

# PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## **Financial Burden of Raising CSHCN: Association With State Policy Choices**

Susan L. Parish, Paul T. Shattuck and Roderick A. Rose

*Pediatrics* 2009;124;S435-S442

DOI: 10.1542/peds.2009-1255P

The online version of this article, along with updated information and services, is located on the World Wide Web at:

[http://www.pediatrics.org/cgi/content/full/124/Supplement\\_4/S435](http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S435)

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2009 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



# Financial Burden of Raising CSHCN: Association With State Policy Choices

**AUTHORS:** Susan L. Parish, PhD, MSW,<sup>a</sup> Paul T. Shattuck, PhD, MSSW,<sup>b</sup> and Roderick A. Rose, MS<sup>a</sup>

<sup>a</sup>*School of Social Work, University of North Carolina, Chapel Hill, North Carolina; and* <sup>b</sup>*George Warren Brown School of Social Work, Washington University, St Louis, Missouri*

## KEY WORDS

Medicaid, SCHIP, health expenditures, cost of illness, children with special health care needs

## ABBREVIATIONS

CSHCN—children with special health care needs

SCHIP—State Children's Health Insurance Program

FPL—federal poverty level

NS-CSHCN—National Survey of Children With Special Health Care Needs

[www.pediatrics.org/cgi/doi/10.1542/peds.2009-1255P](http://www.pediatrics.org/cgi/doi/10.1542/peds.2009-1255P)

doi:10.1542/peds.2009-1255P

Accepted for publication Aug 3, 2009

Address correspondence to Susan L. Parish, PhD, MSW, 325 Pittsboro St, CB 3550, Chapel Hill, NC 27599-3550. E-mail: [parish@unc.edu](mailto:parish@unc.edu)

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2009 by the American Academy of Pediatrics

**FINANCIAL DISCLOSURE:** *The authors have indicated they have no financial relationships relevant to this article to disclose.*

## abstract

**OBJECTIVE:** We examined the association between state Medicaid and State Children's Health Insurance Program (SCHIP) income eligibility and the financial burden reported by low-income families raising children with special health care needs (CSHCN).

**SAMPLE AND METHODS:** Data on low-income CSHCN and their families were from the National Survey of Children With Special Health Care Needs ( $N = 17\,039$ ), with a representative sample from each state. State Medicaid and SCHIP income-eligibility thresholds were from publicly available sources. The 3 outcomes included whether families had any out-of-pocket health care expenditures during the previous 12 months for their CSHCN, amount of expenditure, and expenditures as a percentage of family income. We used multilevel logistic regression to model the association between Medicaid and SCHIP characteristics and families' financial burden, controlling state median income and child- and family-level characteristics.

**RESULTS:** Overall, 61% of low-income families reported expenditures of  $> \$0$ . Among these families, 30% had expenses between \$250 and \$500, and 34% had expenses of more than \$500. Twenty-seven percent of the families reporting any expenses had expenditures that exceeded 3% of their total household income. The percentage of low-income families with out-of-pocket expenses that exceeded 3% of their income varied considerably according to state and ranged from 5.6% to 25.8%. Families living in states with higher Medicaid and SCHIP income-eligibility guidelines were less likely to have high absolute burden and high relative burden.

**CONCLUSIONS:** Beyond child and family characteristics, there is considerable state-level variability in low-income families' out-of-pocket expenditures for their CSHCN. A portion of this variability is associated with states' Medicaid and SCHIP income-eligibility thresholds. Families living in states with more generous programs report less absolute and relative financial burden than families living in states with less generous benefits. *Pediatrics* 2009;124:S435–S442

Our aim was to examine how low-income families' financial burden related to caring for children with special health care needs (CSHCN) is associated with variability in the generosity of state Medicaid and State Children's Health Insurance Program (SCHIP) income-eligibility criteria. Our general hypothesis was that poor and near-poor families (defined here as having a household income at  $\leq 200\%$  of the federal poverty level [FPL]) who lived in states with more generous public benefits would experience lower financial burden, controlling for family demographics, the severity of their child's conditions, and the affluence of their state of residence. We tested this hypothesis by using data from the 2005–2006 National Survey of Children With Special Health Care Needs (NS-CSHCN) and state-level measures of Medicaid and SCHIP income-eligibility standards.

CSHCN use more health care and related services than typically developing children, which increases the likelihood of high financial burden.<sup>1,2</sup> Financial burden has been operationally defined for a previous 12-month period in 3 different ways: whether a family had any health expenditures related to the child's special needs; absolute burden (actual expenditures); and relative burden (amount of expenditures relative to income).<sup>1–3</sup> High absolute burden is associated with poor child health, being black or Hispanic, being uninsured, and having high family income and socioeconomic status (those who have more, spend more).<sup>1–4</sup> High relative burden is associated with poverty. Poor families spend a larger proportion of their household income compared with nonpoor families, although they spend less in absolute dollars.<sup>2</sup>

Financial burden varies significantly among states as well as among families.<sup>3,4</sup> State variability in mean burden

could be a result of differences across states' populations. States with healthier populations might have lower mean burden because they require less care. However, Shattuck and Parish<sup>3</sup> found that families with similar demographic and child-need characteristics had widely different financial burden depending on their state of residence; state mean annual absolute burden ranged from \$562 to \$972, and mean relative burden ranged from \$14.5 to \$32.3 per \$1000 of household income after controlling for a range of child- and family-level factors, including child health.

