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## **Medical Home and Out-of-Pocket Medical Costs for Children With Special Health Care Needs**

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*Pediatrics* 2011;128;892; originally published online October 17, 2011;

DOI: 10.1542/peds.2010-1307

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<http://pediatrics.aappublications.org/content/128/5/892.full.html>

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# Medical Home and Out-of-Pocket Medical Costs for Children With Special Health Care Needs



**WHAT'S KNOWN ON THIS SUBJECT:** Families whose children with special needs receive health care in a medical home setting are less likely to report financial stress attributable to medical expenses incurred on behalf of those children. Financial stress is measured subjectively through parents' perceptions.



**WHAT THIS STUDY ADDS:** Families whose children with special needs receive health care in a medical home setting incur significantly lower out-of-pocket costs per \$1000 of household income compared with similar families without a medical home. This study used objective measures of financial stress.

## abstract

**OBJECTIVE:** We examined key factors that affect out-of-pocket medical expenditures per \$1000 of household income for children with special health care needs (CSHCN) with a broad range of conditions, controlling for insurance type and concentrating on the potentially moderating role of the medical home.

**METHODS:** A Heckman selection model was used to estimate whether the medical home influenced out-of-pocket medical costs per \$1000 of household income for children covered by either private or public health insurance. Data from the 2005–2006 National Survey of CSHCN ( $N = 31\,808$ ) were used.

**RESULTS:** For families that incurred out-of-pocket medical costs for their CSHCN, these costs represented 2.2% to 3.9% of income. Both insurance type and the medical home had significant effects on out-of-pocket costs. Lower out-of-pocket medical costs per \$1000 of income were incurred by children with public insurance and those receiving care coordination services.

**CONCLUSIONS:** Families with CSHCN incur lower out-of-pocket medical costs when their children receive health care in a setting in which the care-coordination component of the medical home is in place.  
*Pediatrics* 2011;128:892–900

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### KEY WORDS

health care costs, out-of-pocket costs, medical home, children with special health care needs, insurance

### ABBREVIATIONS

CSHCN—children with special health care needs  
NS-CSHCN—National Survey of Children With Special Health Care Needs

[www.pediatrics.org/cgi/doi/10.1542/peds.2010-1307](http://www.pediatrics.org/cgi/doi/10.1542/peds.2010-1307)

doi:10.1542/peds.2010-1307

Accepted for publication Jul 22, 2011

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

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

Raising children is expensive, and many families struggle financially. US Department of Agriculture estimates of the annual costs of raising a child range from \$11 610 to \$13 480 for a 2-child, 2-parent, middle-income household.<sup>1</sup> Financial struggles can be even more difficult for families raising children with special health care needs (CSHCN) with >20% of such families reporting financial problems attributable to their child's condition.<sup>2-5</sup> Evaluation of this issue is essential, because >1 in 5 households (21.8%) with children in the United States are estimated to have  $\geq 1$  CSHCN.<sup>6</sup> This translates into nearly 14% of US children or >10 million CSHCN, defined by the Maternal and Child Health Bureau as children who "have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."<sup>7</sup>

Out-of-pocket medical expenditures are estimated to be twice as high for CSHCN as for children without chronic conditions.<sup>2</sup> Being uninsured or having private insurance, being an adolescent, being black, having a more severe condition, and living in lower-income households increase the likelihood of experiencing higher out-of-pocket health expenditures.<sup>2,4,8</sup> Out-of-pocket expenditures also vary according to the medical condition. In 1997–2000, such expenditures averaged \$161 per year for children with mental retardation, \$613 for children with autism, and \$687 for children with a diagnosis of depression.<sup>9-13</sup>

More than 80% of families with CSHCN in the 2001 National Survey of CSHCN (NS-CSHCN) reported having annual out-of-pocket medical expenditures for their children, which averaged \$752.<sup>14</sup> In the 2005–2006 NS-CSHCN, nearly one-third of families surveyed had

more than \$1000 in annual out-of-pocket medical costs.<sup>15</sup> Similar results were found in a study that used 1999 and 2000 Medical Expenditure Panel Survey data.<sup>16</sup>

Families with CSHCN are less likely to report financial problems if their children receive health care in a medical home.<sup>3,15,16</sup> The medical home concept originated with the American Academy of Pediatrics in 1967 and was posited as a method for improving the care of CSHCN.<sup>17</sup> A medical home involves care that is accessible, family-centered, coordinated, comprehensive, continuous, compassionate, and culturally effective. The care-coordination aspect of the medical home might be key. Families whose "health care providers communicated with other service providers and who helped them feel like partners in their child's care were significantly less likely to report financial or employment problems."<sup>8</sup>

