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## Family Impacts among Children with Autism Spectrum Disorder: The Role of Health Care Quality

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### Abstract

**Objectives**—To compare health care quality and family employment and financial impacts among children with special health care needs (CSHCN) with autism spectrum disorder (CSHCN+ASD), CSHCN with functional limitations (CSHCN+FL), and CSHCN lacking these conditions (other CSHCN). To test whether high health care quality was associated with reduced family impacts among CSHCN+ASD.

**Methods**—Data from the 2009-2010 National Survey of CSHCN were used to compare 3025 CSHCN+ASD, 6505 CSHCN+FL, and 28 296 other CSHCN. Weighted multivariate logistic regression analyses examined six age-relevant, federally-defined health care quality indicators and five family financial and employment impact indicators. Two composite measures were additionally used: (1) receipt of care that met all age-relevant quality indicators; and (2) had two of the five adverse family impacts.

**Results**—Across all health care quality indicators CSHCN+ASD fared poorly, with only 7.4% meeting all age-relevant indicators. CSHCN+ASD had worse health care quality than other CSHCN, including CSHCN+FL. CSHCN+ASD also had high rates of adverse family impact, with over half experiencing two or more adverse impacts. Rates of adverse family impact were higher in CSHCN+ASD than other CSHCN, including CSHCN+FL. Among CSHCN+ASD, those whose

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health care that met federal quality standards were less likely to have multiple adverse family impacts than CSHCN+ASD whose health care did not meet federal quality standards.

**Conclusions**—CSHCN+ASD are more prone to experience poor health care quality and family impacts than other CSHCN, even CSHCN+FL. Receipt of care meeting federal quality standards may potentially lessen adverse family impacts for CSHCN+ASD.

### Keywords

autism spectrum disorder; disabled children; family health; family burden; financial burden; quality of health care; delivery of health care; integrated

## Introduction

Autism spectrum disorder (ASD) affects up to 1 in 50 US school-aged children,<sup>1</sup> and recent evidence suggests that the diagnosis is becoming more prevalent.<sup>1,2</sup> ASD involves problems with social communication and behavior, and the condition, and its comorbidities, have been associated with impaired child and family functioning.<sup>3,4</sup> Many children with ASD require intensive educational, behavioral, and healthcare services, which require significant financial, time, and care coordination investments for families.<sup>5,6</sup>

In general, parents of children with special health care needs (CSHCN) are at increased risk of under- or unemployment,<sup>7,8</sup> financial stress,<sup>9</sup> family burden,<sup>10</sup> poor health-related quality of life,<sup>11</sup> worse physical and mental health, and poorer psychological well-being.<sup>12,13</sup> For CSHCN with ASD in particular, data from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) demonstrate that the families have higher risk for financial and employment burden than families of other CSHCN, including CSHCN with other emotional, developmental, or behavioral problems. However, medical home care was associated with lower family financial impact.<sup>14</sup> In another national dataset, Montes and Halterman found that 39% of children with ASD had parents reporting that childcare problems affected their employment decisions, compared to 9% of typically developing children.<sup>15</sup>

This study seeks to address several gaps in existing literature addressing health care quality and adverse family impacts in ASD. First, accelerating ASD diagnosis rates over the past five years, including a near doubling of prevalence in national parent-reported surveys,<sup>2</sup> have led to demographic changes in children considered to have ASD. With diagnoses occurring among younger children,<sup>16,17</sup> children with less severe<sup>1</sup> or more variable<sup>17</sup> phenotypes, and psychiatric or developmental comorbidities,<sup>17,18</sup> family burdens may have changed since prior studies. For instance, family impacts may have lessened as younger and relatively healthier children are diagnosed with ASD, or may have increased as children with ASD have become more medically complex, or as health care benefits have become less generous.<sup>19</sup> Likewise, health care quality may have changed: quality may have improved as providers become more familiar with ASD, or deteriorated as health and educational systems become overburdened by children with ASD.

Prior studies additionally did not consider that ASD is associated with increased functional deficits compared to other emotional, behavioral, and developmental conditions.<sup>20</sup> Consequently, some of the family burden associated with ASD may be due to higher prevalence of functional deficits in this population rather than factors unique to ASD.<sup>21</sup> Finally, prior studies only assessed medical home as a correlate of family burden, though other quality measures, such as insurance adequacy, have strong associations with family burden overall,<sup>22,23</sup> and may be important modifiers of family burden for ASD.

This study therefore further investigates the relationship of health care quality with family burden among children with ASD. The study uses a national dataset with more recent data, a broader array of family impacts, and a federal quality measurement framework, the Maternal Child Health Bureau's [MCHB's] System of Care Core Outcomes. The study additionally accounts for differences between ASD versus other special health care needs that limit functioning.

We hypothesized that adverse family impacts would be prevalent among children with ASD, and would be worse than other CSHCN (who experience substantial adverse impacts) and particularly worse than CSHCN with functional limitations (considered the highest-risk group of CSHCN).<sup>24</sup> We also hypothesized that though health care quality would be worse in ASD compared to other CSHCN, high-quality care would be associated with fewer adverse impacts among CSHCN with ASD.

## Methods

### Data source

The 2009-2010 NS-CSHCN is a random-digit dial survey designed and sponsored by the MCHB and administered by the Centers for Disease Control's National Center for Health Statistics (NCHS).<sup>25</sup> A household is included in the sample if it contains 1 CSHCN <18 years. The MCHB defines CSHCN as those who "have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related service of a type or amount beyond that required by children generally."<sup>26</sup> Special health care needs status is assessed using the CSHCN Screener, a non-condition-specific, consequences-based measure.<sup>27</sup> In the survey, a parent or guardian (herein called "parent") is interviewed about one CSHCN per household. Prevalence for all variables can be weighted to represent non-institutionalized populations of US children and CSHCN. The combined landline and cell phone response rate in the 2009-2010 NS-CSHCN was 25.5%; completed interview response rate was 80.8%.<sup>25</sup> The NCHS Institutional Review Board approved the survey protocol.

