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Profiling Health and Health-Related Services for Children With Special Health Care Needs With and Without Disabilities

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ABSTRACT

OBJECTIVE: The aims of this study were to profile and compare the health and health services characteristics for children with special health care needs (CSHCN), with and without disabilities, and to determine factors associated with unmet need.

METHODS: Secondary data analysis of the 2005–2006 National Survey of Children with Special Health Care Needs was conducted. The sociodemographics, health, and health services of CSHCN with and without disabilities were compared. Multivariable logistic regression was employed to examine factors associated with unmet need for health services.

RESULTS: Children from minority racial and ethnic groups and children living in or near poverty were over-represented among CSHCN with disabilities, compared with other CSHCN. Statistically higher percentages of CSHCN with disabilities had behavioral problems (39.6% vs 25.2%), anxiety/depressed mood (46.1% vs 24.0%), and trouble making/keeping friends (38.1% vs 15.6%) compared with other CSHCN. Thirty-two

percent of CSHCN with disabilities received care in a medical home compared with 51% of other CSHCN. CSHCN with disabilities had higher rates of need and unmet need than other CSHCN for specialty care, therapy services, mental health services, home health, assistive devices, medical supplies, and durable medical equipment. The adjusted odds of unmet need for CSHCN with disabilities were 71% higher than for other CSHCN.

CONCLUSION: CSHCN with disabilities had more severe health conditions and more health services need, but they less commonly received care within a medical home and had more unmet need. These health care inequities should be amenable to policy and health service delivery interventions to improve outcomes for CSHCN with disabilities.

KEYWORDS: children with special health care needs; disabilities; medical home; unmet need

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WHAT'S NEW

Children with special health care needs (CSHCN) with disabilities are identified as a distinct group of CSHCN because of their sociodemographic, health, and health services characteristics. CSHCN with disabilities had more psychosocial problems and health service needs than other CSHCN. We also document inequities in health services by highlighting the rates of unmet need and low percentages of care within a medical home for CSHCN with disabilities.

CHILDREN WITH SPECIAL health care needs (CSHCN) are those children with chronic physical, developmental, emotional, or behavioral conditions who need or use health and related services of a type or amount beyond that typically required by children.¹ A child can qualify as having special health care needs if he/she has a chronic condition that has lasted or is expected to last at least 1 year and is associated with at least 1 of the following 5 consequences: needing or using prescription medication; needing or using more medical care, mental health, or educational services than is usual for most children of

the same age; being limited or prevented in any way in his/her ability to do the things most children of the same age can do; needing or receiving special therapy; and/or needing or receiving treatment or counseling for any emotional, developmental, or behavioral problem.² Over 20% of CSHCN qualify because they are limited or prevented in their abilities to do things that most children of the same age can do³ and, thus, are considered to be disabled based on the International Classification of Functioning, Disability and Health (ICF) framework for understanding disability.⁴

CSHCN with disabilities are a special and vulnerable subset of CSHCN because the consequences of having a disabling health condition can be profound.⁵ Children with disabilities are reported to have extensive health care needs, high rates of health services utilization and costs, and poorer access to needed health services.^{6–8} Furthermore, the consequences related to disability in childhood extend beyond experiences with the health care system and can include difficulties with school and participation in life events.^{3,9} These consequences can have long-term impacts on health outcomes, life opportunities, and participation in adulthood.¹⁰ Because of the negative

impacts of disability, it is important for pediatric health providers to understand the population of children with disabilities to provide optimal health care and advocate for the services and assistance they need to be successful in life.

