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## Differences in Access to Care of Children with Intellectual Disability Versus Children with Autism Spectrum Disorder

Kelly J. Haller

Wright State University - Main Campus, haller.28@wright.edu

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**Differences in Access to Care of Children with Intellectual Disability Versus Children with  
Autism Spectrum Disorder**

Kelly Haller

John C. Duby, MD, Professor and Chair of Pediatrics

Research Track: Population Health

*Scholarly Project Final Report*

**By checking this box, I indicate that my mentor has read and reviewed my final project report prior to submission**

**Abstract**

*Objective:* With the increase in ASD awareness and diagnosis, concerns are raised as to whether children with ID have more unmet health care needs than children with ASD. The purpose of this study was to assess the unmet health care needs of children with ID compared to children with ASD and whether inconsistent health insurance coverage is associated with any differences.

*Methods:* The 2016-2017 NSCH identified children with diagnoses of ID and ASD (with or without ID). Caregivers were asked if the child had an unmet need for health care during the past 12 months, and the type of care that was not received. Caregivers were asked if a child had consistent health insurance coverage during the past 12 months. Adjusted odds ratios (AOR) and 95% confidence intervals for needed health care not received were calculated and adjusted for sex of the child, insurance, and parent's highest education level.

*Results:* In the 2016-2017 NSCH, the frequency of ID and ASD was 1.05% and 2.6%, respectively. Children with ID had 4.72 (95% CI: 1.93-11.49) times the odds of needing medical care and not receiving it as children with ASD (with or without ID). Similar odds ratios resulted

for the other categories, with the exception of mental health where children with ID had 0.41 (95% CI: 0.19-0.92) times the odds of needed but unmet mental health care compared to children with ASD. In addition, children with ID had 0.36 (95% CI: 0.19-0.72) times the odds of having consistent health insurance compared to children with ASD during the past 12 months.

Key Words: Intellectual Disability, Autism Spectrum Disorder, Children with Special Health Care Needs, National Survey of Children's Health

## **Introduction/Literature Review**

### Introduction

With the increase in autism spectrum disorder (ASD) awareness and diagnosis, the question arises as to whether children with other disabilities are receiving the services and care they need. Particularly, the question arises as to whether children with intellectual disability (ID) are receiving fewer necessary services and less coordinated care than children with ASD. Additionally, it was questioned whether children with ID have consistent insurance that allows them to access the care they need. This study is a secondary data analysis of the 2016-2017 National Survey of Children's Health (NSCH) in order to develop a response to this question.

### Autism Spectrum Disorder and Intellectual Disability

Developmental delay and disabilities are chronic conditions that have an early onset in life and present with challenges in motor, language, cognitive, or behavioral development that affect a child's ability to carry out age-appropriate activities.<sup>1</sup> Both autism spectrum disorder and intellectual disability are types of developmental disabilities. ASD is diagnosed when a child has social communication and interaction deficits, restricted behaviors, and repetitive behaviors.<sup>2</sup> A

diagnosis of ID is made when a child is noted to have impaired general mental abilities and impaired adaptive functioning throughout development.<sup>2</sup>

The National Survey of Children's Health (NSCH) is a representative survey of children between the ages of zero and seventeen that compiles data at national and state levels on multiple issues concerning children's health. The 2016-2017 NSCH data shows that approximately 2.8% of children have a parent-reported diagnosis of ASD.<sup>3</sup> The 2016-2017 NSCH data reports that 1.2% of surveyed families reported a diagnosis of ID.<sup>3</sup> Of note, the CDC and NSCH studies have shown an increase in ASD diagnosis.<sup>4</sup> Multiple factors have contributed to this increase, including increased parental awareness, broadening of diagnostic criteria, and increased detection by physicians at earlier ages.<sup>4</sup>

#### Special Health Care Needs of Children with ID and ASD

Children with special health care needs (CSHCN) require specialized care and require additional health care and therapy, such as speech, occupational, or physical therapy, through multiple service providers. Coordinated care is important to address the many needs of these children. Early intervention in children with either ASD or ID has been found to be beneficial in children's development.<sup>5</sup>

