

A National Profile of Health Care Utilization and Expenditures for Children With Special Health Care Needs

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Objectives: To provide the first nationally representative data on total health care expenses, out-of-pocket health care expenses, and information on the extent to which out-of-pocket expenses are financially burdensome for families of children with special health care needs (CSHCN). To also compare utilization and expenditure patterns for children with and without special health care needs.

Design: We used data from the 2000 Medical Expenditure Panel Survey (MEPS). We present univariate, bivariate, and multivariate statistics on utilization and expenditures adjusted for the complex sample design.

Participants: The 2000 MEPS data set contains 6965 children younger than 18 years. Using the CSHCN definition adopted by the federal Maternal and Child Health Bureau and operationalized using the *CSHCN Screener*, 949 children (15.6%) were identified as children with special health care needs.

Main Outcome Measures: Compared with other children, CSHCN had 3 times higher health care expenditures (\$2099 vs \$628; $P < .01$). The 15.6% of CSHCN ac-

counted for 42.1% of total medical care costs (excluding dental costs) and 33.6% of total health care costs (including dental costs) attributed to children in 2000. Families of CSHCN were best protected against inpatient hospital care expenses and most exposed to dental care expenses. Families of CSHCN experiencing high out-of-pocket expenses (exceeding 5% of family income) were approximately 11 times more likely to be from households with incomes below 200% of the federal poverty level (odds ratio, 10.9; 95% confidence interval, 3.55-33.76) than to be from families with incomes at or above 400% of the federal poverty level.

Conclusions: Families with CSHCN experience much higher expenditures, including out-of-pocket expenditures, than other children. Insurance plays an important protective role for families of CSHCN, but it still provides incomplete protection. Health policy changes that would extend the breadth and depth of insurance coverage are needed to ensure that all families of CSHCN are protected against burdensome expenses.

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CHILDREN WITH SPECIAL health care needs (CSHCN), defined as those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally,¹ use more health care services than other children^{2,3} and consequently have higher health care expenditures. One study⁴ estimated that CSHCN account for about 80% of all health care expenses for children even though they make up less than 20% of the child population. However, that estimate was based on an assessment of the literature on utilization patterns for children with chronic illnesses and disabilities and was not based

on representative national expenditure data.

In fact, there are no studies that document health care expenditures for CSHCN using nationally representative data. Several studies have assessed health care utilization and spending patterns for children with selected chronic conditions. Lozano et al⁵ provided estimates of the costs of caring for children with asthma. Chan and colleagues⁶ examined health care costs for children with attention-deficit/hyperactivity disorder, while Ringel and Sturm⁷ estimated the costs of childhood mental health disorders. Analyses of expenditures for lower income children with disabilities receiving Supplemental Security Income have been published by Neff et al⁸ and Kuhlthau et al.⁹ Other studies have used administrative data from health

plans, Medicaid, and Title XXI programs to examine health care spending patterns for children and adolescents with chronic conditions.¹⁰⁻¹²

Although these studies continue to be of great value, none has used the CSHCN definition cited above and adopted by the federal Maternal and Child Health Bureau (MCHB) as the basis for estimating expenditures. Although it is possible to define CSHCN in many ways, the MCHB definition is used in all 50 states for planning and policy purposes. Understanding the nature of health care expenses for this population is important for health planning efforts by public agencies such as the federal and state Title V CSHCN programs. Information on the distribution of health care expenditures is also important for devising appropriate benefit packages and efficient payment mechanisms under public and private health insurance. Information on the correlates of high health care expenditures, especially those with high out-of-pocket expenses, is important in developing strategies to protect families against experiencing catastrophic health care expenses. All of this information can be useful to practitioners in understanding the needs of their CSHCN patients.

New data from the Medical Expenditure Panel Survey (MEPS) are now available to fill many of the existing gaps in our knowledge of health care expenditures for CSHCN. The 2000 edition of MEPS incorporated the *CSHCN Screener*, a tool for identifying CSHCN, that was specifically designed to operationalize the federal definition presented above. The 2000 MEPS provides a new capacity to assess the nature and distribution of health care expenditures for CSHCN. Using this survey, we provide the first national data on health care expenses and out-of-pocket health care expenses for children with and without special health care needs. We also use the survey to describe the extent to which out-of-pocket expenses are financially burdensome for families of CSHCN.

