

Defining Underinsurance Among Children with Special Health Care Needs: A Virginia Sample

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Objectives: The study sought to: 1) examine the national Children with Special Health Care Needs (CSHCN) survey to determine whether there are items that can serve to operationalize alternative definitions of underinsurance; 2) construct definitions from the survey items that are consistent with Structural and Economic definitions of underinsurance and devise an algorithm for determining underinsurance for each; and 3) compare these two underinsurance definitions with the Maternal and Child Health definition of inadequate insurance, a definition that takes an Attitudinal approach to the construct. **Methods:** Analyses included Virginia children who were insured throughout the survey period. Survey items from the national CSHCN survey were examined to identify items related to underinsurance. Items were divided into groups corresponding to three definitions of insurance (Attitudinal, Structural, and Economic). Algorithms were established, and underinsurance rates calculated for each definition. Logistic regression models were constructed to investigate demographic characteristics related to underinsurance. **Results:** Different percentages of Virginia CSHCN were found to be underinsured based on the definitions of Attitudinal (28.9%), Economic (25.6%), and Structural (2.9%). Eight demographic characteristics and the pervasiveness of the child's special health care needs were examined in relation to underinsurance. For the Attitudinal definition, poverty level and pervasiveness were significant predictors in the model. In the model predicting Economic underinsurance status, pervasiveness and three of the demographic characteristics significantly predicted underinsurance status. In the multivariate logistic regression model for the Structural definition, none of the predictors was significantly related to underinsurance. **Conclusions:** These findings demonstrate that alternative definitions of underinsurance yield dramatically different underinsurance rates. Further, even when yielding similar rates, alternative definitions may identify substantially different sets of children. The likelihood of being underinsured has a strong association with low-income status and pervasiveness of the child's special health care needs. Understanding these factors and their implications will be important when planning accessible and comprehensive health plans and care systems for CSHCN.

KEY WORDS: access to care; CSHCN; inadequate insurance; special health care needs; underinsurance.

INTRODUCTION

Health insurance coverage is essential to assure access to necessary care. The U.S. Census Bureau reports that approximately 45 million Americans lacked health insurance in 2003. According to

the Census Bureau data, the number of uninsured children under age 18 was 11.4% (1). In addition to the uninsured population, an unknown number of others may be considered underinsured. Potential consequences of underinsurance for all populations

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include delayed medical care, an exacerbation of illness, and ultimately, a burden for the public and private sectors due to unpaid medical bills. For children with special health care needs (CSHCN), underinsurance is critical not only because it represents a barrier to care, but also because it increases the likelihood of unexpected or excessive health care costs due to worsening health status or complications.

CSHCN, as defined by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, are children

who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally (2).

It is estimated that CSHCN represent approximately 13–18% of children and adolescents in the United States (3, 4). Emerging evidence suggests that CSHCN have higher levels of unmet need for routine and specialty health care, compared to the general pediatric population (3, 5). Almost 20% of low-income CSHCN experience some form of unmet health care need and families of CSHCN report significantly higher out-of-pocket spending for health care services (6). These facts emphasize the significance of underinsurance for the population of CSHCN.

Further, insurance barriers in vulnerable populations may have disproportionately adverse impacts such as exacerbation of illness due to delayed medical care or more prolonged hospitalizations (7). Underinsurance puts children with chronic conditions at increased risk for medical complications; for example, children and youth with diabetes are at significantly increased risk for severe hypoglycemia (8). Limited coverage and inadequate reimbursement can result in significant gaps in services and an increased probability of compromised health outcomes (9).

Measuring the adequacy of health insurance has proven to be a challenging enterprise (10). Underinsurance can be broadly defined as insurance whose depth and breadth of coverage is in some way inadequate. However, the term lacks conceptual clarity and there is no universally accepted definition. Indeed, there is no general consensus even on basic questions such as whether health insurance is intended to protect against catastrophic medical bills or to provide coverage for all routine care, and there are

no universally accepted benchmarks for what should be considered adequate insurance.

Studies measuring the adequacy of health insurance have used different definitions of underinsurance and reveal wide variability in the estimates of the underinsured. Ward *et al.* (11) summarized this literature and identified three primary types of definitions of the construct: Economic, Structural, and Attitudinal.