State variability in financial burden could also be a result of differences in the extent of public supports, most notably Medicaid and SCHIP. Families who live in states with more generous benefits might have lower financial burden, especially low-income families targeted by these programs. Indeed, financial burden in families with publicly insured CSHCN is lower among those with public insurance.<sup>3,5</sup> However, we are unaware of research that has examined the simultaneous contributions of child-, family-, and state-level policy factors to variability in financial burden.

Understanding whether Medicaid and SCHIP buffer the financial burden of low-income families raising CSHCN is important for several reasons. First, these families spend a disproportionately large share of their limited income on their child's care.<sup>2</sup> Second, state Medicaid and SCHIP policy decisions are modifiable. States have considerable leeway in determining program funding and eligibility.<sup>6</sup> Third, Medicaid and SCHIP policies affect a substantial number of children. SCHIP enrollment in June 2007 was  $\sim 4.4$  million children,<sup>7</sup> and  $\sim 1$  in 4 children are insured through Medicaid.<sup>8</sup> Fourth, advocating for adequate funding of Medicaid and SCHIP is a top priority of both

the American Academy of Pediatrics Division of State Government Affairs and American Academy of Pediatrics state chapters.<sup>9</sup> Ranking states on malleable policy factors and related family outcomes can help target finite advocacy resources more effectively. This issue is especially salient given that the SCHIP program was reauthorized in February 2009. This reauthorization permits states to cover children in families with an income of up to 300% of the FPL. Fifth, information about the associations between family financial burden and public insurance can help clinicians better understand the challenges that face children's families. Sixth, these findings can help advance our conceptual understanding of the linkages between political context and individual health, which are often discussed but seldom investigated.<sup>10–14</sup> Finally, we hope that these findings will stimulate and inform further research into the connections between state policies and child outcomes.

## METHODS

### Data Sources

Child- and family-level data were drawn from the 2005–2006 wave of the NS-CSHCN, described elsewhere in this supplemental issue of *Pediatrics*.<sup>15</sup> States' Medicaid and SCHIP income-eligibility guidelines were drawn from the National Academy on State Health Policy.<sup>16</sup> State median income values for families with children were drawn from the Annie E. Casey Foundation.<sup>17</sup>

### Sample

We focused our study on low-income families, whose incomes were at  $\leq 200\%$  of the FPL. Our final analytic sample included 17 039 children from the NS-CSHCN. Table 1 describes these children and their families. We excluded 506 families for whom information on out-of-pocket costs was missing.

**TABLE 1** Description of the Population of Low-Income CSHCN, 2005–2006, and State-Level Measures of Income and Insurance-Eligibility Thresholds

	% or Mean (SD)
Child and family variable	
Income < 100% FPL	38
Race: minority	30
Ethnicity: Hispanic	17
Child's age	9.75 (7.92)
Highest grade level among anyone in household: did not graduate high school	13
Child's condition or problem is severe	12
Child's condition or problem is moderate	39
Child's health care needs are not stable	9
Parent is a single mother	47
Child participated in services funded by the IDEA	33
Child ever not insured in previous 12 mo	13
Child has public health insurance only	54
Child has private and public health insurance	11
Child is uninsured	7
State variables	
Median income for families with children < 18 y old, \$1000s	53.19 (7.23)
Medicaid income-eligibility standard, children 6–18 y old, multiples of FPL	1.12 (0.21)
SCHIP income-eligibility standard, children 6–18 y old, multiples of FPL	2.09 (0.44)
Dependent variables	
Had out-of-pocket costs	61
Among those having out of pocket costs:	
Had out-of-pocket costs of \$1–\$249	36
Had out-of-pocket costs of \$249–\$500	30
Had out-of-pocket costs of more than \$500	34
Had out-of-pocket costs < 1% of income	34
Had out-of-pocket costs 1%–3% of income	39
Had out-of-pocket costs > 3% of income	27

IDEA indicates Individuals With Disabilities Education Act (early intervention and special education).

## Measures

### Dependent Variables

Three measures of financial burden were based on NS-CSHCN questions that asked families to report how much they paid during the previous 12 months for their child's medical care: \$0, \$1 to \$249, \$250 to \$500, \$501 to \$999, \$1000 to \$5000, or \$5001 or more. The definition used for medical care included out-of-pocket payments for a variety of health-related needs including copayments, medications, special foods, and durable equipment but excluded insurance premiums and reimbursable costs.