### Sample

In this analysis, CSHCN with ASD (CSHCN+ASD) were compared to CSHCN without ASD who had functional limitations (CSHCN+FL) and CSHCN who had neither ASD nor functional limitations (Other CSHCN). CSHCN+ASD were defined as those CSHCN age 3-17 whose parent answered "yes" to, "Has a doctor or other health care provider *ever* told you that your child had autism, Asperger's disorder, pervasive developmental disorder, or

other autism spectrum disorder?” and “yes” to, “Does your child *currently* have autism or an autism spectrum disorder?”

We compared CSHCN+ASD to CSHCN+FL because CSHCN+FL are generally considered as the highest-acuity group of CSHCN--only about 24% of CSHCN have FL, but this group uses more health care resources than other CSHCN.<sup>28</sup> In the survey, CSHCN+ FL were defined as CSHCN age 3-17 whose parents gave affirmative responses to the items, “Is your child limited or prevented in any way in his/her ability to do the things most children of the same age can do?” and “Is your child's limitation in abilities because of *any* medical, behavioral, or other health condition?” and who did not have ASD as defined above. Children with current ASD and functional limitations were classified as CSHCN+ASD, although sensitivity analyses examined this group separately. We also compared CSHCN +ASD to other CSHCN. “Other CSHCN” were defined as CSHCN age 3-17 with neither ASD nor FL.

## Measures

Health care quality was measured using the MCHB's Six Core Outcomes, which were designed to promote the community-based system of services mandated for CSHCN under Title V and Healthy People 2020.<sup>29</sup> Outcomes include shared-decision making between families and health care providers; receipt of medical home care; consistent, adequate health insurance coverage over the past 12 months; *receipt of preventive medical and dental care*; *access to community-based services*; and receipt of health care transition services for youth with special health care needs. Each measure had multiple subcomponents (Table 1). We also constructed a composite measure of CSHCN meeting all age-relevant quality measures.

Family employment and financial impacts were defined by five measures: Family paid > \$1000 in out-of-pocket medical expenses annually, family experienced financial problems due to child's health condition(s), family member cut-back and/or stopped working due to child's health condition(s), family member avoided changing jobs due to concerns about maintaining the child's health insurance, and family member spent 11 hours coordinating/providing care weekly. We also created composite measure assessing if CSHCN experienced 2 family impacts.

Regression models included socio-demographic variables previously associated with differences in health status, health care quality, or autism severity,<sup>14,30,31</sup> including child age, gender, race/ethnicity/language, household income relative to federal poverty level (FPL), insurance type, and geographic region. We also examined the frequency of the most common health conditions among all CSHCN in all three groups of interest, as well as number of total health conditions (Table 2).

## Data analyses

Analyses were performed in SPSS version 19 (Armonk, NY), using the Complex Samples module to account for the NS-CSHCN's sampling structure.

**Socio-demographic characteristics and health conditions**—Descriptive statistics and chi-square tests compared socio-demographic factors, type, and number of health conditions among CSHCN+ASD, CSHCN+FL, and other CSHCN (Table 2).

**Health care quality and employment/financial impact among CSHCN, by ASD and FL status**—Bivariate analyses compared each of the family employment and financial impacts along with the family impact composite measure in CSHCN+ASD versus other CSHCN, and in CSHCN+ASD versus CSHCN+FL (Figure 1). Logistic regression models were fit to further explore these differences controlling for socio-demographic factors (Table 3). A similar analytic approach was used to compare the receipt of health care quality among CSHCN+ASD, other CSHCN, and CSHCN+FL (Figure 2, Table 3).

**Relationships between health care quality and family impacts**—To better understand the association of health care quality with family impacts, logistic regression models were created among CSHCN+ASD only. Each model assessed the relationship of each family impact factor with each health care quality variable, controlling for socio-demographic factors and functional limitations (Table 4). Multivariate associations of quality measure subcomponents with the composite family impact measure ( 2 of 5 family impacts) were also examined (Table 5).

**Sensitivity Analyses**—To assess whether ASD severity was associated with quality health care receipt, ASD severity (mild versus moderate/severe) was added to logistic regression models assessing the relationship of quality variables and the composite family impact indicator. To assess whether adverse family impacts were different among low-income CSHCN+ASD, models were fit to test associations of health care quality with family paid >\$1000 out of pocket in medical expenses, among CSHCN at <200% FPL (Appendix 3). To assess the influence of FL, we performed bivariate and multivariate analyses of health care quality and family impact comparing CSHCN+ASD with FL, CSHCN+ASD but no FL, CSHCN+FL, and other CSHCN (Appendices 1 and 2). To compare whether some outcomes were specific to ASD, we analyzed the relationship of health care quality indicators with the composite family impact indicator among other CSHCN sub-populations, including CSHCN +FL, CSHCN with developmental delay, and CSHCN with attention deficit hyperactivity disorder (ADHD).

## Results

### Study population

Of the 37 826 children qualifying as CSHCN, 3025 (8.1%) were classified as CSHCN +ASD, 6505 (18.2%) were CSHCN+FL, and 28 296 (73.8%) were other CSHCN, giving population prevalences of 134/10,000 CSHCN+ASD, 308/10,000 CSHCN+FL and 1216/10,000 other CSHCN in the US non-institutionalized population of children age 3-17. 65.1% of CSHCN+ASD also had functional limitations.