Individuals diagnosed with an intellectual disability are more likely to also have co-existing physical disabilities, hearing problems, vision impairments, mental health issues, and communication disorders than individuals in the general population.<sup>6</sup> It is suggested that children with intellectual disabilities receive surveillance and potential care from a team of physicians, speech and language pathologists, behavioral therapists, occupational therapists, physical therapists, educators, and social workers.<sup>7</sup>

## Unmet Needs

Unmet health care service needs include inability to access necessary services for a child or family, such as therapy services (occupational, speech, physical, or language), prescription medicine, respite care, or mental health care.<sup>8</sup> Specifically regarding therapy, 21.6% of CSHCN between the ages of zero and four had unmet needs for physical, occupational, or speech therapy, based on the 2009-2010 NSCH.<sup>9</sup>

Significant previous research has been done comparing the needs of children with ASD to children with other specialized health care needs in general. A previous study using data from the 2016 NSCH showed that children with ASD can have four times as many unmet healthcare needs as children without.<sup>10</sup> Parents of children with ASD were more likely to report difficulty using health care services, inadequate insurance coverage, lack of coordinated care, and shared decision making compared to parents of children with other developmental disabilities in general or mental health conditions.<sup>11</sup> 2016 NSCH data showed that children with ASD were less likely to meet the criteria to have a medical home than other children and were less likely to get necessary referrals for specialty care.<sup>4</sup> Interestingly, a previous study did find that families of children with ASD expressed greater dissatisfaction than families of children with other developmental disabilities regarding communication and coordination of care with their child's primary care physician and were more likely to express having unmet needs.<sup>12</sup>

Insurance access, adequacy, and consistency play a role in a child's health care needs being met. State health policy regarding sufficient insurance coverage is important route to ensuring access to care for CSHCN.<sup>13,14</sup> Parents of children with ASD increasingly reported inadequate insurance coverage compared to parents of children with ID in the 2009-2010 NSCH.<sup>15</sup>

### Importance of Care Coordination

Care coordination, most effective when care is received in a medical home, results in more specialty health care needs being met for CSHCN.<sup>16</sup> Care coordination is also associated with decreased odds of functional disability among children with special needs.<sup>17</sup> Increasing access to and coordination of necessary health care services after a child is diagnosed with ASD or ID could improve the outcomes for the child and family.<sup>9</sup>

### **Hypothesis**

With the increase in ASD awareness and diagnosis, concerns are raised as to whether children with ID have more unmet health care needs than children with ASD. The purpose of this study was to assess the unmet health care needs of children with ID compared to children with ASD and whether inconsistent or inadequate health insurance coverage is associated with any differences. Coordination of care was also studied regarding the two groups. No formal studies have been published regarding the unmet needs of children with a sole diagnosis of ID. This study is a novel approach that intends to consider these children and whether their needs are being met. It was hypothesized that children with a diagnosis of ID will have more unmet health care needs and less consistent and adequate insurance than children with a diagnosis of ASD.

This study will provide pediatricians and parents with information regarding whether CSHCN are receiving the care they require, and whether there is a difference between care received by children with ID versus children with ASD. This study is innovative in assessing access to care of children with ID, as no available literature addresses this issue.

## **Methodology**

### Data and Participants

The National Survey of Children's Health (NSCH) is conducted by the U.S. Census Bureau, with participation of 71,811 families in the 2016-2017 survey period, providing information on a child in the home. Families were initially contacted with a pre-survey screener mailed to their home asking about the four youngest children in each family, with one child then being randomly chosen to be the focus of the full survey. Parents or caregivers (hereafter referred to as "parents") then answered questions about the one child on a secure website. Additional details about the survey methodology are available elsewhere from the Health Resources and Services Administration at <https://mchb.hrsa.gov/data/national-surveys/data-user>.