METHODS

The MEPS is designed to produce national estimates of health care use, expenditures, and insurance coverage of the US civilian noninstitutionalized population. The survey uses an overlapping panel design in which data are collected through a preliminary contact followed by a series of 5 rounds of interviews during a 2½-year period.¹³ Data were collected for each sample person at the event level and summed up across rounds to produce the annual utilization and expenditure data. The overall response rate for the survey was 65.8%. A total of 6965 children younger than 18 years with valid response data were included in our study. A knowledgeable adult, usually a parent, answered questions in person and by telephone about health and health services use for children younger than 18 years.

VARIABLE CONSTRUCTION

The *CSHCN Screener* identified children who had a medical, behavioral, or other health condition that has lasted or is expected to last at least 1 year, and reported at least 1 of the following consequences of the condition: using or needing more medical care, mental health services, or education services than other children of the same age; using or needing prescription medication; having limitations in their ability to do the things

most children of the same age do; using or needing special therapies, such as physical, occupational, or speech therapy; or using or needing emotional, developmental, or behavioral treatment or counseling. Parents completed a written version of the CSHCN Screener for each child in the family. The CSHCN Screener was designed to operationalize the MCHB definition of CSHCN, excluding those “at risk” for special health care needs. The development process and technical properties of the CSHCN Screener are described elsewhere.¹⁴

Total health care expenditures, or costs, included expenditures for hospital inpatient and outpatient services, physician services, dental services, services provided by health care professionals other than physicians (eg, nurse practitioners, physical therapists, psychologists, and social workers), prescribed medications, diagnostic tests, and certain types of medical equipment and supplies including eyeglasses and contact lenses. Some specialized long-term care services and equipment, as well as services provided in schools, and institutionalized settings are excluded from MEPS.

A key outcome variable in this study is the financial burden of out-of-pocket expenses. Out-of-pocket expenditures are defined as the payments made by families for health care and include out-of-pocket spending on deductibles and other forms of cost sharing. Cost sharing includes copayments and coinsurance, and direct expenditures for health care services, equipment, and supplies not covered by insurance (excluding premiums). We measure financial burden using absolute and relative methods. The absolute measures are based on whether the child’s out-of-pocket expenses exceed the thresholds of \$500 and \$1000 annually. Although somewhat arbitrary, these thresholds are commonly used to indicate burdensome levels of individual health care expenditures. The relative measures include the share of annual family income spent out-of-pocket on the child’s health care (ie, the ratio of out-of-pocket expenses for health care per \$1000 of family income) and out-of-pocket expenditures exceeding 5% of family income.

STATISTICAL ANALYSIS

Estimates presented in the tables and text have been statistically weighted to reflect national population totals. The weights, provided by the data collection agency, are equal to the inverse of the sampling probability for each case, adjusted for non-response. We present our results in the form of distributional statistics (**Figure 1** and **Figure 2**) as well as bivariate (**Tables 1, 2, 3, and 4**) and multivariate (**Table 5**) statistical analyses. Logistic regression models were used in the first 3 multivariate models and ordinary least-squares regression was used for the last model in Table 5. We used a semilog linear model for the last regression because the underlying distribution of expenses was skewed. Standard errors and test statistics for the bivariate and multivariate analyses were derived using Stata software (Stata Corp, College Station, Tex) that takes into account the complex sample design of the survey.¹⁵ Our analysis of secondary data from the MEPS was approved by the University of California (San Francisco) Committee on Human Research.

RESULTS

PREVALENCE OF SPECIAL HEALTH CARE NEEDS

An estimated 11 million US children (15.6%) younger than 18 years had a special health care need in 2000. Prevalence of special health care needs varied according to the demographic and socioeconomic characteristics of chil-

