

Health Care Changes for Children with Special Health Care Needs, 2005–2011

Thomas Sannicandro¹ · Susan L. Parish¹  · Esther Son^{1,2} · Robyn M. Powell¹

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Abstract *Objective* This study compared health care utilization of children with special health care needs in 2005/06 and 2009/10. *Methods* Using data from the National Survey of Children with Special Health Care Needs, this study compared the health care utilization of children with special health care needs in 2005/06 ($n = 40,723$) and 2009/10 ($n = 40,242$). Descriptive statistics characterize the sample during the 2005/06 and 2009/10 surveys. Logistic regression models examined the unmet needs for specific health care and support services, delayed care, coordinated care, and medical home. *Results* Compared to 2005/06, in 2009/10 children with special health care needs had greater unmet dental and therapy needs and less care coordination of health services as well as access to medical home services. *Conclusions* These findings indicate that additional measures are needed to improve the health care access of children with special health care needs.

Keywords Health care utilization · Health services · Children with special health care needs · Disability

Abbreviations

NS-CSHCN National Survey of Children with Special Health Care Needs
FPL Federal poverty level

✉ Susan L. Parish
slp@brandeis.edu

¹ Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University, 415 South Street, MS 035, Waltham, MA 02454, USA

² Department of Social Work, City University of New York at Staten Island, New York, NY, USA

Significance

The findings suggest that children with special health care needs face increased barriers to receiving appropriate health care services.

Introduction

In the last two decades, there has been an increased focus by policymakers on improving health care services for children with special health care needs (Lotstein et al. 2005). According to the Maternal and Child Health Bureau, children with special health care needs are defined as those who “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al. 1998). In terms of both size and need, this population is significant. Indeed, an estimated 11.2 million children in the United States under the age of 18 have special health care needs (US Department of Health 2013).

Previous research indicates that children with special health care needs use more health care services than typically developing children. A 2004 study found that 74 % of children with special health care needs required routine medical care and 51 % needed subspecialty physician care (Mayer et al. 2004). Moreover, children with severe limitations in daily activities are more likely to experience unmet needs than children who have fewer limitations (Chiri and Warfield 2012). In addition, children with severe limitations in daily activities are at increased risk of receiving delayed or neglected care and are less likely to access medical home services and have a greater need of

care coordination (Flores 2010; Huang et al. 2005; Magana et al. 2012; Strickland et al. 2009). There have also been racial and ethnic disparities, with Black and Latino parents significantly less likely than White parents to report that their provider was sensitive to the family's values and spent enough time with their child (Magaña et al. 2015).

This study contributes to the understanding of this population's unmet medical needs by comparing health care utilization of children with special health care needs between 2005 and 2011. We hypothesized that health care service utilization and quality improved over this time period because of increased public policy attention to improving children's health care and access to medical home services. We tested this hypothesis by comparing data from the 2005/06 and 2009/10 surveys of the National Survey of Children with Special Health Care Needs (NS-CSHCN).

Methods

Data Source

This study analyzed and compared data drawn from the 2005/06 and 2009/10 surveys of the NS-CSHCN. Information on the design and methodology of the NS-CSHCN have been described extensively elsewhere (Kogan et al. 2009). In short, funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, the NS-CSHCN was designed to provide national and state-specific prevalence estimates of children with special health care needs as well as information on needs and health care utilization of this population (Blumberg et al. 2008; Bramlett et al. 2014). The NS-CSHCN was first conducted in 2001. Two subsequent surveys have since been conducted: 2005/06 and 2009/10. The present study analyzed data from the 2005/06 and 2009/10 surveys.

Study Sample

Subjects for the present study included all children in the 2006/06 ($n = 40,723$) and 2009/10 ($n = 40,242$) surveys of the NS-CSHCN. Households were randomly selected based on telephone numbers generated for the National Immunization Survey and screened for children under the age of 18 with special health care needs (Blumberg et al. 2008; Bramlett et al. 2014). Children with special health care needs were identified based on increased utilization of health care services due to a condition expected to last more than one year (Bethell et al. 2011). This national data set was collected on a stratified basis so that each state would have approximately 750 respondents in the sample (Blumberg et al. 2008; Bramlett et al. 2014).

The 2009–2010 NS-CSHCN included a sample of cell phone numbers in order to increase coverage of the cell-phone-only population; the 2005–2006 NS-CSHCN did not. Sampling bias based on the type of phone (landline vs. cell phone) was controlled for through the use of a special sampling weight for only the 2009–2010 datasets (Centers for Disease Control and Prevention and Local Area Integrated Telephone Survey 2009).