Since the operationalization of the new definitional framework for CSHCN over a decade ago, fewer health services research studies specifically focus on children with disabilities, and only a handful of recent studies have focused on the subgroup of CSHCN with disabilities.^{2,8,9,11,12} Instead, most studies have focused on the general population of CSHCN and have identified issues around access, health insurance, quality of medical care, financial impacts on families, and health disparities.^{12,13–16} Few studies have looked at services specifically related to children with disabilities/functional limitations, such as durable medical equipment and assistive aids, although some studies identify the presence of functional limitations as a risk factor for unmet need and difficulty with health care access.^{8,9,17,18} Therefore, a gap in the health services literature exists for CSHCN with disabilities. The purpose of this project is to fill the gap in the literature by profiling and comparing CSHCN with disabilities to other CSHCN to identify sociodemographic, health, and health services differences and to determine factors associated with unmet need. We hypothesize that CSHCN with disabilities have more severe and less stable health conditions than other CSHCN and have more extensive health services needs, but have higher rates of unmet needs and less commonly receive care within a medical home than other CSHCN. We further hypothesize that after controlling for health condition severity and sociodemographic characteristics often associated with health care inequities, that CSHCN with disabilities have increased odds of unmet service need.

METHODS

DATASET

The 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) is a nationally representative sample of CSHCN that was conducted by the National Center for Health Statistics (NCHS), the Maternal and Child Health Bureau, and the Centers for Disease Control and Prevention between April 2005 and February 2007.¹⁹ The NS-CSHCN offers a special opportunity to evaluate CSHCN with disabilities because it is the most extensive and up-to-date version of these periodic surveys of CSHCN.¹⁹ The State and Local Area Integrated Telephone Survey mechanism was used to randomly identify 4 million household phone numbers. A computer-assisted telephone interview system was used to screen households for eligible children and to administer the CSHCN survey. From the 192 083 households with children, 364 481 children were screened for having special health care needs via the CSHCN Screener and 42 332 (11.6%) qualified. If a household had more than 1 identified child with special health care needs, 1 child was randomly chosen to be included in the sample.³ For these children, full

interviews were conducted with the adult in the household most familiar with the child's special health care needs (usually the mother), with a completion rate of 96.2%.³

CONCEPTUALIZING DISABILITY AND HEALTH SERVICES

To frame our research we used 2 conceptual models. The first model, the ICF, provided a framework for classifying CSHCN as having disabilities or not. Individuals who are limited in their ability to do what people are typically able to do can be considered to have disabilities at 1 or more of the following levels: bodily impairments, activity limitations, or participation restrictions.²⁰ This robust framework is well aligned with the CSHCN Screener, which identifies CSHCN who are considered by their caregiver to be limited in their ability to do the things that most children of the same age can do because of a medical, behavioral, emotional, or developmental condition that has lasted or is expected to last at least 1 year.² Based on these CSHCN Screener questions, we dichotomized CSHCN into those with disabilities and those without. We note that the ICF framework for disability relates health conditions to functioning but does not require the identification of a specific etiology nor does it require a minimum amount of time for the condition to be present.²⁰ Because disability among CSHCN is more narrowly defined than in the ICF framework, the NS-CSHCN population estimates may subsequently be lower than other reports.

The second model, the behavioral model of health services use, framed our analyses of health utilization and unmet need. This model frames health service use and access to health services based on predisposing characteristics and enabling resources.²¹ Individuals with the need for health services may have those needs met through realized access or might have unmet needs and experience health care inequities.²² For example, the presence of a mobility limitation might predispose an individual to need durable medical equipment, and their insurance might act as an enabling factor. There are certainly other factors that hinder or enable access. Therefore, we used this model to guide us in determining which factors should be included in our multivariable logistic regression analysis of presence of unmet need. Using these 2 frameworks, the ICF and the behavioral model of health services use, we examined factors that relate to the experience of disability in childhood.

SOCIODEMOGRAPHIC, HEALTH, AND PSYCHOSOCIAL CHARACTERISTICS

The sociodemographic variables of interest for this study included gender, age, race/ethnicity, income, insurance status, household composition, and highest educational attainment in the household. Age was categorized into the following groups: 0 to 4 years (preschool age), 5 to 13 years (school age), and 14 to 17 years (high school age). Race/ethnicity was categorized into 4 groups: white non-Hispanic, black non-Hispanic, Hispanic, and other. Income was divided into 3 categories by using federal poverty level (FPL) criteria: less than 200% FPL, 200% to 399% FPL, and 400% or greater of the FPL. Insurance

status was categorized into the following categories: full year private insurance, full year public insurance, full year private and public coverage, full year other comprehensive insurance, and uninsured at the time of the interview. Household composition included the following categories: single mother, 2 parent, and other type of household composition. The highest educational attainment in the household was defined as less than high school, graduated from high school, and more than high school.

