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# Unmet Need for Therapy Among Children with Autism Spectrum Disorder: Results from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs

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**Abstract** *Objectives* We examined population-based trends in unmet need for therapy service in children with autism spectrum disorder (ASD) compared to other children with special health care needs (CSHCN), and identified factors associated with unmet need for therapy. *Methods* A pooled cross-sectional comparison of the 2005–2006 and 2009–2010 waves of the National Survey for Children with Special Health Care Needs (NS-CSHCN) was used. Weighted bivariate analyses were used to compare children ages 3–17 years with ASD ($n = 5113$) to other CSHCN ($n = 71{,}294$) on unmet need for therapy services. Survey weighted multivariate models were used to examine child, family, and contextual characteristics associated with unmet need. *Results* A greater percentage of children with ASD across both surveys were reported to need therapy than other children with CSHCN. Among children with a reported need, children with ASD were 1.4 times more likely to report an unmet need for therapy compared to other CSHCN (OR 1.42, 95 % CI 1.18–1.71). Variables significantly associated with unmet need for therapy services included not receiving a well-child visit in the past year (OR 5.81, CI 3.83–8.81), surveyed in 2009 (OR 1.42, CI 1.18–1.71), child being female (OR 1.27, CI 1.05–1.53), uninsured (OR 1.72, CI 1.15–2.56), and having greater functional limitation (OR 2.44, CI 1.80–3.34). *Conclusions for Practice* Children with ASD require supportive services such as occupational, physical, and speech therapy but are less likely to receive such services than other CSHCN. Receiving a well-child visit in the past year was strongly associated with receipt of needed therapy services.

**Keywords** Access · Autism spectrum disorder · Health disparities · Special health care needs · Therapy services

## Significance

*What is Known* Nearly 75 % of children with autism spectrum disorder (ASD) are reported to need occupational, physical, or speech therapy services. Little is known about unmet therapy needs or the factors that limit access.

*What this Study Adds* Across two cross-sectional population-based datasets, children with ASD were 1.4 times more likely to have an unmet need for therapy services than other CSHCN. A greater percentage of children, regardless of diagnosis, had an unmet therapy need in 2009–2010 than in 2005–2006. Children foregoing an annual well-child visit were nearly six times more likely to have an unmet therapy need.

## Introduction

Children with autism spectrum disorders (ASD) frequently present with medical, mental health, and educational needs that are addressed by multiple service providers. Children

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with ASD heavily utilize person and financial resources associated with medical and educational systems [11, 13, 26]. Occupational therapy (OT), physical therapy (PT), and speech therapy (ST) are among the most used services by children with ASD in both educational [9] and medical systems, and previous literature suggests that children with ASD use these services significantly more than other children with special health care needs (CSHCN) [10, 28]. Furthermore, these therapies are recommended habilitative services by the American Academy of Pediatrics for addressing communication and functional needs [23].

In spite of the demand and recommendation for therapies, accessing needed services has been problematic. Minimizing health disparities and improving access to services is a current focus of Healthy People 2020, with specific Maternal, Infant and Child Health objectives (MICH-29) targeting improved diagnosis and access to appropriate intervention for children with ASDs [30]. The Interagency Autism Coordinating Committee (IACC, [19] recently identified that disparities in quality care for persons with ASD are a priority and recommended continued research into service access. Although significant literature exists on diagnostic disparities for children with ASD and access to medical services such as genetic counseling in comparison to other CSHCN (e.g. [21]), few studies have examined access to therapy services in children with ASD, with most investigating access in the early-mid 2000s [10, 16, 20, 28]. Of these, Chiri and Warfield [10] conducted the only population based study to examine differences in access to therapy services in children with ASD to other CSHCN in the 2005–2006 National Survey for Children with Special Health Care Needs (NS-CSHCN). These authors found significant predictors of having an unmet therapy need for children with ASD included being female, uninsured and having limited functional abilities. The most significant factor impacting access reported by families of children with ASD relative to other CSHCN was provider knowledge and skill.

Health care policy for children with ASD changed greatly with the passage of the [12] (Public Law 111–148), more recently reauthorized as the Autism CARES Act of 2014. This law had the explicit goals of increasing awareness of ASD, reducing barriers to screening and diagnostic services, improving evidence-based research, and increasing training of professionals to provide screening and intervention for persons with ASD. This policy had the potential to indirectly increase access to needed services and improve provider-related problems through increased funding for training. The purpose of this study was to examine population-based differences in unmet therapy need, and caregiver-reported access problems among children with ASD before and after the policy change identified above, and in comparison to other CSHCN who also needed therapy. Examining data from two cross-sectional time points provides relevant information on change in unmet need over time for this population, and yields important information regarding the impact of individual and contextual variables, as defined by Andersen's Behavioral Model of Health Service Use [2] that may impact access to therapy. Our research questions were: 1. What is the difference in the percent of children with ASD who demonstrate unmet therapy need compared to other CSHCN at both survey time points? 2. To what extent are individual and contextual characteristics associated with unmet therapy need across both surveys?

