Is There Differential Retention of Children with Special Health Care Needs In SCHIP?

ABSTRACT

Objective. To determine whether children with special health care needs (CSHCN) are more likely to remain in New Jersey's State Children's Health Insurance Program (SCHIP) and less likely to become uninsured than non-CSHCN.

Patients and Methods. We used the 2003 NJ FamilyCare (NJFC) Supplement to the New Jersey Family Health Survey. Children were randomly selected from the universe of children enrolled in NJFC as of May 2002 (N=675), and their families surveyed during summer 2003. The CSHCN Screener (developed by The Child and Adolescent Health Measurement Initiative) was used to identify five types of special health care needs (SHCN). To assess whether differential retention into SCHIP was occurring, we estimated multinomial logistic regression models of final enrollment status according to the presence of any (one or more) SHCN, controlling for demographic characteristics.

Results. Roughly one out of every five children in NJ FamilyCare had at least one SHCN. Older children and boys had greater odds of having special health care needs than others. Children with special health care needs had only one-quarter the odds of becoming disenrolled and uninsured, compared to children without special health care needs, even when controlling for age, sex, race/ethnicity, and SCHIP plan level. There was no difference in likelihood of finding other health insurance according to CSHCN status.

Conclusions. Children with special health care needs were more likely than children without such needs to be covered by health insurance at the time of the survey – either by retaining SCHIP coverage or having disenrolled and found other insurance. There appears to be differential retention in NJ FamilyCare, which is good news for families with CSHCN and their advocates. However, higher health care costs for these children should be considered in federal and state budget planning for SCHIP.

Key Words: children with special health care needs (CSHCN); chronic health conditions; health insurance; State Children's Health Insurance Program (SCHIP); uninsured

Abbreviations: SCHIP—State Children's Health Insurance Program; CSHCN—children with special health care needs; NJFC—New Jersey FamilyCare; FPL—federal poverty level; NSCSHCN—National Survey of Children with Special Health Care Needs; NJFCS—New Jersey FamilyCare Supplement; SHCN–special health care needs.

A decade ago, the US government enacted one of the most successful pieces of legislation to reduce uninsurance among children – the State Children's Health Insurance Program (SCHIP), which was created in 1997 under the Social Security Act to provide insurance to children from poor families who do not qualify for Medicaid.[1] States welcomed SCHIP from the beginning, with over six million children insured by the program as of 2005.[2] While rates of enrollment are useful to determine overall coverage rates, disenrollment patterns are equally critical because they capture which children are staying in the program. As federal reauthorization of the program is slated for 2007, it is important to know the health status and other characteristics of the SCHIP-insured population that might affect costs.[3]

Ensuring continuity of coverage in publicly funded programs such as SCHIP is critical for all children, but especially for those with special needs such as asthma or diabetes because these children require more and more frequent health care services. A recent study of five SCHIPs found that children with special needs were more likely than children without special needs to use the emergency department, mental health care, specialty care, and acute care.[4] Children with special health care needs (CSHCN) are a special population defined by the Maternal and Child Health Bureau 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."[5]

According to the 2001 National Survey on Children with Special Health Care Needs (NSCSHCN), roughly nine-and-a-half million children in the United States have special health care needs.[6] The CSHCN Screener is a non-categorical, outcome-based approach to identifying children with special needs.[7] Rather than asking about specific childhood chronic conditions (which overlooks many of the less common chronic conditions), this approach ask parents about their children's need for or use of health care services beyond those typical of healthy children. Consequently, the measure captures children who have rare conditions or special needs such as cerebral palsy or cystic fibrosis, as well as those afflicted by common chronic conditions such as asthma or diabetes. A study by Youngblade and colleagues found a higher congruence of reporting a special need between adolescents and their parents using the consequence-based CHSCN Screener than is typically reported for diagnosis-based approaches.[8]

This attribute is of special import for policy makers and researchers who need to monitor the quality of care for all children with special health care needs who enroll in public health insurance programs.