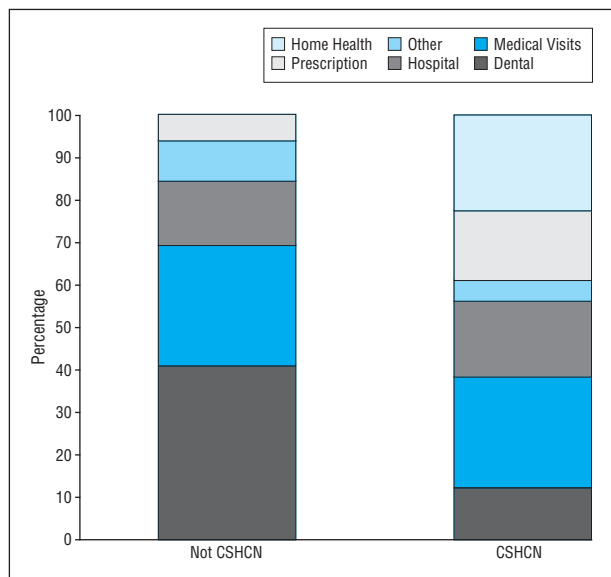


Figure 1. Composition of health care expenditures for children with and without special health care needs in the United States in 2000. CSHCN indicates children with special health care needs.

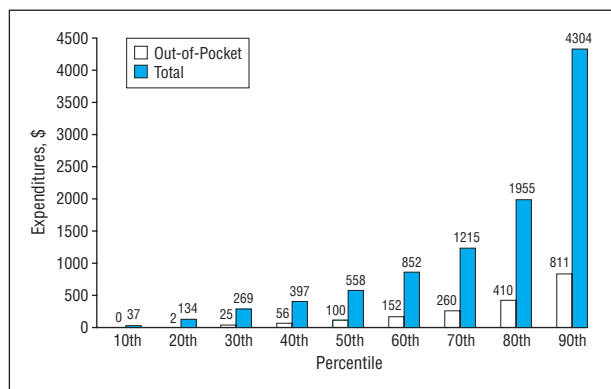


Figure 2. Percentage distribution of total and out-of-pocket expenditures for children with special health care needs in the United States in 2000.

dren and their families (Table 1). Prevalence was higher among school-age children, boys, white non-Hispanic children, and insured children. About 6% of CSHCN in 2000, estimated to be about 510 000 children nationally, did not have health insurance.

USE OF HEALTH SERVICES

Utilization data from the MEPS indicate that CSHCN use many more services than other children (Table 2). Specifically, CSHCN had about 4 times the number of hospitalizations (89 vs 22 discharges per 1000; $P < .01$) and spent more than 7 times as many days in hospitals as other children (370 vs 49 days per 1000; $P < .01$). Although CSHCN account for less than 16% of the child population, they accounted for 52.5% of children's hospital days.

The MEPS data also show that CSHCN had more than twice as many physician visits (4.35 vs 1.75; $P < .01$) and 7 times as many nonphysician visits (2.17 vs 0.30; $P < .01$) as other children on an annual basis. Nonphysician health professionals include nurse practitioners and physician

assistants who work on their own or with a physician, as well as psychologists, social workers, and physical therapists. Although the average number of emergency department visits was low, CSHCN had about 1.5 times more annual visits than other children (0.22 vs 0.14; $P < .01$). There were also significant differences present for prescription medication usage; CSHCN used 5 times the number of prescribed medications per year than other children (6.94 vs 1.22; $P < .01$) and used substantially more home health provider days on an annual basis than other children (1.73 vs 0.002; $P < .01$); approximately 87% of home health care days were accounted for by CSHCN. In contrast, the annual volume of dental care visits was similar for children with and without special health care needs.

EXPENDITURES FOR HEALTH SERVICES

Total health care expenditures averaged \$2099 for CSHCN, more than 3 times the average of \$628 for children without special health care needs ($P < .01$) (Table 3). A comparison of expenditures by type of health service shows differences that parallel those described for utilization. For example, CSHCN had almost 4 times higher hospital care expenses (\$361 vs \$96; $P < .01$), more than double the amount of physician services expenses (\$406 vs \$150; $P < .01$), and 6 times greater nonphysician services expenses than children without special health care needs (\$144 vs \$24; $P < .01$). Average expenditures on prescribed medications were 10 times higher (\$340 vs \$34; $P < .01$) and home health expenses were much greater than those of other children. Average expenditures for CSHCN on "other" medical services were about twice those for other children (\$37 vs \$16; $P < .01$). There were no significant differences in average expenditures for dental services (\$241 vs \$259; $P = .20$).

The relative differences in expenditures result in very different patterns of health care expenses for children with and without special health care needs (Figure 1). For example, dental care accounts for only about one tenth of total expenses for CSHCN but more than one third of expenditures for children without special health care needs. In contrast, prescription medications and home health care together account for one third of health care expenses for CSHCN but account for only about one twentieth of spending for other children.