Nearly 50% of CSHCN are estimated to have a medical home.<sup>6</sup> Research suggests that lower-income and non-white children are less likely to have a medical home, and children whose mothers have more education are more likely to have a medical home.<sup>18-20</sup> Although a few studies have analyzed how receiving care in a medical home setting affects subjective measures of family financial status, none, to our knowledge, has analyzed the relationship between the 4 components of the medical home and out-of-pocket expenditures for CSHCN by using more-objective monetary measures. This article explores factors affecting out-of-pocket medical expenditures for CSHCN, controlling for insurance type and concentrating on the potentially moderating role of the medical home. We hypothesized that CSHCN who had a medical home would incur lower out-of-pocket medical costs.

## METHODS

### Study Sample

This study used data from the 2005–2006 NS-CSHCN.<sup>6,21</sup> The sample included children from birth to 17 years of age who were covered by either private or public health insurance, but not both, in the past year. Household income data were missing for 9% of the sample, and nearly 5% of the remaining sample did not complete all questions necessary for calculation of a medical home variable.<sup>14</sup> The only significant difference between the missing and included samples was higher out-of-pocket costs for CSHCN covered by private insurance in the included sample. The final sample size used in this analysis was 31 808 (23 175 children with private insurance and 8633 children with public insurance).

### Dependent Variable

Rather than using subjective questions about financial problems attributable to costs associated with CSHCN, we measured out-of-pocket medical costs (in dollars) incurred on behalf of CSHCN per \$1000 of household income in the past year. Previous research suggested that recall of this type of cost information is valid, provided that the recall time period does not exceed 12 months, and that patients tend to underestimate the costs of health care.<sup>22,23</sup>

The dependent variable numerator was computed by using a categorical survey question that asked how much each family spent on out-of-pocket (unreimbursed) medical expenses in the past year for CSHCN. We used the midpoint of each category as the numerator for the dependent variable with the exception of the last category (at least \$5000), for which we used \$6018, the median out-of-pocket costs incurred annually by CSHCN with out-of-pocket costs above \$5000 in the 2005 and 2006

Medical Expenditure Panel Survey.<sup>14</sup> Data for the dependent variable denominator, that is, household income (in thousands of dollars), were not available in the public release file. However, we were able to obtain data on median incomes according to poverty level, household size, and state, as compiled by researchers at the National Center for Health Statistics from actual incomes reported by survey respondents.

### Independent Variables

The independent variable of interest was the medical home variable. This variable was operationalized through the definition developed by the Child and Adolescent Health Measurement Initiative into 4 components, including whether (1) the child had a usual source of care and/or personal provider, (2) the care provided was “family centered,” (3) care-coordination services were received, and (4) the family had no problems getting all of the referrals needed.<sup>24</sup> Nearly 55% of children in the private insurance sample and 42% of children in the public insurance sample met the criteria for all 4 components and thus received care in a medical home.

The remaining independent variables were grouped as need, enabling, and predisposing variables.<sup>25</sup> Need variables were those measuring aspects of the child’s medical condition that might affect directly the out-of-pocket costs associated with the provision of health care for the child. These variables included the child’s medical diagnoses and the severity of the child’s condition, as rated by the responding parent. Seventeen diagnoses were combined into 12 categories for this analysis (Table 1). In addition, we included variables indicating whether the child had both emotional, developmental, or behavioral conditions (including attention-deficit/hyperactivity

disorder, autism, mental retardation, and emotional problems) and physical health diagnoses (all other conditions) and whether the child was delayed in receiving care or had unmet medical needs.

Enabling variables measured the resources the family had in place that might affect out-of-pocket costs. These variables included whether the child had been uninsured for  $\geq 1$  month during the previous year, household income as a proportion of the poverty level, whether the family had unmet mental health needs, and the presence of other children who also might incur medical costs, including other CSHCN, in the household. Household income as a proportion of the poverty level was likely an indicator not only of the ability to pay but also of the family’s ability to negotiate the complexities of health service access and utilization for their children.

Predisposing variables were those that likely affected out-of-pocket costs for the focal child only indirectly. These variables included the age, gender, race, and ethnicity of the child, the family structure, the education level of the primary caregiver, the immigrant status of the family, and the urban or rural location of the household.