Attitudinal definitions emphasize consumer perceptions and satisfaction as they relate to health care. Underinsurance is identified when at least one health benefit the person would prefer to receive is not covered by insurance, when there is at least one symptom that the person believed required treatment for which insurance coverage treatment was not provided, or when a person is dissatisfied with their insurance plan.

Economic definitions focus on a person's ability to pay for health care, including the cost of the insurance premiums, co-pays, and deductibles. An Economic definition of underinsurance defines a limit above which the expense of health care coverage becomes a burden and interferes with access to care. Using this definition, underinsurance is identified when out-of-pocket expenses for necessary medical care exceed a specified percent of the person's income within a given time frame, or when a person delays health care due to out-of-pocket costs associated with the services.

Structural definitions of insurance consider the type of benefits offered by the program and the range of providers whose services are covered under the plan. A Structural approach to defining underinsurance uses a benchmark benefits package as a basis of comparison. Under such a definition, underinsurance is identified when at least one benefit in the benchmark package is not covered by the individual's health insurance plan.

These three approaches to defining the construct (11) suggest measurable indicators for the examining adequacy of health care plans in concrete terms. Collectively they provide a conceptual framework for describing the phenomenon of underinsurance.

Adequacy of health care insurance coverage is one of the core outcomes identified as a target for CSHCN by the MCHB's National Agenda (12) and subsequently incorporated into Healthy People 2010. As a result, items related to the *inadequacy* of insurance, or underinsurance, were included in the National Survey of Children with Special Health Care Needs, henceforth referred to as the CSHCN survey.

Five survey items addressed this core outcome. The first two items identified children who did not have insurance coverage for some or all of the period in question. The remaining three questions addressed how frequently the insurance met their child's needs; how reasonable were costs that were not covered by insurance; and the frequency with which the insurance plan provided access to needed providers. Given their focus on parents' perceptions, these latter questions were conceptualized as operationalizing an Attitudinal definition of underinsurance.

In Virginia, as in other states, the issue of underinsurance has policy and budget implications for both Medicaid and the state's child health insurance program (SCHIP). In addition, state Title V programs that serve CSHCN have been asked by the MCHB to examine insurance issues for this population within their states. In Virginia, a proportion of Title V monies are set aside in a Pool of Funds designated to cover specified medical services for the uninsured and children who lack insurance coverage for necessary services. As these funds are limited, criteria are set for their use. The study of underinsurance among the insured population may potentially yield valuable information to inform future policy decisions, such as "eligibility" criteria for accessing Pool of Funds dollars.

Interest in this topic led to a collaborative study involving the Title V CSHCN Program at the Virginia Department of Health and the Virginia Leadership Education in Neurodevelopmental Disabilities Program (Va-LEND) at Virginia Commonwealth University. Representatives from both programs designed a study in which Attitudinal, Structural, and Economic definitions of underinsurance were used as a basis to analyze underinsurance for children with special health care needs in Virginia, using data from the national CSHCN survey. The purposes of the study were threefold: 1) to examine the CSHCN survey to determine whether there are items that can serve to operationalize the Structural and Economic definitions of underinsurance; 2) to construct Structural and Economic definitions from the items and devise an algorithm for determining underinsurance for each; and 3) to compare these two underinsurance definitions with the MCHB (Attitudinal) definition, using data from the Virginia sample of CSHCN.

METHODS

The National Survey of Children with Special Health Care Needs was sponsored by the Maternal

and Child Health Bureau (MCHB) and the National Center for Health Statistics (13). The survey sample was constructed to allow for both national- and state-level findings. The project screened 373,055 children for special health care needs and completed 38,866 CSHCN interviews, including at least 750 in each state. CSHCN survey data were collected between October 2000 and April 2002. Children in the survey were screened for special health care needs using the Child and Adolescent Health Measurement Initiative CSHCN screener (14).

Survey data were released in the summer of 2003, and the state-level data for CSHCN in Virginia became the basis for the present study. The study was developed as part of a Research Training Enhancement Project funded by the Division of Research, Training and Education, MCHB to strengthen the research component of the Va-LEND Program, an MCHB funded interdisciplinary leadership training program. The study was conducted as a group workshop to offer program trainees the opportunity to participate in the planning and execution of a policy-relevant research effort. Personnel from the Virginia State Department of Health Title V Program collaborated in the effort and contributed to the selection of the topic, the introduction to relevant literature, and the interpretation of findings.