Average out-of-pocket expenditures (those paid directly by the family) for CSHCN are twice those for other children (\$352 vs \$174; $P < .01$) (Table 3). For both groups, the largest component of out-of-pocket expenses was for dental services. Among CSHCN, the share of health care bills paid out-of-pocket varied dramatically by type of service. Whereas Table 3 shows that only about 2% of inpatient hospital expenses were paid out-of-pocket, 15% of physician and nonphysician services, 29% of prescription medicine, and 55% of dental expenses were paid out-of-pocket for CSHCN.

As is true for other populations, total expenditures and out-of-pocket expenses for CSHCN are highly skewed (Figure 2). The median total expense for health care was \$558, while the upper decile of children accumulated expenses of \$4304 or more. This upper decile of children accounted for 61% of all health care expenses for CSHCN.

Table 1. Prevalence of Special Health Care Needs Among Children Younger Than 18 Years in 2000*

Population Characteristic	Sample	Sample of CSHCN	Estimated Total Population (in Thousands)	Estimated No. of CSHCN (in Thousands)	Prevalence, %
Total	6965	949	68 539	10 699	15.61
Age, y					
<6	2017	180	20 171	2076	10.29
6-11	2557	354	24 585	4020	16.35
12-17	2391	415	23 783	4602	19.35
Sex					
Male	3567	564	35 346	6482	18.34
Female	3398	385	33 193	4216	12.70
Race/ethnicity					
White, non-Hispanic	3273	568	43 495	7886	18.13
Black, non-Hispanic	1183	156	10 863	1553	14.30
Hispanic	2291	213	11 227	1122	9.99
Other	218	12	2954	135	4.58
Poverty status					
<200% FPL	3356	406	25 161	3812	15.15
200%-399% FPL	2187	308	23 228	3470	14.94
≥400% FPL	1422	235	20 150	3415	16.95
Insurance status					
Insured	6149	890	62 418	10 187	16.32
Uninsured	816	59	6121	510	8.33

Abbreviations: CSHCN, children with special health care needs; FPL, federal poverty level.

*Data source: 2000 Medical Expenditure Panel Survey.

Table 2. Use of Health Services by Special Needs Status Among Children Younger Than 18 Years in 2000*

	Hospital Discharges per 1000	Hospital Days per 1000	Physician Visits†	Nonphysician Visits‡	Emergency Department Visits	Prescribed Medications	Home Health Provider Days	Dental Visits
With SHCN§	89 (15)	370 (93)	4.35 (0.251)	2.17 (0.251)	0.22 (0.022)	6.94 (0.350)	1.73 (0.669)	1.29 (0.115)
Without SHCN	22 (3)	49 (7)	1.75 (0.052)	0.30 (0.028)	0.14 (0.006)	1.22 (0.048)	.002 (0.001)	1.23 (0.049)
All children	31 (2)	96 (16)	2.15 (0.062)	0.62 (0.048)	0.15 (0.006)	2.16 (0.076)	0.27 (0.103)	1.22 (0.047)

Abbreviation: SHCN, special health care needs.

*Data source: 2000 Medical Expenditure Panel Survey; data are given as number (SE) and represent the annual average.

†Includes office-based and hospital outpatient visits to physicians.

‡Includes office-based and hospital outpatient visits to nonphysicians. Nonphysician visits include visits to chiropractors, midwives, nurses and nurse practitioners, optometrists, podiatrists, physician's assistants, physical therapists, occupational therapists, psychologists, social workers, technicians, receptionists/clerks/secretaries, or other medical providers.

§‡ Test significant at .01 level when comparing children with and without special health care needs.

Home health and hospital expenses accounted for the majority of the expenditures for the upper decile of children.

Out-of-pocket expenses were also skewed. The median annual out-of-pocket expense for health care was \$100, while the top 10% had expenses totaling \$811 or more. This upper decile accounted for 54% of out-of-pocket expenses for CSHCN. Expenses for dental care and prescription medications accounted for the majority of out-of-pocket expenses for children in this group.