CSHCN are defined as having more chronic health conditions than the general population of children, therefore differential selection and retention are of concern in terms of determining adequate funding levels for SCHIP. Those selection processes imply that sicker people are more likely to enroll and remain enrolled than healthy people, causing the overall health of those in SCHIP to be worse than that in the SCHIP-eligible population. It is important to note that differential selection and retention concern parents' choices and actions related to SCHIP enrollment and renewal, *not* selectivity into SCHIP based on eligibility criteria for the program. Title XXI of the Social Security Act specifically forbids such "cherry-picking" in that states "may not deny eligibility based on a child having a preexisting medical condition."[9]

Differential selection has been suggested by evidence from SCHIP initiatives in other states. An analysis of New York, Florida, and Kansas found that CSHCN make up between 17% and 25% of the total enrolled population,[10] higher than the estimates of 13 to 18% CSHCN found in the general population based on the NSCSHCN,[11] and 17% among low-income uninsured children from a recent study by Newacheck and colleagues.[12] Additionally, a study of Florida's SCHIP using the Questionnaire for Identifying Children with Chronic Conditions found that enrolled children were twice as likely to have chronic conditions as children in the income-restricted national subsample.[13]

Since CSHCN are more concentrated in SCHIP than in the SCHIP-eligible population, it appears that parents selectively choose to enroll their child based on health status. Moreover, a study of parental attitudes about the need for health insurance showed that parents of CSHCN were least likely to report that their child does not need insurance (2.8%, compared to 7.1% for non-CSHCN).[14] An analysis of the Healthy Kids program in Florida showed that children with physical health needs were less likely to disenroll from the program, and more likely to re-enroll.[15] Taken together, these studies suggest that parents of children with special needs recognize the greater incentive to keep their children enrolled in SCHIP.

This study extends previous analyses of differential retention of CSHCN by contrasting three possible health insurance outcomes, controlling for demographic characteristics and SCHIP plan (income) level: 1) remaining enrolled in SCHIP, 2) disenrolling from SCHIP but finding other health insurance, and 3) becoming uninsured upon disenrollment. By investigating transitions out of SCHIP according to SHCN status, we complement studies that compare static (snapshot) CSHCN prevalence between SCHIP enrollees and children who are SCHIP-eligible but not enrolled.

METHODS

Data Source and Study Sample

We used data from the 2003 NJ FamilyCare Supplement (NJFCS), a telephone survey of families with children currently or formerly enrolled in New Jersey's SCHIP as of May 2002. The NJFCS collected information about health status, access to care, insurance coverage, and health care utilization as well as experiences with enrollment, renewal, disenrollment, and satisfaction with NJ FamilyCare (NJFC; New Jersey's SCHIP initiative), and the Children with Special Health Care Needs screener (see below).[16]

The NJFCS was conducted between May and September 2003 and the respondents were the adults most knowledgeable about the child in the program. Families were randomly selected to participate if one or more of their children had been enrolled in NJFC in the previous year. To ensure adequate representation of both enrolled and disenrolled children, the sample was stratified according to enrollment status as of January 2003 based on administrative records. The sample was also stratified by SCHIP plan level (see below), and whether or not parents were also enrolled in NJ FamilyCare. A total of 679 families participated in the study, yielding a 52% response rate. Children who were still enrolled, and the majority of disenrolled children, had been in the program for at least one year; disenrolled children left the plan between one and twelve months prior to their interview.

One child from each family who was enrolled in NJFC in May 2002 was chosen at random as the "index" child. If two children were chosen from the same family, the eldest was selected as the index child. Children who disenrolled and were no longer qualified for NJFC because of income or age requirements, or who were missing data on final enrollment status, were excluded from this analyses

(N=4), resulting in a final analytic sample of 675 index children. All estimates presented are weighted to reflect accurately the universe of children enrolled in NJ FamilyCare as of May 31, 2002.[16]

Measures

Identification of Children with Special Health Care Needs

Children were identified as having special needs according to the Children with Special Health Care Needs Screener developed by The Child and Adolescent Health Measurement Initiative of the Foundation for Accountability.[7] Based on the Maternal and Child Health Bureau's definition of CSHCN, the screener includes the following questions to identify children experiencing health-related consequences that have lasted or are 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?