Compared to other CSHCN, CSHCN+ASD more likely to be younger, male, and reside in the West or Northeast U.S. ( $P < .001$ ). Compared to CSHCN+FL, CSHCN+ASD were more likely to have higher family income; be White, Non-Hispanic; and be both publicly and

privately insured ( $P < .001$ ). A majority of CSHCN in all three groups had multiple conditions (of 20 conditions asked about in the survey); rates of multiple conditions were highest among CSHCN+ASD. The most common comorbid conditions in all groups were allergies, asthma, and ADHD (Table 2).

### Adverse Family Impacts

The general pattern to the findings was that adverse family employment and financial impacts were substantial in all three groups; however, adverse impacts were most prevalent among CSHCN+ASD, of intermediate prevalence in CSHCN+FL, and of lower prevalence in other CSHCN (Figure 1). CSHCN+ASD were more likely than other CSHCN to experience each of the five adverse family employment or financial impacts as well as the composite indicator (≥ 2 adverse family impacts), on both bivariate (Figure 1), and multivariate (Table 3) analyses. Performance was particularly poor for *family member cut back or stopped working*, with over 6 times the adjusted odds in CSHCN+ASD compared to other CSHCN. Compared to CSHCN+FL, CSHCN+ASD also fared worse. On both bivariate and multivariate analyses, CSHCN+ASD were more likely than CSHCN+FL to have a family member that experienced financial problems, cut back and/or stop working, spent ≥ 11 hours per week providing or coordinating care for the child, in addition to the composite family impact indicator (Figure 1, Table 3). CSHCN+FL, though less affected than CSHCN+ASD on the above outcomes, still had significantly more family burden than other CSHCN on all indicators (Figure 1).

### Health Care Quality

Health care quality findings followed a similar pattern, with CSHCN+ASD experiencing the poorest health care quality, CSHCN+FL receiving better health care quality than CSHCN+ASD but worse health care quality than other CSHCN, and other CSHCN having the best relative health care quality (Figure 2, Table 3). CSHCN+ASD performed particularly poorly for the composite quality measure: only 7.4% of CSHCN+ASD reported care meeting all federal quality standards. Compared to CSHCN+FL, CSHCN+ASD had worse quality for all outcomes except *consistent, adequate insurance*, and *receipt of preventive care*. All findings were consistent on both bivariate (Figure 2), and multivariate (Table 3) analyses.

### Association between Health Care Quality and Family Impact

Overall, CSHCN+ASD who received quality health care were less likely to experience adverse family impacts: Among CSHCN+ASD, receipt of each quality indicator, with the exception of *receipt of preventive care*, was associated with lower odds of each adverse family impact (Table 4). Quality indicators also appeared to have a cumulative association with family impact: those families whose care met all age-relevant quality indicators had the lowest adjusted odds of having each family impact factor, with the exception of *spending > 11 hours coordinating/providing care*, and lowest adjusted odds of composite indicator (Table 3). *Receipt of preventive care*, however, performed differently: it was not significantly associated with lower adjusted odds of any of the adverse family impacts and was associated with increased adjusted odds of having a family member who spent ≥ 11 hours weekly coordinating/providing care.

Findings on measure subcomponents and their associations with the composite family impact indicator presented a mixed picture. Measure subcomponents associated with health care communication and coordination (shared decision making subcomponents, medical home subcomponents *family-centered care, no problems accessing needed referrals, received needed care coordination*, all of the ease of access to community-based services subcomponents, transition subcomponent *doctors encouraged self-management skills*) were associated with lower adverse family financial and employment impact. However, subcomponents associated with access to and receipt of routine care did not have the expected relationships: *preventive dental visit, usual source of care, personal doctor or nurse*, and *child insured* were not associated with lower odds of family impact, and *preventive medical visits* was associated with increased odds of adverse family impacts (Table 4).

### Sensitivity analyses

The findings that receipt of preventive care, usual source of care, and personal doctor or nurse were associated with no effect or adverse effect on families ran counter to initial hypotheses. Therefore, additional sensitivity analyses were conducted. ASD severity (mild versus moderate/severe) was entered into regression models, but led to no significant change in the adjusted odds ratios of adverse family impacts. Adjusting for insurance adequacy also did not notably alter the findings. Finally, to assess generalizability, analyses in other subpopulations, including CSHCN+FL, CSHCN with developmental delay, and CSHCN with ADHD, were conducted, demonstrating a similar pattern: *preventive medical and dental care, usual source of care and personal doctor and nurse* were associated with non-significant, or higher prevalence of adverse family impacts.

Because of concerns that the 35% CSHCN+ASD who did not have FL might have unpredictable effects on the sample of CSHCN+ASD, we performed bivariate and multivariate analyses stratifying CSHCN+ASD by FL status (Appendices 1 and 2). Overall, CSHCN+ASD but no FL had less severe family impacts and higher reported health care quality than CSHCN+ASD with FL. On multivariate analyses CSHCN+ASD but no FL were most similar to CSHCN+FL overall. *Receipt of preventive care and consistent, adequate insurance*, which showed no differences between CSHCN+ASD and CSHCN+FL in the main analysis, also did not differ in the comparison of CSHCN+ASD and FL versus CSHCN+ASD but no FL.