PREDICTORS OF HEALTH CARE SPENDING

The prevalence of financially burdensome health care expense for CSHCN is presented in Table 4. Certain demographic and socioeconomic characteristics, including age, race/ethnicity, and poverty status, were significantly associated with out-of-pocket expenditures exceeding \$500. Race/ethnicity, sex, and poverty were significantly asso-

ciated with out-of-pocket expenses in excess of 5% of family income. Children with special health care needs with expenses above 5% of family income were disproportionately from households with incomes below 200% of the federal poverty level (FPL).

The 4 multivariate analyses in Table 5 show whether and how age, sex, race/ethnicity, poverty, and insurance status of CSHCN are independently related to out-of-pocket health care spending. The first equation shows that adolescents (odds ratio [OR], 2.09; 95% confidence interval [CI], 1.10-3.97) and uninsured children (OR, 2.07; 95% CI, 0.99-4.33) had 2 times higher odds of experiencing out-of-pocket expenditures in excess of \$500. Those CSHCN who were black (OR, 0.39; 95% CI, 0.17-0.90) or living in households at less than 200% of the FPL (OR, 0.37; 95% CI, 0.21-0.65) had significantly lower odds of out-of-pocket expenses in excess of \$500. Similarly, CSHCN who were black (OR, 0.02; 95% CI, 0.003-0.21) or from low-income families (OR, 0.43; 95%

Table 3. Average Total Health Care Expenditures and Out-of-Pocket Expenditures by Special Needs Status for Children Younger Than 18 in 2000*

	All Services	Hospital Inpatient Services†	Physician Services‡	Nonphysician Services§	Emergency Department Services	Prescribed Medications	Home Health Care	Dental Services	Other Services
Average total health care expenditures									
With SHCN	2099# (252.0)	361 (83.2)#	406 (41.9)#	144 (23.0)#	66 (10.2)#	340 (35.0)#	481# (240.2)	241 (32.4)	37 (6.2)#
Without SHCN	628 (35.0)	96 (16.6)	150 (8.8)	24 (2.8)	48 (6.5)	34 (1.9)	1 (0.6)	259 (24.2)	16 (1.1)
All children	852 (49.0)	133 (17.9)	191 (11.3)	45 (4.5)	49 (5.2)	85 (6.5)	76 (36.5)	250 (19.8)	19 (1.3)
Out-of-pocket expenditures									
With SHCN	352 (34.3)#	6 (2.1)¶	65 (8.1)#	20 (3.6)#	6 (1.9)	97 (6.6)#	<1	133 (27.0)¶	19 (2.5)
Without SHCN	174 (13.6)	7 (2.2)	27 (1.4)	5 (0.6)	5 (0.7)	14 (1.0)	<1	105 (12.5)	11 (0.8)
All children	203 (12.6)	6 (1.7)	33 (1.6)	9 (1.4)	5 (0.6)	30 (1.9)	<1	107 (11.2)	12 (0.8)
Share of total expenditures paid out-of-pocket (%)									
With SHCN	16.8 (2.6)	1.7 (0.7)	16.0 (2.6)	13.9 (3.3)	9.1 (3.2)	28.5 (3.5)	<1	55.2 (13.4)	51.4 (10.9)
Without SHCN	27.7 (2.7)	7.3 (2.6)	18.0 (1.4)	20.8 (3.5)	10.4 (2.0)	41.2 (3.7)	<1	40.5 (6.1)	68.8 (6.9)
All children	23.8 (2.0)	4.5 (1.4)	17.3 (1.3)	20.0 (3.7)	10.2 (1.6)	35.3 (3.5)	<1	42.8 (5.6)	63.2 (6.0)

Abbreviation: SHCN, special health care needs.

*Data source: 2000 Medical Expenditure Panel Survey; data given in US dollars (SE), unless otherwise indicated.

†Includes expenses for facility and separately billing physician. Hospital facility expenses include all expenses for direct hospital care, including room and board, diagnostic and laboratory work, radiography, and similar charges, as well as any physician services included in the hospital charge. Separately billing physician expenses typically cover services provided to patients in hospital settings by providers like radiologists, anesthesiologists, and pathologists, whose charges are often not included in hospital bills.

‡Includes expenses for office-based and hospital outpatient visits to physicians. Expenses for hospital outpatient visits include expenses of facility and separately billing physician.