### Analyses

The data were analyzed descriptively and in a multivariate model. The dependent variable, that is, out-of-pocket medical costs per \$1000 of household income, was continuous but truncated at \$0. Costs were estimated for each insurance type sample according to whether the child had a medical home, to allow prediction of the full effects of the medical home on out-of-pocket costs. The models were estimated by using a Heckman selection model in Stata 11 (Stata Corp, College Station, TX) with correction for the complex sampling scheme of the NS-CSHCN.<sup>26</sup>

Some families reported no out-of-pocket medical costs for their CSHCN. The Heckman model allowed us to correct for this selection effect by identifying first factors influencing whether there were out-of-pocket costs (probit model) and then factors influencing the level of those costs for families that incurred them (ordinary least-squares regression). Out-of-pocket medical costs were estimated as a function of the needs of the child, family resources, and family sociodemographic characteristics.

## RESULTS

### Study Population

Descriptive statistics and out-of-pocket medical costs for each of the samples are shown in Table 1. Children covered by private insurance were significantly different from children covered by public insurance with respect to both health conditions and sociodemographic characteristics. Larger proportions of children with public insurance were diagnosed in every disability category with the exception of diabetes, and those children’s conditions were reported as being more severe than those reported for children with private insurance. Children with public insurance were more likely to have unmet medical needs, delays in needed medical care, and gaps in insurance coverage in the past year. Their families were more likely to include single mothers with lower incomes, and other family members were more likely to report unmet mental health needs. Children with public insurance were somewhat younger than children with private insurance; there was a larger proportion of children younger than 5 years and a smaller proportion in high school. Such children also were more likely to be members of minority groups and/or immigrants, to live in rural ar-