### Measures

This study is a secondary analysis of publicly available data. The number of questions asked to each family varied, as specific answers to certain questions indicated families should answer another question set or allowed them to skip a question set. The full data set from the 2016-2017 NSCH set was obtained in order to analyze the pertinent question sets and data. 22 items from this survey were statistically analyzed for this study. A full list of questions used to create outcome measures for this study is included in Table 2 in the Appendix.

### Data Analysis

The 2016-2017 NSCH identified children with diagnoses of ID (n=425) and ASD (with or without ID, n=1853). All analyses were run based on the unweighted sample. Responses to a question coded in SPSS Software as "90" (not in universe aka not asked to age group of responder) or "99" (missing d/t respondent or system errors, or no valid answer) were excluded from analysis. Univariate analyses were performed with Pearson's Chi-Squared Test for all data.

Adjusted odds ratios (AOR) and 95% confidence intervals were calculated for all variables with significant Chi-Squared results ( $p < 0.05$ ). All odds ratios were adjusted for sex of the child, insurance (public versus private), and highest level of education among reported adults.

## **Results**

All data discussed below are included in Table 2 in the Appendix.

### Reporting of Disabilities

Children with ID had 5.26 (95% CI: 3.53-7.87) the odds of having parents more likely to consider their child to have a developmental delay than the parents of children with ASD. Additionally, the children with ID had 2.79 (95% CI: 1.90-4.10) times the odds of having parents who described their child's developmental disability as severe rather than mild as the parents of children with ASD.

### Special Health Care Needs of Children with ID and Children with ASD

The NSCH used the Children with Special Health Care Needs (CSHCN) screener to assess what services children may qualify for, which reflects the federal Maternal and Child Health Bureau's consequences-based definition of CSHCN to comprehensively assess children's needs. Children with ID had 1.96 (95% CI: 1.51-2.56) times the odds of qualifying as having functional limitations as children with ASD. Additionally, children with ID had 1.42 (95% CI: 1.10-1.84) times the odds of qualifying for specialized therapy as children with ASD.

Many children with special health care needs receive special services such as speech, occupational, or behavioral therapy to meet their developmental needs. In the past twelve months, 91.9% of children with ID and 88.1% of children with ASD received special services,



such as speech, occupational, or behavioral therapy ( $p < 0.05$ ). Children with ID were more likely to need these special services beginning at a younger age. Children with ID had higher odds of receiving these special services before the age of three as opposed to between the ages of three and five (OR: 2.17, 95% CI: 1.66-2.85) and between the ages of six and seventeen (OR: 2.48, 95% CI: 1.75-3.51) compared to children with ASD.

Children with ID had 1.33 (95% CI: 1.02-1.73) times the odds of having a doctor spend 20 minutes with them during a preventive check-up rather than less than 20 minutes compared to children with ASD. Children with ID had 2.02 (95% CI: 1.30-3.13) times the odds of having parents who felt that their child's doctor always spent enough time with their child rather than just sometimes or never compared to parents of children with ASD.

Children between the ages of 12 and 17 with ID had 0.61 (95% CI: 0.43-0.87) times the odds of having time alone with their health care provider during their last check-up as children with ASD.

Unlike other medical needs, children with ID were less likely to need mental health care, and consequently, less likely to receive it. Of children with special health care needs, children with ID had 1.63 (95% CI: 1.22-2.19) times the odds of not qualifying to need mental health care as children with ASD. Children between the ages of 3 and 17 with ID had 2.43 (95% CI: 1.90-3.12) times the odds of not receiving mental health care in the past 12 months but not needing to rather than receiving mental health care during this time compared to children with ASD.

