

Unmet Need, Cost Burden, and Communication Problems in SCHIP by Special Health Care Needs Status

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Abstract Children with special health care needs (CSHCN) require more health care than other children; hence adequate health insurance is critical. The Maternal and Child Health Bureau defined three components of adequacy: (1) coverage of needed benefits and services; (2) reasonable costs; and (3) ability to see needed providers. This study compares cost burden, access to care, and patient/provider communication within New Jersey's SCHIP for CSHCN versus those without such needs. We used data from the 2003 NJ FamilyCare (NJFC) Supplement to the New Jersey Family Health Survey on 444 children enrolled in NJFC and 145 children disenrolled from NJFC but covered by other insurance at the time of the survey. The CSHCN Screener was used to identify CSHCN. CSHCN in NJFC had 1.5 times the odds of an unmet need for health care; 2.7 times the odds of a cost burden; and 2.2 times the odds of any coverage or service inadequacy than those without SHCN, even when demographic factors and NJFC plan level (which is based on

income) were taken into account. CSHCN enrolled in NJFC have more difficulties in some areas of access to care and cost burden. Patterns of access to care, cost burden, and patient/provider communication were similar for children formerly in NJFC who had other types of insurance at the time of the survey. Future studies should use comprehensive measures of adequacy of coverage, including attitudinal, structural and economic perspectives.

Keywords Children with special health care needs · Chronic health conditions · Health insurance · State Children's Health Insurance Program · Underinsured

Introduction

The 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) estimated that 10.2 million children or 13.9% of children in the United States have special health care needs [1]. By definition, CSHCN “require health and related services of a type or amount beyond that required by children generally,” including services for chronic physical, developmental, behavioral, or emotional conditions [2]. CSHCN also have higher medical expenditures and poorer health status than children without such needs [3].

The Maternal and Child Health Bureau (MCHB) established adequate health insurance as one of the six core outcomes to be achieved for CSHCN, some aspects of which are included in Healthy People 2020 [4]. The insurance core outcome has three elements: (1) *presence* of coverage, (2) *continuity* of coverage, and (3) *adequacy* of coverage, where presence of coverage refers to having insurance coverage or not, continuity means having no gaps in coverage during the past 12 months, and adequacy

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means coverage that provides a full range of needed services, including reasonable costs and the ability to see the necessary health care providers.

The MCHB states that “all families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need” [4]. Health insurance can protect families with CSHCN from the financial burden of health care costs [5–7]. Fortunately CSHCN are more likely to be insured than non-CSHCN [8–10]. They are more likely to enroll and remain enrolled in public coverage options such as the State Children’s Health Insurance Program (SCHIP) [11, 12].

Yet continuous health coverage may be insufficient to ensure that CSHCN have access to necessary, affordable care. Like the *uninsured*, the *underinsured*, or those who lack adequate coverage, have problems with access to health care and financial burdens associated with that care. Davidoff found in a nationally representative sample that CSHCN were more likely than non-CSHCN to have greater difficulty obtaining coverage that met their children’s needs and had reasonable out-of-pocket costs—but that study included children from families at all income levels [8]. Not surprisingly, families with CSHCN who were not adequately insured were more likely to report difficulty using community-based systems of care; delayed or forgone care; unmet need for health care; difficulty receiving specialty referrals; and not receiving comprehensive care in a medical home [13–16].

A recent examination of the 2005–2006 National Survey of CSHCN found that New Jersey had the highest adjusted rate of underinsurance for children with special needs at 38%, so understanding the dynamics of inadequate coverage experienced by some of New Jersey’s insured children is especially pertinent [17]. Further, given that SCHIP provides health insurance coverage for many low-income CSHCN, it is critical to examine adequacy of coverage in SCHIP. Szilagyi et al. found that SCHIP improved access, reduced unmet needs, and improved continuity with usual source of care for CSHCN [18].