The first dependent variable was whether the family had any expenditures. The second dependent variable (computed for families with expenditures greater than \$0) was a 3-category indicator of the amount of absolute burden: \$1 to \$249, \$250 to \$500, or \$501 or more. The third dependent variable was a 3-category measure of relative burden (total expenditures as a percentage of family income): less than 1%, 1% to 3%, or more than 3% of income. This latter measure was created by using a multistep process. First, we transformed the survey's categorical measure of expenditures into dollars by using the midpoints of the first 4 strata. For those who reported \$5000 or more, we used the median out-of-pocket health expenditure for CSHCN who had more than \$5000 in expenditures from the 2005 Medical Expenditure Panel Survey (\$5920).<sup>18</sup> We obtained a measure of families' median household income through direct correspondence with the National Center on Health Statistics (S. J. Blumberg, PhD, National Center for Health Statistics, "Median Income From the National Survey of Children With Special Health Care Needs Stratified by State, Household Size, and Federal Poverty Level," 2007, personal written communication).

Then, we calculated a measure of relative burden as the ratio of dollars spent on care to income. Finally, we created our 3-category relative-burden indicator from the burden/income ratio.

A categorical variable, rather than the burden/income ratio variable itself, was used to model relative burden, because neither income nor burden were themselves available, only intervals representing ranges in which each participants' income and burden fell. The thresholds of less than 1%, 1% to 3%, and >3% were selected, because exploratory analyses demonstrated that the models did not run successfully with more than 3 categories, and nonlinear models of categorical data perform better when the dependent variable is balanced.

### Individual Covariates

Covariates included an indicator of household income relative to the FPL (income < 100% or between 100% and 200% of the FPL); binary indicators of the child's race (white or nonwhite, which included children reported as being black, Asian, multiracial, Native American, Aleut, or Pacific Islander) and Hispanic ethnicity (yes or no); child's age, mean centered within each state; parent's high school drop-out status (yes or no); parent ratings of the severity of the child's condition (minor, moderate, or severe); and the stability of the child's needs related to his or her condition (needs are or are not stable). Finally, measures of insurance coverage and service participation included: child participated in early intervention or special education services regulated by the Individuals With Disabilities Education Act; child was ever uninsured in previous 12 months; child had public health insurance only; child had private and public health insurance; and child was currently uninsured.

### State Covariates

One state-level covariate was modeled: median income for families with children aged 17 or younger in 2005, measured in thousands of dollars.<sup>17</sup>

### State-Independent Variables

Two state-policy variables were investigated: (1) the Medicaid income-eligibility standard for children aged 6 to 18 years; and (2) the SCHIP income-eligibility standard for children aged 6 to 18 years. The income-eligibility standards were expressed in multiples of the FPL. The Medicaid income-eligibility standard ranged from 1 to 2.25 times the FPL. The SCHIP standard ranged from 1.4 to 3.5 times the FPL, excluding Tennessee, which did not have an SCHIP program.

### Analytic Strategy: 2-Part Hierarchical Generalized Linear Models

A 2-part model distinguished families with no financial burden from those who reported a burden of more than \$0.<sup>19</sup> In the first part, we used logistic regression to model the probability of having any out-of-pocket costs. In the second part, which excludes families with no out-of-pocket costs, we modeled the 3-category absolute financial-burden variable and then the 3-category relative-burden variable. These part-2 models used multinomial logistic regression to estimate the probability of 2 higher categories of burden relative to the lowest: \$250 to \$500 and \$501 or more vs \$1 to \$249 for absolute financial burden, and 1% to 3% of income and more than 3% vs less than 1% of income for relative financial burden.

Multilevel regression models are appropriate for nested data. In this case, families are nested in states. Nested data can lead to inference problems if not analyzed by using appropriate methods that correctly adjust SEs for

the correlation between families who lived in the same state. A multilevel model facilitates examination of the correlates of financial burden at both the family and state levels. A logistic regression modeled in a multilevel data environment is known as a hierarchical generalized linear model.<sup>20</sup> As in regular logistic regression, coefficients can be transformed into odds ratios that describe a family's odds of having the specified level of burden.

We used an informed model-fitting process in Mplus 3.1, entering individual correlates of burden first and then entering state median income and the policy variables.<sup>21,22</sup> An approximate measure of the amount of state-level variance explained by the state covariate and independent variables, calculated as the percentage change between the "full" model (with all state-level covariates) and null model (having only individual-level covariates) is reported.