## Methods

### Data Sources and Sampling

We used the 2005–2006 and 2009–2010 NS-CSHCN data for this study (National Center for Health Statistics, Centers for Disease Control and Prevention, [7]. These cross-sectional surveys collected information about utilization and access to health services, child needs, satisfaction with services, insurance and other family and child demographic information [3]. We used variables from the screening, household and main interview datasets. The study was deemed exempt by institutional board review prior to data analysis.

Detailed sampling methods for these surveys have been described elsewhere [3, 6]. Survey changes were made between the 2005 and 2009 NS-CSHCN surveys (CDC, [8]. Primary changes which impacted our analyses included: inclusion of cell-phone and landline phone users in the 2009–2010 NS-CSHCN sample, minor changes in the question ascertaining 'autism spectrum disorder' (Table 1), racial data in 2005 was provided in 4 categories (white, black, multiple, other) and 3 categories in 2009 (white, black, other).

A total of 364,841 and 372,698 households were screened in 2005–2006 and 2009–2010, respectively, with children under the age of 18 years. The screening process identified whether a child with a SHCN lived at the residence through several questions (Table 1). Caregivers of screened CSHCN were invited to participate in the longer main interview survey.

### Sample

The main interview dataset for each survey year was used to define the analytic sample. The full sample of CSHCN for each survey year included for analysis was 40,723 (2005–2006) and 40,242 (2009–2010). Respondents were persons who were familiar with the child and their healthcare needs; we use the term 'caregivers' throughout.

**Table 1** Group and outcome variable questions from the National-Survey for Children with Special Health Care Needs, 2005–2006 and 2009–2010

| Variable (Data file) | Question |
|---|---|
| Ascertainment of a special health care need<br>(Screening) | 1. Must answer YES to one of the following questions:<br>Does your child currently need or use medicine prescribed by a doctor, other than vitamins?<br>Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?<br>Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?<br>Does your child need or get special therapy, such as physical, occupational, or speech therapy?<br>Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling?<br>2. Must answer YES to follow up questions asking whether the child's limitation or need was due to any medical, behavioral, or other health condition<br>3. Must answer YES to follow up questions asking whether the condition is expected to last 12 months or longer |
| Autism spectrum disorder diagnosis (main interview) | "To the best of your knowledge, does [child] currently have autism or autism spectrum disorder, that is, an ASD?" (2005–2006 survey) (Y/N)<br>"Does [child] currently have Autism, Asperger's Disorder, pervasive developmental disorder (PDD), or other autism spectrum disorder?" (2009–2010 survey) (Y/N) |
| Need for therapy<br>(main interview) | "During the past 12 months, was there any time when [child] needed physical, occupational or speech therapy?" (Y/N) |
| Unmet need for therapy<br>(main interview) | [*Question asked after "Y" to previous question on perceived therapy need*] "Did [child] receive all the therapy that (he/she) needed?" (Y/N) |
| Therapy access problems<br>(main interview) | "Why did [child] not get all the therapy s/he needed?"<br>Eleven selected reasons were examined in this study:<br>1. Therapy not at convenient times,<br>2. Provider did not know how to treat,<br>3. Dissatisfaction with provider,<br>4. Cost too much,<br>5. Not available/No transportation,<br>6. Did not know where to go,<br>7. Lack of school resources,<br>8. No insurance,<br>9. Health plan problem,<br>10. Can't find provider who accepts insurance,<br>11. No referral |

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009–2010. Survey instruments available at: http://www.cdc.gov/nchs/slaits/cshcn.htm

## Autism Spectrum Disorder Variable

Children with current ASD in 2005–2006 ($n = 2123$) and 2009–2010 ($n = 3055$) were identified by caregivers as having a diagnosis when asked the questions shown in Table 1. In 2009–2010, the survey also inquired if a child *ever* had Autism, Asperger's Disorder, PDD, or other ASD; for the purposes of this analysis, children from 2009 survey year were only included in the sample of ASD if they "currently" had an ASD. We included children over the age of 3 years to ensure the sample included children likely to have received a formal diagnosis ($n = 5113$). Other CSHCN were those who were not identified as having a current ASD in either the 2005–2006 or 2009–2010 dataset between 3 and 17 years old ($n = 71{,}294$).

## Measures

Survey questions eliciting caregiver responses regarding ASD diagnosis, therapy need, unmet need, and access problems are shown in Table 1. No information about educational or behavioral services specifically was available in either survey. As such, analyses did not address these services.