#### Unmet Needs

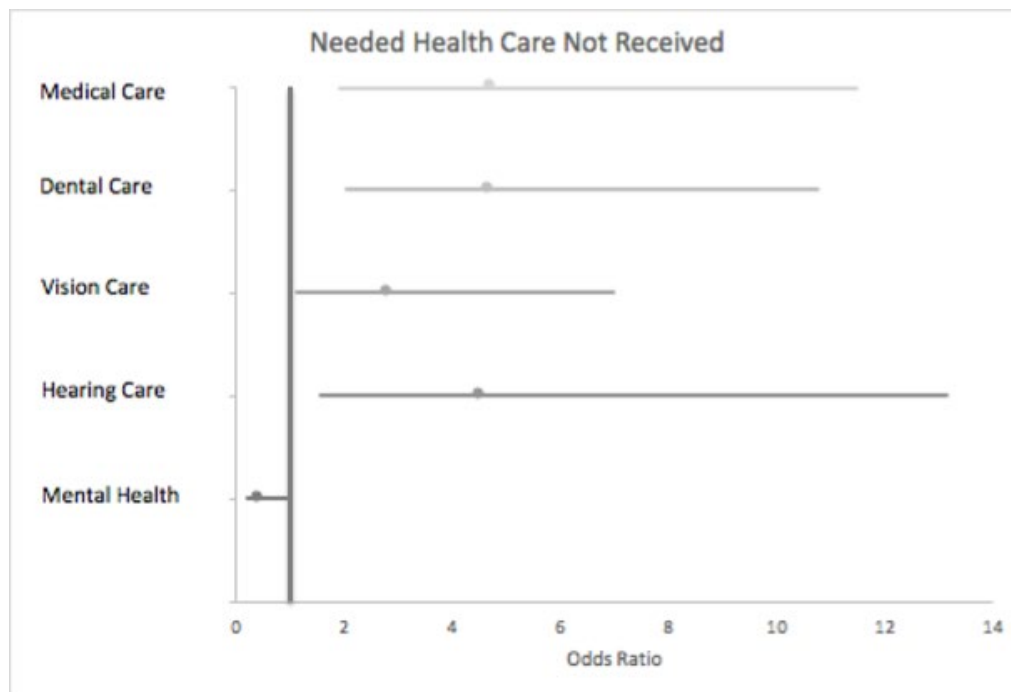
Children with ID had 4.72 (95% CI: 1.93-11.49) times the odds of needing medical care and not receiving it as children with ASD (with or without ID). Similar odds ratios resulted for the other categories, with the exception of mental health where children with ID had 0.41 (95%

CI: 0.19-0.92) times the odds of needed but unmet mental health care compared to children with ASD. The results for the unmet needs of care are shown in Table 1 and displayed in a Forest Plot in Figure 1.

*Table 1. Odds of Having Unmet Basic Health Care Needs for Children with ID Compared to Children with ASD*

<b>Needed Health Care Not Received:</b>	<b>p Value</b>	<b>AOR</b>	<b>Confidence Interval (95%)</b>
Medical Care	p=0.001	4.72	1.93-11.49
Dental Care	p=0.000	4.67	2.03-10.75
Vision Care	p=0.026	2.81	1.13-6.99
Hearing Care	p=0.006	4.52	1.55-13.16
Mental Health Services	p=0.029	0.41	0.19-0.92

*Figure 1. Forest plot displaying Odds of Having Unmet Basic Health Care Needs for Children with ID Compared to Children with ASD*



Access and visits to specialists also varied. Children with ASD had more difficulty getting to see a specialist other than a mental health professional, as children with ID had 0.51 (95% CI: 0.28-0.92) times the odds of needing to see such a specialist but not doing so rather than seeing a specialist as children with ASD.

Insurance plays a role in children having their health care needs met. Children with ID had 0.36 (95% CI: 0.19-0.72) times the odds of having consistent health insurance during the past 12 months as children with ASD. Assessing whether a child's current insurance coverage met his or her health needs was not statistically significant ( $p=0.135$ ). Assessing whether a child's current insurance coverage allows him or her to see a needed provider was also not statistically significant ( $p=0.151$ ).

#### Care Coordination

Children with ID had 0.67 (95% CI: 0.51-0.88) times the odds of having parents who desired extra help with arranging or coordinating their child's care among different health care providers and/or services in the past twelve months as children with ASD.