Following an introduction to the construct of underinsurance, CSHCN survey items were scrutinized by a multidisciplinary group of approximately 10 faculty and trainees to identify a pool of 36 items relevant to underinsurance. Through a consensus process, items were then divided into three groups corresponding to the three definitions of underinsurance (Attitudinal, Structural, and Economic). After a delay in which participants reflected further on proposed definitions, the group then narrowed the items to be included in the definitions and proposed three algorithms for establishing the underinsured status, corresponding to the conceptual categories of underinsurance definitions. The final algorithm for each definition was established by group consensus.

Analysis Plan

Data analyses were conducted using the svyprop and svylogit procedures in the statistical analysis package, *Stata 8.1*. Use of these procedures allows for the generation of standard errors appropriate to the complex sample design. Logistic regression models were created using demographic characteristics as predictor variables and underinsurance status as the

response variable. The purpose of these analyses was to better understand the context for underinsurance as it exists in the sample. To the extent that a definition of underinsurance is significantly associated with relevant demographic characteristics, the definition gains social validity.

RESULTS

Analyses were limited to Virginia children who were insured throughout the survey period ($n = 680$; 91.6% [$SE = 1.15$] of the Virginia CSHCN sample). The sample for the present study was 57.6% male ($SE = 0.02$). The mean age of the sample was 9.8 years ($SE = 0.20$). The race distribution was: 74.6% White ($SE = 2.13$) and 19.4% Black ($SE = 1.96$); 2.7% ($SE = 0.56$) indicated they were of Hispanic ethnicity.

The items selected for the Attitudinal definition were those survey items included in the MCHB core "adequate insurance" outcome (excluding the two coverage items). For the purpose of the definition, an adaptation of the convention used for the MCHB core outcomes was adopted, that is, a response of "never" or "sometimes" to the items was viewed as indicative of underinsurance. Table I lists the survey items and the percent of insured Virginia CSHCN for whom each item was positive (i.e., indicative of underinsurance). The algorithm chosen identifies as underinsured any child for whom at least one of the

Table I. CSHCN Survey Items—Attitudinal Definition

Survey items	% true among insured Virginia children	Standard error
Does ("S" CHILD)'s ^a health insurance offer benefits or cover services that meet (his/her) needs? Never or Sometimes	10.8	1.46
Does ("S" CHILD)'s health insurance allow (him/her) to see the health care providers (he/she) needs? Never or Sometimes	6.5	1.14
Are the costs not covered by ("S" CHILD)'s health insurance reasonable? Never or Sometimes	24.4	2.06
If any one (or more) of these items is true, the child is underinsured according to the attitudinal definition	28.9	2.15

^a"S" CHILD refers to the child with special health care needs.

items was positive. Using this definition, 28.9% of Virginia CSHCN were found to be underinsured according to the Attitudinal definition.

Items selected as relevant to the Economic definition are listed in Table II, along with the percent of insured Virginia children with special health care needs for whom the item was positive (i.e., indicative

Table II. CSHCN Survey Items—Economic Definition

Survey items	% true among insured Virginia children	Standard error
Did you delay or not get health care for ("S" CHILD) ^a because: ... You didn't have enough money to pay the health care provider?	2.3	0.60
Child did not receive needed ... routine preventive care because cost too much	0.2	0.16
... care from a specialty doctor because cost too much	0.4	0.24
... dental care because cost too much	1.3	0.53
... prescription medications because cost too much	0.4	0.25
... physical, occupational, or speech therapy because cost too much	0.2	0.15
... mental health care or counseling because cost too much	1.0	0.43
... substance abuse treatment or counseling because cost too much	0.0	—
Parent or family did not receive needed ... respite care because cost too much	0.3	0.30
... genetic counseling because cost too much	0.1	0.06
... mental health care or counseling because cost too much	0.9	0.55
Have you needed additional income to cover ("S" CHILD)'s medical expenses?	14.7	1.65
Has ("S" CHILD)'s health care caused financial problems for your family?	18.0	1.86
If any one (or more) of these items is true, the child is underinsured according to the Economic Definition	25.6	2.08

^a"S" CHILD refers to the child with special health care needs.

of underinsurance). The algorithm again identifies as underinsured any child for whom at least one of the items was positive. Using this definition, 25.6% of Virginia CSHCN were found to be underinsured according to the Economic definition.