§Includes expenses for office-based and hospital outpatient visits to nonphysicians, such as chiropractors, midwives, nurses and nurse practitioner, optometrists, podiatrists, physician's assistants, physical therapists, occupational therapists, psychologists, social workers, technicians, receptionists/clerks/secretaries, or other medical providers.

||Includes expenses for vision aids, other medical supplies, and equipment.

¶ χ^2 Test significant at the .05 level when comparing children with and without special health care needs.

χ^2 Test significant at the 0.01 level when comparing children with and without special health care needs.

CI, 0.22-0.86) were less likely to exceed the threshold of out-of-pocket expenditures in excess of \$1000.

The third and fourth columns of Table 5 show the level of financial burden experienced by families as assessed by out-of-pocket spending relative to income. Families with low incomes experienced higher levels of financial burden. Compared with families with incomes above 400% of the FPL, children in households with incomes less than 200% of the FPL were 11 times more likely than their counterparts to experience out-of-pocket expenses exceeding 5% of family income (OR, 10.9; 95% CI, 3.55-33.76). When financial burden was expressed as a share of income, children in households with incomes less than 200% of the FPL spent about 164% more of their family's income on health care (95% CI, 87%-267%) and those living in households with incomes between 200% and 400% of the FPL spent about 46% (95% CI, 7%-102%) more than their counterparts in households with incomes at or above 400% of the FPL. Although insurance status was not independently related to having out-of-pocket expenses in excess of 5% of family income, children in households without insurance spent 86% more of their family incomes on health care than families with health insurance.

COMMENT

Results from the 2000 MEPS indicate that 15.6% of children had a special health care need at the time of the survey. This estimate differs from the 12.9% prevalence es-

timate generated from the 2001 National Survey of CSHCN.¹⁶ Although both surveys used the same screening questions to identify CSHCN, they differed in mode; the MEPS used a parent-administered written questionnaire for each child in the household, and the National Survey of CSHCN used a telephone interview method where the screening questions were administered "family style" for all children in the household at one time. These differences in administration may account for the prevalence differential.

The MEPS provides the first nationally representative data on health care utilization and expenditures for CSHCN using an identification tool designed to capture the federal MCHB definition of the population. Because children are defined as having special health care needs if they have an elevated need for services, we expected to find higher use and expenditures for this population. Indeed, our purpose was to quantify the extent of differences in use and expenditures for children with and without special health care needs. Our results show that CSHCN use many more services and have significantly higher health care expenses than other children. For inpatient hospital care, services provided by nonphysician health professionals, prescriptions, and home health services, use levels for CSHCN that are at least 5-fold higher than those of other children. Only volume of dental care visits is similar for the 2 populations. These differences translate into higher expenditures for CSHCN; there is a 3-fold difference overall and even larger differences for hospital care, nonphysician services, pre-

Table 4. Prevalence of Financially Burdensome Health Care Expenses by Special Needs Status Among Children Younger Than 18 in 2000*

Characteristic	Out-of-Pocket Expenditures in Excess of \$500 per Year, %	Out-of-Pocket Expenditures in Excess of \$1000 per Year, %	Out-of-Pocket Expenditures in Excess of 5% of Family Income, %	Out-of-Pocket Expenditures per \$1000 Family Income
All Children	8.23 (0.54)	4.04 (0.38)	1.75 (0.23)	\$3.56 (0.23)
With SHCN	18.11 (1.86)‡	8.24 (1.26)‡	2.62 (0.61)†	\$6.20 (0.65)‡
Without SHCN	6.40 (0.42)	3.27 (0.34)	1.59 (0.23)	\$3.06 (0.25)
CSHCN				
Age, y				
<6	11.23 (2.97)†	4.95 (2.08)‡	1.95 (1.30)	\$4.43 (0.83)
6-11	16.49 (2.25)	5.31 (1.15)	1.62 (0.68)	\$5.88 (0.61)
12-17	22.64 (3.03)	12.27 (2.37)	3.79 (1.30)	\$7.04 (1.19)
Sex				
Male	17.26 (2.17)	6.73 (1.18)	1.91 (.50)‡	\$5.74 (.63)
Female	19.43 (2.86)	10.55 (2.21)	3.71 (1.04)	\$6.92 (1.18)
Race/ethnicity				
White, non-Hispanic	20.48 (2.31)‡	10.09 (1.61)‡	2.84 (0.78)†	\$6.47 (0.43)
Black, non-Hispanic	6.74 (2.45)	0.20 (0.21)	0	\$3.37 (0.63)
Hispanic	17.78 (4.45)	6.60 (2.97)	2.63 (0.93)	\$6.58 (1.53)
Other	13.43 (9.88)	5.71 (5.63)	19.58 (8.54)	\$4.51 (2.13)
Poverty status				
<200% FPL	9.66 (1.82)‡	4.09 (1.23)‡	5.91 (1.55)‡	\$9.48 (1.86)
200%-399% FPL	20.38 (2.83)	8.37 (0.21)	0.72 (0.43)	\$6.91 (0.79)
≥400% FPL	25.25 (3.63)	12.73 (2.49)	.86 (0.65)	\$5.15 (0.78)
Insurance status				
Insured	17.74 (1.95)	8.34 (1.30)	2.43 (0.64)	\$6.09 (0.67)
Uninsured	25.62 (5.95)	6.22 (3.10)	6.37 (2.96)	\$9.40 (2.18)