### Child and Family Characteristics

Andersen's Behavioral Model of Health Service Use [2], a predominating theoretical sociocultural model for understanding health care access, was used to identify variables that could influence unmet therapy need. Individual characteristics were those that influenced a child's ability to receive all needed therapy services, including predisposing factors (child age, race, ethnicity, gender), family enabling factors [child insurance status, household federal poverty level (FPL)], and child need characteristics (functional limitation). Additionally, because other health behaviors such as pediatrician visits typically precede referral and enhance coordination of therapy services, receipt of a well-child checkup in the past year was included as a potential variable influencing therapy access. All variables were categorical except for age. Categorical levels are displayed fully in Table 2.

### Contextual Characteristics

To examine the influence of contextual characteristics, metropolitan statistical area (MSA) status was used to classify children as living in a non-urban or urban environment based on survey definitions of metropolitan areas [3, 6]. MSA status was suppressed for cases living in states with either few urban or few rural populations [3, 6]. To include all possible cases in the analysis, cases living in states with few MSAs were classified as non-urban and cases living in states with large numbers of MSAs were classified as urban per the approach described by Dusing et al. [15].

### Data Analysis

#### *Data Cleaning*

Standard analytic public use files for both waves were downloaded from the CDC website and imported into Stata (StataCorp) MP2 version 12. Files were concatenated with careful matching of variables. All observations were retained to ensure adequate variance estimation using the provided sampling weights, and an indicator for survey year was created. A new stratification variable was created using state, year, and sample type (cell v. landline) in order to accommodate differences in the sample design by survey year. Analyses originally used imputed datasets that controlled for missingness in race, ethnicity, and poverty level, and which increased the sample size by 46. We compared regression coefficients and *P* values for predictors of unmet need with and without the imputed data, and comparisons revealed no substantive differences (Carretta et al., unpublished). Therefore, all analyses used the non-imputed dataset to make full use of Stata survey features, and cases were excluded with missing data.

### Statistical Analysis

Pooled analyses on the combined data sets were conducted using Stata 12 survey procedures [27]. Bivariate methods to examine row and column independence with Rao-Scott design-based F statistics [24, 25] were used to examine demographic characteristics, therapy need, unmet therapy need, and access problem variables by diagnosis group for each survey year while accounting for the complex survey design. Analyses of subgroups or specific survey years utilized appropriate subpopulation commands in Stata, and evaluation of the estimates and overlap of the 95 % CIs allowed for descriptive comparisons between years. Due to the small sample of caregivers who reported any specific access problem, cell-phone strata with similar weights were collapsed for the 2009–2010 data in order to obtain confidence interval estimates and F-statistics for the access problem analyses [17]. All other analyses used specified weighting and strata as recommended [3, 7] and all odds ratios and rates are reported as adjusted.

Multivariate logistic regressions examining associations of child and family factors with unmet need compared a base model with a diagnosis and year interaction term to models with added predisposing, enabling, and need categorical variables. The interaction term was not statistically significant, although diagnosis and year were, thus the interaction term was dropped from future analyses to preserve degrees of freedom. Models were examined for specification errors, multicollinearity and goodness of fit; the best model is reported. Planned regression analyses utilized an alpha of $p \leq .01$ to minimize type I error.

## Results

### Sample Characteristics

Children with ASD were more likely to be male and were significantly younger than other CSHCN (Table 2). In both child groups, there were significantly more white children than children of other races. No overall differences in FPL were observed between the groups at both survey years. Children with ASD were significantly more likely than other CSHCN to have 'both public and private' insurance in both survey years. In both survey years, caregivers of children with ASD more frequently reported that their child's condition impacted everyday function 'Usually' or 'Always' than caregivers of other CSHCN.