Because of concerns that families of poor CSHCN+ASD might respond negatively to family paid > \$1000 in out-of-pocket medical expenses annually because they lacked \$1000, we fit models for this variable among the subpopulation of CSHCN+ASD who were at <200% FPL. These models showed a similar pattern of significance to the main analysis; however, families <200% FPL who met the composite quality indicator had extremely low odds of paying >\$1000 out of pocket (AOR 0.04 [0.01-0.20]; Appendix 3).

### Discussion

Compared to other CSHCN, including CSHCN+FL, CSHCN+ASD experienced higher rates of adverse family employment and financial impacts, with more than half reporting two or

more adverse impacts. Additionally, CSHCN+ASD had poor health care quality, with <1 in 10 CSHCN+ASD receiving care meeting federal quality standards. However, when CSHCN+ASD received care meeting federal quality standards, they had fewer adverse family impacts. Effects were especially pronounced for quality measures assessing health care communication and coordination, which may be very important for families of children with ASD.<sup>32</sup> Findings were stable after eliminating CSHCN+ASD but no FL from the sample, and after adjusting for severity of ASD.

Notably, the findings do not show a causal direction: longitudinal studies are needed to clarify whether better health care quality leads to decreased family burden, or whether decreased family burden leads to access to higher health care quality. Regardless of the causal direction, better health care quality and reduced family burden are both important goals for families affected by ASD, so improving either one may be beneficial.

Results are consistent with prior literature about the relationship of health care quality with family burden among CSHCN.<sup>9,14</sup> Specifically, Kogan et al. showed that medical home is associated with less family burden for CSHCN+ASD,<sup>14</sup> a finding replicated in this more recent dataset. However, our findings indicate that a broader range of quality measures have associations with family impacts among CSHCN+ASD. In particular, the demonstrated relationship of insurance adequacy and health care quality among CSHCN+ASD adds to literature about the importance of insurance coverage for CSHCN+ASD.<sup>33</sup> It is also noteworthy that family impacts among CSHCN+ASD remain prevalent despite increasing numbers of children carrying an ASD diagnosis.

These findings suggest several potential responses: First, since the normative experience of families of CSHCN+ASD is to encounter employment and financial burden, providers should proactively address these burdens when recommending ASD services. Providers might find creative ways to bundle visits to reduce co-pays, direct families to free services (such as early intervention and special education), and advocate for more convenient services that allow families to maintain employment or reduce travel time and costs.<sup>34,35</sup> Patient Protection and Affordable Care Act (ACA) legislation provisions, such as elimination of insurance coverage caps and older age limits for young adults covered by parental insurance policies,<sup>36</sup> may be particularly helpful for families of youth with ASD, since youth with ASD have high rates of unemployment<sup>37</sup> and may not be able to obtain affordable coverage otherwise. Additionally, Medicaid-eligible CSHCN+ASD living in states implementing health homes under Section 2703 of the ACA may be better able to access care coordination services,<sup>33</sup> another health care quality component found to be strongly associated with reduced family impact in our study.

The finding that measures of care coordination and provider communication quality had more impact on family burden than receipt of services alone also has important implications. The findings suggest that improving the content of health care and its linkages across settings may be relatively more important than provision of routine care *per se*.<sup>9</sup> Another possible interpretation is that families experiencing greater burden are less able to find care that includes high levels of coordination and communication, so reducing family burden could be associated with an improvement in the quality of care for these domains. Either



interpretation suggests that accessible, coordinated care is very important for CSHCN+ASD and their families; such programs should be encouraged. Promising examples of care coordination efforts might include programs providing enhanced case management for families of CSHCN+ASD, thereby helping parents of CSHCN+ASD connect with community resources, or programs that help families facilitate communication between the educational and health care systems. Further research is needed to determine the effectiveness of non-medical and systems level interventions for children with ASD and their families.<sup>38</sup>

Strengths of this study include its large, nationally representative sample and its use of an established federal quality framework. Limitations include that all family outcomes and health care quality measures were based on parent report. Although parent report has been shown to be a reliable measure of health care quality,<sup>39</sup> there was no direct measure of service receipt. Many CSHCN+ASD and CSHCN+FL had multiple conditions, and there was no way to discern if family impacts or functional limitations related to any specific health condition. We had limited capacity to examine variation in family impact according to income and disease severity. There was no quantifiable measure of family financial burden other than parent report that family paid > \$1000 in out-of-pocket medical expenses annually, and we did not assess burden relative to family income. Some family impact variables, such as family member cut-back/stopped working, may be unreliable for unemployed parents. Likewise, the analysis considered neither health care costs for other family members nor insurance premium costs, which might contribute to family burden. The study examined multiple quality and family impact measures. Though most findings had a consistent pattern, some could have been found by chance. Finally, the 2009-10 NSCSHCN had a low response rate, mainly due to the survey's cell phone sample,<sup>25</sup> limiting external validity.

Overall, the study's findings provide an important signal to clinicians and policymakers: Adverse family employment and financial stressors are routine among CSHCN+ASD and should be regularly assessed. In addition, health care quality in this expanding population is persistently poor. Nonetheless, the data presented here suggest that health care quality and family impact are linked, making quality improvements in these areas particularly important. We hope that the research presented here will motivate those involved in the care of CSHCN +ASD to focus on comprehensive, family-oriented quality improvement in this vulnerable population.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Abbreviations

<b>ACA</b>	Patient Protection and Affordable Care Act
<b>AOR</b>	Adjusted Odds Ratio
<b>OR</b>	Odds Ratio
<b>ASD</b>	Autism Spectrum Disorder
<b>CI</b>	Confidence Interval
<b>CSHCN</b>	Children with Special Health Care Needs
<b>CSHCN+ASD</b>	Children with special health care needs that have current autism spectrum disorder
<b>CSHCN+FL</b>	Children with special health care needs that have functional limitations
<b>FPL</b>	federal poverty level
<b>NS-CSHCN</b>	National Survey of Children with Special Health Care Needs
<b>MCHB</b>	Maternal and Child Health Bureau