Children with ID had 1.91(95% CI: 1.08-3.38) times the odds of having parents who felt their child's doctor(s) always made it easy for them to raise concerns or disagree with recommendations as children with ASD as opposed to never making it easy for them. Additionally, children with ID had 2.17 (95% CI: 1.19-3.95) times the odds of having parents who felt their child's doctor(s) always worked with them to decide health care or treatment options than children with ASD. 24.8% of children with ID had parents that were satisfied with communication between their child's doctor(s) and school, child care provider, or special education program compared to 18.8% of children with ASD ( $p<0.05$ ). However, when adjusting

for sex of the child, insurance, and parent's highest education level, the difference in percentages was not statistically significant.

## **Discussion**

This study assessed whether children with ID and children with ASD have differences in their unmet health care needs, insurance access, and care coordination. Though ASD has higher prevalence than ID in children in the United States, children with ID have more functional limitations and need more specialized therapy as shown by the CSHCN screening assessment. Results show that children with ID are more likely to need and therefore more likely to receive specialized services such as speech, occupational, and/or behavioral therapy, as well as at a younger age, than children with ASD. This study shows that children with ID have parents who view their children as having higher needs and more severe developmental delays, which could contribute to parents of children with ID needing to provide more at-home care.

The results from this study show that children with ID are having longer-lasting doctor visits than their counterparts with ASD. It is proposed that this may be influenced by the often additional comorbid health conditions faced by children with ID more so than children with ASD. The parents of children with ID are more pleased with the amount of time their child's doctor spends with their child as well. Though children with ID between the ages of 12 and 17 are having less one-on-one time alone with their physician than children with ASD, individuals with ID are known to rely on support providers to identify health care concerns, communicate with health professionals, and engage in health-promoting behaviors.<sup>18</sup>

Regarding unmet health care needs, the results from this study show that children with ID have greater unmet medical, dental, vision, and hearing care needs than children with ASD.

Children with ASD, however, had greater unmet health care needs in receiving mental health care and specialist care other than mental health care. One notable area where the needs of children with ID and ASD differ is mental health care, with children with ASD being more likely to require care from a mental health professional.<sup>19</sup> The results from this study continued to support that. Children with developmental delay in need of developmental therapies have been shown to have increased parent-reported unmet health care needs.<sup>9</sup> Successful ways to increase the amount of care needs being met for CSHCN is through increasing coordinated care, especially through the creation of a family medical home and ensuring a child's access to insurance.<sup>1,11,16,17</sup>

Insurance plays a role in children having their health care needs met.<sup>20</sup> Analysis showed that children with ID were less likely to have consistent health insurance coverage during the past twelve months. No statistical significance was found between the two groups of children and whether the coverage met their needs or allowed them to see needed providers, though a previous NSCH survey (2009-2010) found that children with ASD were more likely to have inadequate insurance coverage. Cost or insurance issues are a significant barrier holding children with developmental delays under the age of four back from receiving needed therapies.<sup>9</sup> Since CSHCN utilize the largest amount of pediatric health care services, having health insurance that is consistent, affordable, and adequate is vital to these children.<sup>20</sup>

The children with ID have parents who feel more comfortable raising concerns with their child's doctor and working with the providers to decide care and treatment. The results showing that only 24.8% of children with ID and 18.8% of children with ASD had parents that were satisfied with communication between their child's doctor(s) and school, child care provider, or special education program suggests that the communication occurring is more positively viewed

by the parents of children with ID, but severely lacking for both children with ID and ASD. Results also showed that parents of children with ASD are more likely to desire additional help when managing their child's care between healthcare providers. The previous study done by Liptak and colleagues, however, did find that families of children with ASD are more likely to express dissatisfaction about care coordination and communication, as well as share more negative reviews.<sup>13</sup> Another difficulty in care coordination for children with ASD is that these children are less likely to meet the criteria for a medical home than other children.<sup>6</sup> The increased behavioral challenges of children with ASD may be driving the results found, resulting in challenges to access of services for the families of children with ASD. However, there is no data supporting this supposition. Increasing opportunities for children with ASD and their families to utilize a medical home could help improve outcomes for both these children and their families.<sup>9</sup>

Due to the nature of the recent changes to the NSCH made before the 2016-2017 survey, comparisons of data from this survey set and data from previous years are unable to be made. It will be interesting, however, to compare the results of the 2016-2017 survey with any future survey data put out by the NSCH. Additionally, it may be possible to use this research to develop a tool for health care providers to assess the unmet needs of children with ID and ASD during routine visits and provide referrals or suggestions for ways to meet any unmet needs.

