Syracuse University

SURFACE

Center for Policy Research

Maxwell School of Citizenship and Public Affairs

3-2001

Unfinished Business: Inadequate Health Coverage for Privately Insured, Seriously Ill Children

Nancy Swigonski
Indiana University

Eleanor D. Kinney
Indiana University

Deborah A. Freund
Claremont Graduate University

Thomas J. Kniesner
TKniesne@Maxwell.Syr.Edu

Follow this and additional works at: https://surface.syr.edu/cpr

Part of the Labor Economics Commons, and the Medicine and Health Sciences Commons

Center for Policy Research
Working Paper No. 25

UNFINISHED BUSINESS: INADEQUATE HEALTH
COVERAGE FOR PRIVATELY INSURED,
SERIOUSLY ILL CHILDREN

Nancy Swigonski, Eleanor D. Kinney,
Deborah A. Freund, and Thomas J. Kniesner

Center for Policy Research
Maxwell School of Citizenship and Public Affairs
Syracuse University
426 Eggers Hall
Syracuse, New York 13244-1020
(315) 443-3114 │ Fax (315) 443-1081
e-mail: ctrpol@syr.edu

May 2000
[Revised March 2001]

$5.00

CENTER FOR POLICY RESEARCH – Spring 2001

Timothy M. Smeeding, Director
Professor of Economics & Public Administration

Associate Directors

Margaret M. Austin
Associate Director,
Budget and Administration

Douglas Holtz-Eakin
Chair, Professor of Economics
Associate Director, Center for Policy Research

Douglas Wolf
Professor of Public Administration
Associate Director, Aging Studies Program

John Yinger
Professor of Economics and Public Administration
Associate Director, Metropolitan Studies Program

SENIOR RESEARCH ASSOCIATES

Scott Allard ....Public Administration
Dan Black ....Economics
Stacy Dickert-Conlin..Economics
William Duncombe ....Public Administration
Gary Engelhardt ....Economics
Deborah Freund.................................Public Administration
Vernon Greene....................................Public Administration
Leah Gutierrez ....Public Administration
Madonna Harrington Meyer ....Sociology
Christine Himes ....Sociology
Jacqueline Johnson ....Sociology
Bernard Jump.....................................Public Administration
Duke Kao ....Economics

Eric Kingson............................. ....Social Work
Thomas Kniesner ....Economics
Jeff Kubik..Economics
Jerry Miner ....Economics
John Moran...Economics
Jan Ondrich ....Economics
John Palmer ....Public Administration
Lori Ploutz-Snyder............Health and Physical Education
Grant Reeher ....Political Science
Stuart Rosenthal ....Economics
Jodi Sandfort....................................Public Administration
Michael Wasylenko ....Economics
Assata Zerai...Sociology

GRADUATE ASSOCIATES

Reagan Baughman ....Economics
Robert Bifulco..................................Public Administration
Caroline Bourdeaux ....Public Administration
Christine Caffrey..Sociology
Christopher Cunningham ....Economics
Tae Ho Eom ....Public Administration
Seth Giertz ....Economics
Andrzej Grodner...Economics
Rain Henderson ....Public Administration
Pam Herd..Sociology
Lisa Hotchkiss ....Public Administration
Peter Howe ....Economics
Benjamin Johns ....Public Administration
Anil Kumar..Economics

Kwangho Jung....................................Public Administration
James Laditka.....................................Public Administration
Xiaoli Liang...Economics
Donald Marples ....Economics
Neddy Matshalaga..Sociology
Suzanne Plourde...Economics
Nora Ranney.......................................Public Administration
Catherine Richards ....Sociology
Adriana Sandu ....Public Administration
Mehmet Serkan Tosun...................................Economics
Mark Trembley....................................Public Administration
James Williamson ....Economics
Bo Zhao ....Economics

STAFF

JoAnna Berger ....Receptionist
Martha Bonney ....Publications/Events Coordinator
Karen Cimilluca...........................Librarian/Office Coordinator
Kati Foley.................................Administrative Assistant, LIS
Esther Gray....................Administrative Secretary
Kitty Nasto ....Administrative Secretary
Denise Paul......................................Editorial Assistant, *NTJ*

Mary Santy .... Administrative Secretary
Amy Storfer-Isser....................Computer Support,
....Microsim Project
Debbie Tafel ....Secretary to the Director
Ann Wicks .... Administrative Secretary
Lobrenzo Wingo...................Computer Consultant

Abstract

During the 1980s and 1990s there were great increases of health insurance coverage for poor children through the Children's Health Insurance Program (CHIP) and extended Medicaid eligibility. Problems remain for the small number of children with serious medical conditions whose care is a high proportion of total health care expenditures on children. We report on the adequacy of health insurance coverage for a sample of children with serious and rare illnesses treated at the single tertiary care pediatric hospital in Indiana. One-third of privately insured children in our data had inadequate insurance. Compared to families with inadequate health insurance families with adequate insurance were 50 percent less likely to delay care for themselves and 67 percent less likely to delay care for a child. Our research identifies policy relevant deficiencies in private health coverage for seriously ill children ineligible for either Medicaid or CHIP.

Introduction

About 10 percent of children account for 60–70 percent of children's total health care expenditures (Neff and Anderson 1995; Newacheck, Hughes, and Cisternas 1995; Newacheck and McManus 1988; Hobbs, Perrin, and Ireys 1985). High medical care use children come from all socio-economic groups and so have both public and private health coverage. Many children are ineligible on income grounds for public programs. We report on the adequacy of health insurance coverage for a sample of children with serious and rare illnesses treated at the single tertiary care pediatric hospital in Indiana. Our empirical examination indicates a problem of inadequate coverage for privately insured seriously ill children that has been not addressed by recent coverage expansions or federal and state reform legislation targeted at insurer underwriting practices restricting access to private coverage for seriously ill people.