See Appendix A for the exact wording of questions. New variables were created for each of the five screener items. Participants who responded "yes" to both the existence of a specific need and to the yearlong duration of that need were classified as positive for the indicator. To be classified as having a special health care need, the child must have been classified "yes" for at least one of the five questions about the different areas of need and the associated follow-up question on the condition lasting a year or longer.

Final Enrollment Status in NJ FamilyCare

Final enrollment status was based on the answer to a question on enrollment in the SCHIP at the time of the survey in 2003, verified through NJFC administrative records to determine insurance coverage. Final enrollment status was classified as one of the following three values: 1) currently enrolled

in NJFC; 2) disenrolled from NJFC but still insured (either through parents' employment or other insurance); and 3) disenrolled from NJFC, uninsured, but still eligible for the program. Two children who had disenrolled and were no longer eligible due to age or income requirements were excluded.

SCHIP Plan Level

NJ FamilyCare has one of the highest income eligibility levels of all states, covering otherwise uninsured children from families with incomes up to 350% of the federal poverty level (FPL). NJFC is divided into four plan levels labeled A through D. Plan A is a Medicaid expansion program, which covers children in families up to 133% of the FPL, Plans B and C covered those with family incomes between 133% and 200% of the FPL, and Plan D provided coverage to children with family incomes between 200% and 350% of the FPL. In 2003, 350% of the FPL was about $65,300 for a family of two adults and two children.[17] 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 purposes because of the narrow range of incomes covered in each plan.

Health Measures

To validate the CSHCN screener, we compared it against two other health measures from the survey: parent's rating of the child's health (classified "excellent," "very good," "good," "fair," and "poor") and an asthma indicator (yes/no).

Control Variables

To control for potential confounding, several demographic characteristics were also considered, including age, sex, and race/ethnicity coded as shown in Table 1.

Data Analyses

Chi-squared (χ^2) tests were conducted to determine associations between demographic and plan factors and prevalence of SHCN. Multinomial logistic regression models were used to assess differential retention of CSHCN by comparing the odds of being 1) disenrolled and insured, and 2) disenrolled and uninsured, compared to children who were still enrolled in NJFC, controlling for demographic factors. All

statistics were weighted to state level population of children enrolled in NJFC as of May 31, 2002 using sampling weights provided for the NJFC survey.[16]

RESULTS

Table 1 presents the demographic and health characteristics of the study sample, as well as the prevalence of CSHCN according to those characteristics. Prevalence of SHCN was higher among older children and boys ($p<.01$). The older two age groups had more than twice the prevalence of SHCN as the youngest age group (25% and 20% versus 9%). Boys had approximately one-and-a-half times the odds of having special needs of their female counterparts (24% and 16%, respectively). The prevalence of children with health care needs was roughly equal in the different SCHIP plans (across incomes up to 350% of the FPL), with roughly one in five children at each plan level having at least one SHCN.

Table 1 about here

Overall, the prevalence of SHCN was 21% of the SCHIP sample, and the mean number of SHCN was 0.45. The most common type of special health care need was medication use (15.1% of enrolled children), followed by greater health services than most children (10.3%), activity limitations (8.1%), emotional problems (7.0%) and need for special therapy (4.3%; not shown). Prevalence of special health care needs increased markedly with worsening parent-rated health, from 10.5% of children whose health was rated "excellent" to 62.5% of those rated "poor." Asthma was associated with a six-fold greater risk of SHCN. The vast majority of children remained enrolled in NJ FamilyCare at the time of the survey (88%), with about 7% disenrolled but with other health insurance and 6% disenrolled and uninsured.