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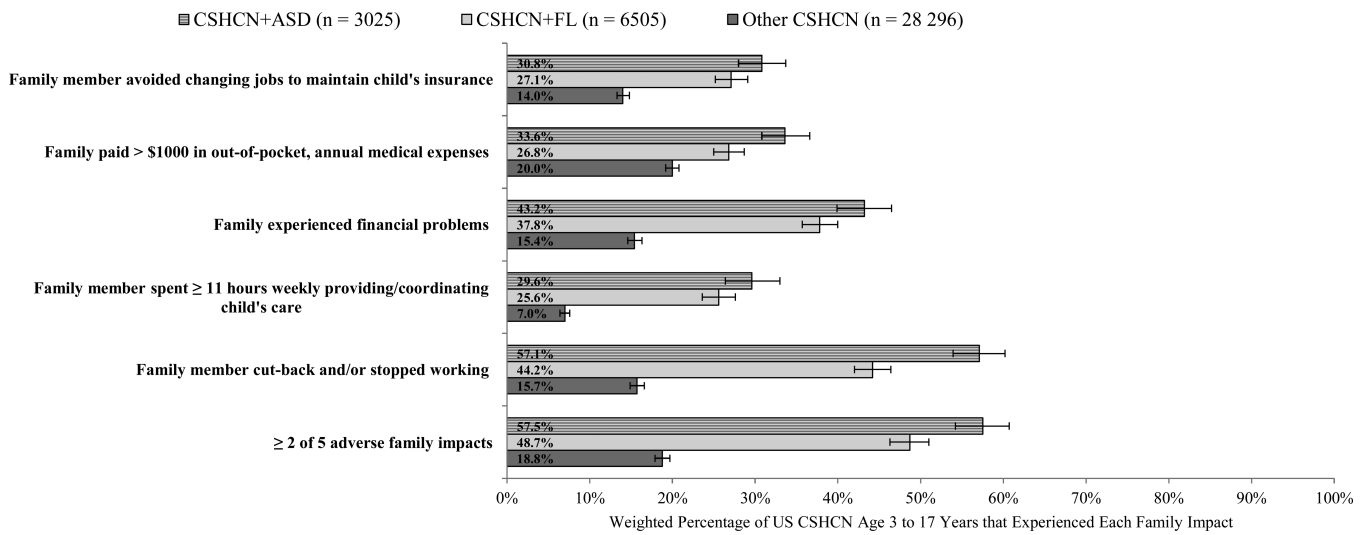
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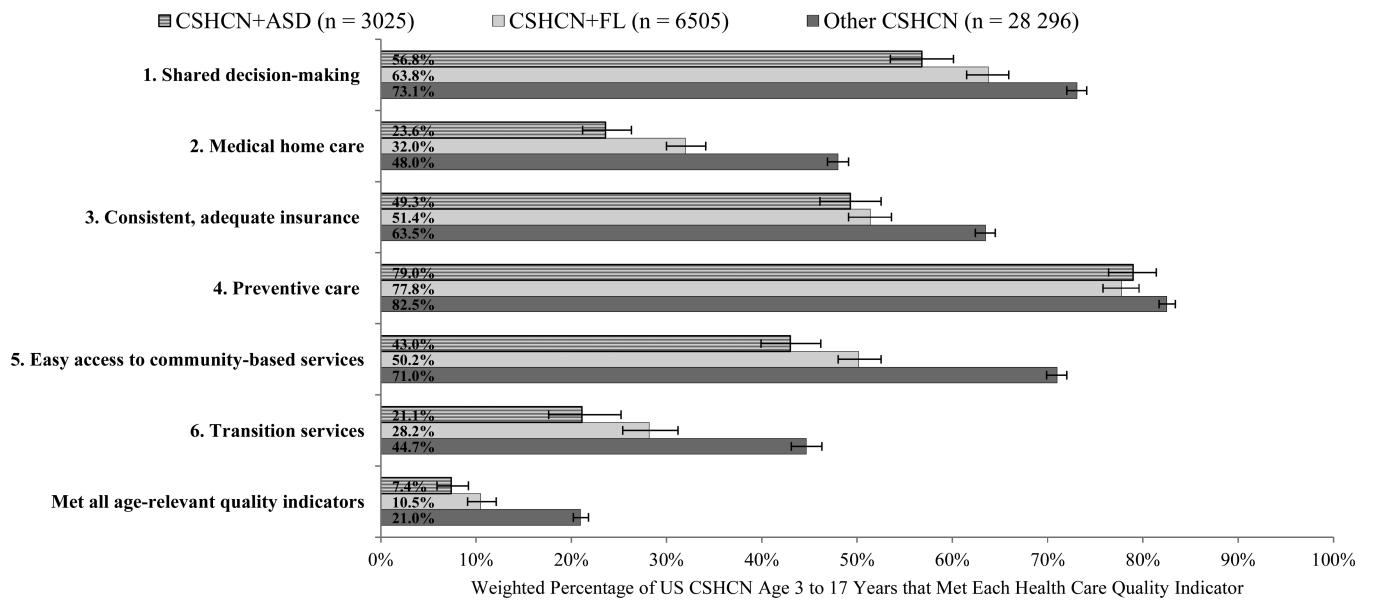
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**What's New**

Children with ASD experienced more adverse family impacts and lower health care quality than other children with special health care needs, including those with functional limitations. Quality health care was associated with reduced family impact among children with ASD.