Another of the MCHB’s six critical indicators for CSHCN is presence of a medical home: “a source of ongoing, comprehensive, coordinated, family-centered care” [1]. Family-centered care encompasses communication between patients and health care providers: whether the provider spends enough time, listens carefully, is culturally sensitive, and provides needed information. To our knowledge, only a few studies have compared patient/provider communication among children with and without special needs, and their findings are inconclusive. One nationally representative study found no difference according to SHCN status in chances of adequate communication with doctors among children who had a personal doctor or nurse, but that CSHCN had slightly lower

chances than non-CSHCN of adequate communication among those without a personal doctor or nurse [19]. A study in Alabama found that CSHCN more frequently reported that a provider spent enough time and communicated well than non-CSHCN (85% vs. 79%), but did not control for demographics or insurance status [20]. In bivariate analysis that included both insured and uninsured children, Szilagyi and colleagues found that families with non-CSHCN expressed better provider communication than CSHCN in Florida and Kansas, whereas families with CSHCN reported better communication in New York [21].

Our study builds upon previous work by investigating whether there are differences in access to care, cost burden, and quality of patient/provider communication for CSHCN and their healthier counterparts in New Jersey’s SCHIP, and by comparing them against children who were formerly enrolled in NJFC but had other health insurance at the time of the study.

Data and Methods

Data Source and Study Sample

We used data from the 2003 New Jersey FamilyCare Supplement (NJFCS), a telephone survey conducted between May and September 2003 of families with children currently or formerly enrolled in New Jersey’s SCHIP (NJ FamilyCare; NJFC) as of May 2002. The NJFCS collected information about health status, access to care, insurance coverage, and special health care needs (SHCN) status [22]. Families were randomly selected to participate if one or more of their children were enrolled in NJFC in the previous year.

The sample was stratified based on administrative records as of January 2003 by enrollment status, by NJFC plan level, and by whether parents were also enrolled in NJFC. NJFC is divided into four plan levels based on income. Plan A is a Medicaid expansion plan that covers children in families with income up to 133% of the Federal Poverty Level (FPL); Plan B 133–150% of the FPL; Plan C 151–200% of the FPL; and Plan D 201–350% of the FPL. In 2003, 350% of the FPL was about \$65,300 for a family of two adults and two children [23]. Plans C and D involve cost sharing in the form of monthly premiums and co-payments on a sliding scale based on family income. The survey combined Plans B and C for sampling because of the narrow range of incomes covered in those two plans.

Children were chosen at random from those enrolled in NJFC in May 2002. Respondents were the adults most knowledgeable about the child. A total of 679 families participated in the study, yielding a 52% response rate. Comparison against administrative records of all children

enrolled in NJ FamilyCare between 2000 and 2002 show that girls, non-Hispanic black children, and those under age 5 years were underrepresented among survey respondents. The research protocol was approved by the Institutional Review Board for the Protection of Human Subjects in Research at the researchers' university.

Children who no longer qualified for NJFC because of income or age or who were missing final enrollment status were excluded from the analyses ($N = 4$). To ensure that adequacy measures reflected insurance coverage *per se*, we excluded children who disenrolled from NJFC and became uninsured ($N = 86$), and focused on comparison of children currently insured by NJFC ($N = 444$) against children who had disenrolled from NJFC but were covered by other insurance at the time of the survey ($N = 145$).

Measures

Identification of CSHCN

CSHCN were identified using the Children with Special Health Care Needs Screener [24, 25]. Based on the MCHB's definition of CSHCN, the screener identifies children experiencing health-related consequences that have lasted or are expected to last 12 months or longer. Children were classified as having a SHCN if they responded "yes" to at least one of the five questions listed below about areas of need, and also responded that the condition had lasted or was expected to last 12 months or longer.

- Need or use medicine prescribed by doctor?
- Need or use more medical care, mental health or educational services than usual because of any health condition?
- Limited or prevented in any way from usual activity because of any health condition?
- Any special therapy because of any health condition?
- Any emotional, developmental, or behavioral problem requiring treatment or counseling?

As identified by the CSHCN screener, one hundred and five children (21%) enrolled in NJFC at the time of the survey had at least one SHCN. We operationalized adequate health insurance and patient/provider communication using questions from the NJFCS on MCHB core areas: health insurance (1) covers needed services, or *access to care*; (2) covers a reasonable share of costs including premiums and uncovered services, or *cost burden*; and (3) patient/provider communication.