We identified 2 questions from the survey to describe the health status of CSHCN with and without disabilities. Parents/caregivers reported the severity of their child's health conditions/problems (no severity, mild, moderate, and severe) and how stable the child's health was (changed all the time, changed once in a while, or was usually stable). In addition, we compared the percentages of CSHCN with and without disabilities whose parents reported that their child felt anxious or depressed, had behavior problems, and/or had trouble keeping and making friends. As a measure of health impact, we report the percentage of CSHCN with and without disabilities who missed 20 or more days of school because of their health problems.

HEALTH SERVICES: THE MEDICAL HOME, SERVICE NEED, AND UNMET NEED

To evaluate health services, we measured care within a medical home, and need and unmet need for a variety of services. The presence of a medical home was operationalized using the following 5 Maternal and Child Health Bureau criteria: having a personal doctor or nurse, having a usual source of care, receiving family-centered care, having no problem with getting referrals when needed, and receiving effective care coordination when needed.^{23,24} For our analysis, having a usual source of care, having a personal doctor or nurse, and having family-centered care were dichotomized as present or not. The criterion of having no problems with referrals was measured as yes, no, and did not require; therefore, the percentage of children getting the service when needed was calculated as a fraction of those who reported needing it. The criterion for care coordination was calculated in the same way as having no problems with referrals. Therefore, both the referral outcome and care coordination outcome were considered met if individuals did not have a need, or when need was reported, it was also reported met. We also created a composite measure to classify children as receiving care in a medical home when all 5 criteria were met. To address need, we identified whether the sample child used specialty care; prescription medication; physical therapy, occupational therapy, and/or speech therapy; mental health care; home health care; mobility aids; communication aids; medical supplies; durable medical equipment; and/or respite care in the 12 months preceding the survey. When one of the aforementioned items/services were needed but not received in the 12 months preceding the survey, the need was considered unmet. Additionally, we created a composite measure of unmet need as the presence of 1 or more of the aforementioned types of unmet need for our multivariable analysis.

STATISTICAL ANALYSIS

We performed univariate and bivariate analyses to evaluate the differences between CSHCN with and without disabilities. Survey weights provided by the NCHS^{19,25} were used to obtain population level estimates. Multivariable logistic regression was conducted to identify factors associated with unmet need for services based on the behavioral model of health services use. We used the multiple imputation files available from the NCHS to account for the 9% missing income values²⁶ and did not otherwise impute values of missing covariates. Instead, we compared the fit of models that included and excluded missing covariate values, and we found negligible differences between parameter estimates or confidence intervals for any covariate. We performed a Hosmer-Lemeshow goodness of fit test designed to take into account the complex survey design and found that our model had a good fit, with $P = .44$. The adjusted estimated prevalences of unmet need among CSHCN were calculated from the regression model. All analyses were conducted using STATA 11 (StataCorp, College Station, TX) to account for the complex nature of the survey design and to appropriately weight the estimates. The Committee on Human Research at the University of California, San Francisco, approved this study in the exempt category.

RESULTS

SOCIODEMOGRAPHICS, HEALTH, AND PSYCHOSOCIAL CHARACTERISTICS

We estimate that in 2005 to 2006, 13.9% of children in the United States had special health care needs. Of these children, 21.5% qualified as having disabilities for this study because they had at least 1 functional limitation, as shown in Table 1. This equates to 2.2 million children with disabilities associated with chronic conditions and 8 million other CSHCN. Boys, minority children, children living near or in poverty, uninsured and publicly insured children, children living in households headed by a single mother, and children living in homes in which the highest educational attainment was high school or less were over-represented in the sample of CSHCN with disabilities compared with CSHCN without disabilities. For example, 52.2% (95% confidence interval [CI], 50.3–54.1) of CSHCN with disabilities live in homes with incomes below 200% of the FPL compared with 37.9% (95% CI, 36.9–38.9) of CSHCN without disabilities.