Abbreviations: CSHCN, children with special health care needs; FPL, federal poverty level.

*Data source: 2000 Medical Expenditure Panel Survey; data given in percentage (SE) unless otherwise indicated.

† χ^2 Test significant at the .05 level when comparing children with and without special health care needs.

‡ χ^2 Test significant at the .01 level when comparing children with and without special health care needs.

scriptions, and home health care. Altogether, CSHCN constitute 15.6% of the child population but 33.6% of total health care expenditures. Excluding dental care expenses, CSHCN accounted for 42.1% of total medical care costs for children in 2000. These shares would be measurably larger if specialized long-term care services and equipment, as well as services provided in educational settings and institutional care facilities, were included in the scope of MEPS. According to the 2000 Decennial Census, approximately 89,000 children resided in health-related institutional settings in 2000.¹⁷ These children have very high health care expenditures, though the actual amount is unknown since there are no comprehensive national surveys of institutionalized children.

On average, out-of-pocket expenses for CSHCN are about twice those of other children. However, their share of total expenditures paid out-of-pocket is only about half that of other children. Part of the explanation for this seemingly contradictory finding is that CSHCN have more inpatient hospital days and use more home health care than other children, services that are better covered by health insurance. In this sense, CSHCN are better protected against out-of-pocket expenses than other children. For other services, including physician services and dental services, CSHCN are afforded no greater protection. Given that their overall out-of-pocket expenses are much higher than other children, wrap-around policies that improve financial protection for services like am-

bulatory care, prescription medications, and dental care would be of great value to families of CSHCN.

We were particularly interested in the subpopulation of CSHCN with high out-of-pocket expenses. The out-of-pocket expenditure distribution for CSHCN indicates that most CSHCN have modest out-of-pocket expenses. High out-of-pocket costs are concentrated in a small segment of the CSHCN population. These families can face extremely burdensome expenses, especially considering the out-of-pocket amounts reported here are for only 1 family member. Families of CSHCN were shown to be much more vulnerable in this respect. On average, their children are 2 to 3 times more likely to have out-of-pocket expenses exceeding absolute thresholds (ie, >\$1000 per year) or exceeding relative thresholds (ie, >5% of family income).

We conducted several multivariate analyses to discern which CSHCN are at greatest risk of experiencing burdensome out-of-pocket expenses. Among the mutable variables included in our analyses, income and insurance status stand out as critical predictors of financially burdensome health care expenses. Although CSHCN in low-income families (<200% FPL) are less likely than those in middle and higher income families to experience high absolute out-of-pocket expenses, they are much more likely to experience financially burdensome expenses when expenses are measured relative to income. These findings suggest that CSHCN in low-income fami-

Table 5. Predictors of Health Care Expenditures, Out-of-Pocket Expenses, and Financially Burdensome Expenses for Children Younger Than 18 Years With Special Health Care Needs in 2000*