Access to Health Care

We created proxy measures of *unmet needs for services*, which include (a) medical care or surgery; (b) mental

health care or counseling; and (c) dental care. For instance, "During the past 12 months was there a time when you (or someone in your family) wanted medical care or surgery but could not get it at that time?" We created a summary indicator of whether a child had unmet needs for any of those types of services.

Cost Burden

Six indicators were used to measure cost burden (Table 2). The first two captured changes in prescription drug use due to costs: whether the index child (1) *did not get* or *delayed getting prescriptions* because it cost too much, and (2) *took less of a medication* to make the prescription last longer. Two other items asked respondents about the amount paid out of pocket for *prescription drugs* and *dental care* that was not covered by insurance, with response ranges as shown in Table 2. Analyses of prescription drug items was restricted to those who had taken a prescription medication in the past month, in order to focus on those who needed medications; likewise, analyses of dental costs included only those who saw a dentist in the past year. The hardship imposed on the family by health care costs generally was measured using two items: (1) "How *serious a financial problem* have medical costs been to you and your family household in the last year?" with possible responses "major", "minor", and "no problem." (2) For families who were required to pay premiums (families with incomes above 150% of the FPL), the survey asked *how often paying the premium was financially difficult*, with possible responses of "almost every month", "every couple of months", "rarely", or "never". We created a summary indicator of whether a child experienced any of these types of cost burden.

Patient/Provider Communication

The quality of communication between patients and providers was measured using three indicators. If the child had gone to the doctor in the past 12 months, the respondent was asked "how often did doctors or other health providers: (1) explain things to you in a way you could understand? (2) show respect for what you had to say? and (3) spend enough time with you?" Responses were collected using a 4-point Likert scale ranging from "never" to "always." Respondents who answered "never" or "sometimes" were classified as having that type of communication barrier. We created a summary indicator of problems with any of these types of patient/provider communication.

A global summary measure was used to indicate whether a child had any (one or more) of the three types of

inadequacies: unmet need for medical services, cost burden, or patient/provider communication problem.

Analytic Methods

Chi-square (χ^2) tests were conducted to determine bivariate associations between SHCN status and each of the detailed adequacy outcomes shown in Table 2. Multivariate logistic regression was used to test the association between SHCN status and the four summary measures of adequacy among children enrolled in NJFC at the time of the survey, controlling for demographic characteristics and NJFC plan level. All statistics were weighted to the universe of children enrolled in NJFC as of May 31, 2002, using sampling weights for the NJFC survey [22].

Results

Demographic composition of the sample, weighted to the state population, is shown in Table 1. Most of the children currently enrolled in NJFC were school-age (84%), with slightly more males than females (59%). The sample was 61% non-Hispanic White, and roughly equally distributed among the three NJFC plan groups based on income. Overall, 22% of children in our sample had special needs.

Unmet Need

Table 2 shows the percentages of children that had problems with unmet need, cost burden, and patient/provider communication. The two left-most columns compare children with and without SHCN who were enrolled in NJFC at the time of the survey. Unmet need for services was relatively low for all children in NJFC, with fewer than 5% unable to get medical care or mental health care, and 12% unable to get dental care. CSHCN were slightly more likely than non-CSHCN to have unmet need for mental health care and counseling services: 5.1 and 1.4%, respectively ($P = 0.03$).

Cost Burden

CSHCN had more problems than non-CSHCN with some aspects of affordability: they were over five times as likely to not get or delay getting prescriptions (19.2% vs. 3.8%; $P < 0.001$); more likely to report any out-of-pocket drug or dental payments (73.7% vs. 59.2%; and 62.8% vs. 52.7%, respectively), and showed a trend toward taking less of a medication to make the prescription last longer (6.8% vs. 5.0%; NS). Families with CSHCN were nearly twice as likely as those without CSHCN to report that medical costs were a “major” financial problem (40.8% vs. 24.6%,

Table 1 Demographic and health characteristics of children currently enrolled in NJ FamilyCare, 2003 New Jersey FamilyCare Survey