**Table 2** Weighted child characteristics by study group and survey year

| | 2005–2006 National Survey for Children with Special Health Care Needs | | | 2009–2010 National Survey for Children with Special Health Care Needs | | |
|---|---|---|---|---|---|---|
| | ASD (n = 2 088) % [95 % CI] | Other CSHCN (n = 36 285) % [95 % CI] | *P* | ASD (n = 3 025) % [95 % CI] | Other CSHCN (n = 35 009) % [95 % CI] | *P* |
| Age, mean years | 9.9 [9.6–10.1] | 10.6 [10.5–10.7] | <.001 | 9.9 [9.7–10.1] | 10.6 [10.6–10.7] | <.001 |
| Gender | | | <.001 | | | <.001 |
| Male | 79.0 [76.0–81.7] | 58.3 [57.4–59.1] | | 80.4 [77.7–82.8] | 57.8 [56.9–58.8] | |
| Female | 21.0 [18.3–24.0] | 41.7 [40.9–42.6] | | 19.7 [17.3–22.3] | 42.2 [41.2–43.1] | |
| Race | | | .33 | | | <.001 |
| White | 73.6 [70.4–76.6] | 70.8 [70.0–71.7] | | 71.3 [67.9–74.5] | 68.5 [67.5–69.4] | |
| Black | 15.2 [12.9–17.9] | 16.9 [16.2–17.7] | | 11.1 [9.2–13.4] | 17.2 [16.4–18.1] | |
| Multiple[a] | 3.3 [2.4–4.4] | 4.0 [3.6–4.3] | | N/A | N/A | |
| Other | 8.0 [6.2–10.2] | 8.2 [7.7–8.8] | | 17.6 [14.6–20.9] | 14.3 [13.6–15.1] | |
| Ethnicity | | | .71 | | | .62 |
| Non-hispanic | 88.0 [85.3–90.3] | 88.5 [87.9–89.1] | | 84.4 [81.8–86.7] | 83.8 [82.9–84.6] | |
| Hispanic | 12.0 [9.7–14.7] | 11.5 [10.9–12.1] | | 15.6 [13.3–18.2] | 16.2 [15.4–17.1] | |
| Poverty level | | | .10 | | | .03 |
| <200 % FPL | 44.1 [40.4–47.7] | 40.5 [39.5–41.4] | | 40.0 [36.6–43.1] | 43.7 [42.7–44.8] | |
| 200–400 % FPL | 30.0 [26.5–33.7] | 30.2 [29.4–31.0] | | 32.7 [29.5–36.1] | 28.6 [27.7–29.4] | |
| >400 % FPL | 26.0 [23.1–29.1] | 29.4 [28.5–30.2] | | 27.5 [24.7–30.6] | 27.7 [26.9–28.6] | |
| Insurance status | | | <.001 | | | <.001 |
| Private | 47.5 [44.0–51.0] | 60.3 [59.4–61.2] | | 44.4 [41.3–47.5] | 51.9 [50.9–52.9] | |
| Public | 31.5 [28.2–34.9] | 27.3 [26.5–28.2] | | 32.4 [29.3–35.7] | 34.2 [33.2–35.1] | |
| Private and public | 15.2 [12.9–17.7] | 6.8 [6.4–7.3] | | 17.4 [14.9–20.2] | 7.1 [6.6–7.6] | |
| Other insurance | 2.5 [1.7–3.6] | 2.0 [1.8–2.3] | | 3.1 [2.9–3.6] | 3.3 [2.2–4.4] | |
| Uninsured | 3.4 [2.4–4.8] | 3.5 [3.2–3.9] | | 2.7 [3.2–3.9] | 3.6 [2.0–3.7] | |
| MSA status | | | .18 | | | .58 |
| Urban | 83.9 [81.6–86.0] | 82.3 [81.7–82.8] | | 83.1 [80.7–85.2] | 82.4 [81.8–83.0] | |
| Non-urban | 16.1 [14.1–18.4] | 17.7 [17.2–18.3] | | 16.9 [14.8–19.3] | 17.6 [17.0–18.2] | |
| Condition impacts on function | | | <.001 | | | <.001 |
| Never | 5.5 [4.2–7.1] | 38.6 [37.8–39.5] | | 6.2 [4.8–7.8] | 36.1 [35.2–37.0] | |
| Sometimes | 30.4 [27.1–34.0] | 42.0 [41.1–42.9] | | 27.2 [24.6–29.9] | 42.5 [41.5–43.4] | |
| Usually | 16.8 [14.5–19.4] | 7.9 [7.5–8.4] | | 19.0 [16.8–21.5] | 9.1 [8.5–9.6] | |
| Always | 47.3 [43.8–50.8] | 11.5 [10.9–12.1] | | 47.6 [44.4–50.9] | 12.4 [11.7–13.1] | |
| Received annual well-child checkup | | | .005 | | | .36 |
| Yes | 95.8 [94.0–97.1] | 97.6 [97.3–97.9] | | 98.5 [97.5–99.1] | 98.9 [98.6–99.0] | |
| No | 4.2 [2.9–6.0] | 2.4 [2.1–2.7] | | 1.5 [0.9–2.5] | 1.1 [1.0–1.4] | |

*Abbreviations ASD* autism spectrum disorder, *CI* confidence interval, *CSHCN* Children with Special Health Care Needs, *FPL* federal poverty level

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009–2010

[a] N/A reported in 2009–2010 because this derived category was unavailable in the 2009–2010 NS-CSHCN

## Need and Unmet Need for Therapy Services

Caregivers of children with ASD reported a significantly greater therapy need than caregivers of other CSHCN at both survey time points (Table 3). Among children who needed therapy, significantly more of those with ASD were reported to have an unmet therapy need in both 2005–2006 and 2009–2010 samples (Table 4). When comparing children with ASD across these cross-sectional time points, estimates and confidence intervals revealed a significantly greater percentage of children with ASD had a reported unmet therapy need in 2009 than in 2005 (24.7 vs. 17.9 %, respectively).