Final Enrollment Status by SHCN Status and Demographic Factors

Table 2 presents odds ratios and 95% confidence intervals from multinomial logit models of children's final enrollment status (either disenrolled but still insured, or disenrolled and uninsured, when each is compared to remaining enrolled in NJFC), controlling for age, sex, race/ethnicity, and SCHIP plan level. CSHCN had only one-fourth the odds of being disenrolled and uninsured compared to non-CSHCN. Hispanic children were more than three times as likely as non-Hispanic white children to become uninsured.

Table 2 about here

CSHCN status, age, sex, and race/ethnicity were not associated with chances of being disenrolled from SCHIP but having other health insurance. Only children in Plan D (201% to 350% of the FPL) were more likely to find other insurance once disenrolled than children in Plan A.

DISCUSSION

Our analysis of survey data of children from New Jersey's SCHIP suggests that children with chronic health conditions appear to remain in SCHIP longer than healthy children. The data provide evidence of differential retention, with a considerably lower chance of becoming disenrolled and uninsured among children with special health care needs than among their healthier counterparts. CSHCN had only one-quarter the chances of being disenrolled from NJ FamilyCare and uninsured as children without such needs, even when demographic characteristics and SCHIP plan level were taken into account. However, CSHCN had similar odds of disenrolling from NJFC and obtaining other insurance as children without special needs. Consequently, children with special health care needs were more likely than non-CSHCN to remain covered either by SCHIP or other health insurance at the time of the survey (98% of CSHCN and 93% of non-CSHCN). To our knowledge, ours is the first study to analyze patterns of subsequent insurance status among children with special health care needs who disenroll from SCHIP.

The prevalence of CSHCN in NJFC—roughly one in five children—was higher than the 13% prevalence rates in the general child population at both state and national levels based on the 2001 National Survey of Children with Special Health Care Needs.[6,18] However, the prevalence of CSHCN in NJFC was within the range found in studies of SCHIP programs in other states that used the same approach to measuring CSHCN.[10, 13, 15]

A variety of approaches have been used to identify CSHCN,[19 ,20] causing some confusion in the use of that terminology and acronym as well as associated variation in prevalence estimates. The current study and others compared above use a survey approach, asking the child's parents one or more questions from the Children with Special Health Care Needs Screener, [7,21] or the Questionnaire for Identifying Children with Chronic Conditions (QuiCCC)[22] – both non-categorical approaches to classifying special

health care needs. For example, an Urban Institute study compared several states, each of which used different variants of the screener approach on SCHIP applications or relied on health care providers to identify CSHCN.[20] They report CSHCN prevalence rates ranging from 1% to 8% of enrolled children, but also conclude that "states are dissatisfied with the ability of their systems to identify CSHCN," particularly with a single-question screener approach on the application.

Other studies use ICD-9 codes on administrative claims or encounter data to identify minor, moderate, and major chronic conditions, which they classify as SHCN, often yielding lower estimates of CSHCN prevalence than those using the CSHCN screener. For instance, one study that measured disabilities and chronic health conditions using Clinical Risk Groups based on ICD-9 codes from claims and encounter records found that less than 10% of children enrolled in Medicaid or SCHIP had SHCN.[23]

Consistent with patterns observed in the general population and in SCHIPs in New York, Kansas and other states, we found that older children and males were more likely to have a special health care need, but that there was no significant variation in prevalence by family income.[10,18] SHCN were more common among children with asthma and with poor parent-rated health, helping to validate the CSHCN screener as an indicator of chronic health problems.[4,6] New Jersey FamilyCare has different levels of coverage for different income levels, and the coverage at higher income levels does not provide the number and range of benefits as the Medicaid expansion plans. We found that children in the highest plan level, which covers families from 201% to 350% of the FPL, were more likely to obtain other insurance than those from lower income families upon disenrolling from New Jersey FamilyCare, perhaps because families in higher income ranges are more likely to transition to employer-based health insurance.