This study was a secondary analysis of a national survey dataset. Being a cross-sectional study, a major weakness is the lack of a true cause and effect relationship, making any associations found difficult to interpret. Additionally, incidence is unable to be studied, and only prevalence of a disease can be evaluated. The timing of the survey collection may not be representative of the nation's population at all times. Bias is also a possibility when it comes to

cross-sectional studies, especially in a dataset such as the NSCH, where parents are the reporters of all data.

## **Conclusion**

Children with ID are more likely to have unmet healthcare needs for medical, dental, hearing, and vision care than children with ASD. This suggests children with ID, more so than those with ASD, have unmet basic health care needs. Additionally, children with ID are less likely than children with ASD to have consistent health insurance, which hinders their ability to receive quality, sufficient care. Children with ASD, however, are more likely to have unmet mental health care needs and access. Additionally, these children are less likely to have coordinated care or aspects of a medical home in place.

This information will be helpful to health care providers and parents of children with ID and ASD. By understanding the unmet needs of children with ID and ASD, providers and parents can develop resources for meeting health care needs.

## Appendix

Table 2. AORs of Having Selected Health Care Characteristics According to Parent-Reported ID and/or ASD Status, United States, 2016-2017

Variable		Children with ID (n(%))	Children with ASD (n(%))	Children with ID vs Children with ASD, AOR (95% CI)
Outcome Measures	Categories			
<i>Reporting of Disabilities</i>				
Does this child have a developmental delay?	<b>1. Yes</b> 2. No	393 (92.7%)**	31 (68.6%)	5.26 (3.53-7.87)**
How severe is this child's developmental delay, if the child currently has a developmental delay?	Mild (reference)	57 (15.3%)**	338 (30.9%)	reference
	Moderate	188 (50.4%)**	535 (48.9%)	1.85 (1.31-2.61)**
	Severe	128 (34.3%)**	220 (20.1%)	2.79 (1.90-4.10)**
<i>Special Health Care Needs of Children with ID and Children with ASD</i>				
Has this child ever received special services to meet his or her developmental needs such as speech, occupational, or behavioral therapy?	<b>1. Yes</b> 2. No	387 (91.9%)*	1627 (88.1%)	1.43 (0.95-2.14)
How old was this child, in years, when he or she began receiving special services?	At age less than 3 years old	179 (48.4%)**	432 (27.4%)	2.48 (1.75-3.51)**
	At age 3-5 years old	129 (34.9%)**	769 (48.8%)	1.14 (0.80-1.62)
	At age 6-17 years old (reference)	62 (16.8%)**	374 (22.4%)	reference
Children qualifying on the CSHCN Screener functional limitations criteria	<b>1. Meet screening criteria</b> 2. Do not meet screening criteria	326 (76.7%)**	1077 (58.1%)	1.96 (1.51-2.56)**
Children qualifying on the CSHCN Screener specialized therapy criteria	<b>1. Meet screening criteria</b> 2. Do not meet screening criteria	322 (75.8%)**	1187 (64.1%)	1.42 (1.10-1.84)**
CSHCN with and without ongoing emotional, developmental and/or behavioral health special needs	<b>1. CSHCN qualifying on mental health criteria</b> 2. CSHCN NOT qualifying on mental health criteria	317 (74.6%)**	1390 (75.0%)	1.63 (1.22-2.19)**
Thinking about the last time you took this child for a preventive check-up, about how long was the doctor or health care	Less than 10 minutes	48 (12.5%)**	223 (13.6%)	1.27 (0.88-1.88)
	10-20 minutes (reference)	193 (50.4%)**	951 (58.1%)	reference



