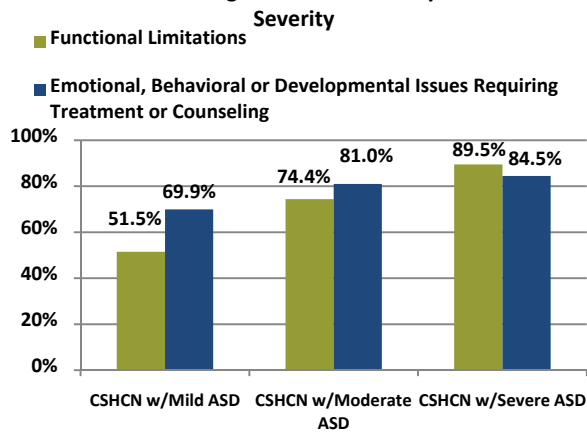


## National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2011/12 NSCH

### Who Are Children with Autism Spectrum Disorders?

According to the Centers for Disease Control and Prevention (CDC), “Autism Spectrum Disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. ... ASDs are ‘spectrum disorders.’ That means ASDs affect each person in different ways, and can range from mild to severe. Consequently, nearly all children with ASD qualify as children with special health care needs (CSHCN), because they experience at least one type of ongoing condition that results in an above routine need for health and related services.<sup>2</sup> The CSHCN Screener, which operationalizes this definition, was used in both the 2011/12 National Survey of Children’s Health (NSCH) and 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) to identify CSHCN. Based on findings from the 2011/12 NSCH and 2009/10 NS-CSHCN, 7.9% to 8.0% of U. S. CSHCN age 2-17 years had current ASD\*. Among CSHCN age 2-17 years, prevalence of ASD ranges across states from 4.5% in Mississippi to 14.3% in New Jersey according to data from the 2009/10 NS-CSHCN.

**Figure 1. Prevalence of Functional Limitations and Emotional, Behavioral or Developmental Issues among CSHCN with ASD by ASD Severity**

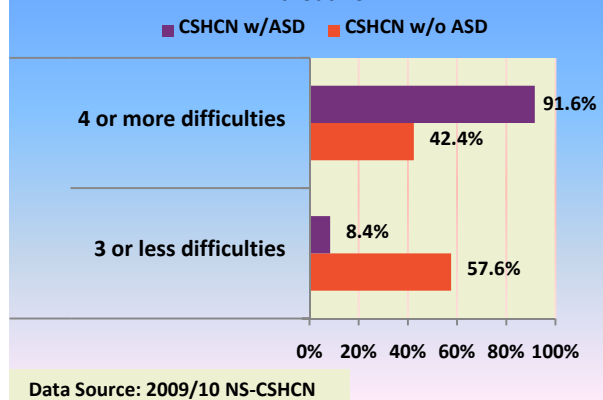


Data Source: 2009/10 NS-CSHCN

Four in five (80.6%) CSHCN with ASD are boys, and 71.6% of CSHCN with ASD were diagnosed between 0 – 5 years of age. Among CSHCN with ASD, parents described approximately half (49.5%) as having mild ASD, 36.2% as having moderate ASD and 14.3% as having severe ASD. Positivity bias in parent reports of child functioning may lessen the severity of conditions described.<sup>3</sup> A larger proportion of CSHCN with moderate or severe ASD experience functional limitations in their ability to do things that other children their age can do and/or emotional, behavioral or developmental (EBD) issues requiring treatment or counseling compared to CSHCN with mild ASD (Figure 1). While 65% of CSHCN with ASD experience functional limitations along with any other type of special health care need, 91.6% of CSHCN with ASD experience four or more functional difficulties from the list of 14 specific difficulties related to bodily functions, activities or participation, and emotional or behavioral factors asked about in the 2009/10 NS-CSHCN (Figure 2). Only a subset of functional difficulties lead to functional limitations. Most CSHCN with ASD (93.2%) additionally have at least one other condition from the list of 20 conditions asked about in the 2009/10 NS-CSHCN.