	Sample composition	
	Unweighted <i>N</i> 444	% of sample ^a 100.0
Demographic characteristics		
Age group		
0–5 year olds	70	16.1
6–12 year olds	196	43.2
13–18 year olds	178	40.7
Sex of child		
Girl	178	40.9
Boy	266	59.1
Race/Ethnicity		
Non-Hispanic White	177	40.4
Non-Hispanic Black	70	15.6
Hispanic	162	35.9
Other Race	35	8.2
NJFC plan level		
Plan A (<133% of FPL)	167	37.9
Plans B & C (133–200% of FPL)	200	45.5
Plan D (201–350% of FPL)	77	16.6
Special health care need status		
Yes (1 or more SHCN)	94	22.1
No	350	77.9

^a Weighted to state level population of children enrolled in NJFC as of May 31, 2002 using normalized sampling weights provided [22]

$P < 0.001$), and less than half as likely to report that they were “never” a financial problem (17.3% vs. 41.4%; $P < 0.001$). Nearly half of families with CSHCN (45%) had difficulty paying premiums almost every month or every couple of months compared to 29% of those without CSHCN ($P < 0.001$).

The right-hand column of Table 2 shows that children formerly enrolled in NJFC who had other types of insurance had similar patterns for most aspects of access to care, cost burden, and patient provider communication as those still enrolled in NJFC. The exception was a higher preponderance of out-of-pocket dental costs exceeding \$500 per year among those with other insurance (40% vs. 20% among those currently in NJFC; $P = 0.02$).

Patient/Provider Communication

CSHCN were nearly twice as likely as non-CSHCN to report that providers sometimes or never showed respect (26% vs. 14%), and they reported similar problems with providers not explaining things well (22% vs. 18%) or spending enough time (27% vs. 18%); all $P < 0.001$.

Table 2 Access to care, cost burden, and patient/provider communication problems, by special health care needs status, 2003 New Jersey FamilyCare survey

	Enrolled in NJFC at time of survey			Formerly in NJFC, had other insurance at time of survey (<i>N</i> = 145)
	% of non-CSHCN (<i>N</i> = 339)	% of CSHCN (<i>N</i> = 105)	% of all currently enrolled (<i>N</i> = 444)	
<i>Unmet needs</i>				
Patient could not get:				
Medical care or surgery	4.6	4.1	4.3	4.4
Mental health care/counseling	1.4	5.1** ^a	2.2	0.0
Dental care	11.3	13.3	11.9	8.9
1+ types of health care	13.6	18.4	14.4	13.3
<i>Cost burden</i>				
Changed prescription use ^b				
Didn't get/delayed prescription due to cost	3.8	19.2***	11.1	11.1
Took less of medication to make it last longer	5.0	6.8	5.9	11.0
Out of pocket prescription drug costs ^c				
None	35.8	26.4	31.4	14.3
<\$200	29.6	30.6	30.1	42.9
\$200–\$500	24.7	37.5	30.7	42.9
\$500+	4.9	5.6	5.3	0
Out of pocket dental costs ^c				
None	43.2	37.1	41.8	41.9
<\$200	13.5	21.6	15.1	7.0
\$200–\$500	20.2	19.6	20.1	11.6
\$500+	19.0	21.6	19.8	39.6**
How serious a problem have medicals costs been?				
Major problem	24.6	40.8***	28.2	31.8
Minor problem	33.9	41.8	35.7	36.4
No problem	41.4	17.3	36.1	31.8
How often are premiums difficult to pay? ^d				
Almost every month	21.2	16.7***	20.6	21.4
Every couple of months	7.9	28.3	12.5	25.0
Rarely	20.1	28.3	21.8	10.7
Never	47.1	26.7	42.3	39.3
Patient/provider communication problems ^e				
Provider sometimes or never:				
Explained things	18.2	21.6***	18.9	22.2
Showed respect	14.2	25.8***	16.7	20.0
Spent enough time	18.2	26.5***	20.0	22.2

Weighted to state level population of children enrolled in NJFC as of May 31, 2002 using sampling weights provided [22]

^a * denotes $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$. Symbols in the column for CSHCN denote results of tests for whether children currently enrolled in NJFC differed by SHCN status. Symbols in the column for enrolled in other health insurance denote results of tests for whether children in NJFC differed compared to those with other insurance