**Table 3** Need for therapy services for children with ASD compared to other CSHCN

| | 2005–2006 National Survey for Children with Special Health Care Needs | | | | 2009–2010 National Survey for Children with Special Health Care Needs | | | |
|---|---|---|---|---|---|---|---|---|
| | ASD (n = 2 088) % [95 % CI] | Other CSHCN (n = 36 285) | F[a] | *P* | ASD (n = 3 025) % [95 % CI] | Other CSHCN (n = 35 009) | F[b] | *P* |
| Needed therapy services in past year | | | 1417.16 | <.001 | | | 1476.18 | <.001 |
| Yes | 75.1<br>[72.1–77.9] | 19.4<br>[18.7–20.1] | | | 75.4<br>[72.7–77.9] | 21.5<br>[20.7–22.3] | | |
| No | 24.9<br>[22.1–27.9] | 80.6<br>[79.9–81.3] | | | 24.6<br>[22.1–27.3] | 78.5<br>[77.7–79.3] | | |

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009–2010

*Abbreviations ASD* autism spectrum disorder, *CSHCN* Children with Special Health Care Needs

[a] Design-based F (1, 38,264). Strata = 51, PSU = 38,315, subpopulation observations = 38,315

[b] Design-based F (1, 37,898). Strata = 102, PSU = 38,000, subpopulation observations = 38,000

**Table 4** Unmet need for therapy among children with ASD compared to other CSHCN

| | 2005–2006 National Survey for Children with Special Health Care Needs | | | | 2009–2010 National Survey for Children with Special Health Care Needs | | | |
|---|---|---|---|---|---|---|---|---|
| | ASD (n = 1 507) % [95 % CI] | Other CSHCN (n = 6 888) | F[a] | *P* | ASD (n = 2 190) % [95 % CI] | Other CSHCN (n = 7 287) | F[b] | *P* |
| Received all needed therapy services in past year | | | 9.25 | .002 | | | 25.68 | <.001 |
| Yes | 82.1<br>[78.7–85.0] | 87.1<br>[85.5–88.5] | | | 75.3<br>[72.1–78.3] | 83.7<br>[82.1–85.1] | | |
| No | 17.9<br>[15.0–21.3] | 12.9<br>[11.5–14.5] | | | 24.7<br>[21.7–27.9] | 16.4<br>[14.9–17.9] | | |

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009–2010

*Abbreviations ASD* autism spectrum disorder, *CSHCN* Children with Special Health Care Needs

[a] Design-based F (1, 8344). Strata = 51, PSU = 8395, subpopulation observations = 8395

[b] Design-based F (1, 9375). Strata = 102, PSU = 9477, subpopulation observations = 9477

### Frequency of Reported Access Problems

Significant differences between ASD and other CSHCN groups on type of access problem were seen only in the 2005–2006 survey year. In 2005, caregivers of children with ASD were significantly more likely to report that the therapy ‘provider did not know how to treat’ their child, and that therapy was ‘not available in their area/transportation problem’ (Table 5). The top four reasons across both survey years for an unmet need within both groups of children were: ‘cost too much’, ‘lack of school resources’, ‘health plan problem’, ‘not available in the area/no transportation’.

### Access to Therapy Services: Multivariate Results

After controlling for predisposing, enabling, and need characteristics, children with ASD were 1.4 times more likely than other CSHCN to have an unmet therapy need (Table 6). All sample children in 2009–2010, regardless of diagnosis, had greater odds of having an unmet therapy need than children sampled in 2005–2006. Children who