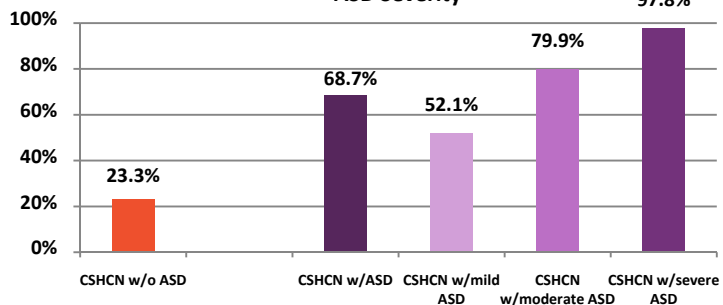
**Figure 2. Prevalence of Functional Difficulties among CSHCN with ASD Compared to CSHCN without ASD**

Functional Difficulties



Data Source: 2009/10 NS-CSHCN

**Figure 3. Daily Activities Consistently Affected among CSHCN without ASD Compared to CSHCN with ASD and by ASD Severity**



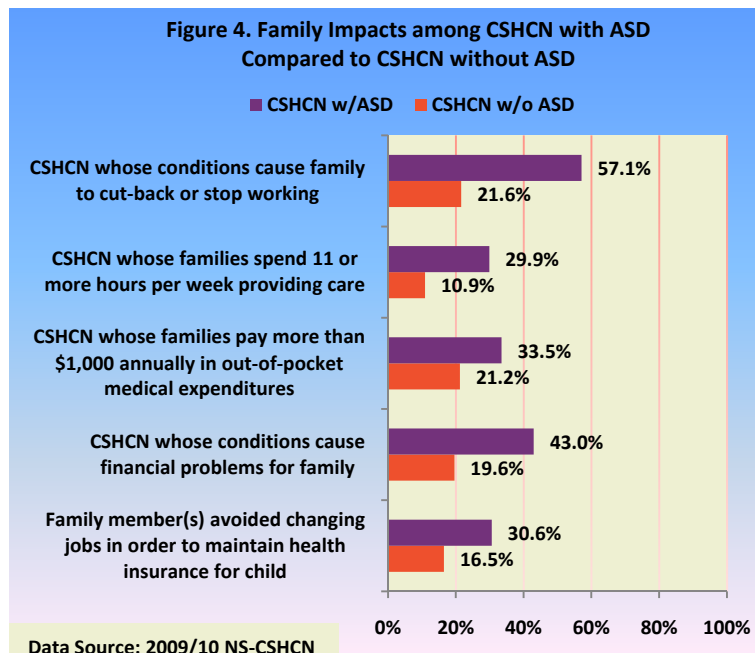
Data Source: 2009/10 NS-CSHCN

CSHCN with ASD experience complex health care needs that may influence their overall health status and daily activities. Based on 2011/12 NSCH data, a lower proportion of CSHCN with ASD (61.1%) were reported by their parents to have excellent or very good overall health status compared to CSHCN without ASD (69.5%) and non-CSHCN without ASD (87.9%). In the 2009/10 NS-CSHCN, two-thirds (68.7%) of CSHCN with ASD had health conditions that consistently affected their daily activities, often a great deal, compared to only 23.3% of CSHCN without ASD (Figure 3). Among CSHCN with severe ASD, 97.8% had conditions that consistently affected their daily activities, relative to 79.9% of CSHCN with moderate ASD and 52.1% of CSHCN with mild ASD.

\*Variations in sampling and administration between the 2009/10 NS-CSHCN and 2011/12 NSCH lead to expected variations in prevalence.

### Impact on Families

Families of CSHCN with ASD are also impacted by their children's health care needs (Figure 4). Across all measures used to assess the impact of health system performance on families in the 2009/10 NS-CSHCN, a higher proportion CSHCN with ASD had families who were impacted by their children's special health care needs compared to families of CSHCN without ASD. Moreover, based on 2011/12 NSCH findings, over half (54.7%) of CSHCN with ASD had parents who reported feeling aggravated with their child once or more during the past month compared to CSHCN without ASD (20.2%) and non-CSHCN (8.8%) age 2-17 years. Parental stress varied by disease severity: 40.6% of CSHCN with mild ASD had parents who reported feeling aggravated with their child in the past month versus 66.4% of CSHCN with moderate or severe ASD.