Measures

Dependent Variables

We examined three areas of unmet needs for children with special health care needs: referral to services, dental care, and therapy. The referral variable reflects the need for a referral and difficulty in getting the referral. Referrals are for specialty care or services (The Child and Adolescent Health Measurement Initiative 2012). For the dental care variable, the respondent had trouble getting other dental care, such as orthodontial care, braces and retainers, or periodontal care. The variable unmet therapy, measures that the respondent was unable to get physical, occupational or speech therapy. Careful attention was paid to the selection of the variables used in this study to insure that the measurements were the same for the two time periods.

Each variable was binary to identify whether the child had difficulty accessing services or could not obtain services. In addition, we also examined whether the child received assistance in coordinating care or medical home services. For coordinated care the variable was in response to the question, is there anyone who helps you make sure that the child gets all the health care and services (he/she) needs? The medical home variable was a composite measure designed to operationalize the American Academy of Pediatrics definition of medical home (Child and Initiative 2011). These variables were binary. All variables were based on the family's reporting.

Independent Variable

The study's key independent variable was the NS-CSHCN survey year. This was a constructed binary variable used to identify whether the child was in the 2005/06 or 2009/10 survey.

Covariates

A number of socio-demographic variables were controlled for Child-level covariates included age, race (non-Hispanic White, non-Hispanic Black, Hispanic, and "Other") as well as how often the disability affects the child completing daily activities (never, sometimes, usually or always).

Family-level covariates included income relative to the federal poverty level, whether the head of household was a single mother, whether the child has health insurance, and number of children in the household.

Analyses

Descriptive statistics characterize and compare the sample of children and their families from the 2005/06 and 2009/10 surveys. Chi square analyses were used to test differences between the 2005/06 and 2009/10 surveys on the sample's characteristics of health service utilization, assistance with care coordination, and use of medical home services. The Pearson Chi square statistic was corrected for the survey design with the second-order correction and converted into an F statistic in order to obtain a proper p value from the designed-based F statistic (Rao and Scott 1984). The F statistic was used to test bivariate associations. Because all five of the outcome measures were binary, logistic regression models were estimated using a pooled baseline (2005/06) and follow up (2009/10) to examine if the differences over time were robust. Odds ratios and 95 % confidence intervals are reported for ease of interpretation. To ensure proper variance estimation, statistical estimates were calculated for the complex sample design. For all statistical analyses, Stata 12.0 was used (F. Chevarley 2005). For descriptive statistics, all variables were weighted to represent the population of non-institutionalized children 0–17 nationally.

Results

Table 1 describes the sample and presents the weighted descriptive statistics comparing children and their families in the 2005/06 and 2009/10 surveys. Compared to the 2005/06-survey sample, children and their families differed in several ways in the 2009/10-survey. During the 2009/10-survey, there was a significant difference in severity of child's disability with an increased report of the child's disability consistently affecting their ability to complete daily activities ($F = 30.91$, $p < 0.001$) and a decreased report of the child's disability never affecting their daily activities ($F = 28.86$, $p < 0.001$). Significant differences in race and ethnicity also existed, whereby during the 2009/10-survey fewer families reported their race as White ($F = 90.37$, $p < 0.001$) and more reported their race as Hispanic ($F = 98.22$, $p < 0.001$) or "Other" ($F = 12.48$, $p < 0.001$). Compared with the 2005/06-survey, during the 2009/10-survey, families were significantly more likely to be living in poverty, with more families reporting their income between 0 and 99 % of the federal poverty level ($F = 25.15$, $p < 0.001$) and fewer reporting their income

between 200 % and 399 of the federal poverty level ($F = 4.93$, $p < 0.05$) or greater than 400 % of the federal poverty level ($F = 6.59$, $p < 0.01$). In addition, markedly less families were headed by single mother ($F = 32.94$, $p < 0.001$) during the 2009/10-survey. Finally, during the 2009/10-survey, a larger number of children were living in each household ($t = 35.23$, $p < 0.001$).

Table 2 presents the weighted, unadjusted health service utilization outcomes of children, stratified by the NS-CSHCN survey year (2005/06 and 2009/10). As the bivariate comparisons show, children with special health care needs experienced significant unmet needs during the 2009/10-survey compared with the 2005/06-survey. During the 2009/10-survey, respondents reported statistically greater difficulty obtaining referrals ($F = 5.55$, $p < 0.05$), dental care ($F = 127.63$, $p < 0.001$), and therapy ($F = 42.39$, $p < 0.001$). More than twice the number of respondents of the 2009/10 time-period reported difficulty obtaining dental care when compared to the 2004/05 time-period. Additionally, in the 2009/10 time-period, there was a 50 % increase in difficulty obtaining therapy. Moreover, compared to the 2005/06-survey, respondents in the 2009/10-survey reported receiving less help coordinating care ($F = 420.70$, $p < 0.001$) and less use of medical home services ($F = 44.52$, $p < 0.001$).