**Table 5** Therapy access problems by group and year

| | 2005–2006 National Survey for Children with Special Health Care Needs | | | | | 2009–2010 National Survey for Children with Special Health Care Needs | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | ASD | | Other CSHCN | | Design corrected F | ASD | | Other CSHCN | | Design corrected F |
| | % | 95 % CI | % | 95 % CI | | % | 95 % CI | % | 95 % CI | |
| *Provider access problems* | | | | | | | | | | |
| Not convenient times | | | | | 0.09 | | | | | 0.14 |
| No | 94.1 | 88.8–97.0 | 94.8 | 92.1–96.6 | | 89.9 | 85.2–93.2 | 90.8 | 87.2–93.5 | |
| Yes | 5.9 | 3.0–11.2 | 5.2 | 3.4–7.9 | | 10.2 | 6.8–14.8 | 9.2 | 6.5–12.8 | |
| Provider did not know how to treat | | | | | 12.21[b] | | | | | 0.08 |
| No | 94.2 | 88.9–97.0 | 98.6 | 97.6–99.1 | | 96.4 | 91.9–98.4 | 96.9 | 93.8–98.4 | |
| Yes | 5.8 | 3.0–11.1 | 1.4 | 0.9–2.4 | | 3.7 | 1.6–8.1 | 3.1 | 1.6–6.2 | |
| Dissatisfaction with provider | | | | | 0.59 | | | | | 0.18 |
| No | 94.8 | 85.9–98.2 | 91.5 | 83.1–95.9 | | 97.4 | 95.0–98.6 | 96.7 | 93.0–98.5 | |
| Yes | 5.2 | 1.8–14.1 | 8.5 | 4.1–16.9 | | 2.7 | 1.4–5.0 | 3.3 | 1.5–7.0 | |
| Cost too much | | | | | 0.28 | | | | | 2.70 |
| No | 82.8 | 75.3–88.3 | 84.8 | 80.4–88.3 | | 74.9 | 68.1–80.7 | 80.8 | 76.8–84.3 | |
| Yes | 17.3 | 11.7–24.7 | 15.2 | 11.7–19.6 | | 25.1 | 19.4–31.9 | 19.2 | 15.7–23.2 | |
| *Community access problems* | | | | | | | | | | |
| Not available in area/no transportation | | | | | 6.42[b] | | | | | 1.98 |
| No | 80.9 | 72.0–87.4 | 90.1 | 86.6–92.8 | | 85.2 | 79.8–89.3 | 89.0 | 85.7–91.6 | |
| Yes | 19.1 | 12.6–28.1 | 9.9 | 7.2–13.4 | | 14.8 | 10.7–20.2 | 11.0 | 8.4–14.3 | |
| Did not know where to go for therapy | | | | | 2.06 | | | | | 3.65 |
| No | 94.6 | 89.7–97.2 | 97.1 | 94.9–98.4 | | 95.4 | 89.8–98.0 | 98.3 | 96.8–99.1 | |
| Yes | 5.4 | 2.8–10.3 | 2.9 | 1.6–5.1 | | 4.6 | 2.0–10.2 | 1.7 | 0.9–3.2 | |
| Lack of school resources | | | | | 0.44 | | | | | 3.61 |
| No | 74.1 | 65.2–81.5 | 77.3 | 72.0–81.9 | | 80.0 | 73.5–85.2 | 86.0 | 82.5–88.9 | |
| Yes | 25.9 | 18.5–34.8 | 22.7 | 18.2–28.0 | | 20.0 | 14.8–26.5 | 14.0 | 11.1–17.5 | |
| *Insurance plan access problems* | | | | | | | | | | |
| No insurance | | | | | 0.43 | | | | | 0.06 |
| No | 94.0 | 87.6–97.2 | 92.1 | 88.4–94.7 | | 93.2 | 87.6–96.3 | 92.6 | 89.6–94.7 | |
| Yes | 6.0 | 2.8–12.4 | 7.9 | 5.3–11.6 | | 6.8 | 3.7–12.4 | 7.4 | 5.3–10.4 | |
| Health plan problem | | | | | 3.34 | | | | | 4.52[a] |
| No | 84.0 | 77.2–89.1 | 75.7 | 68.3–81.8 | | 83.6 | 77.6–88.2 | 89.6 | 86.4–92.1 | |
| Yes | 16.0 | 10.9–22.8 | 24.3 | 18.2–31.8 | | 16.4 | 11.8–22.4 | 10.4 | 7.9–13.6 | |
| Can’t find provider who accepts insurance | | | | | 3.04 | | | | | 3.98[a] |
| No | 93.3 | 87.2–96.7 | 97.0 | 94.5–98.4 | | 92.4 | 85.8–96.0 | 96.7 | 94.3–98.1 | |
| Yes | 6.7 | 3.3–12.9 | 3.0 | 1.6–5.5 | | 7.7 | 4.0–14.3 | 3.3 | 1.9–5.7 | |
| No referral | | | | | 1.06 | | | | | 0.23 |
| No | 98.8 | 96.8–99.6 | 97.8 | 95.6–98.9 | | 98.0 | 92.3–99.5 | 97.1 | 94.6–98.4 | |
| Yes | 1.2 | 0.5–3.2 | 2.3 | 1.1–4.4 | | 2.0 | 0.5–7.7 | 2.9 | 1.6–5.4 | |

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009–2010

*Abbreviations ASD* autism spectrum disorder, *CI* confidence interval, *CSHCN* Children with Special Health Care Needs