Although several studies describe health insurance coverage for seriously ill children (Centers for Disease Control 1995; Aday et al. 1993; Aday 1992; Fox and Newacheck 1990; Newacheck 1990), the problem of inadequate insurance coverage for children with serious illness is still poorly documented. We find that although most seriously ill children have health coverage, many with private insurance have coverage deficiencies according to prevailing definitions of health insurance adequacy. Families with an inadequately insured child also often delay uncovered care for the child or, more likely, delay care for another family member. Our exploratory examination of seriously ill children in Indiana leads us to conclude that there is cause for concern and a need for more research regarding the adequacy of coverage for seriously ill children with private coverage even in view of recent legislative reforms.

Health Insurance Coverage For Seriously Ill Children

According to U.S. Census data for 1994–1995, just over 10 percent of children in both Indiana and the nation were uninsured (Liska, Brennan, and Bruern, 1998). The major source of coverage for all children is private health insurance. Of all children in 1994–1995, about 62 percent had employer-sponsored health coverage and 4 percent had other private or public health coverage (Liska et al. 1998). In Indiana, 69 percent of children had employer-sponsored coverage, and 5 percent had other public or private coverage (Liska et al. 1998).

Private Insurance Programs

There is great variation in benefits and coverage among private health insurance plans due chiefly to limited regulation of employer-sponsored plans under federal law (Ginsburg, Gabel, and Hunt 1998; Jensen and Gabel 1988). Specifically, the Employee Retirement Income Security Act of 1974 (ERISA), which regulates employer-sponsored health plans, preempts most state insurance regulation including state law protections for plan enrollees. Congress has not yet amended ERISA to assure comparable consumer protections for ERISA-regulated plans. In addition, many employer-sponsored plans self-insure rather than purchase state-regulated commercial health insurance to avoid state regulation, including state-mandated benefit laws.

The availability, affordability and adequacy of employer-sponsored health insurance have decreased in recent years (Ginsburg, Gabel, and Hunt 1998; Jensen, Morrisey, Gaffney, and Liston 1998; Blumberg and Liska 1996; Bovbjerg, Griffin, and Carrol 1993). Cost sharing and benefit limits have increased in recent years in many private health insurance plans (Ginsburg, Gabel, and Hunt 1998; Sullivan and Rice 1991). The decline in coverage has been most substantial among low-income children (Weinick, Weigers,

and Cohen 1998; U.S. General Accounting Office [GAO] 1996a; Holl et al. 1996; Fronstin 1995), which inspired the Children's Health Insurance Program (CHIP) in 1997.

Several recent state and federal legislative initiatives have tried to expand private health coverage for the seriously ill using so-called mandated coverage. An example is the creation of state high-risk insurance pools to provide coverage for the seriously ill who cannot otherwise obtain health insurance privately. High-risk insurance pools are now available in most states, including Indiana. Federal law, specifically COBRA, requires employers to extend coverage for extensive periods to family members of terminated employees although at the employee's expense. Coverage through state high-risk pools and the COBRA extension can be expensive and limited.

States and the federal government have also enacted legislation to address problems with scope of health insurance coverage. To limit insurer practices that narrow health coverage, such as pre-existing conditions exclusions, most states have enacted so-called small market legislation, which limits medical underwriting and other exclusionary insurer practices (Oliver and Fiedler 1997; GAO 1995). In 1996, Congress imposed restrictions similar to the states' on federally-regulated employer sponsored plans as well as on independent state-regulated plans to maximize portability of health insurance and to restrain underwriting limits for seriously ill with health coverage (Nichols and Blumberg 1998). However, policy measures to recast underwriting and other insurance practices have not addressed all problems related to scope of coverage and have done little to control the cost of private health coverage (Oliver 1999; GAO 1998; Kuttner 1997).

Public Insurance Programs

The Medicaid program requires states to insure all children under age six in families with incomes up to 133 percent of the federal poverty income level. States also have the option of covering children in

families with incomes up to 185 percent of poverty income and most, including the state we study (Indiana), have expanded coverage for children. In 1994–1995, 23 percent of children nationally and about 16 percent of children in Indiana had Medicaid coverage (Liska et al. 1998). Benefits under Medicaid are comprehensive and provide what has been deemed adequate health insurance coverage for eligible children. Many parents elect to take Medicaid coverage in lieu of available private insurance coverage because of Medicaid's free comprehensive benefit package (Cutler and Gruber 1996; Dubay and Kenny 1995).

The joint federal/state Children's Special Health Care Needs (CSHCN) program targets poor and near-poor children with serious illnesses who are financially ineligible for Medicaid. CSHCN serves approximately 755,000 children nationally and about 5000 in Indiana (Aron, Loprest, and Steverle 1995). State programs vary. Indiana's CSHCN program provides health insurance coverage for one of 22 medical conditions in families with incomes of up to 250 percent of the federal poverty level.

In 1997, Congress established the Children's Health Insurance Program (CHIP) to expand health insurance coverage for children with family incomes up 200 percent of poverty (Weinick et al. 1998; Rosenbaum et al. 1998; Ullman 1998). Under CHIP, states have great flexibility in program design, although benefit packages must be comparable to benchmark plans such as the standard Blue Cross and Blue Shield plan for federal employees, the state's health plan for state employees, or the commercial HMO having the largest enrollment in the state. States are also prohibited from imposing pre-existing condition exclusions or excluding children on the basis of diagnosis in designing CHIP benefit packages. Indiana covers all children up to 150 percent of the federal poverty income level through Medicaid or CHIP. Estimates of Indiana children with family incomes below 200 percent of the federal poverty level range from 129,000 to 143,000 (ICHIP 1998). Neither CHIP nor Medicaid directly addresses the issue of insurance generosity for privately insured children.