### Missing Data

Because of missing data on several NS-CSHCN individual-level variables, our analyses were conducted on multiply imputed data we created by using SAS Proc MI.<sup>23</sup> A macro written in SAS combined estimates from Mplus.<sup>24–28</sup>

### Weighting and Variance Adjustment

We are unaware of statistical software that simultaneously accommodates multilevel data and the variance adjustment required for stratified random sampling. Simulations we conducted showed that both multilevel analysis and variance-adjusted analysis resulted in properly corrected and similar SEs for individual-level covariates but variance adjusted analyses produced insufficiently corrected SEs for state-level variables. Therefore, we used multilevel data analysis because of the nested nature of the data. All results were weighted to the US Cen-

sus estimates for the age, gender, race, and ethnicity of the population.

## RESULTS

Table 1 summarizes the dependent measures of financial burden. Among low-income families, 61% reported having some financial burden (out-of-pocket costs > \$0). Of those reporting any burden, 30% reported absolute expenditures between \$250 and \$500, whereas 34% reported expenditures that exceeded \$500 for the previous 12-month period. Twenty-seven percent of those who reported any out-of-pocket costs had relative burden that exceeded 3% of their total household income.

Table 2 presents the percentage of low-income families within individual states who reported having any burden, absolute burden of more than \$500, and high relative burden (expenditures of >3% of total income). Table 2 also presents the state rankings for the percentage that had high relative burden (>3% of total household income). There was considerable variability in the proportion of states' low-income populations with any burden, which ranged from 33.5% in the District of Columbia to 84.4% in Utah. A wide range of families had an absolute annual burden of more than \$500, from 7.3% in the District of Columbia to 35.2% in Utah. Finally, the percentage with high relative burden ranged from 5.6% in the District of Columbia to 25.8% in Montana. In 34 states, at least 15% of the state's low-income population with CSHCN had spending that exceeded 3% of income. It is notable that 25% of the families who reported any burden had expenditures that exceeded 5% of their total income.

Table 3 lists the results of the regression models. Although the child- and family-level findings are reported in the table, we focus here on the state-level results. Controlling for state median income for families with children and all child and

**TABLE 2** Percent of Low-Income Families of CSHCN With Financial Burden According to State

	Medicaid Income-Eligibility Standard <sup>a</sup>	SCHIP Income-Eligibility Standard <sup>a</sup>	Any Burden	Absolute Burden of \$500 or More	Relative Burden of >3% of Income	Rank: Relative Burden of >3% of Income
Alabama	100	200	58.0	16.7	15.4	23
Alaska	100	175	57.9	24.5	19.1	39
Arizona	100	200	67.7	25.8	18.0	36
Arkansas	200	200	67.8	16.5	12.9	11
California	100	250	65.6	20.5	12.2	9
Colorado	100	185	72.0	26.2	19.8	41
Connecticut	185	300	61.1	21.5	17.0	31
Delaware	100	200	60.3	20.1	15.5	25
District of Columbia	100	200	33.5	7.3	5.6	1
Florida	100	200	66.3	23.9	19.4	40
Georgia	100	235	55.4	19.8	13.6	15
Hawaii	100	200	53.9	14.2	7.4	3
Idaho	100	185	64.8	25.6	18.6	38
Illinois	100	200	64.3	21.1	15.9	28
Indiana	100	200	58.2	21.8	15.3	21
Iowa	100	200	65.7	21.8	14.8	18
Kansas	100	200	62.4	25.4	16.9	30
Kentucky	100	200	56.4	15.8	15.9	29
Louisiana	100	200	47.2	12.3	10.4	7
Maine	125	200	57.3	18.0	14.3	17
Maryland	100	300	59.7	21.3	17.2	33
Massachusetts	150	200	59.5	24.7	13.1	14
Michigan	100	200	66.2	26.9	20.3	44
Minnesota	150	200	67.5	30.4	23.3	49
Mississippi	100	200	59.8	15.4	15.2	20
Missouri	100	300	56.3	19.6	12.9	12
Montana	100	150	73.5	28.3	25.8	51
Nebraska	100	185	62.9	28.6	20.0	42
Nevada	100	200	68.6	29.8	18.2	37
New Hampshire	185	300	71.9	23.3	15.7	26
New Jersey	100	350	70.7	25.5	20.8	46
New Mexico	185	235	56.5	19.6	14.8	19
New York	100	208	49.6	12.7	10.2	6
North Carolina	100	200	68.4	20.9	15.7	27
North Dakota	100	140	69.7	32.8	23.3	48
Ohio	150	200	54.5	14.7	9.2	4
Oklahoma	100	185	57.4	21.5	15.5	24
Oregon	100	185	63.7	26.9	21.5	47
Pennsylvania	100	200	57.5	19.3	15.4	22
Rhode Island	100	250	45.5	12.0	6.7	2
South Carolina	100	150	58.8	19.6	11.9	8
South Dakota	100	200	58.5	27.2	17.3	34
Tennessee	200	<sup>b</sup>	64.4	22.6	20.3	43
Texas	100	200	66.6	21.9	12.9	13
Utah	100	200	84.4	35.2	23.7	50
Vermont	225	300	55.5	19.0	12.4	10
Virginia	100	200	62.4	22.5	17.0	32
Washington	200	250	55.4	14.7	9.2	5
West Virginia	100	200	58.4	18.0	14.3	16
Wisconsin	100	200	59.5	21.4	17.9	35
Wyoming	100	200	62.1	29.5	20.8	45
US overall	—	—	61.4	20.6	15.0	—

<sup>a</sup> Income-eligibility guidelines are shown in percentages of income relative to the FPL.