[a] $P \leq .05$

[b] $P \leq .01$

**Table 6** Multivariate logistic regression results associated with unmet need for therapy

| | Unmet need for therapy services | |
|---|---|---|
| | OR | 95 % CI |
| Child has other SHCN | Ref | |
| Child has current ASD | 1.42[b] | 1.18–1.71 |
| Surveyed in 2005–2006 | Ref | |
| Surveyed in 2009–2010 | 1.42[b] | 1.18–1.71 |
| Age (continuous) | 0.97[b] | 0.95–0.99 |
| Male | Ref | |
| Female | 1.27[b] | 1.05–1.53 |
| White | Ref | |
| Black race | 1.25 | 0.98–1.60 |
| Multiple race | 1.04 | 0.65–1.68 |
| Other race | 1.22 | 0.90–1.65 |
| Non-Hispanic ethnicity | Ref | |
| Hispanic ethnicity | 0.95 | 0.72–1.26 |
| <200 % FPL | 1.19 | 0.92–1.55 |
| 200–400 % FPL | 1.29[a] | 1.02–1.63 |
| >400 % | Ref | |
| Non-urban | Ref | |
| Urban | 1.10 | 0.90–1.35 |
| Private insurance | Ref | |
| Public insurance | 0.71[b] | 0.56–0.90 |
| Private and public insurance | 0.68[b] | 0.52–0.90 |
| Other comprehensive insurance | 1.02 | 0.62–1.69 |
| Uninsured | 1.72[b] | 1.15–2.56 |
| ‘Never’ condition affected ability to do things | Ref | |
| ‘Sometimes’ condition affected ability to do things | 1.16 | 0.84–1.61 |
| ‘Usually’ condition affected ability to do things | 1.93[b] | 1.37–2.71 |
| ‘Always’ condition affected ability to do things | 2.44[b] | 1.80–3.34 |
| Received annual well-child visit | Ref | |
| Did not receive annual well-child visit | 5.81[b] | 3.83–8.81 |

Model adjusted for sample type (landline, cellphone); used pooled data from both survey years of children with a reported unmet need for therapy

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009–2010

*Abbreviations FPL* federal poverty level, *OR* odds ratio

[a] Significance $P \leq .05$

[b] Significance $P \leq .01$

did not receive a needed well-child checkup in the past year were nearly six times more likely to have an unmet therapy need compared to children who received an annual well-child check. Other characteristics that increased the odds of having an unmet need across both groups included: younger age and female sex, greater functional limitation, and being uninsured. Being uninsured nearly doubled the odds of having an unmet therapy need compared to being privately-insured, however, children who were publically insured or who had both public and private insurance had less odds of reporting an unmet need compared to children with private insurance.

## Discussion

This is the first population-based study investigating unmet therapy need across two cross-sectional time points. Although a positive finding of our study was that greater than 75 % of children with ASD and CSHCN obtained all needed therapy across both time points, unmet need was greater in 2009 than in 2005 for all children. The unweighted percent of children with unmet therapy need increased 6.8 % for children with ASD from 2005 to 2009, but only 3.5 % for other CSHCN during the same time period, suggesting that unmet need increased more for children with ASD over the same time period. This trend warrants future evaluation due to extensive efforts to improve access and care for this population. From a policy perspective, the CAA of 2006 did not explicitly seek to increase access to therapy services, although a possible unintended effect of this law may have been in heightening awareness of ASD thus influencing parent perceptions of need for services, including therapy. It is possible and likely that other unobserved system and policy variables also influenced these results, leading to important implications for researchers and policymakers described below.

Andersen's Behavioral Model suggests that system and policy may impact access; in our study, unobserved service delivery system differences may have existed between 2005 and 2009, influencing caregiver reported unmet need. These include: state policies which impacted service provisions (e.g. autism insurance mandates, Medicaid autism waivers), provider availability in settings serving CSHCN and children with ASD, and the increasing prevalence of children with ASD entering the system between the two survey time points. Future research should examine the combined and separate effects of state-level policy on autism access, and should consider economic models (supply/demand) to further examine unmet therapy need.

The impact of the U.S. national recession on families' financial status [5] and disposable income to pay out-of-pocket co-pays or treatment costs may have impacted unmet therapy need for all children. There is some support for this in our findings. In 2009, the most frequently reported reason for not receiving therapy services in both groups was 'cost too much', and a greater percentage of parents of both groups reported this reason in 2009 than in 2005. Although poverty level was not associated with unmet therapy need, it is recognized that families of children with ASD have high out-of-pocket expenses for care [26], which may have influenced their decision to access therapy. Health policy has sought to emphasize mandates and waivers for private and public insurance funding for autism-related services, however, most therapy providers treating outside of school systems do not accept insurance unless they are associated with a pediatric hospital, paralleling other literature suggesting that mental health providers accept insurance less frequently than other physicians [4]. Thus, policymakers should consider alternative ways of incentivizing practitioners to provide care through existing insurance plans, perhaps including innovative practice models in which care teams include therapy practitioners who can bill for services as part of the team [18]. Additionally, health-related flexible spending accounts (FSA) allow families to receive reimbursement for non-covered medical services, but maximum limits for FSAs for families of CSHCN may need to be increased given evidence of large out-of-pocket expenses [26].