**TABLE 1** Descriptive Statistics and Out-of-Pocket Medical Costs for CSHCN Covered by Private or Public Insurance

Variables	Proportion, %		OOP Costs Per \$1000 of Income, Mean, \$		Actual OOP Costs, Mean, \$	
	Private Insurance (N = 23 175)	Public Insurance (N = 8633)	Private Insurance (N = 23 175)	Public Insurance (N = 8633)	Private Insurance (N = 23 175)	Public Insurance (N = 8633)
Overall			21.27	17.86	1298	317
Variables suggesting financial stress						
OOP medical costs for CSHCN in previous year						
With OOP costs above \$0	96.8	45.5 <sup>a</sup>	21.96	39.15	1341	694
With OOP costs >5% of income	12.2	6.9 <sup>a</sup>	94.74	186.97	4163	2939
With OOP costs >10% of income	3.2	4.2	166.68	255.35	4267	3601
Costs caused family financial problems	15.1	20.3 <sup>a</sup>	52.98	46.97	2576	879
Family needs additional income for child's medical expenses	13.4	16.9 <sup>a</sup>	54.37	58.15	2616	1 026
Has medical home	54.4	41.5 <sup>a</sup>	16.68	10.40	1088	215
Has usual doctor/source of care	99.2	97.5 <sup>a</sup>	21.11	17.77	1300	318
Care is family-centered	72.8	59.2 <sup>a</sup>	19.64	12.59	1252	271
Care coordination received	67.4	60.7 <sup>a</sup>	16.94	11.45	1085	235
No problem getting referrals	94.2	91.1 <sup>a</sup>	20.49	15.84	1252	279
Need variables						
Child's medical condition <sup>b</sup>						
Asthma	37.6	40.9 <sup>a</sup>	19.65	19.64	1177	300
Attention-deficit/hyperactivity disorder	25.3	35.8 <sup>a</sup>	23.98	19.85	1469	333
Autism	4.4	6.1 <sup>a</sup>	37.88	28.96	2129	472
Mental retardation	6.6	18.6 <sup>a</sup>	37.63	31.11	2006	474
Diabetes mellitus	1.5	1.7	38.25	28.29	2280	614
Heart or blood condition	4.4	7.4 <sup>a</sup>	35.68	30.77	1717	510
Emotional condition	15.6	30.0 <sup>a</sup>	35.03	26.50	1930	404
Cystic fibrosis, cerebral palsy, or muscular dystrophy	1.3	3.1 <sup>a</sup>	41.49	47.20	2398	845
Seizure disorder or migraines	13.2	23.6 <sup>a</sup>	30.65	28.06	1700	456
Joint condition/arthritis	3.1	5.8 <sup>a</sup>	37.15	39.11	2008	558
Allergies	54.7	50.8 <sup>a</sup>	20.80	21.15	1253	358
Blind/deaf	3.2	5.5 <sup>a</sup>	26.40	21.69	1608	354
Child has both physical and emotional, developmental, or behavioral conditions	21.2	38.0 <sup>a</sup>	31.41	27.33	1734	441
Severity of child's medical condition						
Mild	67.4	44.3 <sup>a</sup>	15.97	10.04	1039	193
Moderate	28.1	41.3 <sup>a</sup>	29.55	18.12	1722	364
Major	4.5	14.3 <sup>a</sup>	49.09	41.29	2541	564
Child has unmet health needs	8.9	18.4 <sup>a</sup>	36.92	30.02	1867	497
Enabling variables						
Gaps in health insurance in previous year	3.0	10.3 <sup>a</sup>	35.25	36.12	1336	960
Household income in previous year						
≤100% of poverty level	2.4	50.1 <sup>a</sup>	95.37	23.02	1004	207
101%–200% of poverty level	12.9	36.8 <sup>a</sup>	35.37	13.88	1142	388
201%–400% of poverty level	40.0	10.9 <sup>a</sup>	21.30	9.99	1242	496
>400% of poverty level	41.2	2.0 <sup>a</sup>	13.32	6.79	1409	708
Mother's/caregiver's education level						
Did not complete high school	1.8	15.1 <sup>a</sup>	21.96	13.38	949	162
High school completion only	14.3	39.0 <sup>a</sup>	26.29	19.01	1124	266
Post-high school education/training	83.8	45.5 <sup>a</sup>	20.38	18.20	1332	409
Other family members have unmet mental health needs	1.4	3.4 <sup>a</sup>	54.11	50.59	2500	695
Child is only child in household	30.5	30.7	27.00	27.05	1448	400
Multiple CSHCN in household	30.5	37.5 <sup>a</sup>	19.11	15.30	1234	304
Delays getting health care	5.7	9.9 <sup>a</sup>	34.48	29.97	1737	495
Predisposing variables						
Child's age						
0–4 y	15.0	18.6 <sup>a</sup>	19.95	12.24	1228	281
5–10 y	34.5	36.7	19.83	17.72	1209	299
11–13 y	20.6	20.6	22.57	20.38	1390	356
14–17 y	29.9	24.1 <sup>a</sup>	22.70	20.34	1374	339
Child is male	59.2	58.8	20.50	18.36	1254	310
Child is female	40.8	41.2	22.38	17.15	1,362	327

**TABLE 1** Continued

Variables	Proportion, %		OOP Costs Per \$1000 of Income, Mean, \$		Actual OOP Costs, Mean, \$	
	Private Insurance	Public Insurance	Private Insurance	Public Insurance	Private Insurance	Public Insurance
	(N = 23 175)	(N = 8633)	(N = 23 175)	(N = 8633)	(N = 23 175)	(N = 8633)
Child's race						
White	80.4	53.2 <sup>a</sup>	21.54	20.23	1347	380
Black	9.3	29.9 <sup>a</sup>	18.05	12.94	905	199
Other or multiple races	9.8	15.9 <sup>a</sup>	21.75	19.24	1256	321
Child is Hispanic	10.5	21.4 <sup>a</sup>	22.97	18.48	1245	279
Immigrant family	1.8	8.5 <sup>a</sup>	31.76	14.72	1513	253
Lives in urban area	77.0	70.0 <sup>a</sup>	20.68	17.09	1294	313
Lives in rural area	23.0	30.0 <sup>a</sup>	26.60	19.56	1348	302
Family structure						
Married couple	76.7	36.8 <sup>a</sup>	19.07	15.30	1312	381
Single mother	18.0	47.5 <sup>a</sup>	29.98	19.05	1270	262
Other family structure	4.1	6.6 <sup>a</sup>	24.24	16.72	1233	369

OOP indicates out-of-pocket.

<sup>a</sup> Significantly different from children with private insurance, at the 95% confidence level.