Operationalizing the Concept of Inadequate Health Coverage

Private health coverage for children has received little attention although many privately insured children have what can be deemed inadequate coverage (Monheit 1994). About 17 percent of the privately insured children under age 19 are underinsured based on the actuarial value of their insurance compared to the Blue Cross and Blue Shield standard option plan for federal employees (Short and Banthin 1995). Approximately 8 percent are underinsured based on the probable exposure to medical expenses over 10 percent of family income. Most studies of insurance adequacy focus on the non-elderly population generally (Monheit 1995; Short and Banthin 1995; Bodenheimer 1992; Bashshur, Smith, and Stiles 1993).

One way to put into practice the concept of inadequate insurance is to consider exposure to high uncovered financial risk. We take consideration of three variables: (1) the probability of incurring an expense for medical care in a year, (2) the size of the expense, and (3) the relationship of the expense to income (Farley 1985). Insurance could also be considered inadequate if it has an actuarial value less than the standard Blue Cross and Blue Shield plan for federal employees or the more generous fee-for-service package proposed in President Clinton's Health Security Act (H.R. 3600, 103d Cong., 1st Sess. (1993)) (Short and Banthin 1995). Finally, one might categorize insurance adequacy based on both the characteristics of the insurance and the insured's perceptions of its adequacy. Insurance could then be said to be inadequate in one or more of the following circumstances: (1) coverage of too few services, (2) excessive out-of-pocket expenditures regardless of family income, and (3) consumer perceived inadequacy of insurance (Bashshur et al. 1993).

We define inadequate insurance if the characteristics of the health insurance sharply limit coverage compared to the benefit packages of the Medicaid program or conventional private health insurance such as the Blue Cross and Blue Shield standard option plan. In our empirical research insurance is defined as

inadequate if it has (1) a permanent pre-existing condition exclusion, or (2) no annual out-of-pocket limit on medical expenditures, or (3) at least two of the following limitations: (a) a deductible greater than $1,000; (b) coinsurance rates greater than 20 percent (or the complete exclusion of coverage) for hospitalization, physician services or prescription drugs; or (c) a lifetime maximum payout of less than $50,000. For comparability the indicators of insurance inadequacy we use are prevalent in previous research (Short and Banthin 1995; Bashshur et al. 1993; Bodenheimer 1992; Pepper Commission 1991).

We appreciate the controversy of defining adequacy of coverage based on insurance characteristics rather than on percentage of potential risk of loss to income. Focusing on insurance characteristics is informative for privately insured seriously ill children for several reasons. First, measures based on loss probability estimates are excellent for typifying inadequate insurance in a population but may not be good predictors of inadequate insurance for identified individuals. Second, for most people with moderate incomes their insurance policy provisions, particularly permanent pre-existing condition exclusions or high deductibles, can have a significant impact on net income when use of services is substantial. Third, we can examine whether our definition of inadequacy of coverage correlates with reports in delays in care, in turn illustrating not only the theoretical but also the practical significance of defining adequacy based on insurance characteristics for the families of children with serious illness.

Methods

Because few seriously ill people appear in samples of the general population previous researchers using random samples have had trouble detecting health insurance related problems specific to the seriously ill (Monheit 1994). We focus on already ill children rather than a general population of children to obtain a sufficient number of seriously ill children for statistically informative estimates. Table 1 reports the low

incidence in the general population of serious childhood diseases, which emphasizes the need for a targeted sample of ill children such as ours examined here.

Admittedly our targeted sample is not representative of the general population of children. It is important to recognize first the source of non-randomness in our sample. To be in our data a child must have an illness, which is a background variable, but to be in our data a child need not have any particular characteristics of insurance coverage directly, the outcome of interest. By choosing a sample based on an explanatory variable (health status) what we do is similar to research that over-selects African Americans to be able to study racial differences in health outcomes with reasonable statistical precision. The over-representation of African Americans by design does not create a biased picture of how race affects health because there is no reverse causality—health does determine race. Our situation is analogous in that there is no obvious reverse causality running from current insurance adequacy to the current presence of a serious health condition, most prevalently cancer and blood disorders. Our results should be informative on how the presence of a severe health condition can limit insurance coverage without worry that our estimates are contaminated by unnoticed reverse causality.

A second possible complexity in determining what influences health insurance adequacy is the possibility that persons who have relatively good health insurance, an outcome of interest, are systematically more or less likely to participate in a survey of insurance adequacy. Consider an explanatory variable that one believes to be positively related to insurance adequacy, say income. Suppose families with above average incomes are more likely to have adequate insurance and also more willing to discuss it. The estimated effect of income on insurance adequacy will be overstated because it represents two things: the true positive effect of income on insurance adequacy and the willingness to tell someone insurance adequacy. On the other hand, one can imagine the situation where a family with bad health insurance is more

likely to participate in a survey of health insurance adequacy. Now let families with low incomes, who are more likely to have inadequate insurance, also be more willing than most to tell someone about their health insurance. Now the estimated effect of income on insurance will be understated because it reflects two things: the true negative effect of low income on insurance adequacy plus the willingness of the inadequately insured to tell someone. Our data source would not release the information to permit study of survey non-respondents. There is no good way, then, to adjust our multivariate analysis for any latent connection between insurance adequacy and the willingness to report it or even to speculate on the direction of any bias in our results from using our admittedly non-random sample of children.