<sup>b</sup> Tennessee had no SCHIP program in 2005–2006.

family covariates, states' SCHIP and Medicaid income-eligibility standards were not significantly associated with the probability of having any out-of-pocket expenditures. The full model, including all state covariates, explained 11% of the state-level variance (column 2).

As compared with families who reported out-of-pocket costs of less than \$250, families who lived in states with higher Medicaid and SCHIP income-eligibility guidelines had significantly lower odds of absolute burdens between \$250 and \$500, by 23% and 11%,

respectively (column 3). In other words, the predicted odds of having an absolute burden between \$250 and \$500 for a family in a state with a Medicaid-eligibility threshold of 200% of the FPL was 77% of the corresponding predicted odds for a family who

**TABLE 3** Multinomial Multilevel Logistic Regression Predicting Measures of Family Financial Burden

	Any Out-of-Pocket Costs, OR (95% CI) <sup>a</sup>	Absolute Burden of \$250–\$500, OR (95% CI) <sup>b</sup>	Absolute Burden of More Than \$500, OR (95% CI) <sup>b</sup>	Relative Burden of >3% of Income, OR (95% CI) <sup>c,d</sup>
<b>Intercept and child and family variables</b>				
Intercept (conditional mean for reference conditions)	0.04 (0.04–0.05) <sup>e</sup>	0.93 (0.83–1.04)	0.73 (0.64–0.84) <sup>e</sup>	2.05 (1.67–2.51) <sup>e</sup>
Income < 100% FPL	0.65 (0.59–0.71) <sup>e</sup>	0.84 (0.75–0.94) <sup>f</sup>	0.67 (0.58–0.78) <sup>e</sup>	–
Race: minority	0.50 (0.46–0.55) <sup>e</sup>	0.75 (0.65–0.86) <sup>e</sup>	0.48 (0.42–0.54) <sup>e</sup>	0.72 (0.60–0.86) <sup>e</sup>
Ethnicity: Hispanic	0.72 (0.60–0.85) <sup>e</sup>	0.85 (0.69–1.05)	0.75 (0.57–0.98) <sup>g</sup>	0.91 (0.69–1.21)
Child’s age	1.02 (1.01–1.03) <sup>f</sup>	1.03 (1.02–1.03) <sup>e</sup>	1.03 (1.02–1.04) <sup>e</sup>	1.03 (1.01–1.04) <sup>f</sup>
Highest grade level among anyone in household: did not graduate from high school	0.59 (0.53–0.67) <sup>e</sup>	1.11 (0.91–1.35)	0.65 (0.54–0.78) <sup>e</sup>	1.16 (0.93–1.44)
Child’s condition or problem is severe	1.14 (0.99–1.31)	1.31 (1.15–1.50) <sup>e</sup>	3.64 (3.17–4.17) <sup>e</sup>	4.05 (3.18–5.16) <sup>e</sup>
Child’s condition or problem is moderate	1.09 (1.00–1.18) <sup>g</sup>	1.24 (1.12–1.37) <sup>e</sup>	1.80 (1.60–2.01) <sup>e</sup>	1.74 (1.45–2.09) <sup>e</sup>
Child’s health care needs are not stable	1.23 (1.05–1.44) <sup>f</sup>	1.64 (1.37–1.95) <sup>e</sup>	2.27 (1.86–2.78) <sup>e</sup>	2.88 (2.27–3.66) <sup>e</sup>
Parent is a single mother	0.83 (0.76–0.90) <sup>e</sup>	1.15 (1.03–1.29) <sup>g</sup>	0.96 (0.88–1.05)	1.59 (1.39–1.83) <sup>e</sup>
Child participated in services funded by the IDEA	0.88 (0.81–0.95) <sup>f</sup>	1.28 (1.13–1.45) <sup>e</sup>	1.41 (1.28–1.54) <sup>e</sup>	1.40 (1.23–1.60) <sup>e</sup>
Child ever uninsured in previous 12 mo	2.72 (2.28–3.25) <sup>e</sup>	1.50 (1.27–1.78) <sup>e</sup>	1.84 (1.55–2.20) <sup>e</sup>	2.28 (1.91–2.71) <sup>e</sup>
Child has public health insurance only	0.06 (0.05–0.07) <sup>e</sup>	0.43 (0.35–0.53) <sup>e</sup>	0.21 (0.18–0.26) <sup>e</sup>	0.42 (0.34–0.51) <sup>e</sup>
Child has private and public health insurance	0.11 (0.09–0.12) <sup>e</sup>	0.68 (0.54–0.85) <sup>e</sup>	0.43 (0.35–0.55) <sup>e</sup>	0.78 (0.55–1.11)
Child is uninsured	0.13 (0.11–0.16) <sup>e</sup>	0.81 (0.62–1.05)	0.90 (0.64–1.27)	1.31 (0.96–1.77)
<b>State variable</b>				
Median Income for families with children, \$1000s	0.99 (0.99–0.99) <sup>e</sup>	1.00 (1.00–1.01)	1.01 (1.00–1.01) <sup>f</sup>	1.02 (1.01–1.02) <sup>e</sup>
Medicaid income-eligibility standard, multiples of FPL	0.89 (0.80–1.00)	0.77 (0.68–0.88) <sup>e</sup>	0.70 (0.59–0.85) <sup>e</sup>	0.77 (0.60–0.99) <sup>g</sup>
SCHIP income-eligibility standard, multiples of FPL	1.00 (0.94–1.07)	0.89 (0.81–0.99) <sup>g</sup>	0.83 (0.75–0.92) <sup>e</sup>	0.68 (0.58–0.80) <sup>e</sup>
<b>Random effects</b>				
Variance of random intercept	0.06 <sup>e</sup>	0.005	0.03	0.06 <sup>f</sup>
Residual intraclass correlation	0.02	0.002	0.01	0.02
Proportion reduction in random intercept variance from model without state variables	0.11	0.57	0.26	0.30