^b In 12 months preceding survey. Of those who took a prescription in the last month before the survey; $N = 167$

^c In 12 months preceding survey. Of those who visited the dentist in the past year; $N = 393$

^d Out of cases that paid premiums (Plans C & D only; 150–350% of the FPL)

^e Any of three health care provider care issues coded “sometimes or never.” 9% of cases did not see a provider and were a valid skip

Multivariate Analyses

As shown in Table 3, adjusting for demographics and NJFC plan level had very little effect on the odds ratios for SHCN status for any of the four adequacy measures. Even when demographics and NJFC plan level were taken into account, CSHCN enrolled in NJFC at the time of the survey were more likely than others in NJFC to have one or more *unmet need* for medical, dental or mental health care (adjusted OR = 1.5); to have at least one *cost burden* (adjusted OR = 2.70); or to meet the *global indicator of inadequacy* (adjusted OR = 2.22), but there was no significant difference in the prevalence of communication problems according to SHCN status. Children in Plan D, which provides benefits comparable to a standard employment-based plan, were more likely than those in Plans B or C to have at least one unmet need, cost burden or overall coverage inadequacy. In terms of demographics, girls had lower odds of unmet needs, communication problems, and any inadequacy, and those aged 0–5 years lower odds of cost burdens.

Discussion

Our study of children enrolled in New Jersey's SCHIP in 2003 shows that the program provided equally good coverage for children with and without SHCN on several key aspects of access, affordability, and communication with providers. Regardless of SHCN status, virtually all families reported that they had been able to receive needed medical care and dental care. However, unmet need for mental health care was higher among CSHCN, consistent with a case study of SCHIP in five states, which also revealed difficulties obtaining home health care, mental health services, and physical, occupational, and speech therapies, especially among children with more severe SHCN [26]. This higher unmet need for mental health services yielded overall greater odds of at least one unmet need for some type of health care service among CSHCN. In our low-income sample, one out of seven children reported an unmet need for at least one type of medical care (medical, dental, or mental health), comparable to the one in six who report such a need based on the New Jersey data from the 2005–2006 NS-CSHCN [1] and an Agency for Healthcare Research and Quality study of five SCHIP initiatives [26].

Families with CSHCN had 2.7 times the odds of experiencing a cost burden, compared to those without CSHCN. Most of these additional cost burdens manifested in delays getting needed prescriptions, difficulty paying insurance premiums, and overall health care costs. For instance, about 40% families with CSHCN reported that medical costs had been a major problem, compared to approximately 25% of families without CSHCN. Such patterns are to be expected

among families who qualified for SCHIP because they have low incomes with which to meet such expenses. However, in our study twice as many CSHCN had major financial difficulties compared to the 2005–2006 National Survey of CSHCN, in which about one in five publicly-insured families reported financial problems related to expenses for CSHCN [1]. Roughly one in four families with CSHCN paid \$1,000 or more in out-of-pocket health care costs, a similar share to that found in the New Jersey sample of the National Survey of CSHCN [1]. A study of the National Health Interview Survey found that households with CSHCN pay more out-of-pocket compared to other families, regardless of income [8]. Some cost burdens did not differ by SHCN status among those in New Jersey's SCHIP: children with and without SHCN in our sample reported similar levels of out-of-pocket expenditures for prescription drugs, and few families reported that their child had taken less medication to make a prescription last longer.

We found no difference in prevalence of patient/provider communication problems according to SHCN status once demographics and NJ FamilyCare Plan Level were taken into account. In our sample, dissatisfaction with patient/provider communication ranged from 22 to 27% of families CSHCN enrolled in NJFC—slightly higher than the rates for similarly worded items in the most recent national survey of children with special needs (11–24%) [1].

Other aspects of adequacy differed between those currently insured by NJFC or and those formerly enrolled in NJFC who had other insurance at the time of the survey. For some measures concerning prescription drugs and dental care, children covered by private insurance reported more problems than NJFC-enrolled children. Almost twice as many families who had other insurance took less of medication to make the prescription last longer, and nearly four out of ten reported out-of-pocket dental costs exceeding \$500.