<sup>b</sup> New to the 2005–2006 NS-CSHCN were questions regarding the child's specific diagnosis. Parents were asked, "To the best of your knowledge, does the child currently have the following conditions: (1) asthma, (2) attention-deficit disorder or attention-deficit/hyperactivity disorder, (3) autism or autism spectrum disorder, (4) Down syndrome, mental retardation, or developmental delay, (5) depression, anxiety, an eating disorder, or other emotional problems, (6) diabetes, (7) heart problems, including congenital heart disease, (8) blood problems, (9) cystic fibrosis, (10) cerebral palsy, (11) muscular dystrophy, (12) epilepsy or other seizure disorder, (13) migraine or frequent headaches, (14) arthritis or other joint problems, and/or (15) allergies." Parents also were asked whether their child was deaf or blind, which were combined into a single category for this analysis. Because of small sample sizes, we also combined heart and blood problems into 1 category, cystic fibrosis, cerebral palsy, and muscular dystrophy into 1 category, and seizure disorders and migraines into 1 category.

**TABLE 2** Proportion of Subjects in Each Out-of-Pocket Cost Category With Delays in Needed Health Care or Unmet Health Care Needs, According to Type of Insurance and Medical Home

Out-of-Pocket Costs <sup>a</sup>	Proportion, %											
	Private Insurance						Public Insurance					
	With Medical Home			Without Medical Home			With Medical Home			Without Medical Home		
	Total	Delayed Care	Unmet Needs	Total	Delayed Care	Unmet Needs	Total	Delayed Care	Unmet Needs	Total	Delayed Care	Unmet Needs
\$0	57.9	4.1	7.4	42.1	12.3	16.8	44.7	4.9	8.2	55.3	8.6 <sup>b</sup>	19.6 <sup>b</sup>
\$1–\$249	61.8	2.4	2.9	38.2	5.4 <sup>b</sup>	10.3 <sup>b</sup>	42.3	5.6	10.4	57.7	15.2 <sup>b</sup>	25.6 <sup>b</sup>
\$250–\$499	58.7	2.7	2.7	41.3	7.3 <sup>b</sup>	11.9 <sup>b</sup>	37.0	6.4	11.3	63.0	18.9 <sup>b</sup>	30.1 <sup>b</sup>
\$500–\$999	53.3	2.5	4.3	46.7	11.3 <sup>b</sup>	16.2 <sup>b</sup>	30.4	7.8	10.7	69.6	25.0 <sup>b</sup>	44.3 <sup>b</sup>
\$1000–\$5000	46.0	2.9	4.4	54.0	11.4 <sup>b</sup>	19.6 <sup>b</sup>	27.0	4.8	10.5	73.0	19.3 <sup>b</sup>	35.1 <sup>b</sup>
More than \$5000	30.5	5.6	9.4	69.5	13.1	24.4 <sup>b</sup>	14.5	4.5	26.5	85.5	19.2	34.5

<sup>a</sup> This variable was constructed from 2 questions in the NS-CSHCN, the first asking whether out-of-pocket medical costs for the CSHCN (including all types of health-related needs such as copayments, dental or vision care, medications, special foods, adaptive clothing, durable equipment, home modifications, or any kind of therapy but not health insurance premiums or costs that were or will be reimbursed by insurance or another source) were more than \$500, \$250 to \$500, less than \$250, or nothing and the second asking whether these costs were more than \$5000, \$1000 to \$5000, or less than \$1000.

<sup>b</sup> Significantly different from children with the same insurance type and a medical home, at the 95% confidence level.

eas, and to have siblings who also had special health care needs.

On average, families with CSHCN who had private insurance spent \$1298, or 2.1% of their household incomes (\$21.27 per \$1000), on out-of-pocket, unreimbursed, medical costs for their CSHCN. Families with CSHCN who had public insurance spent \$317, or 1.8% of their household incomes (\$17.86 per \$1000). Out-of-

pocket medical costs for the child exceeded 5% of household income for 12.2% of families with private insurance, and costs exceeded 10% of household income for 3.2% of those families. Comparable figures for families with public insurance were 6.9% and 4.2%. In both samples, families whose children had a medical home spent significantly less, on average (families with private insur-

ance: \$1088 [or 1.6% of income]; families with public insurance: \$215 [or 1% of income]), than did families whose child did not have a medical home. Families with public insurance were significantly more likely to report that their children's medical expenses caused family financial problems (20.3%) or that they needed additional income to pay for the medical expenses (16.9%). Medi-

**TABLE 3** Heckman Selection Model for Out-of-Pocket Medical Costs per \$1000 of Household Income for CSHCN With Private Insurance