CSHCN with disabilities had conditions that “changed all the time” 4 times as frequently as other CSHCN, and their conditions were rated as “severe” 7 times as frequently (Table 1). Feeling anxious and/or depressed was twice as commonly reported for CSHCN with disabilities than other CSHCN (46% vs 24%; $P < .001$). Additionally, nearly 40% of CSHCN with disabilities had behavioral problems compared with only 25% of other CSHCN; $P < .001$. Similarly, 38% of CSHCN with disabilities had trouble making or keeping friends compared with only 16% of other CSHCN; $P < .001$. Of CSHCN with disabilities, 12% missed more than 3 weeks

Table 1. Distributions of Sociodemographic and Child Health and Related Characteristics of CSHCN by Disability Status*

Characteristic	CSHCN With Disabilities		CSHCN Without Disabilities	
	Sample Distribution n = 8739 Percentage (95% CI)†	Estimated Population (In Millions)	Sample Distribution n = 31 984 Percentage (95% CI)	Estimated Population (In Millions)
All	21.5 (20.8–22.1)	2.2	78.5 (77.9–79.2)	8.0
Gender‡				
Boys	61.8 (60.0–63.5)	1.4	58.7 (57.8–59.6)	4.7
Girls	38.2 (36.5–40.0)	0.8	41.3 (40.4–42.2)	3.3
Age, y				
0–4	15.5 (14.3–16.9)	0.3	16.3 (15.5–17.0)	1.3
5–13	55.4 (53.7–57.2)	1.2	56.1 (55.1–57.0)	4.5
14–17	29.0 (27.4–30.7)	0.6	27.7 (26.9–28.5)	2.2
Race/ethnicity‡				
White non-Hispanic	62.2 (60.4–64.0)	1.4	66.2 (65.2–67.1)	5.3
Black non-Hispanic	17.9 (16.5–19.4)	0.4	15.8 (15.1–16.6)	1.3
Hispanic	12.7 (11.4–14.1)	0.3	11.5 (10.9–12.2)	0.9
Other	7.2 (6.4–8.2)	0.2	6.5 (6.1–7.0)	0.5
Income‡				
<200% FPL§	52.2 (50.3–54.1)	1.1	37.9 (36.9–38.9)	2.8
200%–399% FPL	27.0 (25.4–28.7)	0.54	31.0 (30.1–31.9)	2.3
≥400% FPL	20.8 (19.4–22.3)	0.42	31.1 (30.3–32.0)	2.3
Insurance status‡				
Private	45.5 (43.7–47.2)	1.0	62.9 (61.9–63.8)	5.0
Public	36.7 (35.0–38.5)	0.8	25.7 (24.8–26.6)	2.1
Private and public	11.7 (10.7–12.9)	0.3	6.2 (5.7–6.6)	0.5
Other insurance	1.9 (1.5–2.3)	0.04	2.0 (1.8–2.3)	0.2
Uninsured	4.2 (3.9–5.0)	0.09	3.3 (3.0–3.6)	0.3
Household composition‡				
Two parent	59.5 (57.7–61.3)	1.3	66.4 (65.5–67.3)	5.1
Single mother	35.3 (33.5–37.1)	0.7	28.4 (27.5–29.3)	2.2
Other	5.2 (4.6–6.0)	0.1	5.2 (4.8–5.6)	0.4
Highest educational attainment in the home‡				
Less than high school	8.7 (7.6–9.8)	0.2	6.3 (5.8–6.9)	0.5
High school	27.7 (26.0–29.4)	0.6	21.8 (21.0–22.7)	1.8
Greater than high school	63.7 (61.9–65.4)	1.4	71.8 (70.9–72.7)	5.8
Condition severity‡				
None/not applicable	2.4 (2.0–3.0)	0.05	18.5 (17.8–19.2)	1.5
Minor	18.7 (17.4–20.0)	0.4	50.1 (49.2–51.1)	4.0
Moderate	53.2 (51.4–55.0)	1.2	27.6 (26.7–28.4)	2.2
Severe	25.7 (24.2–27.3)	0.6	3.9 (3.5–4.3)	0.3
Condition stability, health care needs‡				
Were usually stable	48.9 (47.1–50.7)	1.1	70.5 (69.6–71.4)	5.6
Changed once in a while	35.6 (34.0–37.3)	0.8	25.8 (25.0–26.7)	2.1
Changed all the time	15.5 (14.2–16.8)	0.3	3.7 (3.2–4.1)	0.3
Missed ≥20 days of school‡	12.0 (10.9–13.3)	0.2	3.3 (3.0–3.8)	0.2
Feels anxious or depressed‡	46.1 (44.3–47.9)	1.0	24.0 (23.2–24.8)	1.9
Has behavioral problems‡	39.6 (37.8–41.4)	0.8	25.2 (24.4–26.0)	2.0
Has trouble making or keeping friends‡	38.1 (36.3–39.9)	0.8	15.6 (14.9–16.3)	1.2