Advantages and Limitations of Study

This study has several notable advantages. First, the NJFCS included only children who were currently or had previously been enrolled in a State Children's Health Insurance Program, allowing a comparison of cost burden and access to care for low-income CSHCN. Second, the NJFCS included the widely-used CSHCN screener, a non-categorical approach that captures a broader range of chronic conditions involving increased need for or use of medical services than measuring chronic health conditions by asking about specific conditions such as asthma or diabetes [24]. Third, the NJFCS measured multiple dimensions of access to health care and cost burden on families, as well as quality of patient/provider communication.

This study also has several limitations. Out-of-pocket costs for prescriptions and dental care might be

Table 3 Estimated odds ratios for indicators of unmet need, cost burden, and communication problem, by SHCN status, demographics and plan level, among those enrolled in NJ FamilyCare, 2003 New Jersey FamilyCare Survey ($N = 444$)

	Unmet needs ^{a,b}		Cost burden ^{b,c}		Commun. prob. ^{b,d}		Any problem ^{b,e}	
% with specified adequacy problem	14.4		51.8		35.9		71.1	
<i>UNADJUSTED</i>	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
1+ special health care need	1.41	(0.77–2.57)	2.71	(1.68–4.39)	1.50	(0.94–2.39)	2.45	(1.36–4.39)
–2 log likelihood (<i>df</i>)	367.06	(1)	597.33	(1)	532.83	(1)	496.74	(1)
<i>ADJUSTED</i>	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
1+ special health care need	1.50	(0.79–2.85)	2.70	(1.62–4.51)	1.37	(0.84–2.23)	2.22	(1.21–4.08)
Age group (years)								
0–5	0.96	(0.41–2.25)	0.30	(0.16–0.56)	0.74	(0.37–1.50)	0.35	(0.17–0.69)
6–12	0.60	(0.32–1.10)	0.78	(0.51–1.22)	1.13	(0.72–1.78)	0.84	(0.51–1.38)
[13–18] ^f								
Girl	0.45	(0.24–0.83)	0.98	(0.64–1.49)	0.54	(0.35–0.84)	0.53	(0.34–0.85)
Race/Ethnicity								
[Non-Hispanic White]								
Non-Hispanic Black	1.36	(0.67–2.73)	0.85	(0.49–1.49)	0.62	(0.32–1.14)	1.04	(0.56–1.91)
Hispanic	0.33	(0.08–1.37)	1.09	(0.51–2.33)	1.52	(0.74–3.13)	1.87	(0.71–4.93)
NJFC plan level (% of FPL)								
Plan A (<133%)	1.41	(0.70–2.85)	0.54	(0.34–0.86)	1.34	(0.82–2.20)	0.49	(0.29–0.83)
[Plans B & C (133–200%)]								
Plan D (201–350%)	3.52	(1.70–7.27)	3.27	(1.74–6.15)	0.90	(0.49–1.68)	2.98	(1.32–6.75)
–2 log likelihood (<i>df</i>)	341.94	(8)	553.19	(8)	513.64	(8)	462.60	(8)

^a One or more unmet need for medical, mental health or dental care

^b Weighted to state level population of children enrolled in NJFC as of May 31, 2002 using sampling weights provided [22]

^c One or more of: out-of-pocket dental costs >\$500; out-of-pocket prescription costs >\$500; medical costs a major problem; premiums difficult to pay monthly or often; delayed, did not take, or took less of prescription medication because of cost

^d One or more of: doctor/provider sometimes or never explained things; showed respect; spent enough time

^e One or more unmet need, cost burden, or communication barrier

^f Reference category in brackets []

underestimated because some families may have foregone such care altogether, and therefore been excluded from the analyses which only considered those who had a prescription filled and went to the dentist, respectively. Further, several items in the survey, including the measures of unmet need for health care and questions about out-of-pocket costs and problems paying premiums, pertained to the family as a whole. Thus, it is difficult to determine whether the problem with access to care or financial burden was attributable to the cost of providing care for CSHCN or other members of the family. Further studies should use data such as that from the NS-CSHCN, which collects information on the number of CSHCN in each family [27]. Finally, other potential barriers to care such as excessive wait times and transportation to medical facilities could explain why some families reported unmet need for care and financial burden despite having insurance, but we did not examine those issues.