Variable <sup>a</sup>	Value
Change in OOP costs per \$1000, estimate (95% CI), %	
Medical home components	
Has usual doctor and/or source of care <sup>b</sup>	−7.51 (−51.58 to 76.65)
Care is family-centered <sup>b</sup>	−3.94 (−24.60 to 22.38)
Receives care coordination services <sup>b</sup>	−32.55 (−47.60 to −13.17) <sup>c</sup>
Has no problem getting referrals <sup>b</sup>	−23.18 (−48.85 to 15.37)
Household income in previous year	
≤100% of poverty level <sup>b</sup>	39.80 (−11.14 to 119.95)
101%–200% of poverty level (reference)	
201%–400% of poverty level <sup>b</sup>	−36.21 (−54.61 to −10.36) <sup>c</sup>
>400% of poverty <sup>b</sup>	−56.27 (−69.61 to −37.08) <sup>c</sup>
Gaps in health insurance in previous year	76.66 (13.61 to 174.68) <sup>c</sup>
Delayed needed health care	15.89 (−31.57 to 96.27)
No. of unmet health needs	0.16 (−15.30 to 18.43)
Other family members have unmet mental health needs	150.46 (36.46 to 359.72) <sup>c</sup>
School level of child	
Preschool (reference)	
Elementary school	−36.91 (−59.70 to −1.23) <sup>d</sup>
Middle school	−48.57 (−69.40 to −13.56) <sup>c</sup>
High school	−31.68 (−56.18 to 6.51)
Child is only child in household	6.75 (−21.89 to 45.88)
Multiple CSHCN in household	−4.31 (.28.71 to 28.42)
Probability of OOP costs, coefficient estimate (95% CI)	
Medical home components	
Has usual doctor and/or source of care	0.139 (−0.459 to 0.737)
Care is family-centered	−0.267 (−0.598 to 0.064)
Receives care coordination services	−0.481 (−0.836 to −0.126) <sup>c</sup>
Has no problem getting referrals	0.311 (−0.429 to 1.052)
Household income in previous year	
≤100% of poverty level	0.046 (−0.545 to 0.637)
101%–200% of poverty level (reference)	
201%–400% of poverty level	0.237 (−0.210 to 0.683)
>400% of poverty level	0.715 (0.182 to 1.248) <sup>c</sup>
Predicted OOP costs per \$1000 of household income for full sample, \$ <sup>e</sup>	19.53
Predicted probability of incurring OOP costs, %	96.6
Predicted OOP costs per \$1000 of household income for sample with positive OOP costs, \$ <sup>e</sup>	19.98

OOP indicates out-of-pocket; CI, confidence interval.

<sup>a</sup> Although all independent variables were included in the estimation of each model, only the independent variables of interest are shown. Variables not shown include diagnosis, severity of medical condition, race, ethnicity, family structure, education level of primary caregiver, immigrant status, and urban location. Full results are available on request from Dr Porterfield.

<sup>b</sup> Adjusted coefficients to account for variables in both estimation and selection equations.

<sup>c</sup> Significant at the 99% confidence level.

<sup>d</sup> Significant at the 95% confidence level.

<sup>e</sup> Predicted value of the dependent variable when all independent variables are at their mean values.

cal costs per \$1000 of household income were highest (\$47–\$58) for families that reported that they needed additional income, for families with other members who had unmet mental health needs (\$50–\$54), and, in the private insurance sample, for families in poverty (\$95). Out-of-pocket costs increased with the severity of conditions in both samples.

### Delayed Care, Unmet Medical Needs, and the Medical Home

Higher levels of unmet needs and delayed care were reported by those with no or very high out-of-pocket costs (Table 2). The highest levels of reported unmet needs were for mental health care and counseling; physical, occupational, or speech therapy; and dental

care, regardless of insurance type. CSHCN with public insurance, compared with private insurance, were significantly more likely to experience unmet needs or delayed medical care. CSHCN with public insurance were less likely to receive care in a medical home, and those without a medical home were more likely to report unmet needs or delayed medical care. Regardless of insurance type, Table 2 shows a linear inverse relationship between the proportion of CSHCN who received health care in a medical home setting and out-of-pocket costs.

### Insurance and the Medical Home

Table 3 shows results from the Heckman model estimating out-of-pocket medical costs per \$1000 of household income for children with private insurance, whereas Table 4 shows results for children with public insurance. Although all independent variables were included in 1 or both of the equations in this model, only variables of interest are shown.