The Sample

The sample we use covers children aged 1 to 18 treated for a serious medical condition at the Riley Hospital for Children of the Indiana University School of Medicine, Indianapolis, Indiana. Riley Hospital is the only children's hospital in Indiana and is the state's major pediatric tertiary care center. The children sampled have diseases for which Riley Hospital treats more than 80 percent of Indiana's afflicted minor residents. Table 2 displays the frequency of diagnoses, which include childhood cancers, inborn errors of metabolism, rheumatological diseases, and chronic renal failure.

Because of confidentiality concerns Riley Hospital first contacted families and invited them to participate in the study. The hospital then sent out one letter to 1,943 parents of children that met the sampling criteria. The hospital released contact information on 436 consenting participants. The 22 percent response rate is typical of surveys in which only one mailing is sent to the respondent pool (Fink 1995; Frey 1989; Groven 1989; Goyder 1988). About 18 percent of the respondents were additionally excluded because they either did not meet the study's age criteria (6 percent) or they did not have a selected serious disease (12 percent).

8

Telephone interviews of the usable respondents occurred between April and August 1994. The parent or guardian who knew the most about the child's illness and insurance answered the questions. Interviews focused on the child's health, insurance coverage, cost of treatment, and health care choices using a so-called active interviewing technique (Holstein and Gabrium 1995). About 91 percent of the eligible respondents completed interviews. After deleting an additional 8 percent of the ultimate survey respondents because of missing data on one or more independent variables we are left with 299 children with the necessary information. We study in detail the insurance adequacy of the 83 percent with private insurance.

Multivariate Statistical Analysis

The first multivariate statistical model we use is a logit regression intended to reveal the separate influences on insurance adequacy of key demographic, economic, and health status factors. For each of the insurance adequacy criteria, 3 to 8 percent of the participants did not know what was covered in their policy. Specifically, in the sample of privately insured persons we study, 8 percent did not know if there was a pre-existing exclusion on their policies, 6 percent did not know their yearly deductible, and 8 percent did not know if there was an upper limit on out-of pocket expenses. When respondents did not know the characteristics of their insurance we coded their insurance as adequate, which produces a conservative estimate of the number of children with inadequate insurance to explain in our multivariate model.

In supplemental multivariate logit regressions we examine how demographic, economic, and health status factors plus insurance inadequacy affect the likelihood someone delays seeking or taking treatment. Reported delays in obtaining care because of a lack of insurance for the child or the family meter access to health care. Specifically, subjects were asked whether they delayed care for the child or themselves or

another family member because of lack of insurance coverage. Examining delayed care too gives us a more complete picture of the impact of inadequate insurance on families of children with serious illness.

Explanatory Variables. Our choice of particular explanatory variables follows Aday's conceptualization where access to health care depends on so-called predisposing, enabling, and need factors (Aday et al. 1993). Predisposing factors, which are deemed to underlie a lack of insurance coverage, here include race, marital status, and education. Enabling factors, which should facilitate access to health coverage, here include family income, employment status, and insurance status. Need factors, which reflect need for health care, here include the child's health status and length of time since diagnosis.

Results

Averages and category proportions for explanatory variables appear in Table 3. The parents in our data are predominantly privately insured, white, highly educated, and employed with moderate to high incomes. Children had a variety of serious medical conditions; the most frequent serious illness is a childhood cancer (30 percent). Despite their illnesses the majority of children are considered to be in a condition of excellent, very good, or good health.

Health Insurance Coverage

Insured persons' health insurance coverage can be public or private. Public coverage includes Medicare, Medicaid, Children's Special Health Care Needs, and health insurance for the military and their dependents. Private coverage here means (1) either mandated private coverage by federal law or Indiana's high-risk pool, and (2) all other private coverage, referred to as market insurance. The primary source of the children's insurance coverage is private health insurance that is a fringe benefit of a parent's employment. About 79 percent of the children in our sample had conventional private insurance, 5 percent had private

insurance through mandated programs such as the COBRA extension or Indiana's high-risk pool, 13 percent had insurance from public programs, and 3 percent had no insurance.

In our data, parents of children with public insurance were less likely than parents of children with either no insurance or private insurance to be employed, white, have more than 12 years of education, have moderate to high incomes and to be married. Compared to parents with mandated or market private insurance, parents of children with no insurance were more likely to have low incomes.

Adequacy of Insurance Coverage

Table 4 shows that according to our definition of adequacy a third of the privately insured children had inadequate health coverage, some for multiple reasons. About 66 percent of the inadequately insured were in that situation because their insurance lacked an annual out-of-pocket limit on medical expenditures. About 29 percent of the inadequately insured were that way because their insurance had a permanent pre-existing condition exclusion. About 16 percent of the inadequately insured were that way because they had a policy containing two of the three characteristics mentioned earlier: relatively high deductible, high coinsurance rate, or small maximum lifetime payout.

Approximately 90 percent of the children we study did not have a pre-existing condition exclusion in their insurance. Almost one-half of the children without a permanent pre-existing condition exclusion had the same insurance policy as at diagnosis and were not at risk for the exclusion. About one-third of the small number of respondents with mandated insurance in Indiana's high-risk pool reported having had inadequate insurance previously.