Overall, most of the children had received a well-child visit in the past year, a positive finding. Our finding that children forgoing well-child visits were nearly six times more likely to have an unmet need for therapy, even after adjusting for other factors, is new. This finding has relevance in that insurance requires physician referral for most OT and ST; additionally, the primary care physician is valuable in referral to community based services that include therapy [1]. Other research evaluating the impact of the medical home on high quality care and access to specialty care services in this population supports the importance of the primary care provider in ensuring access (e.g. [16]. The importance of this relationship should be examined in future research.

Our findings indicate that children in our study with public insurance had fewer unmet therapy needs than children with private insurance alone, suggesting that having public insurance is protective against unmet therapy need. Although our study was not causal, other research using administrative claims data found that children with public insurance have more therapy visit claims than children with private insurance [31]. Similarly, children with ASD living in states with generous Medicaid reimbursement rates have been found to be less likely to have access to care problems [29]. Differences in access based on type of insurance suggest that private insurance limits access for some children. This is a ripe area for future investigation.

Previous studies have been mixed with regard to whether predisposing characteristics contribute to unmet therapy need services. We found that younger children are more likely to display therapy access problems, something that has not been previously reported. Typically, early intervention and schools provide therapy to young children with functional difficulties, and in fact, nearly 25 % of expenditures for children with ASD are spent on related services such as therapy [9]. However, as the number of children with ASD has grown, schools and community resources are thinly stretched to accommodate more children at younger ages. Future research should examine specific access problems to early intervention and school. Educational policy is a future area for investigation.

We found no differences in reported unmet therapy need among racial and ethnic minorities, mirroring findings of Chiri and Warfield [10]. It has been suggested that cultural differences in perceived therapy need among minorities may influence the reporting of unmet need [22], and perceived therapy need should be identified as a potential source of reporting bias which could have impacted these results.

Lastly, our findings suggest that caregivers of children with greater reported functional difficulty have significantly greater likelihood of having an unmet therapy need.

Although caregiver perceptions may have influenced this finding, others have also demonstrated that child factors, specifically the presence of comorbid intellectual disability, results in higher service utilization and perceived unmet needs [33]. Greater functional needs of the child are associated with greater parent stress and burden; thus, this finding warrants further investigation.

## Limitations

We acknowledge several limitations. First, data gathered as part of the NS-CSHCN are based on caregiver-reported diagnosis which were not confirmed with specific diagnostic measures. Offsetting this limitation, parents engaging in survey research have been found to be reliable and accurate in corroborating actual diagnosis results [14]. Second, comparing two separate population-based surveys requires careful consideration, because each survey year is based on cross-sectional and not longitudinal data. Thus, the caregiver respondents were different for each survey year and differences in our outcome variable may be due to sample differences. Our approach, however, is considered appropriate and feasible for variables measured consistently at each time point [32], and our analyses adjusted for sample type. The NS-CSHCN is also weighted to adjust for population differences at each time point, a strength of using population-based data. The question ascertaining ASD diagnosis changed slightly between survey years, however, the reported prevalence of ASD in each survey year is consistent with existing prevalence rates, suggesting that this change in question structure had limited impact on the included cases. Third, the 2009 survey included a sample collected via cell-phone. Although adjustments were made within the weighting and analyses for sample type, it is possible that sampling differences may have impacted results.

## Implications

Across both study groups, unmet therapy need worsened across the two survey time points, warranting future investigation to determine if this trend continues. Although specific child factors were associated with unmet need (age, female gender, more greatly affected by condition), practitioners, researchers, and policymakers should consider mutable factors in future investigations addressing unmet therapy needs, including insurance, well-child visits, and future investigation into caregiver-reported access problems of cost, school resources, and availability of providers.

In addition, children with ASD continue to be significantly more likely than other CSHCN to have an unmet therapy need. Although the CAA of 2006 did not aim to directly impact specific service types, further work should evaluate the indirect influence this policy had on improving care and access. Policy analysis on the effects of state level autism insurance mandates and Medicaid autism waivers are warranted, as are future studies of educational funding and policy.

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### Compliance with Ethical Standards

**Conflict of interest** The authors declare that they have no conflict of interest.

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