### System of Care Performance

The federal Maternal and Child Health Bureau (MCHB) assesses health system performance for CSHCN with six core outcomes (for more information on the core outcomes, please see the [System of Care for CSHCN](#) data brief on the DRC Web site). Table 1 displays how CSHCN with ASD compare to CSHCN without ASD on each of the six core outcomes based on 2009/10 NS-CSHCN data. Among CSHCN with ASD, only 7.4% met all age-relevant core outcomes compared to 18.7% of CSHCN without ASD.

Table 1. Health System Performance by Core Outcome\*

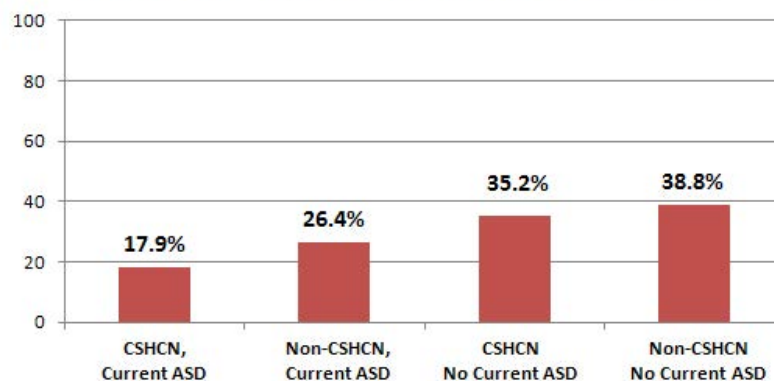
MCHB System of Care Core Outcomes	CSHCN w/ASD	CSHCN w/o ASD
Outcome #1: Families of CSHCN are partners in decision-making	56.7%	71.2%
Outcome #2: CSHCN receive care within a medical home	23.9%	44.7%
Outcome #3: CSHCN have adequate health insurance for needed services	49.4%	61.3%
Outcome #4: CSHCN are screened early and continuously for special health care needs	78.5%	80.2%
Outcome #5: Community-based service systems are easy for families of CSHCN to use	42.8%	67.1%
Outcome #6: Youth with special health care needs receive transition to adulthood services	21.1%	41.4%

\*Data Source: 2009/10 NS-CSHCN

### Minimum Quality of Care

A minimum quality of care summary measure was derived from the following three measures of health system performance in the 2011/12 NSCH: (1) adequate health insurance coverage; (2) receipt of coordinated, ongoing, comprehensive care within a medical home; and (3) had at least one preventive medical visit in the past 12 months. About one in three (34%) CSHCN with ASD met the quality of care summary measure criteria, a lower proportion compared to non-CSHCN without ASD age 2-17 years (Figure 5). Among CSHCN with no current ASD, an even smaller proportion (26%) met the minimum quality of care summary measure criteria according to 2011/12 NSCH data.

Figure 5. Percent of Children Age 2-17 Meeting All Minimum Quality Summary Measure Criteria by CSHCN and ASD Status