Insurance Adequacy

Table 5 presents our multivariate logit model results. For convenience the individual effect of an explanatory variable is its so-called odds ratio and the associated likely range into which the odds ratio falls

11

with reasonable statistical certainty. No predisposing or enabling variables have a statistically significant relationship to insurance adequacy. Our main finding concerning insurance adequacy is a statistically significant negative relationship between the number of years since diagnosis and adequacy of insurance even holding constant the effects of health status, education, race, sex, marital status, income, and employment. On average, a person who was diagnosed with a serious condition a year ago has about a 90 percent chance of having adequate insurance compared to someone just diagnosed.

Reported Delays in Care

As noted by the frequency data in Table 4, parents were more likely to delay care for themselves or to delay care for other children than to delay care for their seriously ill child. Compared to parents with adequate insurance, parents with inadequate insurance were about 2.5 times more likely overall to delay care for their child. Similarly, 43 percent of inadequately insured parents reported delays in treatment for themselves or another family member, compared to the 26 percent of parents who were adequately insured who reported delays in treatment in Table 4. We now examine whether adequacy of coverage connects to decisions to seek medical advice and treatment both for our focal seriously ill children and other family members when one also considers the intervening factors we have labeled predisposing variables, enabling variables, and need variables.

Our data are also not rich enough to allow for the possibility of joint causality running back and forth between the decision to delay care and the adequacy of health insurance in the last two columns of results in Table 5. The statistical solution to disentangling the effect of insurance adequacy on delay of care from a possible effect of likely delay of care on insurance purchase (as reflected by adequacy) requires having at least one variable that a researcher believes determines insurance adequacy but is not itself determined by delay of care decisions. The extra variable, known as an instrument or an instrumental variable, could enable

12

one to infer the causality running from insurance adequacy to care delays. We neither have available an obvious instrument to stand in for observed insurance adequacy nor is it clear how any bias in our multivariate results discussed below may be at work because it is not obvious whether and how persons who report delaying care will have adjusted their insurance adequacy in light of an anticipated need for immediate health care.

The results in the third and fourth columns of Table 5 confirm that even after we hold statistically constant the effects of intervening factors there remains a negative effect of adequacy of coverage on delay in getting medical care. Compared to persons with inadequate insurance, persons with adequate insurance were half as likely to delay care for either themselves or other family members and two-thirds less likely to delay care for their child. For emphasis we cite Figure 1, which directly quotes respondents on how decisions concerning an expensive medical procedure led them to consider extreme strategies for obtaining the requisite health coverage.

Discussion

Our sample parents were predominantly white, highly educated, employed, and had middle to high family incomes. Over 96 percent had health insurance coverage. Nevertheless, over 30 percent of the privately insured children were inadequately insured. Some children faced selective exclusions because of pre-existing conditions, which often means having no coverage for the disease generating most of their medical expenses. Respondents frequently had insurance with no annual limit on out-of-pocket expenditures and in turn faced exposure to high medical bills. Over one-third of children insurance mandated through the state of Indiana's high-risk pool reported having inadequate insurance at some point. Our results indicate that inadequate insurance is prevalent among children with serious illnesses and that inadequate insurance has a significant impact on children's access to care.

We found that predictors of adequate insurance differ from predictors of non-insurance reported in the literature (Comer and Mueller 1992; Aday et al. 1993; Holl et al. 1995; Weinick et al. 1998). Children whose parents were poorly educated, single, had low incomes, or had children who were in poor health were no more likely to have adequate insurance than children who had parents who were more highly educated, had higher incomes, were married, or whose children were in better health. Other researchers have found similar results regarding the lack of an effect for marital status (Comer and Mueller 1992), income (Short and Banthin 1995), and health status (Aday et al. 1993) on adequacy of health insurance.

Race (Weinick et al. 1998; Holl et al. 1995; Aday et al. 1993; Comer and Mueller 1992) is a known predictor of non-insurance, and employment status is a predictor of both non-insurance (Cunningham and Monheit 1990) and inadequate insurance (Comer and Mueller 1992). We did not find a significant association between race or employment status and adequacy of insurance. Other studies have shown an association between age and both non-insurance and adequacy of insurance (Short and Banthin 1995). We found that the number of years since diagnosis had a greater effect on adequacy of insurance than the child's age.

Using a definition of inadequate insurance based on characteristics of insurance rather than the potential risk of loss is admittedly controversial. Limited benefits or high deductibles might not result in coverage that is detrimental to long run health if the insured has sufficient income to pay for the benefit or the deductible. We tested the saliency of our insurance adequacy definition that is based on insurance characteristics by including adequacy as an enabling variable to predict reports in delay of care. Others have reported that non-insurance is correlated with decreased access to care (Wood et al. 1990; Butler et al. 1985). We found that despite our study's large fraction of families having moderate to high incomes,

14

adequacy as defined by insurance characteristics had a significant impact on reports of delay in care for both the child with serious illness and other family members.

Finally, our data suggest that lack of adequate health insurance coverage leads parents to delay care for their seriously ill children or, more likely, to delay medical car for themselves or other family members. Our findings suggest an important public health problem because delays in medical treatment often mean disease becomes more serious before any treatment.

Conclusion and Implications for Practice

Despite coverage expansions for children and state and federal small-market insurance reforms we find that a problem exists with inadequate insurance for privately insured seriously ill children. Physicians and other practitioners should not assume that seriously ill children with private health insurance—even with moderate incomes—have the requisite coverage to pay for all the health care services they want to treat a serious illnesses. It is important to be sensitive to the nature of insurance coverage for privately insured children in designing and implementing treatment regimens. Children with private insurance coverage may actually have less coverage to defray the cost of care than poorer children on CHIP or Medicaid.

Adequacy of insurance health coverage for seriously ill children, particularly children with private insurance, is an important issue both from a public policy and medical practice perspective. Our strong findings, even though based on a small sample from one state, suggest that a problem with private coverage for seriously ill children exists and that future research could be quite valuable in designing health policy.