Another limitation was that our study included only one state—New Jersey—which has generous SCHIP eligibility

up to 350% of the FPL, but also higher cost of living and more cost-sharing and out-of-pocket expenses for NJFC enrollees above 200% of the FPL. Further, the survey response rate was 52%—typical for a telephone survey of low-income families [28].

Conclusion

Directions for Future Research

Adequacy of health insurance coverage has been measured in many different ways, including attitudinal, economic, and structural approaches [29, 30]. The *attitudinal* approach is based on questions like those asked in the NS-CSHCN and our survey, such as “Does your child’s health insurance offer benefits or cover services that meet his/her needs?” [31] The *economic* approach focuses on the costs of coverage, including the percentage of respondents’ income that is used for health care costs, including premiums and co-payments;

our study also applied that approach. The *structural* approach involves determining a benchmark set of benefits and comparing them against those provided to families covered by a given insurance plan—SCHIP or other. Not surprisingly, measuring adequacy of coverage in those three ways can result in very different findings concerning who has adequate health insurance. Oswald et al. found that nearly 30% of CSHCN in Virginia were underinsured according to the attitudinal definition, compared to about a quarter using the economic definition and barely 3% using the structural approach [32]. Future research should consider the pros and cons of each of these approaches to devise a comprehensive, multifaceted perspective on adequacy that can be used as the benchmark for comparison of different programs and plans.

An additional issue is that households with CSHCN have to navigate a complex system of state and federal programs to access available services and supports [26, 33]. Further studies should examine the barriers to accessing health care for CSHCN from the families' perspective, to determine ways in which systems can improve this aspect of adequate care.

Implications for Policy

This study has provided evidence that presence of health insurance does not necessarily confer good access to care and low cost burden. Adequacy of health insurance coverage is not a dichotomy, but a continuum. Research by Kogan et al. suggests that there are “gradations of risk for gaining access to care, even among those who are insured continuously” [14]. In addition to funding and encouraging streamlining of enrollment and renewal of CHIP-eligible children, the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) establishes a new initiative to improve the quality of care provided to all children through new child-specific health quality measures, a new model electronic medical record for children, and demonstration projects on quality improvement [34]. New items have been added to the CAHPS Child Medicaid Questionnaire to identify CSHCN and gather feedback about specialized services and patient/provider communication [35].

The Patient Protection and Affordable Care Act (ACA) [36], signed by President Obama on March 21, 2010, also seeks not only to increase the number of persons with insurance but to enhance the quality of that coverage. The ACA seeks to enhance the quality of health insurance coverage by prohibiting insurers and group plans from imposing pre-existing condition limitations for children, eliminating lifetime dollar limits on benefits, and restricting the use of annual benefit limits [37]. It also seeks to promote availability of high quality pediatric care through a temporary increase in payments to Medicaid primary care

providers, provisions to foster experimentation with pediatric Patient Centered Medical Homes, and support for expanding and improving the health care workforce.

States and the federal government face myriad decisions as they implement the ACA. Provider networks available through Medicaid and CHIP programs have historically differed from those available through private plans. As families' incomes fluctuate, the continuity of care for CSHCN may be threatened if they are forced to switch from Medicaid/CHIP to exchange plan networks and back. The transition issue may be compounded by uncertainty surrounding the continuation of CHIP, which will expire in 2016 unless extended by Congress. The ACA affords states' flexibility to address the perils of such transitions, for example through the Basic Health Plan option, but challenges remain.

The ACA should help reduce the access barriers that we found among CSHCN, but will raise new challenges. If CSHCN now covered by CHIP are moved into exchanges, the coverage available to them may be less comprehensive, or cost-sharing may be greater. Most notably, with over 30 million uninsured individuals projected to gain coverage in 2019 when health reform is fully implemented [38], access to physicians and other health care providers is likely to grow more difficult. Growing demand for services will increase pressures on clinician time, perhaps exacerbating problems with quality of patient/provider communications that we observed. Our study highlights the importance of devoting considerable policy attention to assuring an adequate supply of well-trained pediatricians and other providers as the ACA is implemented.

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Conflict of interest None of the authors have a conflict of interest.

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