SEs are all <0.30. OR indicates odds ratio; CI, confidence interval; IDEA, Individuals With Disabilities Education Act (early intervention and special education).

<sup>a</sup> Reference outcome is all families who do not have out-of-pocket costs.

<sup>b</sup> Reference outcome is families with out-of-pocket costs of less than \$250.

<sup>c</sup> Reference outcome is all families with a relative burden of <1% of household income.

<sup>d</sup> Household income was excluded from relative burden.

<sup>e</sup> *P* < .001.

<sup>f</sup> *P* < .01.

<sup>g</sup> *P* < .05.

lived in a state with an eligibility threshold of 100% of the FPL. The full model with the 3 state variables explained 57% of the state-level variance. Controlling for all model covariates, families who lived in states with more generous Medicaid and SCHIP income-eligibility guidelines had significantly lower odds of having out-of-pocket costs of more than \$500, by 30% and 17%, respectively. The state covariates explained 26% of state-level variance (column 4).

Finally, as compared with families with lower relative burden (<1% of total income), those who lived in states with higher Medicaid and SCHIP income-eligibility standards had significantly lower odds of having high relative burden (>3% of total household income),

by 23% and 32%, respectively. We infer from this finding that in a comparison between states in which eligibility differed by 1 multiple of the FPL, families in states with the higher Medicaid-eligibility threshold were 77% as likely, with respect to odds, to have a relative burden that exceeded 3% of income, and those who lived in states with the higher SCHIP-eligibility threshold were 68% as likely to have a relative burden of 3% or higher. This full model explained 30% of state-level variance (column 5).

## DISCUSSION

After controlling for child- and family-level characteristics and state median income for families with children, there was persistent and marked

state-level variability in the magnitude of financial burden that low-income families faced in raising their CSHCN. These results support previous research that revealed significant state-level variability in financial burden<sup>5</sup> and has indicated that a substantial amount of this variability is associated with states’ Medicaid and SCHIP program characteristics.

The important contribution of this study is the finding that relative and absolute burden tend to be lower in states with more generous Medicaid and SCHIP income-eligibility standards. That is, low-income families who live in states with higher income-eligibility guidelines for their Medicaid and SCHIP programs tend to have less burden, both in total terms and rela-

tive to their household income, as compared with families who live in states with more restrictive income-eligibility guidelines.

The percentage of families in this low-income sample with any out-of-pocket costs (61%) was lower than that found in a general-population sample of CSHCN (82.5%).<sup>3</sup> We do not know the reasons for this finding. Previous research has found that CSHCN who live in poverty are at increased risk of unmet needs for both routine and specialty care.<sup>29</sup> It is possible that the lower proportion of poor families with any out-of-pocket costs is a result of delayed and foregone care rather than a lower prevalence of need for care, but additional research is required to fully understand this issue.

The elevated rates of high relative burden (out-of-pocket expenditures that exceeded 3% of family income) are particularly troubling given that our analyses were restricted to the population of families with household income at or below twice the FPL. This low-income population is specifically targeted for assistance by Medicaid and SCHIP. Yet, our findings indicate that despite their eligibility for benefits, these families reported significant levels of financial burden, burden that is associated with less generous state Medicaid and SCHIP programs. Given

other evidence that families raising children with disabilities face exceptionally high rates of deprivation and material hardship,<sup>30</sup> which likely has a deleterious effect on the children's well-being, policy makers should consider ways to strengthen Medicaid and SCHIP to reduce the financial burdens that these families shoulder.