This study has several notable advantages for the analysis of differential health retention in SCHIP. First is the validity of the indicators of special health care needs, which was highly correlated with other health measures. The CSHCN screener captures a wider range of chronic conditions than surveys that ask only about specific health conditions, and is increasingly used in national health surveys. Second, the availability of two sources to verify enrollment status at the time of the survey allowed the survey responses to be checked against NJFC administrative records to determine whether the index child

remained enrolled. Third, using the combined survey and administrative data allowed us to determine whether those who disenrolled found other health insurance and to assess continued eligibility for NJ FamilyCare among those disenrolled based on family income and age composition.

A limitation of the study is its cross-sectional design, which means that we cannot determine SHCN status at the time the child enrolled. However, the chronic nature of the health conditions screened for suggests that those needs are relatively unlikely to change during the year between enrollment and the survey. Second, this study was limited to one state with comparatively generous SCHIP eligibility. Finally, the survey response rate was 52% - typical for a telephone survey of low-income families,[24] but raising the possibility that the sample was not representative of all NJ FamilyCare enrollees.

Implications for Policy

The policy implications of these results can be viewed from three perspectives—the families of CSHCN, children's health advocates, and SCHIP administrators. First, families who have children with special needs appear to understand the importance of coverage for their children. It is reassuring that most CSHCN are insured, either publicly or privately;[18] however, more research is needed to understand the mechanisms underlying the higher retention of CSHCN in SCHIP, including satisfaction with the program, utilization of health care services, and experiences with the renewal process. Secondly, child health advocates will be pleased that children with special needs have much lower odds of being disenrolled from SCHIP and uninsured. Finally, SCHIP administrators will also be heartened to know that this vulnerable population remains insured, as the goal of SCHIP is to provide coverage for children who would not otherwise have health insurance.

However, because CSHCN by definition use more health services than children without special needs, the higher retention of CSHCN in SCHIP implies greater costs associated with serving this unhealthier population of children. Although CSHCN constitute only a small proportion of enrolled children, they generate a disproportionate amount of expenses incurred.[25] One study of two states' SCHIP plans suggests that CHSCN made up approximately 15% of the total enrollment but accounted for about 60% of program expenditures.[19]

As the federal reauthorization of SCHIP approaches in 2007, Congress has the opportunity to reward states for maintaining high retention levels of CSHCN by adjusting the allotment of funds to account for states with higher proportions of children with special needs. States use a variety of strategies for financing care for CSHCN, including adjusting risk for demographic factors and health status, using carve-outs for specific health conditions, and reinsurance for children whose annual expenses exceed some threshold. A recent study of these strategies by the National Center on Financing for CSHCN concluded that reinsurance combined with risk adjustment for health status appeared to be the best strategy for aligning costs and payments for CSHCN.[26] These strategies acknowledge the higher cost of caring for children who remain covered over time and rewards plans for assuring that they are well served. Unfortunately, the anticipated federal shortfall for SCHIP funding of $10 billion to $12 billion for 2008-2012 raises substantial concerns about the program's ability to meet these needs.[27]

Directions for Future Research

This study found that the majority of CSHCN enrolled in SCHIP retain that coverage; it would be useful to extend that research to investigate how well the program satisfies continuity and adequacy of coverage – the other two components of the health insurance core outcome developed by the Maternal and Child Health Bureau.[5,28] Reaching the health insurance core outcome is crucial for children with special needs because they use more health services than other children. Determining the health care utilization, unmet needs, and financial burden on families with CSHCN enrolled SCHIP will provide a more detailed evaluation of how well the program is serving this vulnerable population.

Future research should also investigate the prevalence and costs of the five types of health care needs encompassed in the Special Health Care Needs Screener (medication use, greater than average health service use, activity limitations, emotional problems, and need for special therapy). More detailed estimates of the components of costs associated with providing care for CSHCN within SCHIP would help ensure the long-term financial sustainability of SCHIP.