Table 3 presents the logistic regression analyses using a pooled baseline (2005/06) and follow-up (2009/10). After controlling for a host of child and family characteristics, significant differences still existed. Compared to the 2005/06-survey, in the 2009/10-survey children with special health care needs were more likely to have unmet dental needs ($OR = 2.17$, $p < 0.001$) and unmet therapy needs ($OR = 1.43$, $p < 0.001$). Moreover, children were less likely to receive coordinated care ($OR = 0.52$, $p < 0.001$) as well as medical home services ($OR = 0.89$, $p < 0.001$).

Notably, several child and familial characteristics were associated with an increased likelihood that a child had greater unmet needs and received less health care services. During the 2009/10-survey, children were more likely to have greater difficulty obtaining referrals if their disability moderately affected their ability to complete daily activities ($OR = 1.43$, $p < 0.001$) or consistently affected their ability to complete daily activities ($OR = 2.04$, $p < 0.001$). Hispanics had difficulty in obtaining referrals ($OR = 1.57$, $p < 0.001$). With regard to unmet dental needs, children were more likely to have unmet needs if their disability moderately affected their ability to complete daily activities ($OR = 1.74$, $p < 0.001$), consistently affected their ability to complete daily activities ($OR = 2.30$, $p < 0.001$), living with one biological and one stepparent ($OR = 1.42$, $p < 0.01$), living in a single-parent household ($OR = 1.29$, $p < 0.01$), or did not have health insurance ($OR = 3.74$,

Table 1 Description of the sample of children with special health care needs during the 2005/06 and 2009/10 NS-CSHCN

Characteristic	2005/06 NS-CSHCN (N = 40,723)		2009/10 NS-CSHCN (N = 40,242)		Test statistic
	%	N	%	N	F
Severity of child’s disability					
Daily activities never affected	37.55	15,755	34.39	14,795	28.26***
Daily activities moderately affected some of the time	38.50	15,646	38.53	15,611	0.00
Daily activities consistently affected, often a great deal	23.95	9205	27.07	9730	30.91***
Race or ethnicity					
White, non-Hispanic	65.30	29,119	59.27	27,989	90.37***
Black, non-Hispanic	16.24	4204	16.13	4010	0.04
Hispanic	11.78	4016	16.75	4479	98.22***
Other	6.68	3193	7.85	3764	12.48***
Family income					
0–99 % FPL	19.58	6332	22.24	6899	25.15***
100–199 % FPL	21.91	8566	21.85	7299	0.01
200–399 % FPL	29.73	13,526	28.50	12,572	4.93*
400 % FPL or greater	28.78	12,299	27.41	13,049	6.59**
Single mothers	31.52	10,258	27.92	7803	32.94***
No health insurance	3.48	1437	3.47	1149	0.00
	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>	<i>T</i>
Age	9.93	0.04	9.90	0.04	0.04
Number of children	2.17	0.01	2.26	0.01	35.23***

All variables are weighted to represent the population of non-institutionalized children 0–17 nationally. Number of observations (N) is unweighted. *M* = mean; *SE* = standard error; FPL = federal poverty level

* *p* < 0.05; ** *p* < 0.01; *** *p* < 0.001

Table 2 Unadjusted outcomes for US children with special health care needs

Outcome	2005/06 NS-CSHCN (N = 40,723)		2009/10 NS-CSHCN (N = 40,242)		Test statistic
	%	N	%	N	F
Difficulty or delay obtaining referral	21.12	2683	23.38	2625	5.55*
Difficulty or delay obtaining dental care	2.58	991	5.43	1698	127.63***
Difficulty or delay obtaining therapy	3.10	1157	4.72	1749	42.39***
Received help coordinating care	3.48	12,846	3.47	8328	420.70***
Used medical home services	33.25	18,977	21.42	18,279	44.52***

All variables are weighted to represent the population of non-institutionalized children 0–17 nationally. Number of observations (N) is unweighted