This study's limitations must be considered to fairly interpret the results. First, these analyses are correlational, and we cannot infer causality between state programs and family financial expenditures. Second, the ordinal measures of household income and families' expenditures may not fully capture a level of detail that would ideally inform policy debates. Third, we were unable to model parental employment, because it was not measured in the NS-CSHCN. However, parental employment is strongly associated with insurance status<sup>31</sup> and financial burden.<sup>32</sup>

A number of important strengths offset the study's limitations. First, the sampling design of the NS-CSHCN resulted in a representative sample of CSHCN from each state. Second, the use of multilevel regression enabled us to examine both individual- and state-level public health program characteristics that are correlated with families' out-of-pocket spending

for their CSHCN. To the best of our knowledge, this is the first such study of its kind.

## CONCLUSIONS

This research used an innovative methodologic approach to examine the association between state-policy characteristics and the financial burdens that low-income families face in raising CSHCN. The inverse relationship found between the generosity of state health insurance eligibility criteria and families' financial burdens suggest that these programs buffer the effects of raising children whose health care needs can often be expensive.

As we write this, the state economies are in a recession that is projected to be deep and difficult. Most states are experiencing budget shortfalls and total state budget gaps for fiscal year 2009–2010 are currently projected to exceed \$230 billion.<sup>33</sup> To lessen these shortfalls, many state governments are looking to cut their Medicaid programs. Indeed, 25 states made cuts in their Medicaid programs after their 2009 state budgets had been passed, and 25 states have also proposed Medicaid cuts to their 2010 budgets.<sup>33</sup> Our results indicate that such cuts may have a particularly detrimental effect on the financial well-being of low-income families raising CSHCN.

## REFERENCES

1. Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. *Arch Pediatr Adolesc Med*. 2005;159(1):10–17
2. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics*. 2004;114(1):79–85
3. Shattuck PT, Parish SL. Financial burden in families of children with special health care needs: variability among states. *Pediatrics*. 2008;122(1):13–18
4. Kuhlthau K, Hill KS, Yucel R, Perrin JM. Financial burden for families of children with special health care needs. *Matern Child Health J*. 2005;9(2):207–218
5. Yu H, Dick AW, Szilagyi PG. Does public insurance provide better financial protection against rising health care costs for families of children with special health care needs? *Med Care*. 2008;46(10):1064–1070
6. Ross DC, Cox L. *Making It Simple: Medicaid for Children and CHIP Income Eligibility Guidelines and Enrollment Procedures*. Menlo Park, CA: Kaiser Family Foundation; 2000
7. Smith V, Rousseau D, Marks C, Rudowitz R. *SCHIP Enrollment in June 2007: An Update on Current Enrollment and SCHIP Policy Directions*. Washington DC: Kaiser Commission on Medicaid and the Uninsured; 2008
8. Kaiser Commission on Medicaid and the Uninsured. *Health Coverage of Children: The Role of Medicaid and SCHIP*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured; 2007
9. American Academy of Pediatrics. 2007 state legislation report. Available at: [www.aap.org/advocacy/stateleg rpt.pdf](http://www.aap.org/advocacy/stateleg rpt.pdf). Accessed October 21, 2008
10. Litaker D, Koroukian SM, Love TE. Context and healthcare access: looking beyond the individual. *Med Care*. 2005;43(6):531–540
11. Phillips KA, Morrison KR, Andersen R, Aday LA. Understanding the context of healthcare utilization: assessing environmental and provider-related variables in the behavioral model of utilization. *Health Serv Res*. 1998; 33(3 pt 1):571–596