**Table 1. National Incidence of Selected Diseases
Represented in the Sample**

Illness	
Childhood Leukemia	4.5 per 100,000 children per year
Cystic Fibrosis	1 per 250,000 and 1 per 1,700 in white and black children per year
Juvenile Rheumatoid Arthritis	3 per 100,000 children
Crohn's Disease	1.7 to 3.5 per 100,000 per year
Turner's Syndrome	1 per 3,000 live-born females per year
Phenylketonuria (PKU)	1 to 2 per 10,000 children
Autism	2 per 1,000 children
Congenital Heart Disease	8 per 1,000 children

Source: Nelson 1992; Walker 1996.

Table 2. Frequencies of Diagnoses
(in percent)

Diagnosis	Public Insurance (n = 50)	Private Insurance (n = 245)	All Insured (n = 299)
Childhood Cancers and Other Hematologic Disorders	34	30	30
Cystic Fibrosis and Other Pulmonary Disorders	14	13	13
Rheumatologic Disorders	8	13	12
Endocrinopathies	4	14	12
Chronic Gastrointestinal Disorders	10	10	10
Turner's Syndrome and Other Genetic Disorders	4	6	6
Chronic Renal Failure and Other Kidney Problems	8	4	5
Metabolic Disorders	4	4	4
Neurological Disorders	6	2	3
Autism	2	2	2
Congenital and Other Heart Disease	4	1	2
Other	2	1	1

Source: The Robert Wood Johnson Foundation Barriers to Health Insurance Project, 1994.

Table 3.   Demographic Characteristics of Children and Parents
By Type of Insurance Coverage
(in percents)

Independent Variables	No Insurance	Public	Mandated Private Insurance	Market Private Insurance	Total Sample
Row Total (n = 249)	3	13	5	79	100
Race					
White	100	85	100	96	95
Black/Non-White	0	15	0	4	5
Child Age (mean range)	9.6	9.9	8.9	9.7	9.7
	(5.4)	(4.9)	(5.4)	(4.1)	(4.9)
Education					
< 12 years	10	2	0	2	3
High School	30	55	21	27	30
> 12 years	60	42	79	71	67
Marital Status					
Married	90	55	93	92	87
Not married	10	45	7	8	13
Parental Employment					
One or both employed	90	72	100	98	95
Not employed	10	28	0	2	5
Family Income					
<$25,000	40	80	21	10	21
$25,000 to $49,999	40	20	43	48	44
≥$50,000	20	0	36	42	35
Years Since Diagnosis					
Mean	5.3	5.5	5.5	7.4	5.6
Standard deviation	4.2	4.1	4.6	4.1	4.1
Health Status					
Excellent to good	90	72	100	81	81
Fair or poor	10	28	0	19	19

Source: The Robert Wood Johnson Foundation Barriers to Health Insurance Project, 1994.

**Table 4. Characteristics of Inadequate Insurance
among Privately Insured Children
(in percent)**

	Total Privately Insured Children	Reasons for Inadequate Insurance[a]
Adequately insured	67	
Inadequately insured	33	
Permanent pre-existing condition exclusion		29
No out-of-pocket limit		66
Two of three characteristics:[b]		16

[a]Insurance of some respondents was inadequate for more than one reason.

[b]Characteristics are: (a) deductible > $1,000; (b) coinsurance for hospital, physician or prescription drug coverage > 20 percent; and (c) lifetime maximum < $50,000.

Source: Robert Wood Johnson Foundation Barriers to Health Insurance Project, 1994.

Table 5. Results of Regression Analysis of Dependent Variables Adjusted Odds Ratios (AOR) and Their 95 Percent Confidence Intervals (CI)[a]

	Adequate Insurance[b] AOR [CI]	Delay Care Ill Child[c] AOR [CI]	Delay Care Family[d] AOR [CI]
Predisposing Variables			
Race of Child			
White vs. Black/Other	3.49 [0.82–14.88]	0.64 [0.17–2.32]	1.57 [0.48–5.08]
Education of Parents			
High school or less vs.> 12 years	1.27 [0.68–2.38]	1.22 [0.59–2.52]	1.03 [0.60–1.78]
Marital Status of Parents			
Married vs. not married	0.59 [0.18–1.91]	0.61 [0.21–1.77]	0.70 [0.29–1.70]
Enabling Variables			
Parental Employment			
One/both employed vs. not	1.20 [0.13–11.18]	5.02 [0.43–47.26]	1.95 [0.54–7.12]
Family Income			
<$25,000	0.44 [0.18–1.12]	0.66 [0.25–1.77]	3.22 [1.56–6.65]
$25,000-49,000 vs. ≥$50,000	1.15 [0.63–2.10]	0.87 [0.41–1.83]	0.97 [0.54–1.75]
Need Variables			
Years since Diagnosis	0.90* [0.85–0.96]	1.00 [0.92–1.08]	1.06* [1.00–1.13]
Health Status			
Excellent, very good, or good vs. fair or poor	0.65 [0.32–1.32]	1.13 [0.50–2.57]	1.34 [0.70–2.55]
Adequate Insurance	Not applicable	0.38* [0.19–0.78]	0.44* [0.26–0.76]

[a]Significant odds ratios have confidence intervals that do not include 1.0.

[b]$N = 249$. Pseudo $R^2 = 0.10$.

[c]$N = 299$. Pseudo $R^2 = 0.09$.

[d]$N = 299$. Pseudo $R^2 = 0.16$.

Source: The Robert Wood Johnson Barriers to Health Insurance Project, 1994.