Table 1. Demographic and Health Characteristics of SCHIP Children in NJFC Sample				
	Sample composition		*Prevalence of CSHCN*[†]	
	Unweighted N	Weighted % of Sample[†]	Weighted %	χ^2 Value
Whole sample	675	100.0	21.1	
Demographic Characteristics				
Age Groups				**11.65
0-5 year olds	113	15.6	9.4	
6-12 year olds	332	44.2	25.2	
13-18 year olds	230	40.1	21.0	
Sex of Child				**5.69
Girl	321	40.2	16.6	
Boy	354	59.8	24.3	
Race/Ethnicity				3.45
Non-Hispanic White	290	39.9	22.2	
Non-Hispanic Black	104	15.8	26.2	
Hispanic	220	36.5	17.8	
Other Race	61	7.7	21.2	
SCHIP characteristics				
SCHIP Plan Level				0.59
Plan A (<133% of FPL)	185	37.5	21.3	
Plans B & C (133-200% of FPL)	244	45.0	22.0	
Plan D (201%-350% of FPL)	246	17.5	18.6	
Health status				
Parent-Rated Health				***48.34
Excellent	260	39.3	10.5	
Very Good	169	23.8	21.3	
Good	194	29.3	27.9	
Fair	38	6.4	46.5	
Poor	14	1.2	62.5	
Asthma				***193.94
No	574	86.3	12.4	
Yes	101	13.7	76.1	
Final Enrollment Status				4.77
Enrolled in NJFC or Medicaid	444	87.5	22.0	
Disenrolled but Insured	145	6.6	20.5	
Disenrolled and Uninsured	86	5.9	7.5	

* p<.05, ** p<.01, *** p<.001

[†] Children with special health care needs (CSHCN) as identified by CSHCN Screener.[7]

TABLE 2. Estimated Odds-Ratios and 95% CI of Children's Final Enrollment Status in NJ FamilyCare from a Multinomial Logistic Regression Model, 2003 NJ FamilyCare Survey

	Disenrolled but with other health insurance				**Disenrolled and uninsured**			
	Model I		Model II		Model I		Model II	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Any SHCN	0.96	0.46-2.02	0.82	0.38-1.77	**0.25**	**0.07-0.89**	**0.25**	**0.07-0.90**
Age Groups								
0-5 year olds			1.00	1.00			1.00	1.00
6-12 year olds			2.09	0.76-5.81			1.66	0.57-4.80
13-18 year olds			1.41	0.48-4.12			1.27	0.42-3.80
Sex								
Girl			1.00	1.00			1.00	1.00
Boy			1.33	0.69-2.56			1.58	0.77-3.22
Race/ethnicity								
Non-Hispanic White			1.00	1.00			1.00	1.00
Non-Hispanic Black			1.26	0.554-2.85			1.62	0.53-4.95
Hispanic			0.64	0.30-1.37			**3.10**	**1.40-6.91**
Other Race			0.40	0.09-1.73			0.93	0.18-4.80
SCHIP Plan Level								
Plan A (<133% FPL)			1.00	1.00			1.00	1.00
Plan B/C (133-200% FPL)			1.69	0.78-3.67			0.88	0.40-1.95
Plan D (201-350% FPL)			**2.63**	**1.11-6.22**			1.16	0.45-2.99
-2 Log Likelihood	17.60		283.71		17.60		283.71	

* Children still enrolled in NJ FamilyCare are the reference group for all models.

† **Bold indicates statistical significance, p< .05.**

APPENDIX A - Children with Special Health Care Needs Screener, NJ FamilyCare Supplement

3a1. Does [index child] currently need or use MEDICINE PRESCRIBED BY A DOCTOR (other than vitamins) because of ANY medical, behavioral, or other health condition?

[] Yes
[] No (GO TO 3b1)
[] Don't Know (GO TO 3b1)
[] Refused (GO TO 3b1)

3a2. Is this a condition that has lasted or is expected to last for AT LEAST 12 months?