Care coordination was the only significant medical home component for children with private insurance (Table 3). Children who received care-coordination services were significantly less likely to have any out-of-pocket costs and, if costs were incurred, they were 32% lower than those incurred by children without care-coordination services. Children with public insurance who received family-centered care, received care coordination, or had no problems with referrals were significantly less likely to incur any out-of-pocket costs (Table 4). Costs incurred by children with care-coordination services and no referral problems were 15% and 16% lower, respectively, than costs incurred by children without those services.

Children with both types of insurance were significantly more likely to incur

**TABLE 4** Heckman Selection Model for Out-of-Pocket Medical Costs per \$1000 of Household Income for CSHCN With Public Insurance

Variable <sup>a</sup>	Value
Change in OOP costs per \$1000, estimate (95% CI), %	
Medical home components	
Has usual doctor and/or source of care <sup>b</sup>	−9.53 (−25.98 to 10.58)
Care is family-centered <sup>b</sup>	−1.70 (−7.66 to 4.64)
Receives care coordination services <sup>b</sup>	−15.18 (−20.51 to −9.49) <sup>c</sup>
Has no problem getting referrals <sup>b</sup>	−16.24 (−25.85 to −5.39) <sup>c</sup>
Household income in previous year	
≤100% of poverty <sup>b</sup>	67.06 (57.05 to 77.72) <sup>c</sup>
101%–200% of poverty (reference)	
201%–400% of poverty <sup>b</sup>	−45.21 (−50.38 to −39.50) <sup>c</sup>
>400% of poverty <sup>b</sup>	−68.20 (−73.80 to −61.40) <sup>c</sup>
Gaps in health insurance in previous year	3.86 (−1.15 to 9.13)
Delayed needed health care	0.41 (−5.09 to 6.23)
No. of unmet health needs	1.13 (−0.72 to 3.02)
Other family members have unmet mental health needs	3.00 (−6.54 to 13.50)
School level of child	
Preschool (reference)	
Elementary school	0.46 (−4.41 to 5.58)
Middle school	2.32 (−3.12 to 8.06)
High school	4.06 (−1.76 to 10.22)
Child is only child in household	35.73 (30.37 to 41.30) <sup>c</sup>
Multiple CSHCN in household	−0.40 (−4.23 to 3.58)
Probability of OOP costs, coefficient estimate (95% CI)	
Medical home components	
Has usual doctor and/or source of care	−0.040 (−0.322 to −0.242)
Care is family-centered	−0.103 (−0.192 to 0.013) <sup>d</sup>
Receives care coordination services	−0.240 (−0.333 to −0.148) <sup>c</sup>
Has no problem getting referrals	−0.310 (−0.476 to 0.145) <sup>c</sup>
Household income in previous year	
≤100% of poverty	−0.376 (−0.467 to −0.285) <sup>c</sup>
101%–200% of poverty (reference)	
201%–400% of poverty	0.100 (−0.029 to 0.230)
>400% of poverty	0.217 (−0.046 to 0.481)
Predicted OOP costs per \$1000 of household income for full sample, \$ <sup>e</sup>	16.66
Predicted probability of incurring OOP costs, %	46.0
Predicted OOP costs per \$1000 of household income for sample with positive OOP costs, \$ <sup>e</sup>	36.54

OOP indicates out-of-pocket; CI, confidence interval.

<sup>a</sup> Although all independent variables were included in the estimation of each model, only the independent variables of interest are shown. Variables not shown include diagnosis, severity of medical condition, race, ethnicity, family structure, education level of primary caregiver, immigrant status, and urban location. Full results are available on request from Dr Porterfield.

<sup>b</sup> Adjusted coefficients to account for variables in both estimation and selection equations.

<sup>c</sup> Significant at the 99% confidence level.

<sup>d</sup> Significant at the 95% confidence level.

<sup>e</sup> Predicted value of the dependent variable when all independent variables are at their mean values.

out-of-pocket costs with more-severe disabilities (data not shown) and higher household incomes (Tables 3 and 4). Out-of-pocket costs per \$1000 of household income decreased as household incomes increased (36% to 56% lower than in households between 100% and 200% of the poverty level for CSHCN with private insurance in households above 200% of the poverty level and 45% to 68% lower for CSHCN

with public insurance with similar characteristics). Compared with CSHCN with public insurance in households with income between 100% and 200% of the poverty level, children in households with incomes below the poverty line spent significantly more (67% more) in out-of-pocket costs per \$1000 of income. Gaps in insurance affected out-of-pocket costs only for CSHCN with private insurance; costs

for those children were 77% higher than those for CSHCN without insurance gaps (Table 3). Similarly, if other family members had unmet mental health needs, then out-of-pocket costs for CSHCN with private insurance were significantly higher (150%). School level also had a significant influence on out-of-pocket costs for CSHCN with private insurance. Families spent similar amounts per \$1000 of household income on CSHCN in preschool and high school and significantly smaller amounts for children in elementary school (37% smaller) and middle school (48% smaller). More (36% more) was spent on out-of-pocket medical costs per \$1000 of household income for CSHCN with public insurance if they were the only children in their households (Table 4).