*CSHCN = children with special health care needs.

†CI = confidence interval.

‡Chi-squared and *t* tests were used to identify statistically significant differences ($P < .01$) between CSHCN with and without disabilities.

§FPL = federal poverty level.

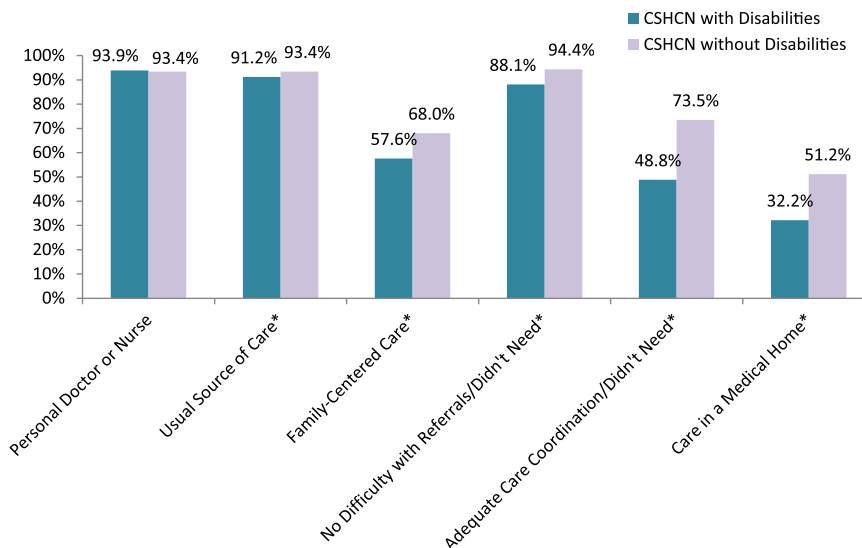
of school compared with 3.3% of CSHCN without disabilities; $P < .001$.

HEALTH SERVICES: THE MEDICAL HOME, SERVICE NEED, AND UNMET NEED

When the medical home was measured as a composite, only 32.2% of CSHCN with disabilities were receiving care within a medical home, compared with over half of other CSHCN (Figure 1). Over 93% of CSHCN reported having a personal doctor or nurse, regardless of disability status. On all other components of the medical home,

statistically significant differences were noted such that CSHCN with disabilities less commonly reported meeting the component criteria. Most notably, only 48.8% of CSHCN with disabilities reported adequate care coordination compared with 73.5% of other CSHCN.

As shown in Table 2, CSHCN with disabilities needed fewer prescription medications but a statistically significant quantity of more of every other item/service studied. Overall, 94.9% of CSHCN without disabilities and 96.7% of CSHCN with disabilities had an identified need for at least 1 item/service. As a composite measure of



*statistically significant difference, p -value<0.01

Figure 1. Percentages of CSHCN with and without disabilities who meet medical home criteria. *Statistically significant difference; $P < .01$. CSHCN indicates children with special health care needs.

unmet need, 22.8% (95% CI, 21.3–24.3) of CSHCN with disabilities had an unmet need for at least 1 of the aforementioned items/services compared with 7.4% (95% CI, 6.9–7.9) of other CSHCN. The unadjusted odds of having at least 1 unmet need for the aforementioned items/services was 3.71 (95% CI, 3.30–4.16) for CSHCN with disabilities compared with other CSHCN. CSHCN with disabilities has statistically higher odds of unmet need for the following services: prescription medication; specialty care; mental health services; physical therapy, occupational therapy, and/or speech therapy; medical supplies; durable medical equipment; and communication aids.