Items selected as relevant to the Structural definition are listed in Table III, along with the per-

cent of insured Virginia CSHCN for whom the item was positive (i.e., indicative of underinsurance). As before, the algorithm identifies as underinsured any child for whom at least one of the items was positive. Using this definition, 2.9% of Virginia CSHCN were found to be underinsured according to the Structural definition.

These findings led to the question of whether the alternative definitions identified the same children as underinsured. Tables were constructed to compare underinsurance percentages for each pair of definitions. Because the number of underinsured children identified by the Structural definition was so low, comparisons involving the Structural definition were difficult to interpret and results are not reported. An examination of the Attitudinal and Economic definitions comparison made it clear, however, that these definitions do not identify identical groups of underinsured children. Of the children identified as underinsured by the Attitudinal definition, about 45% are also identified as underinsured by the Economic definition; similarly, of the children identified as underinsured by the Economic definition, only 52% are also identified as underinsured by the Attitudinal definition.

Next, for each definition, the extent to which other child/household demographic characteristics were associated with the likelihood of being underinsured was examined. Eight characteristics were selected as potentially relevant to the question of underinsurance: 1) in a metropolitan statistical area, 2) in a single-adult household, 3) more than one CSHCN in household, 4) child covered by Medicaid, 5) child covered by private insurance, 6) child has usual source of care, 7) household under 200% of poverty level, and 8) mother has post-high school education. The percent underinsured of children possessing the characteristic was compared to the percent underinsured among those who did not.

For the Attitudinal definition, only the “Household under 200% of poverty level” characteristic yielded different percentages ($F(1, 582) = 7.70, p = 0.006$). For households under 200% of the federal poverty level (FPL), 40.2% of children were underinsured, while for households not under 200% of FPL, 24.7% were underinsured.

For the Economic definition, three of the demographic characteristics yielded different percentages of underinsurance: Single-adult household ($F(1, 677) = 10.82, p = 0.001$), Household under 200% of FPL ($F(1, 597) = 15.34, p = 0.0001$), and mother has post-high school education

Table III. CSHCN Survey Items—Structural Definition

Survey items	% true among insured Virginia children	Standard error
Did you delay or not get health care for (“S” CHILD) ^a because:		
... The type of health care was not covered by your health plan	1.6	0.48
... You could not get approval from your health plan or doctor	1.0	0.37
Child did not receive needed		
... routine preventive care because health plan problem	0.1	0.07
... care from a specialty doctor because health plan problem	0.4	0.24
... dental care because health plan problem	0.5	0.28
... prescription medications because health plan problem	0.2	0.17
... physical, occupational, or speech therapy because health plan problem	0.2	0.12
... mental health care or counseling because health plan problem	0.4	0.26
... substance abuse treatment or counseling because health plan problem	0.1	0.10
Parent or family did not receive needed	0.3	0.30
... respite care because health plan problem		
... genetic counseling because health plan problem	0.1	0.06
... mental health care or counseling because health plan problem	0.2	0.12
If any one (or more) of these items is true, the child is underinsured according to the Structural Definition	2.9	0.68

^a“S” CHILD refers to the child with special health care needs.

Table IV. Pervasiveness and Percent Underinsured

	Pervasiveness (i.e., number of screener criteria met)					<i>F</i>	<i>p</i>
	1	2	3	4	5		
Attitudinal—Percent underinsured (Standard error)	24.0 (2.7)	22.8 (4.1)	45.8 (6.7)	47.2 (8.3)	51.0 (15.5)	5.00	0.0006
Economic—Percent underinsured (Standard error)	16.8 (2.4)	20.1 (4.2)	49.8 (6.5)	55.6 (8.0)	55.6 (14.7)	11.84	0.0000
Structural—Percent underinsured (Standard error)	2.7 (0.9)	2.2 (1.1)	2.2 (1.3)	6.4 (4.2)	7.7 (5.6)	1.06	0.37

($F(1, 661) = 4.37, p = 0.04$). For the first two of these, the characteristic was associated with higher underinsurance rates while for the third, the characteristic was associated with lower underinsurance rates.

For the Structural definition, none of the characteristics were associated with rates of underinsurance.

Next, we sought to determine whether the pervasiveness of the child's special health care needs was associated with underinsurance. Pervasiveness was defined as the number of criteria met on the CSHCN screener instrument for determining special health care needs status. The analysis demonstrated a strong, orderly relationship between pervasiveness and rate of underinsurance for the Attitudinal and Economic definitions. For both of these definitions, meeting more of the criteria was associated with a higher rate of underinsurance (see Table IV).