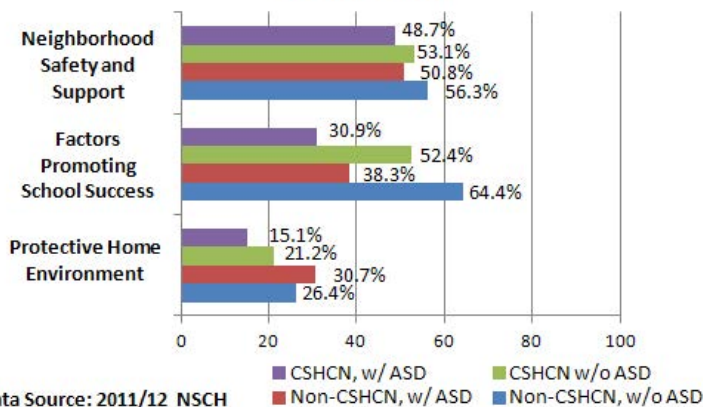


Data Source: 2011/12 NSCH

## Home, School and Neighborhood Environments

The health and well-being of each child is influenced by his or her interconnected home, school and neighborhood environments. Contextual factors from these environments and other child level factors may interact during certain periods of a child's lifespan ultimately promoting resiliency and healthy development or increasing risk for adverse health outcomes. Together, several summary measures from the 2011/12 NSCH provide a more comprehensive picture of how CSHCN, including those with ASD, compare to non-CSHCN in terms of their home, school and neighborhood environments.

**Figure 6. Proportion of CSHCN with ASD Meeting Protective Home, Factors Promoting School Success, and Neighborhood Summary Measure Criteria Compared to CSHCN without ASD and Non-CSHCN**



### Takeaways

- CSHCN with ASD generally experience a greater burden of illness in terms of the types of special health care needs they have as well as the number of functional difficulties and comorbid conditions they experience compared to CSHCN without ASD.
- The impact on families of CSHCN with ASD is greater than that experienced by families of CSHCN without ASD.
- CSHCN with ASD are less likely to meet each system of care core outcome and all age-relevant core outcomes compared to CSHCN without ASD.
- CSHCN with ASD are also less likely to experience a protective home environment, factors promoting school success and neighborhood safety and support compared to CSHCN without ASD and non-CSHCN.
- **System-wide improvements are needed to enhance the health and well-being of CSHCN with ASD.**



CSHCN with ASD were less likely to meet age-relevant criteria for a protective home environment<sup>a</sup> compared to CSHCN without ASD and non-CSHCN (Figure 6). CSHCN with ASD age 6-17 years were also less likely to experience factors promoting school success<sup>b</sup> than school-age CSHCN without ASD and non-CSHCN. On the neighborhood safety and support summary measure<sup>c</sup>, CSHCN with ASD were less likely than CSHCN without ASD and non-CSHCN to meet all age-relevant criteria.

### Protective Home, Factors Promoting School Success and Neighborhood Safety and Support Summary Measures Criteria

<sup>a</sup>**Protective home environment** was measured using the following age-relevant criteria: (1) no exposure to household smoking; (2) family shares meals on four or more days per week; (3) children watch less than two hours of television per day (age 1-17); (4a) children are read/sung to every day (age 0-5); (4b) children have no television in bedroom (age 6-17); (5a) children were breastfed ever (age 0-5); (5b) children usually/always do required homework (age 6-17); and (6b) parents of children have met most/all of child's friends (age 6-17).

<sup>b</sup>**Factors promoting school success** were measured only among children age 6-17 years using the following criteria: (1) children were usually/always engaged in school; (2) children participated in extracurricular activities; and (3) usually/always felt safe at school.

<sup>c</sup>**Neighborhood safety and support** were measured using the following age-relevant criteria: (1) neighborhood is usually/always safe; (2) neighborhood is supportive; (3) neighborhood includes three or more amenities essential to childhood; and (4) school-age children attend safe schools (age 6-17).

### References

- <sup>1</sup>CDC, 2010. Autism Spectrum Disorders (ASDs). "Signs and Symptoms" Web page. Available at <http://www.cdc.gov/ncbddd/autism/signs.html>. Accessed March 21, 2012.
- <sup>2</sup>McPherson, M, Arango, P, Fox, H, et al. "A new definition of children with special health care needs." *Pediatrics*, 1998;102:137-140.
- <sup>3</sup>Simon, AE, Chan, KS, & Forrest, CB. "Assessment of children's health-related quality of life in the United States with a multidimensional index." *Pediatrics*, 2008;121:118-26.

Suggested Citation: Child and Adolescent Health Measurement Initiative (2013). "National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2011/12 NSCH." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at [www.childhealthdata.org](http://www.childhealthdata.org). Revised 7/30/13.