Table 6. Decisions to Delay Medical Treatment among Seriously
Ill Insured Children and Their Families by Adequacy
of Private Health Insurance Coverage
(in percent)

	Adequately Insured	Inadequately Insured	Column Percent
	Children*		
Delayed care	10	23	14
Did not delay care	90	77	86
Row percent	67	33	100
	Family Members*		
Delayed care	26	43	32
Did not delay care	74	57	68
Row percent	67	33	100

*$p \leq 0.01$.
**$p \leq 0.01$.
Source: The Robert Wood Johnson Barriers to Health Insurance Project, 1994.

**Figure 1.   Delays in Care for Serious Ill Children
and their Families**

The parent of a 14 year old white male with renal failure in a family where both parents are employed considered quitting employment and going on welfare to qualify their child for Medicaid:

Well, the donor worked up to have the transplant—we kept putting it off because we didn't know if we had any insurance to get that done. We talked to the hospital and we got a hold of a social worker. Her reaction was that both my husband and I were going to have to quit our jobs and go on welfare. I told the social worker that: no, we were not going to quit our jobs and go on welfare and her reaction was if you don't then you will fall through the cracks. The reason, she told us, we should go on welfare is because we would qualify for Medicaid—if we quit our jobs—because that would pay for (her) surgery.

The parent of an 18 year old white female diagnosed with Turner's syndrome in a family with one parent employed reported:

I delayed getting recheck appointments because it is too costly before you reach the deductible to pay for all of this out of pocket. The kids come first. I take better care of them than I do myself. I was diagnosed with thyroid cancer about four or five years ago and it is a real burden. If they want to see you every month, you stretch it out to every six weeks because it gets very costly.

Acknowledgments

Nancy Swigonski is Assistant Professor of Pediatrics and Adolescent Medicine, Department of Pediatrics, Indiana University School of Medicine, and Investigator, Bowen Research Center, Indiana University School of Public and Environmental Affairs. Eleanor Kinney is the Samuel R. Rosen Professor of Law and Co-Director, The Center for Law and Health, Indiana University School of Law-Indianapolis. Deborah A. Freund is Professor of Public Administration and Senior Research Associate, Center for Policy Research, The Maxwell School of Citizenship and Public Affairs, Syracuse University. Thomas J. Kniesner is the Krisher Professor of Economics and Senior Research Associate, Center for Policy Research, The Maxwell School of Citizenship and Public Affairs, Syracuse University.

References

Aday, L. 1992 "Health Insurance and Utilization of Medical Care for Chronically Ill Children with Special Needs: Health of Our Nation's Children, United States, 1988," *Advance Data*, 215.

Aday, L., E. Lee, B. Spears, C. Chung, A. Youssef, B. Bloom. 1993. "Health Insurance and Utilization of Medical Care for Children with Special Health Care Needs," *Medical Care,* 31(11): 1013–1026.

Aron, L., P. Loprest, and C.Steverle. 1995. *Serving Children with Disabilities: A Systematic Look at the Programs.* Washington, DC: The Urban Institute Press.

Bashshur, R., D. Smith, and R. Stiles. 1993. "Defining Underinsurance: A Conceptual Framework for Policy and Empirical Analysis," *Medical Care Review,* 50(2): 199-218.

Blumberg, L. and D. Liska. 1996. *The Uninsured in the United States: A Status Report.* Washington, DC: The Urban Institute Press.

Bodenheimer, T. 1992. "Underinsurance in America," *New England Journal of Medicine,* 327(4): 274–278.

Bovbjerg, R., C. Griffin, and C. Carroll. 1993. "U. S. Health Care Coverage and Costs: Historical Development and Choices for the 1990s," *Journal of Law, Medicine, and Ethics,* 21(2): 141-162.

Bruen, B. and F. Ullman. 1998. *Children's Health Insurance Programs: Where States Are, Where They are Headed.* Washington, DC: The Urban Institute.

Butler, J., W. Winter, J. Singer, and M. Wenger. 1985. "Medical Care Use and Expenditure Among Children and Youth in the United States: Analysis of a National Probability Sample," *Pediatrics,* 76(4): 495–507.

Centers for Disease Control. 1995. "Disabilities among Children Aged < 17 Years—United States, 1991-1992," *Morbidity and Mortality Weekly Review*, 44(33): 609–613.

Comer, J. and K. Mueller. 1992. "Correlates of Health Insurance Coverage: Evidence from the Midwest," *Journal of Health Care for the Poor and Underserved,* 3(2): 305–320.

Cunningham, P. and A. Monheit. 1990. "Insuring the Children: A Decade of Change," *Health Affairs,* 9(4): 76–90.

Cutler, D. and J. Gruber. 1996. "Does Public Insurance Crowd Out Private Insurance," *Quarterly Journal of Economics*, 111(2): 391–431.

Dubay, L. and G. Kenny. 1995. "The Effects of Medicaid Expansions on Insurance Coverage of Children," *The Future of Children,* 6(1): 152–161.

Farley, P. 1985. "Who Are the Underinsured?" *Milbank Memorial Fund Quarterly,* 63(4): 476–504.

Fink, A. 1995. *How to Sample in Surveys.* Thousand Oaks, CA: Sage Publications, Inc.

Frey, J. 1989. *Survey Research by Telephone.* Newbury Park, CA: Sage Publications, Inc., 2d ed.

Fox, H. and P. Newacheck 1990. "Private Health Insurance of Chronically Ill Children," *Pediatrics,* 85(1): 50-57.