**Figure 1.**  
 Weighted Percentages and 95% Confidence Intervals of Adverse Family Impacts Among US CSHCN Age 3 to 17 Years by ASD and Functional Limitations Status



**Figure 2.** Weighted Percentages and 95% Confidence Intervals of Health Care Quality Indicators Met Among US CSHCN Age 3 to 17 Years by ASD and Functional Limitations Status

**Table 1**

Federal Maternal and Child Health Bureau System of Care for Children with Special Health Care Needs Core Outcomes and Core Outcome Subcomponents<sup>a</sup>

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**Core Outcome 1. CSHCN family members are partners in shared decision-making for child's optimal health**

**Subcomponent 1a.** Child's doctors discuss a range of health care/treatment options

**Subcomponent 1b.** Child's doctors encourage parents to ask questions or raise concerns

**Subcomponent 1c.** Child's doctors make it easy for parents to ask questions or raise questions

**Subcomponent 1d.** Child's doctors respect parent's treatment choices

**Core Outcome 2. CSHCN receive medical home care**

**Subcomponent 2a.** Child has usual source(s) for sick and well care

**Subcomponent 2b.** Child has a personal doctor or nurse

**Subcomponent 2c.** Child experiences problems obtaining needed referrals

**Subcomponent 2d.** Child receives family-centered care

**Subcomponent 2e.** Child receives effective care coordination

**Core Outcome 3. CSHCN have consistent, adequate public and/or private health insurance**

**Subcomponent 3a.** Child is currently insured

**Subcomponent 3b.** Child does not experience gaps in health insurance coverage

**Subcomponent 3c.** Child's current health insurance is adequate

**Core Outcome 4. CSHCN are screened early and continuously for special health care needs**

**Subcomponent 4a.** Child has 1 preventive medical visit during the past 12 months

**Subcomponent 4b.** Child has 1 preventive dental visit during the past 12 months

**Core Outcome 5. CSHCN can easily access community based services**

**Subcomponent 5a.** No difficulties and/or delays receiving services for the child

**Subcomponent 5b.** No parental frustration getting services for the child

**Core Outcome 6. Youth receive services needed for transition to adulthood (age 12 to 17 years)**

**Subcomponent 6a.** Anticipatory guidance for transition to adult health care provided to youth

**Subcomponent 6b.** Child's doctors encourages self-management skills

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Abbreviation: CSHCN, children with special health care needs.

<sup>a</sup> All core outcomes are assessed according to care experiences during the past 12-months. Certain Core Outcome Subcomponents are comprised of multiple survey items, such as medical home subcomponents 2d & 2e. For more information on core outcome variable construction, please visit [www.childhealthdata.org](http://www.childhealthdata.org).



**Table 2**

Sociodemographic Characteristics of Children with Special Health Care Needs Age 3 to 17 years, by Autism Spectrum Disorder and Functional Limitations Status, United States 2009-2010<sup>a</sup>

Subgroup (n)	% of CSHCN +ASD (n = 3025)	% of CSHCN +FL (n = 6505)	% of Other CSHCN (n = 28 296)	ASD vs FL P value <sup>b</sup>	ASD vs Other P value <sup>c</sup>
<b>Overall percent of sample<sup>d</sup></b>	8.1%	18.2%	73.3%	--	--
<b>Age</b>					
3-5 years (n = 5041)	16.7%	14.3%	14.4%		
6-8 years (n = 7122)	21.0%	18.1%	18.7%		
9-11 years (n = 8626)	26.2%	21.9%	22.8%		
12-14 years (n = 8268)	20.9%	21.4%	21.8%		
15-17 years (n = 8769)	15.2%	24.3%	22.4%	< .001	< .001
<b>Sex</b>					
Female (n = 15 064)	19.6%	42.4%	42.1%		
Male (n = 22 694)	80.4%	57.6%	57.9%	< .001	< .001
<b>Race/Ethnicity/Household Language</b>					
Hispanic, Spanish Household Language (n = 1006)	4.2%	6.1%	5.1%		
Hispanic, English Household Language (n = 3031)	11.3%	13.0%	10.4%		
Other Race, non-Hispanic (n = 3438)	10.6%	7.3%	7.6%		
Black, non-Hispanic (n = 3641 )	10.4%	17.9%	15.9%		
White, non-Hispanic (n = 26 092)	63.5%	55.7%	61.0%	< .001	< .001
<b>Household Income</b>					
0%-99% FPL (n = 6305)	18.5%	29.4%	19.8%		
100%-199% FPL (n = 7244)	21.9%	25.1%	21.1%		
200%-399% FPL (n = 11 895)	31.6%	25.6%	29.1%		
400% FPL (n = 12 382)	28.0%	20.0%	30.0%	< .001	0.262
<b>Health Insurance Type</b>					
Uninsured (n = 1105)	2.8%	4.8%	3.4%		
Both Public and Private Insurance (n = 2690)	18.0%	11.0%	6.3%		
Public Insurance Only (n = 10 449)	33.5%	46.7%	32.4%		
Private Insurance Only (n = 22 148)	45.8%	37.5%	57.9%	< .001	< .001
<b>US Geographic Region</b>					
Midwest (n = 8900)	20.8%	23.7%	23.4%		
West (n = 9558)	22.7%	20.4%	18.9%		
South (n = 12 709)	33.6%	39.4%	39.8%		
Northeast (n = 6659)	23.0%	16.4%	17.9%	< .001	< .001
<b>Functional Limitations Status</b>					
Functional limitations (n = 8450)	65.1%	100.0%	0.0%		
No functional limitations (n = 29 376)	34.9%	0.0%	100.0%	< .001	< .001
<b>Frequency of the 3 Most Prevalent Chronic Conditions among CSHCN</b>					