* *p* < 0.05; ** *p* < 0.01; *** *p* < 0.001

p < 0.001). Unmet dental needs were also associated with if the family was living between 200 and 399 % of the federal poverty level (*OR* = 0.68, *p* < 0.001) or above 400 % of the federal poverty level (*OR* = 0.33, *p* < 0.001). Moreover, there was an increased likelihood of having unmet therapy needs if the child’s disability moderately affected their ability to complete daily activities (*OR* = 2.70, *p* < 0.001), consistently affected their ability to complete daily activities (*OR* = 11.87, *p* < 0.001), or if

the child did not have health insurance (*OR* = 1.61, *p* < 0.001). Family makeup and number of children also significantly correlated with unmet therapy needs. Children were less likely to receive coordinated care if they were poor, their biological parents were unmarried, or they did not have health insurance. Finally, children were less likely to have access to medical home services if their disability moderately affected their ability to complete daily activities (*OR* = 0.89, *p* < 0.001) or consistently affected their

Table 3 Odds ratios (95 % CI) for logistic regression models of unmet needs from NS-CSHCN 2005/06 to 2009/10

Variable	Unmet referral	Unmet dental	Unmet therapy	Coordinated care	Medical home
NS-CSHCN survey year 2009/10 ^a	1.04 (0.93, 1.16)	2.17 (1.88, 2.49)***	1.43 (1.25, 1.65)***	0.52 (0.49, 0.55)***	0.89 (0.84, 0.94)***
Severity of child's disability ^b					
Moderately affected some of the time	1.43 (1.22, 1.67)***	1.74 (1.44, 2.11)***	2.7 (2.08, 3.5)***	1.23 (1.15, 1.32)***	0.61 (0.57, 0.64)***
Consistently affected, a great deal	2.04 (1.75, 2.39)***	2.30 (1.88, 2.82)***	11.87 (9.32, 15.11)***	1.64 (1.51, 1.77)***	0.35 (0.32, 0.37)***
Race or ethnicity ^c					
Black, non-Hispanic	0.84 (0.71, 1.01)	1.02 (0.83, 1.26)	1.07 (0.87, 1.32)	1.1 (1.01, 1.21)*	0.69 (0.63, 0.75)***
Hispanic	1.57 (1.33, 1.85)***	1.16 (0.93, 1.45)	1.18 (0.95, 1.46)	1.11 (1, 1.22)*	0.58 (0.53, 0.64)***
Other	1.19 (0.95, 1.48)	1.18 (0.91, 1.53)	1.2 (0.94, 1.52)	1.03 (0.92, 1.15)	0.74 (0.67, 0.83)***
Family income ^d					
0–99 % FPL	1.03 (0.88, 1.22)	1.06 (0.87, 1.28)	0.96 (0.79, 1.16)	0.88 (0.8, 0.97)**	1.14 (1.04, 1.25)**
100–199 % FPL	0.86 (0.72, 1.01)	0.68 (0.55, 0.85)***	1.15 (0.94, 1.41)	0.71 (0.65, 0.78)***	1.44 (1.32, 1.57)***
200–399 % FPL	0.78 (0.65, 0.93)	0.33 (0.25, 0.44)***	0.93 (0.74, 1.16)	0.58 (0.53, 0.65)***	1.54 (1.41, 1.68)***
Parental makeup ^e					
Two parents one step	1.15 (0.94, 1.39)	1.42 (1.12, 1.81)**	0.63 (0.49, 0.81)***	0.92 (0.83, 1.02)	0.82 (0.74, 0.9)***
Single mom	1.07 (0.93, 1.24)	1.29 (1.07, 1.55)**	0.8 (0.67, 0.95)**	0.84 (0.77, 0.91)***	0.81 (0.75, 0.87)***
Other	1.18 (0.93, 1.49)	0.96 (0.70, 1.30)	0.66 (0.5, 0.88)**	1.22 (1.08, 1.37)***	0.71 (0.64, 0.8)***
Number of children	1.06 (1.00, 1.12)	0.98 (0.92, 1.05)	0.92 (0.86, 0.98)**	0.97 (0.94, 1)	1.04 (1.01, 1.07)**
No health insurance	2.34 (1.74, 3.15)	3.74 (2.90, 4.83)***	1.61 (1.21, 2.14)***	0.7 (0.57, 0.86)***	0.5 (0.43, 0.59)***

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

^a Reference category is NS-CSHCN survey year 2005/06

^b Reference category is never affected

^c Reference category is non-Hispanic White

^d Reference category is 0–99 % of federal poverty level

^e Reference category is two parents biological or adoptive

ability to complete daily activities ($OR = 0.35$, $p < 0.001$). They were also less likely to use medical home services if their race was Black ($OR = 0.69$, $p < 0.001$), Hispanic ($OR = 0.58$, $p < 0.001$), or “Other” ($OR = 0.74$, $p < 0.001$) or if they were living with their biological parent and stepparent ($OR = 0.82$, $p < 0.001$), in a single-parent household ($OR = 0.81$, $p < 0.001$), or their family makeup was reported as “Other” ($OR = 0.71$, $p < 0.001$). Familial income, number of children in home, and health insurance status also was correlated with utilization of medical home services.