Finally, we investigated whether the demographic and pervasiveness variables contributed uniquely to the likelihood of being underinsured by entering them into multivariate logistic regression models predicting underinsurance from the nine characteristics (eight demographic characteristics plus pervasiveness). For the Attitudinal definition, poverty level and pervasiveness were significant predictors in the model ($F(9, 559) = 2.60; \text{Prob} > F = 0.006$). In the model predicting Economic underinsurance status, pervasiveness and three of the demographic characteristics (more than one CSHCN in the household, single-adult household, and poverty level) significantly predicted underinsurance status ($F(9, 574) = 5.66; \text{Prob} > F = 0.0000$). In the multivariate logistic regression model for the Structural definition, none of the predictors was significantly related to underinsurance although the test for the overall model was significant ($F(9, 574) = 2.02; \text{Prob} > F = 0.0352$).

DISCUSSION

Underinsurance is a critical construct in understanding the adequacy of the health services system for CSHCN. The present study demonstrates that alternative definitions of underinsurance may yield varying rates of underinsurance and, even when yielding similar rates, may identify substantially different sets of children. While the MCHB core outcome indicator resembles an Attitudinal approach to defining underinsurance, these data suggest that it may be important to incorporate an Economic perspective as well, i.e., that elements of both definitions are essential to fully capture the population of CSHCN who are underinsured.

The findings also highlight an association between underinsurance and low-income status, a relationship noted across both the Economic and Attitudinal approaches. Other related research has also found that low-income families caring for CSHCN are at significant risk for high out-of-pocket expenses (6, 15). In addition, the present findings support the conclusion that the likelihood of being underinsured is directly associated with the pervasiveness of the child's special health care needs.

These data represent the first step in an effort to operationalize and validate alternative definitions of underinsurance that reflect a current conceptual model of the construct. Of the three definitions, the Structural one was the weakest. The Structural underinsurance rate was substantially lower than expected and was not consistent with rates found using the other definitions. However, the CSHCN survey did not include items that allow for a complete representation of the Structural approach to underinsurance. While it may not be possible to gather the information needed for a sound Structural definition in a consumer survey, the present findings offer a suggestion that further study of the Structural approach to underinsurance may be needed.

At the same time, there are limitations associated with the other two definitions, as well, which are inherent in the survey data upon which they are based. Many of the items are subjective and measure parent perceptions rather than objectively verifiable characteristics or outcomes. Future versions of the survey might collect more useable data regarding family income and health care expenditures. The items included in the present definitions are, in some cases, proxies for ideal items that would measure the constructs more directly. Nonetheless, this survey offers virtually the only state-level data related to CSHCN and efforts to operationalize the construct of underinsurance, such as the present study, may spur the development of more direct measures.

Examining several items in the Structural definition, it is surprising that fewer than 1 in 200 families of CSHCN indicated that mental health care, counseling, or respite care were not received because of a health care plan problem; and that only 1 in 500 failed to receive physical, occupational, or speech therapy for that reason. It is possible that families' insurance plan descriptions clearly stated that such services were not covered, and therefore families did not view lack of coverage as a "health plan problem" because they did not expect those services to be covered.

CSHCN present many challenges to the health care system. Nationally, the medical home model has been promoted as the ideal approach to service delivery for all children, and in particular for CSHCN, and underinsurance is relevant to the establishment and maintenance of a medical home (17). However, implementing a medical home requires a proactive process of health care based on partnership among families and service providers (18) and underinsurance may represent a barrier to the establishment of a medical home for CSHCN.

CSHCN are a minority of the population but generate a large percentage of the health care expenses for children (3). CSHCN are likely to be at increased risk for poor health outcomes if health care, prescription medications, or needed therapies are interrupted or postponed. Underinsurance in childhood may lead to deterioration of health or exacerbation of illnesses and to more costly medical care in later life due to emergency or chronic health care needs.

Concern exists that trends in the current health care marketplace may lead to higher levels of underinsurance by any definition. Increases in medical costs and decreasing health coverage have been

widely documented (19). Health insurance premiums and other out-of-pocket medical expenses have increased dramatically over the past decade, and are expected to continue to rise unabated as a result of projected increases in the cost of health care. Our findings suggest that CSHCN, particularly those from low-income families, experience a significant financial burden as a result of this trend. The effects of underinsurance for CSHCN could be exacerbated if existing public insurance programs are replaced by a system of vouchers in the private insurance market as proposed by some policymakers (20).