12. Andersen RM, Davidson PL. Improving access to care in America: individual and contextual indicators. In: Andersen RM, Rice TH, Kominski GF, eds. *Changing the U.S.* CA: John Wiley & Sons, Inc; 2007:3–32
13. Jeffrey AE, Newacheck PW. Role of insurance for children with special health care needs: a synthesis of the evidence. *Pediatrics*. 2006; 118(4). Available at: [www.pediatrics.org/cgi/content/full/118/4/e1027](http://www.pediatrics.org/cgi/content/full/118/4/e1027)
14. Institute of Medicine, Committee on the Consequences of Uninsurance. *Coverage Matters: Insurance and Health Care*. Washington, DC: National Academies Press; 2001
15. Kogan MD, Strickland BB, Newacheck PW. Building systems of care: findings from the National Survey of Children With Special Health Care Needs. *Pediatrics*. 2009; 124(suppl 4):S333–S336
16. National Academy for State Health Policy. Income eligibility levels and costs sharing for children in Medicaid and SCHIP and other populations covered with SCHIP funds: July 2005. Available at: [www.nashp.org/Files/Elig\\_and\\_cost\\_sharing\\_Aug\\_2005.pdf](http://www.nashp.org/Files/Elig_and_cost_sharing_Aug_2005.pdf). Accessed October 9, 2009
17. Annie E. Casey Foundation. Median family (with child) income: 2005. Available at: [www.kidscount.org/datacenter/compare\\_results.jsp?i=340&dt=3&rt=2&yr=6&s=a&rtype=&x=140&y=6](http://www.kidscount.org/datacenter/compare_results.jsp?i=340&dt=3&rt=2&yr=6&s=a&rtype=&x=140&y=6). Accessed October 9, 2009
18. Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey, person-level file. Available at: [www.meps.ahrq.gov/mepsweb/data\\_stats/meps\\_query.jsp](http://www.meps.ahrq.gov/mepsweb/data_stats/meps_query.jsp). Accessed September 2, 2008
19. Duan N, Manning W, Morris C, Newhouse J. A comparison of alternative models for the demand for health care. *J Bus Econ Stat*. 1983;1(2):115–126
20. Raudenbush S, Bryk A. *Hierarchical Linear Models: Applications and Data Analysis Methods*. 2nd ed. Thousand Oaks, CA: Sage; 2002
21. Muthén BO, Muthén L. *Mplus User's Guide*. Los Angeles, CA: Muthén and Muthén; 2004
22. Snijders TAB, Bosker RJ. *Multilevel Analysis: An Introduction to Basic and Advanced Multilevel Modeling*. London, United Kingdom: Sage; 1999
23. Schafer JL. *Analysis of Incomplete Multivariate Data*. Boca Raton, FL: Chapman Hall/CRC; 1997
24. Rose RA, Fraser MW. A simplified framework for using multiple imputation in social work research. *Soc Work Res*. 2008;32(3): 171–178
25. Graham JW. Missing data analysis: making it work in the real world. *Annu Rev Psychol*. 2009;60:549–576
26. Graham JW, Olchowski AE, Gilreath TD. How many imputations are really needed? Some practical clarifications of multiple imputation theory. *Prev Sci*. 2007;8(3):206–213
27. Von Hippel PT. Regression with missing Ys: an improved strategy for analyzing multiply imputed data. *Sociol Methodol*. 2007;37(1): 83–117
28. Rubin DB. *Multiple Imputation for Nonresponse in Surveys*. New York, NY: Wiley; 1987
29. Mayer ML, Skinner AC, Slifkin RT; National Survey of Children With Special Health Care Needs. Unmet need for routine and specialty care: data from the National Survey of Children With Special Health Care Needs. *Pediatrics*. 2004;113(2). Available at: [www.pediatrics.org/cgi/content/full/113/2/e109](http://www.pediatrics.org/cgi/content/full/113/2/e109)
30. Parish SL, Rose RA, Andrews ME, Grinstein-Weiss M, Richman EL. Material hardship among U.S. families raising children with disabilities. *Except Child*. 2008;75(1):71–92
31. NeNavas-Walt C, Proctor BD, Lee CH. *Income, Poverty, and Health Insurance Coverage in the United States*. Washington, DC: US Census Bureau; 2005
32. Parish SL, Seltzer MM, Greenberg JS, Floyd FJ. Economic implications of caregiving at midlife: comparing parents of children with developmental disabilities to other parents. *Ment Retard*. 2004;42(6):413–426
33. National Governor's Association; National Association of State Budget Officers. *The Fiscal Survey of States*. National Association of State Budget Officers, ed. Washington, DC: National Governors Association and the National Association of State Budget Officers. 2009

## Financial Burden of Raising CSHCN: Association With State Policy Choices

Susan L. Parish, Paul T. Shattuck and Roderick A. Rose

*Pediatrics* 2009;124;S435-S442

DOI: 10.1542/peds.2009-1255P

<b>Updated Information &amp; Services</b>	including high-resolution figures, can be found at: <a href="http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S435">http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S435</a>
<b>References</b>	This article cites 14 articles, 4 of which you can access for free at: <a href="http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S435#BIBL">http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S435#BIBL</a>
<b>Citations</b>	This article has been cited by 1 HighWire-hosted articles: <a href="http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S435#otherarticles">http://www.pediatrics.org/cgi/content/full/124/Supplement_4/S435#otherarticles</a>
<b>Subspecialty Collections</b>	This article, along with others on similar topics, appears in the following collection(s): <b>Developmental/Behavior</b> <a href="http://www.pediatrics.org/cgi/collection/developmental:behavior">http://www.pediatrics.org/cgi/collection/developmental:behavior</a>
<b>Permissions &amp; Licensing</b>	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: <a href="http://www.pediatrics.org/misc/Permissions.shtml">http://www.pediatrics.org/misc/Permissions.shtml</a>
<b>Reprints</b>	Information about ordering reprints can be found online: <a href="http://www.pediatrics.org/misc/reprints.shtml">http://www.pediatrics.org/misc/reprints.shtml</a>

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