provider who examined this child in the room with you?	More than 20 minutes	142 (37.1%)**	463 (28.3%)	1.33 (1.02-1.73)*
Did this child's doctors spend enough time with him or her during check-ups in the past 12 months?	Always	237 (59.5%)**	925 (54.3%)	2.02 (1.30-3.13)**
	Usually	133 (33.4%)**	564 (33.1%)	1.83 (1.16-2.90)*
	Sometimes or never (reference)	28 (7.0%)**	216 (12.7%)	reference
Did this child have time alone with health care provider at last check-up, if between the ages of 12-17 years?	<b>1. Had time alone with provider</b> 2. Did not have time alone with provider/Did not have preventive check-up	61 (26.3%)**	355 (37.1%)	0.61 (0.43-0.87)**
<i>Unmet Needs</i>				
During the past 12 months, was there any time when this child needed medical care but it was not received?	<b>1. Yes</b> 2. No	14 (37.8%)**	27 (15.2%)	4.72 (1.93-11.50)**
During the past 12 months, was there any time when this child needed dental care but it was not received?	<b>1. Yes</b> 2. No	22 (59.5%)**	55 (30.9%)	4.67 (2.03-10.8)**
During the past 12 months, was there any time when this child needed vision care but it was not received?	<b>1. Yes</b> 2. No	11 (29.7%)*	26 (14.6%)	2.81 (1.13-6.99)*
During the past 12 months, was there any time when this child needed hearing care but it was not received?	<b>1. Yes</b> 2. No	9 (24.3%)**	14 (7.9%)	4.52 (1.55-13.20)**
During the past 12 months, was there any time when this child needed mental health services but it was not received?	<b>1. Yes</b> 2. No	12 (32.4%)*	95 (53.4%)	0.41 (0.19-0.72)*
During the past 12 months, did this child see a specialist other than a mental health professional?	Yes, received care from a specialist (reference)	240 (56.7%)**	642 (34.9%)	reference
	No, but needed to see a specialist	18 (4.3%)**	87 (4.7%)	0.51 (0.28-0.92)*
	No, did not need to see a specialist	165 (39.0%)**	1109 (60.3%)	0.44 (0.34-0.55)**
Does this child's current insurance coverage meets his or her health needs?	Always	215 (52.7%)	851 (47.5%)	-
	Usually	145 (35.3%)	686 (38.3%)	-
	Sometimes	43 (10.5%)	224 (12.5%)	-
	Never	5 (1.2%)	31 (1.7%)	-
Does this child's current insurance coverage allows him or her to see needed provider?	Always	261 (64.0%)	1085 (60.5%)	-
	Usually	118 (28.9%)	530 (29.6%)	-
	Sometimes	26 (6.4%)	168 (9.4%)	-

	Never	3 (0.7%)	9 (0.5%)	-
Did this child have consistent health insurance coverage during the past 12 months?	<b>1. Insured continuously all year</b> 2. Child had a gap in coverage	392 (92.9%)*	1762 (95.6%)	0.36 (0.19-0.72)**
<b>Care Coordination</b>				
During the past 12 months, have you felt that you could have used extra help arranging or coordinating this child's care among the different health care providers or services?	<b>1. Yes</b> 2. No	98 (26.1%)*	478 (31.4%)	0.67 (0.51-0.88)**
Did this child's doctors make it easy for parents to raise concerns or disagree with recommendations?	Always	149 (65.4%)*	586 (61.7%)	1.91 (1.08-3.38)*
	Usually	63 (27.6%)*	234 (24.7%)	2.20 (1.19-4.07)*
	Never/Sometimes (reference)	16 (7.0%)*	129 (13.6%)	reference
Did this child's doctors work with parents to decide together health care/treatment options?	Always	157 (68.6%)*	587 (61.6%)	2.17 (1.19-4.07)*
	Usually	58 (25.3%)*	245 (25.7%)	2.11 (1.10-4.03)*
	Never/Sometimes (reference)	14 (6.1%)*	121 (12.7%)	reference
*=p<0.05, **=p<0.01				

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