Subgroup (n)	% of CSHCN +ASD (n = 3025)	% of CSHCN +FL (n = 6505)	% of Other CSHCN (n = 28 296)	ASD vs FL P value <sup>b</sup>	ASD vs Other P value <sup>c</sup>
Allergies (n = 18 208)	43.0%	50.6%	50.1%	< .001	< .001
Asthma (n = 12 547)	17.5%	35.5%	37.8%	< .001	< .001
ADHD/ADD (n = 11 327)	44.1%	33.8%	29.1%	< .001	< .001
<b>Number of Health Conditions<sup>e</sup></b>					
2 of the 20 conditions asked about (n = 21 694)	93.3%	75.5%	51.8%		
One or none of the 20 current conditions asked about (n = 16 132)	6.7%	24.5%	48.2%	< .001	< .001

Abbreviations: Other CSHCN, children with special health care needs who have neither current autism spectrum disorder nor functional limitations; CSHCN+FL children with functional limitations that do not have current autism spectrum disorder; CSHCN+ASD, children with special health care needs that have current autism spectrum disorder; FPL, federal poverty level.

<sup>a</sup>Weighted to represent the non-institutionalized population of CSHCN age 3 to 17 years in the United States.

<sup>b</sup>P value for CSHCN with current ASD compared to CSHCN with functional limitations from  $\chi^2$  test of independence.

<sup>c</sup>P value for CSHCN with current ASD compared to other CSHCN (with neither functional limitations nor ASD) from  $\chi^2$  test of independence.

<sup>d</sup>n = Raw number of children sampled. The numbers do not always add up to 100% of the full sample size due to missing values on some variables and/or rounding.

<sup>e</sup>Conditions included ADD/ADHD, allergies, anxiety, arthritis or joint problems, asthma, autism or ASD, behavioral or conduct problems, blood problems, brain injury or concussion, cerebral palsy, cystic fibrosis, depression, developmental delay, Down Syndrome, food allergies, migraine, heart problem or heart disease, intellectual disability or mental retardation, muscular dystrophy, seizure disorder, diabetes

**Table 3**AORs (95% CIs) for Quality of Health Care and Family Impact Indicators, by ASD and FL Status<sup>a</sup>

Indicator	CSHCN+ASD vs Other CSHCN	CSHCN+ASD vs CSHCN+FL
Family Employment and Financial Impact Indicators		
Family member avoided changing jobs to maintain child's insurance	2.95 (2.53-3.44)	1.08 (0.90-1.28)
Family paid > \$1000 in out-of-pocket, annual medical expenses	2.75 (2.33-3.23)	1.18 (0.98-1.41)
Family experienced financial problems	4.57 (3.90-5.34)	1.35 (1.14-1.60)
Family member spent 11 hours weekly providing/coordinating child's care	5.28 (4.34-6.43)	1.39 (1.13-1.72)
Family member cut-back and/or stopped working	6.97 (5.99-8.11)	1.77 (1.50-2.09)
2 of 5 adverse family impacts	6.13 (5.28-7.10)	1.44 (1.22-1.69)
Health Care Quality Measures		
Shared decision-making	0.48 (0.41-0.56)	0.69 (0.58-0.82)
Medical home care	0.32 (0.28-0.38)	0.56 (0.47-0.67)
Consistent, adequate insurance	0.55 (0.48-0.64) <sup>b</sup>	0.89 (0.76-1.05) <sup>b</sup>
Preventive care	0.79 (0.66-0.94)	0.99 (0.81-1.22)
Easy access to community-based services	0.29 (0.25-0.33)	0.66 (0.56-0.78)
Transition services	0.33 (0.25-0.42)	0.57 (0.42-0.76)
Met all age-relevant quality indicators	0.28 (0.22-0.35) <sup>b</sup>	0.57 (0.43-0.76) <sup>b</sup>

Abbreviations: AORs, adjusted odds ratios; CIs, confidence intervals; Other CSHCN, children with special health care needs who have neither current autism spectrum disorder nor functional limitations; CSHCN+FL, children with functional limitations that do not have current autism spectrum disorder; CSHCN+ASD, children with special health care needs that have current autism spectrum disorder.

<sup>a</sup> Adjusted odds ratios control for the following factors: child race/household language, household income, sex, age, region, and insurance type unless otherwise indicated.

<sup>b</sup> Not adjusted for insurance type.

**Table 4**

AORs (and 95% CIs) for Health Care Quality and Adverse Family Impact Indicators Among CSHCN with ASD Age 3 to 17 Years, United States 2009-2010<sup>a</sup>