## DISCUSSION

Results from this study highlight the high costs associated with raising CSHCN and suggest that these high costs are moderated by a medical home, specifically the receipt of care-coordination services. Both descriptive and multivariate analyses showed lower out-of-pocket costs for CSHCN who received health care in a medical home setting that included care coordination.

For the 46% of families with public insurance that incurred out-of-pocket costs, affordability was an issue. Affordability also was an issue for children with private insurance who had gaps in insurance or other family members with unmet mental health needs. Previous research showed that the proportion of families reporting that they had problems paying medical bills increased precipitously when spending exceeded 2.5% of income.<sup>27</sup> In this analysis, we found 12.2% of families with private insurance and 6.9% of families with public insurance spending >5% of their income and 3.2% to 4.2% of families spending >10% of their income on medical costs for

their CSHCN, amounts that were above generally accepted affordability standards.<sup>28</sup>

Clearly, there were financial benefits to families when CSHCN were treated in medical home settings, particularly when care-coordination services were received. A medical home was particularly important for children with public insurance, for whom 2 of the 4 components led to significantly lower out-of-pocket costs.

Although there is no accepted national model of care coordination, many of the elements considered part of this component of the medical home occur in larger pediatric practices that take a team approach to health care.<sup>29,30</sup> Care is coordinated across most, if not all, needed service areas, generally by a nurse or medical social worker.<sup>29–32</sup> Nearly one-third of care-coordination encounters were found to reduce health service use, which suggests that the financial benefits of the medical home might accrue to health care providers and insurers as well as families.<sup>30</sup> If out-of-pocket costs were lower with the medical home model, then it is likely that overall costs of medical care also would be reduced.

Professional care coordination is not currently an expense for which physi-

cians' offices typically can bill insurers; therefore, providing care coordination makes sense only if the savings outweigh the additional costs. There is some suggestion in the literature that these savings come not only through the avoidance of high-cost interventions for CSHCN<sup>30</sup> but also through reductions in family social stressors.<sup>31</sup> Although Medicare demonstration projects on the medical home currently are testing the cost-effectiveness of this model for older adults, our research suggests that the medical home model for CSHCN also warrants additional study.<sup>29</sup> Policy interventions to support more-widespread adoption of the medical home model might eventually help control the unsustainable upward trend in US health care costs.

Although it might be expected that children with unmet medical needs or delays in receipt of needed medical care would have lower out-of-pocket costs, results in Table 2 suggest a more-complex relationship. Cost of care was the reason cited most often for both unmet needs and delayed care. Insurance plan problems, lack of service availability or transportation problems, and lack of school resources were other commonly cited reasons for unmet needs or delayed care.

## CONCLUSIONS

Parents might not be the best reporters with respect to the medical home, because survey questions are based more on perceptions than on objective measures.<sup>33,34</sup> The perspectives of other key players, especially health care providers, in measuring the extent to which CSHCN receive care in a medical home would be helpful, but such data are not available with the NS-CSHCN.<sup>18</sup> It also would be helpful to know whether implementation of a medical home model would reduce costs for all children or just CSHCN. Unfortunately, most of the research on the costs and savings associated with care coordination and other aspects of the medical home for children has been conducted with small nonrepresentative samples. A standard set of questions defining the medical home in national health surveys sponsored by the US government clearly would benefit this area of research and would allow for more-generalizable results and more-accurate comparisons of results across studies and across national data sets for different populations.

## ACKNOWLEDGMENT

The authors would like to thank Stephen J. Blumberg, PhD for his assistance in compiling the National Center for Health Statistics data.

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## Medical Home and Out-of-Pocket Medical Costs for Children With Special Health Care Needs

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*Pediatrics* 2011;128;892; originally published online October 17, 2011;

DOI: 10.1542/peds.2010-1307

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