As stated in the MCHB outcome indicator, the ultimate goal is for all families of CSHCN to have adequate insurance to pay for the services they need. Since the majority of CSHCN do have some health care coverage, developing and using empirically supported definitions of underinsurance will be an important means of assuring quality health care for this population. A coherent definition will lead to improved data and to program changes that support improved health for all children.

The Virginia Department of Health was very interested in this issue because there exist limited funds to support underinsured CSHCN. Little is known about the underinsured CSHCN population and the present study represents a first step in learning more about their needs, about the consequences of underinsurance, and about where to focus resources. An understanding of health care coverage trends and their financial and medical implications is vital to helping design health plans, policies, safety net services, and care systems that meet the needs of CSHCN.

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REFERENCES

1. DeNavas-Walt C, Proctor BD, Mills RJ. *Income, poverty, and health insurance coverage in the United States: 2003*—

- U.S. Census Bureau, *Current Population Reports, P60-226*. Washington, DC: U.S. Government Printing Office, 2004.
2. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A new definition of children with special health care needs. *Pediatrics* 1998;102:137-40.
 3. Mayer ML, Skinner AC, Slifkin RT. Unmet need for routine and specialty care: Data from the National Survey of Children with Special Health Care Needs. *Pediatrics* 2004;113:e109-e15.
 4. van Dyck PC. The National Survey of Children with Special Health Care Needs: Presentation for DataSpeak, 2003. Retrieved May 22, 2003, from Maternal and Child Health Information Resource Center Web site: http://www.mchb.hrsa.gov/mchirc/dataspeak/events/may_03/index.htm
 5. Szilagyi PG. Care of children with special health care needs. *Future Child* 2003;13(1):137-51.
 6. Davidoff AJ. Insurance for children with special health care needs: Patterns of coverage and burden on families to provide adequate insurance. *Pediatrics* 2004;114:394-403.
 7. Aiken KD, Freed GL, Davis MM. When insurance status is not static: Insurance transitions of low-income children and implication for health and health care. *Ambul Pediatr* 2004;4:237-43.
 8. Rewers A, Chase HP, Mackenzie T, Walravens P, Roback M, Rewers M, Hamman RF, Klingensmith G. Predictors of acute complications in children with type 1 diabetes. *JAMA* 2002;287(19):2511-8.
 9. Newacheck PW, McManus M, Fox HB, Hung Y, Halfon N. Access to health care for children with special health care needs. *Pediatrics* 2000;105:760-6.
 10. *Assessing and assisting the underinsured*. Rockville, MD: Health Resources and Services Administration, August 20, 2001.
 11. Ward A, Beebe TJ, Blewett LA, Smaida S. *Issues in defining and measuring adequacy of coverage*. Minneapolis, MN: State Health Access Data Assistance Center, 2002.
 12. Maternal and Child Health Bureau. *National Agenda for Children with Special Health Care Needs: Achieving the Goals 2000*. Rockville, MD: MCHB, Health Resources and Services Administration, 1995.
 13. Blumberg SJ, Olson L, Frankel M, Osborn L, Becker CJ, Srinath KP, Giambo P. *Design and operation of the National Survey of Children with Special Health Care Needs, 2001*. *Vital Health Stat 1* 2003; Series 1, (41):1-136.
 14. Bethell CD, Read D, Stein REK, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambul Pediatr* 2002;2:38-47.
 15. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics* 2004;114:79-85.
 16. American Academy of Pediatrics. Policy statement: Organizational principles to guide and define the child health care system and/or improve the health of all children. *Pediatrics* 2002;110(1):184-6.
 17. Nickel RE, Cooley WC, McAllister JW, Samson-Fang L. Building medical homes for children with special health care needs. *Infants Young Child* 2003;16:331-41.
 18. Collins S. *Hearing on Review of Hospital Billing and Collection Practices, US House of Representatives, Committee on Energy and Commerce, Subcommittee on Oversight and Investigations*. New York: The Commonwealth Fund, June 24, 2004.
 19. Berman S. The brave new bipartisan world of health care reform: How will low-income families with children with special health care needs fare? *Pediatrics* 2004;114:489-90.

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