The adjusted odds of having at least 1 unmet need was 1.68 (95% CI, 1.45–1.94) for CSHCN with disabilities compared with other CSHCN (Table 3). Other child level predictors of unmet need included the “other” race designation, living below 400% of the FPL, increased condition severity levels, and having health care needs that were not usually stable. The family level predictors of unmet need were living in a home headed by a single mother and living in a home where the highest educational attainment level was less than high school. The health systems factors of being uninsured and not receiving care within a medical home were associated with increased adjusted odds of unmet need, 3.03 (95% CI, 2.33–3.95) and 3.40 (95% CI, 2.87–4.03), respectively. The adjusted estimated prevalences of having at least 1 unmet need were highest among CSHCN with severe health conditions (32.0%), CSHCN with conditions that were unstable (24.3%), CSHCN who were uninsured (25.4%), and CSHCN with disabilities (18.6%); as shown in Table 3.

DISCUSSION

Our analysis demonstrates that CSHCN are a distinct subset of CSHCN. Because of their higher rates of severe health conditions, psychosocial issues, and unmet need,

CSHCN with disabilities could benefit from focused attention to address their needs in the health and social realms. We found that CSHCN with disabilities differ from other CSHCN in many ways. Among CSHCN with disabilities, there is an over-representation of boys, blacks, children covered by public insurance, uninsured children, and those living in relative poverty. These differences are even more alarming considering the known sociodemographic disparities between CSHCN and children without special health care needs.^{6,25–28} We also observed that CSHCN with disabilities had more severe and less stable health conditions than other CSHCN. Bramlett and colleagues⁸ categorized CSHCN by functional status and also found differences between CSHCN with functional limitations and those without in terms of health status and health complexity. This is not unexpected, because as conditions such as asthma or cystic fibrosis become more severe, they more likely will limit children’s activities. Conversely, though, a child with mild cerebral palsy might be considered to be very healthy and stable but have disabilities in multiple functional domains. Therefore, practitioners should consider how factors that lead to disability can be mitigated and if stabilizing the child’s health condition might improve functional outcomes.

In addition to the relationships between disability status and condition severity and stability, we found that CSHCN with disabilities more commonly had psychosocial issues compared with other CSHCN. CSHCN with disabilities had more problems with behavior, feeling anxious or depressed, and trouble making or keeping friends. These findings have important practice implications. With the knowledge that CSHCN with disabilities more commonly experience psychosocial problems, health care providers can screen those with disabilities more closely to identify and make recommendations to address psychosocial issues as needed. Addressing psychosocial issues early may help lessen the long-term effects on mental health and

Table 2. Reported Need and Unmet Need for Services for CSHCN, With and Without Disabilities*