3b1. Does [index child] need or use more MEDICAL CARE, MENTAL HEALTH OR EDUCATIONAL SERVICES than is usual for most children of the same age because of ANY medical, behavioral, or other health condition?

[] Yes
[] No (GO TO 3c1)
[] Don't Know (GO TO 3c1)
[] Refused (GO TO 3c1)

3b2. Is this a condition that has lasted or is expected to last for AT LEAST 12 months?

3c1. Is [index child] LIMITED OR PREVENTED in any way in their ability to do the things most children of the same age can do because of ANY medical, behavioral, or other health condition?

[] Yes
[] No (GO TO 3d1)
[] Don't Know (GO TO 3d1)
[] Refused (GO TO 3d1)

3c2. Is this a condition that has lasted or is expected to last for AT LEAST 12 months?

3d1. Does [index child] need or get any SPECIAL THERAPY, such as physical, occupational, or speech therapy because of ANY medical, behavioral, or other health condition?

[] Yes
[] No (GO TO 3e1)
[] Don't Know (GO TO 3e1)
[] Refused (GO TO 3e1)

3d2. Is this a condition that has lasted or is expected to last for AT LEAST 12 months?

3e1. Does [index child] have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets TREATMENT OR COUNSELING?

[] Yes
[] No (GO TO 3f1)
[] Don't Know (GO TO 3f1)
[] Refused (GO TO 3f1)

3e2. Is this a condition that has lasted or is expected to last for AT LEAST 12 months?

REFERENCES

[1] Dubay L, Hill I, Kenney G. Five things everyone should know about SCHIP. The New Federalism: Issues and Options for States. Urban Institute Series A, No. 55. 2002. Available at: http://www.urban.org/url.cfm?ID=310570. Accessed December 2006.

[2] Centers for Medicaid and Medicare Services. SCHIP ever enrolled in year. 2006. Available at: http://www.cms.hhs.gov/NationalSCHIPPolicy/downloads/SCHIPEverEnrolledYearGraph.pdf. Accessed August 2006.

[3] Broaddus M, Park E. Freezing SCHIP funding in SCHIP reauthorization would threaten recent gains in health coverage. Center on Budget and Policy Priorities. 2006. Available at: http://www.cbpp.org/6-5-06health.htm. Accessed December 2006.

[4] Brach C, Lewit EM, VanLandeghem K, Bronstein J, Dick AW, Kimminau KS, et al. Who's enrolled in the State Children's Health Insurance Program (SCHIP)? An overview of findings from the Child Health Research Initiative (CHIRI). *Pediatrics.* 2003; 112:499-507.

[5] McPherson MP, Arango P, Fox HB, et al. A new definition of children with special health care needs. *Pediatrics.*1998; 102:137-140.

[6] U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2001*. Rockville, MD: U.S. Department of Health and Human Services, 2004. Available at: http://mchb.hrsa.gov/chscn.

[7] Foundation for Accountability, Child and Adolescent Health Measurement Initiative. The Children with Special Health Care Needs (CSHCN) Screener, 1998. Available at: http://www.markle.org/resources/facct/doclibFiles/documentFile_446.pdf. Accessed December 2006.

[8] Youngblade LM, Shenkman EA. Congruence between parents' and adolescents' reports of special health care needs in a Title XXI program. *J Pediatr Psychol*. 2003 Sep;28(6):393-401.

[9] General contents of the State child health plan. (1997). 42 U.S.C. § 1397bb. Retrieved from GPO Access database on World Wide Web: http://www.gpoaccess.gov/uscode/.

[10] Szilagyi PG, Shenkman E, Brach C, LaClair BJ, Swigonski N, Dick A, et al. Children with special health care needs enrolled in the State Children's Health Insurance Program (SCHIP): patient characteristics and health care needs. *Pediatrics.* 2003; 112:508-520.