Fronstin, P. 1995. "Children Without Health Insurance: An Analysis of the Increase of Uninsured Children Between 1992 and 1993," *Inquiry*, 32 (Fall): 353–359.

Ginsburg, P., J. Gabel, and K. Hunt. 1998. "Tracking Small-Firm Coverage, 1989-1996," *Health Affairs*, 17(1): 167–171.

Goyder, J. 1987. *The Silent Majority: Nonrespondents on Sample Surveys.* Boulder, CO: Westview Press.

Groven, R. 1988. "An Overview of Nonresponse Issues in Telephone Survey." In R. Groves, P. Biemer, L. Lyberg, and J. Massey (eds.), *Telephone Survey Methodology.* New York: John Wiley & Sons, Inc.

Hobbs, N., J. Perrin, and H. Ireys. 1985. *Chronically Ill Children and Their Families.* San Francisco: Jossey-Bass Publishers.

Holl, J., P. Szilagyi, L. Rodewald, R. Byrd, and M. Weitzman. 1995. "Profile of Uninsured Children in the United States," *Archives of Pediatric and Adolescent Medicine*, 149: 298–406.

Holstein, J. and J. Gabrium. 1995. *The Active Interview.* Thousand Oaks, CA: Sage Publications, Inc..

Indiana Children's Health Insurance Program. 1998. *Indiana's Children Key Indicators of Well Being: A Resource and Data Book for the Governor's Advisory Panel.* Indianapolis: Office of the Governor of Indiana, unpublished.

Jensen, G., M. Morrisey, S. Gaffney, and D. Liston. 1997. "The New Dominance of Managed Care: Insurance Trends in the 1990s," *Health Affairs,* 16(1): 125–136.

Kuttner, R. 1997. "The Kassebaum-Kennedy Bill—The Limits of Incrementalism," *New England Journal of Medicine*, 337(1): 64–67.

Liska, D., N. Brennan, and B. Bruern. 1998. *State-Level Databook on Health Care Access and Financing, 3d Edition.* Washington, DC: The Urban Institute Press.

Monheit, A. 1994. "Underinsured Americans: A Review," *Annual Review of Public Health,* 15: 461–485.

Neff, J. and G. Anderson. 1995. "Protecting Children with Chronic Illness in a Competitive Marketplace," *Journal of the American Medical Association,* 274(23): 1866–1869.

Nelson, W. 1992. *Textbook of Pediatrics.* Philadelphia: Saunders, 14th ed.

Newacheck, P. 1990. "Financing the Health Care of Children with Chronic Illnesses," *Pediatric Annals,* 19(1): 60–63.

Newacheck, P., D. Hughes, and M. Cisternas. 1995. "Children and Health Insurance: An Overview of Recent Trends," *Health Affairs,* 14 (Spring): 244–254.

Newacheck, P. and M. McManus. 1998. "Financing Health Care for Disabled Children," *Pediatrics,* 81(3): 385–394.

Newacheck, P. and W. Taylor. 1992. "Childhood Chronic Illness: Prevalence, Severity, and Impact," *American Journal of Public Health,* 82(3): 364–371.

Nichols, L. and L. Blumberg. 1998. "A Different Kind of 'New Federalism'? The Health Insurance Portability and Accountability Act of 1996," *Health Affairs,* 17(3): 25–42.

Oliver, T. 1999. "The Dilemmas of Incrementalism: Logical and Political Constraints in the Design of Health Insurance Reforms," *Journal of Policy Analysis and Management,* 18(4): 652–683.

Oliver, T. and R. Fiedler. 1997. "State Government and Health Insurance Market Reform." In H.M. Leichter (ed.), *Health Policy Reform in America: Innovations from the States*, 2d ed. Armonk, NY: M.E. Sharpe, pp. 47–100.

Rosenbaum, S., K. Johnson, C. Sonosky, A. Markus, and C. DeGraw. 1998. "The Children's Hour: The State Children's Health Insurance Program," *Health Affairs*, 17(1): 75–89.

Short, P. and J. Banthin. 1995. "New Estimates of the Underinsured Younger than 65 Years," *Journal of the American Medical Association,* 274(16): 1302–1306.

U. S. Bipartisan Commission on Comprehensive Health Care (Pepper Commission). 1990. *A Call for Action,* S. Rep. No. 101-113, 101st Cong., 2d Sess. Washington, DC: Government Printing Office.

U.S. General Accounting Office. 1998. *Health Insurance Standards New Federal Law Creates Challenges for Consumers, Insurers, Regulators.* Washington, DC: U.S. Government Printing Office.

U.S. General Accounting Office. 1996a. *Health Insurance for Children: Private Insurance Coverage Continues to Deteriorate.* Washington, DC: U.S. Government Printing Office.

U.S. General Accounting Office. 1996b. *Health Insurance for Children: State and Private Program Create New Strategies to Insure Children.* Washington, DC: U.S. General Accounting Office.

U. S. General Accounting Office. 1995. *Health Insurance Regulation: Variations in Recent State Small Employer Insurance Reforms.* Washington, DC: U.S. Government Printing Office.

Walker, W. Allan (ed.). 1996. *Pediatric Gastrointestinal Diseases: Pathophysiology, Diagnosis, and Management, Vol. 1.* St. Louis: Mosby-Yearbook Inc..

Weinick, R., M. Weigers, and J. Cohen. 1998. "Children's Health Insurance, Access to Care, and Health Status: New Findings," *Health Affairs,* 17(2): 127–136.

Wood, D., R. Hayward, C. Corey, H. Freeman, and M. Shapiro. 1990. "Access to Medical Care for Children and Adolescents in the United States," *Pediatrics,* 86(5): 666–673.