Health Care Quality Indicator	Adverse Family Impact Indicator					
	Family paid > \$1000 in out-of-pocket medical expenses annually	Family experienced financial problems due to the child's health condition(s)	Family member cut-back and/or stopped working due to the child's health condition	Family member avoided changing jobs due to concerns about maintaining child's health insurance	Family member spent 11 hours coordinating/providing care weekly	2 of 5 Family Financial and Employment Impacts
	1.00	1.00	1.00	1.00	1.00	1.00
Shared Decision-Making	0.51 (0.38-0.67)	0.44 (0.33-0.57)	0.59 (0.45-0.77)	0.55 (0.42-0.72)	0.58 (0.42-0.79)	0.40 (0.31-0.53)
Medical Home Care	0.49 (0.35-0.69)	0.38 (0.27-0.52)	0.59 (0.44-0.80)	0.75 (0.55-1.04) <sup>c</sup>	0.48 (0.34-0.67)	0.52 (0.39-0.71)
Consistent, Adequate Health Insurance <sup>b</sup>	0.21 (0.16-0.28)	0.25 (0.19-0.33)	0.49 (0.37-0.63)	0.49 (0.37-0.64)	0.68 (0.50-0.93)	0.31 (0.24-0.41) <sup>d</sup>
Preventive Medical and Dental Care	1.18 (0.81-1.74) <sup>c</sup>	1.11 (0.79-1.58) <sup>c</sup>	1.05 (0.76-1.47) <sup>c</sup>	0.98 (0.68-1.41) <sup>c</sup>	1.65 (1.12-2.43)	1.12 (0.79-1.59) <sup>c</sup>
Easy Access to Community-Based Services	0.30 (0.22-0.40)	0.28 (0.21-0.38)	0.41 (0.32-0.54)	0.52 (0.38-0.69)	0.42 (0.30-0.58)	0.28 (0.21-0.36)
Youth Transition to Adult Health Services (age 12 to 17 years)	0.53 (0.33-0.86) <sup>d</sup>	0.49 (0.29-0.82)	0.45 (0.27-0.73)	0.56 (0.34-0.93)	0.36 (0.18-0.73)	0.48 (0.30-0.78)
Met All Age-Relevant Quality Indicators <sup>b</sup>	0.19 (0.11-0.30)	0.20 (0.11-0.37)	0.38 (0.23-0.63)	0.36 (0.22-0.61)	0.48 (0.27-0.84)	0.24 (0.15-0.39)

Abbreviations: AOR, adjusted odds ratio; ASD, autism spectrum disorder; CI, confidence interval; CSHCN, children with special health care needs.

<sup>a</sup> AORs compare the odds of the listed adverse family impact among children who received the listed health care quality indicator to the odds of the adverse family impact among children who did not receive the health care quality indicator. All models were adjusted for child age, sex, household income, race/ethnicity/household language, US region of residence, functional limitations and health insurance type unless otherwise indicated.

<sup>b</sup> Health insurance type was not adjusted for the models in this row due to nature of the independent variable of interest.

<sup>c</sup> The difference in the adjusted odds of experiencing the family impact indicator between CSHCN+ASD who met the quality indicator criteria and the CSHCN+ASD who did not meet the quality indicator criteria was not significant ( $P > .05$ ).

<sup>d</sup> Did not control for household language in the regression model due to sample size limitations, only used a race/ethnicity (without household language) variable.

**Table 5**

## Associations between Quality Indicator Subcomponents and Multiple Family Financial and Employment Impact Indicator

Health Care Quality Indicator	AORs (95% CIs) among CSHCN with ASD Age 3 to 17 Years <sup>a</sup>	
	Child experienced	2 of the 5 adverse family financial and employment impacts
<b>Core Outcome 1: Shared Decision-Making Subcomponents</b>		
Child's doctors discussed range of health care/treatment options		0.39 (0.29-0.53)
Child's doctors encouraged parents to ask questions or raise concerns		0.36 (0.26-0.50)
Child's doctors made it easy for parents to ask questions or raise concerns		0.31 (0.21-0.44)
Child's doctor respected parents' treatment choices		0.41 (0.28-0.59)
<b>Core Outcome 2: Medical Home Care Subcomponents</b>		
Child had a Personal Doctor or Nurse		1.48 (0.88-2.48)
Child had Usual Source(s) of Health Care		1.55 (0.96-2.50)
Child Received Family-Centered Care		0.64 (0.49-0.84)
No Problems Accessing Needed Referrals for Child		0.63 (0.40-0.97)
Child Received Needed Care Coordination		0.31 (0.23-0.41)
<b>Core Outcome 3. Health Insurance Adequacy Subcomponents<sup>b</sup></b>		
Child insured		1.38 (0.70-2.72)
Child did not experience gaps in health insurance coverage		0.70 (0.45-1.10)
Child's current health insurance was adequate <sup>c</sup>		0.34 (0.26-0.46)
<b>Core Outcome 4. Preventive Medical and Dental Care Receipt Subcomponents</b>		
Child had 1 preventive medical visit during the past 12 months		1.54 (1.04-2.27)
Child had 1 preventive dental visit during the past 12 months		0.82 (0.54-1.25)
<b>Core Outcome 5: Easy Access to Community-Based Health Services</b>		
Did not experience difficulties or delays accessing services		0.26 (0.20-0.34)
Parent never/sometimes frustrated getting services for child		0.24 (0.17-0.34)
<b>Core Outcome 6: Transition to Adult Healthcare Subcomponents</b>		
Anticipatory guidance for transition to adult health care provided to youth		0.67 (0.43-1.04)
Child's doctors encouraged self-management skills		0.53 (0.35-0.82)

Abbreviations: AOR, adjusted odds ratio; ASD, autism spectrum disorder; CI, confidence interval; CSHCN, children with special health care needs;

<sup>a</sup> AORs compare the odds of 2 of the 5 adverse family financial and employment impacts among children who received the listed health care quality indicator, compared to the odds of 2 of the 5 impacts among children who did not receive the health care quality indicator. Unless otherwise indicated, data were adjusted for child age, sex, household income, race/ethnicity/primary household language, US region of residence, and health insurance type.

<sup>b</sup> The models for the health insurance adequacy subcomponent were not adjusted for health insurance type due to multicollinearity.

<sup>c</sup> Only controlled for race/ethnicity vs the combined race/ethnicity and household language variable due to sample size limitations.