Discussion

Using data from the NS-CSHCN, a national survey designed to provide information on the prevalence of children with special health care needs as well as their needs and health care utilization (Centers for Disease Control and Prevention 2009), this study compared health care utilization of children with special health care needs in

2005/06 and 2009/10. The results indicate that in 2009/10 children with special health care needs experience had greater unmet dental and therapy needs and less care coordination of health services as well as access to medical home services. This finding did not support our hypothesis that that health care service utilization and quality improved over this time period.

Our study also revealed that access to health care services by children with special health care needs was associated with a variety of child and familial socio-demographic characteristics. For instance, our study found that difficulty obtaining referrals was correlated to the severity of a child's disability and their Hispanic ethnicity. Similarly, the severity of children's disability, their family's income status, parent's marital status, and their health insurance status all was associated with unmet dental needs. Moreover, unmet therapy needs were associated with children's severity of disability, parent's marital status, number of children in household, and health insurance status. Finally, utilization of coordinated care and medical home services was correlated to the severity of children's

disability, their family's income status, parent's marital status, number of children in home, and their health insurance status. The utilization of a medical home was related to race and ethnicity for Blacks, Hispanics and other when compared to Whites.

Limitations

The limitations of this study must be considered in order to fairly interpret its contributions. First, because the NS-CSHCN data is cross-sectional, causality cannot be inferred. Further, identification of children with special health care needs was determined by parental reporting, as was health care service utilization. Accordingly, this data is subject to recall bias as well as social desirability bias. Future studies should cross-reference administrative data to limit these biases. Moreover, low response rates may potentially lead to selection bias on unobserved variables. Finally, the NS-CSHCN excludes certain families, such as those without telephone access as well as those who are homeless. When possible, survey weights were adjusted to account for this.

The results show children with greater severity of disability have greater unmet needs in the second survey administration. There is a possibility that this finding may be a result of differences in the samples, rather than trends in access or barriers to care. The changes in access or barriers to care from the 2004/05 to the 2009/10-time period could be a result of the change in the demographic makeup of the sample as opposed to any changes in access. In a previous study examining the 2005/06 and 2009/10 surveys of the NS-CSHCN found racial and ethnic disparities existed, but these disparities did not change from the 2005/06 to the 2009/10 time period (Magaña et al. 2015). The findings in this study could be the result of racial and ethnic changes in the sample rather than changes in overall health care access.

In addition, there are other factors that are potential limitations to this study. There is the possibility that there could be confounding variables that have not adequately controlled for which could affect the interpretation of these findings. There is a possibility there is overlap between the two samples and pooling of the data may have resulted in having one child in the data two times, especially for small states.

Notwithstanding these limitations, this study has many strengths. To the best of our knowledge, this is the first study to compare health care utilization among children with special health care needs across time. Moreover, the use of a large, nationally representative sample of children with special health care needs allows for robust analysis and examination of health care utilization across time.

Findings from this study have important policy implications. Children with special health care needs account for 15 % of children in the United States under the age of 18

(US Department of Health 2013). This population is also significant in terms of health care expenditures. Recent studies have found that health care costs for children with special health care needs account for 41–45 % of overall child health care spending (F. M. Chevarley 2006; Newacheck and Kim 2005). Despite increased focus on this population, our study suggests that children with special health care needs continue to experience significant barriers to receiving appropriate health care services. Moreover, certain subgroups are more likely to face significant disparities. Notably, the 2009/10 survey includes the time period encompassed by the “Great Recession,” the global economic contraction that occurred from December 2007 through June 2009 (Gordon 2011; Jenkins et al. 2012; Newacheck and Kim 2005). Hence, our results indicate that a severe economic downturn can result in decreased health care service utilization for children with special health care needs.

Thus, policymakers concerned about the overall well-being of children with special health care needs should enact measures to better serve this population. States and the federal government must ensure there are adequate resources available to serve this population. In addition, policies should be enacted to monitor progress of health care access and utilization of children with special health care needs with particular attention paid to racial and ethnic disparities.

Conclusion

This study offers new evidence that children with special health care needs are experiencing greater unmet dental and therapy needs and are receiving less help coordinating care and access to medical home services. Thus, children with special health care needs must receive improved health care service utilization and better health care quality.

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Compliance with Ethical Standards

Conflict of interest The authors have no conflicts of interest to disclose.

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