Type of Service or Item	Percentage With Service Need Present			Percentage With Unmet Need for Services		
	CSHCN With Disabilities n = 8719	CSHCN Without Disabilities n = 32 004	CSHCN With Disabilities Compared to Other CSHCN Unadjusted OR (95% CI)†	CSHCN With Disabilities	CSHCN Without Disabilities	CSHCN With Disabilities Compared to Other CSHCN Unadjusted OR (95% CI)
Prescription medication n = 35 179	84.5	86.9	0.82 (0.74–0.92)	3.6	1.4	2.62 (1.97–3.47)
Specialty care n = 21 064	67.6	47.4	2.32 (2.13–2.52)	8.6	4.1	2.25 (1.81–2.79)
Mental health n = 10 171	33.7	22.6	1.74 (1.59–1.90)	17.9	13.8	1.36 (1.11–1.68)
PT/OT/speech therapy** n = 9305	51.3	15.1	5.92 (5.43–6.48)	16.6	10.9	1.63 (1.30–2.05)
Medical supplies n = 7588	29.4	15.7	2.24 (2.04–2.46)	3.9	1.8	2.26 (1.39–3.67)
Durable medical equipment n = 4662	20.8	8.9	2.70 (2.41–3.02)	6.5	2.2	3.03 (1.71–5.38)
Respite care n = 1855	14.3	1.9	8.69 (7.19–10.50)	50.5	43.0	1.35 (0.93–1.95)
Home health n = 1826	11.4	2.6	4.82 (4.06–5.73)	12.9	8.0	1.71 (1.00–2.91)
Mobility aids n = 1823	11.0	2.7	4.53 (3.82–5.37)	9.8	4.2	2.48 (1.00–6.15)
Communication aids n = 898	8.1	0.6	14.99 (11.18–20.09)	26.4	14.6	2.09 (1.08–4.03)
At least 1 of the listed identified n = 39 020	96.7	94.9	1.60 (1.31–1.95)	22.8	7.4	3.71 (3.30–4.16)

CSHCN = children with special health care needs.

*If need was identified as present, the survey asked if that need had been met. Unmet need represents when the service was identified as needed and not met.

**PT = physical therapy; OT = occupational therapy

†OR = odds ratio; CI = confidence interval.

Table 3. Adjusted Estimated Prevalences and Adjusted Odds Ratios of Unmet Need for at Least 1 Health Service/Item

Characteristic	Adjusted Estimated Prevalences* of Unmet Need Percentage (95% CI)†	Adjusted Odds* of Unmet Need (95% CI)
Presence of disability		
No	4.5 (4.0–5.2)	REF‡
Yes	18.6 (17.0–20.3)	1.68 (1.45–1.94)
Gender		
Girls	5.7 (5.0–6.7)	REF
Boys	6.5 (5.8–7.4)	0.98 (0.85–1.13)
Age, y		
0–4	4.8 (3.9–6.0)	REF
5–13	6.3 (5.6–7.2)	1.14 (0.92–1.41)
14–17	6.7 (5.8–7.8)	1.26 (1.00–1.58)
Race/ethnicity		
White non-Hispanic	5.5 (4.9–6.3)	REF
Black non-Hispanic	7.2 (6.0–8.7)	0.73 (0.60–0.91)
Hispanic	8.8 (7.3–10.6)	0.92 (0.75–1.14)
Other	9.8 (7.8–12.2)	1.34 (1.05–1.72)
Income		
<200% FPL§	12.0 (10.8–13.2)	2.19 (1.73–2.77)
200%–399% FPL	5.6 (4.8–6.5)	1.43 (1.15–1.77)
≥400% FPL	3.3 (2.7–4.0)	REF
Insurance status		
Private	4.4 (3.8–5.1)	REF
Public	10.7 (9.6–12.1)	0.98 (0.80–1.20)
Private and public	12.7 (10.5–15.4)	1.10 (0.85–1.41)
Other insurance	5.4 (3.6–8.1)	1.01 (0.66–1.55)
Uninsured	25.4 (21.3–30.0)	3.03 (2.33–3.95)
Household composition		
Two parent	5.0 (4.4–5.8)	REF
Single mother	10.4 (9.2–11.6)	1.23 (1.05–1.44)
Other	7.6 (5.9–9.6)	1.08 (0.83–1.42)
Highest educational attainment in the home		
Less than high school	10.5 (8.2–13.5)	1.47 (1.09–1.98)
High school	7.6 (6.5–8.8)	1.05 (0.77–1.44)
More than high school	5.8 (5.1–6.6)	REF
Condition severity		
None/not applicable	1.5 (0.9–2.5)	REF
Minor	4.2 (3.6–4.9)	2.12 (1.28–3.50)
Moderate	13.6 (12.5–14.8)	4.35 (2.67–7.08)
Severe	32.0 (28.9–35.3)	8.37 (5.01–13.97)
Condition stability-health care needs		
Were usually stable	4.4 (3.8–5.1)	REF
Changed once in a while	10.9 (9.7–12.1)	1.42 (1.22–1.65)
Changed all the time	24.3 (20.7–28.3)	1.62 (1.27–2.07)
Care within the medical home		
Presence	2.6 (2.2–3.2)	REF
Absence	13.6 (12.5–14.8)	3.40 (2.87–4.03)

*Adjusted for all other variables in the model.