[11] Markus A, Rosenbaum S, Stein RE, Joseph J. From SCHIP benefit design to individual coverage decisions. Policy Brief #6. George Washington University Center for Health Services Research and Policy. 2006; (6):1-24. Available at: http://www.gwumc.edu/sphhs/healthpolicy/chsrp/downloads/SCHIP_brief6.pdf. Accessed December 2006.

[12] Newacheck P, Marchi K, McManus M, Fox H. New estimates of Children with Special Health Care needs and implementations for the State Children's Health Insurance Program. Washington DC: The Maternal and Child Health Policy Center. Fact Sheet Number 4, March 1998.

[13] Stein REK, Shenkman E, Wegener DH, Silver EJ. Health of children in title XXI: should we worry? *Pediatrics.* 2003; 112:112-118.

[14] Blumberg SJ, O'Connor KS, Kenney G. Unworried parents of well children: a look at uninsured children who reportedly do not need health insurance. *Pediatrics*. 2005 Aug; 116(2):345-51.

[15] Shenkman E, Vogel B, Boyett JM, Naff R. Disenrollment and re-enrollment patterns in a SCHIP. *Health Care Financ Rev*. 2002; 23:47-63.

[16] Miller JE, Gaboda D, Trail T, Cantor JC. Findings from the 2003 NJ family health survey-NJ FamilyCare supplement. State of New Jersey, Department of Human Services. 2005.

[17] U.S. Census Bureau, Housing and Household Economic Statistics Division. Poverty Thresholds 2003. Available at http://www.census.gov/hhes/www/poverty/threshld/thresh03.html. Accessed December 2006.

[18] Child and Adolescent Health Measurement Initiative. 2001 National Survey of Children with Special Health Care Needs, Data Resource Center on Child and Adolescent Health website. 2005. Available at: www.cshcndata.org. Accessed January 2007.

[19] National Center on Financing for CSHCNs. Identification, service use, and expenditure profiles of children with special health care needs (CSHCNs) in Medicaid, SCHIP, and Title V—Chart book. Gainesville, FL: University of Florida Institute for Child Health Policy. 2004. Available at: http://ichp.ufl.edu/documents/ChartBook%20Ident.Use.Expend.Final.pdf. Accessed December 2006.

[20] Hill I, Lutzky AW, Schwalberg R. Are we responding to their needs? States' early experiences serving Children with Special Health Care Needs under SCHIP. Urban Institute Occasional Paper Number 48. 2001.

[21] Bethel CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: Development and evaluation of a short screening instrument. *J Amb Peds*. 2002. 2(1):38-48.

[22] Stein REK, Westbrook LE, Baumann LJ. The Questionnaire for Identifying Children with Chronic Conditions: A measure based on a non-categorical approach. *Pediatrics.* 1997; 99(4):513-21.

[23] National Center on Financing for CSHCN. Financing and Reimbursement Strategies for Children with Special Health Care Needs: A Series Overview. Focus on Child Health Policy, Issue 1. University of Florida Institute for Child Health Policy. Available at http://ichp.ufl.edu/documents/ Overview%20reimbursement%20strategies.pdf. Accessed December 2006.

[24] Brick JM, Ferraro D, Strickler T, et al. 2002 NSAF Response Rates. Urban Institute, National Survey of America's Families, 2002 Methodology Series, Report No. 8. December, 2003.

[25] Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. *Arch Ped and Adol Med.* 2005; 159:10-17.

[26] National Center on Financing for CSHCN. States' strategies for financing care for CSHCN: How well do they work? Focus on Child Health Policy, Issue 2. University of Florida Institute for Child Health

Policy. 2005. Available at http://ichp.ufl.edu/documents/State%20Strategies.pdf. Accessed December 2006.

[27] Broaddus M, Park E. State Children's Health Insurance Program financing and the need for significant federal funding increases as part of reauthorization. *J Ambul Care Manage*. 2006; 29(4):254-71.

[28] Honberg L, McPherson M, Strickland B, Gage JC, Newacheck P. Assuring adequate health insurance: results of the national survey of children with special health care needs. *Pediatrics.* 2005; 116:1233-1239.