†CI = confidence interval.

‡REF = referent group.

§FPL = federal poverty level.

well-being.²⁹ There is also a need to study more closely the factors that contribute to the differential experience of psychosocial problems between CSHCN with disabilities and other CSHCN in order to intervene on behalf of children in terms of their psychosocial well-being.

We also found that CSHCN with disabilities also experience health care inequities when compared with other CSHCN. Despite having increased need for health services, CSHCN with disabilities had more unmet need and were less commonly receiving care within a medical home. The lack of assistance with care coordination was especially notable. Bramlett and colleagues⁸ also found

that CSHCN with functional limitations experienced health care inequities in terms of insurance adequacy. According to the behavioral model of health service use, a multitude of factors may contribute to health care inequities.^{21,22,30} Our multivariable model points to condition severity as being the most strongly associated with unmet need. But even when controlling for condition severity, disability status was a predictor of unmet need, and a significantly higher percentage of CSHCN with disabilities had at least 1 unmet need than other CSHCN. This indicates that although attending to severity is important, examining health factors beyond the condition

itself is important for understanding health inequities. Both excess needs and excess unmet needs should be considered when tailoring programs and interventions to maximize the health and well-being of CSHCN with disabilities. Policies and practices that address unmet need are particularly relevant to CSHCN with disabilities because of the long-term potential impacts of unrealized access to care that could negatively impact health outcomes and participation in life events. Additionally, we found that the family characteristics of living in or near poverty, having lower educational attainment levels in the home, and living in single mother households increased the odds of unmet need. Practitioners should be cognizant of these risk factors because these families are often disadvantaged in a multitude of ways that may limit their success in their interactions with the health care system. Conversely, the enabling factors of having care within a medical home and having health insurance were associated with decreased odds of unmet need. These associations were expected and have been shown in the literature previously for CSHCN.^{31,32} Thus, our findings add credence to the national call to address health insurance adequacy and care within a medical home for CSHCN with and without disabilities.

LIMITATIONS

In this study we used a screening tool through which parents/guardians identified children who had limitations in their ability to do the things that other children of the same age can do. The CSHCN Screener may not capture all children with disabilities, especially children with relatively mild functional limitations. Furthermore, by limiting our sample to CSHCN, we might have underestimated the number of children with disabilities. We note that the national estimates of disability in childhood vary substantially. Using 2000 Medical Expenditures Panel Survey (MEPS) data, Newacheck and colleagues³³ estimated that 7.3% of children have disabilities when *disability* is defined as a social role limitation or based on the receipt of special services. Nageswaran and colleagues⁹ found that 60% of the estimated 12.8% CSHCN in the United States have functional limitations using the NS-CSHCN 2001. These differences indicate that defining and measuring disability in childhood likely requires refinement and consensus building for improved uniformity. And lastly, we used a cross-sectional survey for our analyses, thus we are limited in our ability to draw conclusions from the data because we are only able to identify associations. Further research is necessary to identify causal relationships between child, family and health systems factors and health care inequities for CSHCN with disabilities.

CONCLUSION

Our study highlights that the health and social challenges faced by CSHCN are more problematic for those with disabilities than those without. Furthermore, despite having more health services needs, CSHCN with disabilities have more unmet need and are not commonly receiving care within a medical home. Pediatric health

providers should be cognizant of these findings and work to address the differences in health and health care delivery in their practices and community settings. Based on the differences noted between CSHCN with and without disabilities, we conclude that special attention needs to be given to those with disabilities to ensure that their health is maximized and the negative impacts of disability are minimized. Our findings also point to the need for continued research on this population to evaluate disparities and identify areas of intervention that successfully ameliorate the negative health and social consequences associated with disabilities and improve health services delivery and access.

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