Characteristic	Out-of-Pocket Expenditures in Excess of \$500 per Year	Out-of-Pocket Expenditures in Excess of \$1000 per Year	Out-of-Pocket Expenditures in Excess of 5% of Family Income	Log of Out-of-Pocket Expenses per \$1000 of Family Income†
Age, y				
<6	1	1	1	NA
6-11	1.55 (0.83-2.92)	1.06 (0.40-2.80)	0.68 (0.14-3.29)	0.13 (-0.38-0.64)
12-17	2.09 (1.10-3.97)‡	2.30 (.92-5.76)	1.92 (.40-9.10)	0.36 (-0.06-0.78)
Sex				
Male	1	1	1	NA
Female	1.17 (0.72-1.90)	1.58 (0.92-2.71)	1.91 (1.03-3.53)‡	0.26 (-0.02-0.55)
Race/ethnicity				
White, non-Hispanic	1	1	1	NA
Black, non-Hispanic	0.39 (0.17-0.90)‡	0.02 (0.003-0.21)§	2.93 (1.19-7.20)‡	0.54 (0.15-0.93)§
Hispanic	1.04 (0.54-2.03)	0.83 (0.31-2.21)		
Other	0.67 (0.13-3.42)	0.64 (0.09-4.70)		
Poverty status				
<200% FPL	0.37 (0.21-0.65)§	0.43 (0.22-0.86)‡	10.94 (3.55-33.76)§	0.97 (0.63-1.30)§
200%-399% FPL	0.82 (0.51-1.33)	0.83 (0.43-1.60)	1.16 (0.12-10.99)	0.38 (0.07-0.70)‡
≥400% FPL	1	1	1	NA
Insurance status				
Insured	1	1	1	NA
Uninsured	2.07 (0.99-4.33)‡	0.98 (0.34-2.79)	2.55 (0.79-8.21)	0.62 (0.12-1.13)‡

Abbreviations: FPL, federal poverty level; NA, not applicable.

*Data source: 2000 Medical Expenditure Panel Survey; data given in odds ratio (95% confidence interval).

†Measured using ordinary least squares regression with log coefficients and confidence intervals. To convert to percent change, take antilog $\beta - 1$.

‡Significant at the 0.05 level.

§Significant at the 0.01 level.

||All 3 racial and ethnic minority categories combined owing to small sample/cell sizes.

lies would greatly benefit from caps on their out-of-pocket expenses. The costs of providing these caps should be modest, given our finding that relatively few low-income families spend more than \$500 out-of-pocket per year on their CSHCN. The findings on the association between insurance coverage and out-of-pocket expenses also have important policy implications. As expected, insurance was shown to be protective against burdensome out-of-pocket expenses. Specifically, the presence of insurance was associated with families paying a substantially lower proportion of their income on out-of-pocket health care expenses. These results indicate that efforts to expand health insurance coverage to the remaining 5% to 10% of CSHCN currently without coverage would provide substantial reductions in the exposure to financially burdensome expenses for CSHCN and their families. Despite the clear importance of insurance, our multivariate analysis indicates that having insurance does not provide all of the protection that vulnerable families need. That is, even after taking into account insurance coverage status, CSHCN in low-income families had more than 10 times the odds of experiencing financially burdensome expenses (having out-of-pocket expenditures in excess of 5% of family income) as the highest income group. Hence, low-income families are underinsured relative to higher income families, at least with respect to being protected against financially burdensome expenses. This finding reinforces the points made about the importance and value of extending the breadth and depth of insurance coverage to fully

protect low-income families with CSHCN. It also suggests that practitioners should attempt to ensure that low-income families in their practices are aware of their insurance options and the availability of other subsidies, such as those provided by the state Title V maternal and child health programs.

CONCLUSIONS

The findings presented here provide the first glimpse of health care utilization and expenditure patterns for CSHCN using a nationally representative population-based survey. Our purpose was to provide a descriptive profile of use and expenditures. Future work should take advantage of the analytic capacity of the MEPS to assess patterns of use by demographics, type of special health care need, and type of insurance coverage. As future editions of the MEPS data are released, annual panels can be combined to permit subgroup analyses not possible using a single year of data.

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tient welfare, improving access to care, and promoting social justice, I failed.

In introducing the Charter of Professionalism, Harold Sox, MD, an experienced internist and someone whose humanity I respect personally, challenged his readers to decide whether the circumstances of practice threaten their own adherence to the traditional values of medicine. For this pediatrician, the answer, regrettably, is yes.

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Correction

Numerical Errors. In the Original Article by Newacheck and Kim titled "A National Profile of Health Care Utilization and Expenditures for Children With Special Health Care Needs," in the January issue of the ARCHIVES (2005;159:10-17), the text contained errors due to a computer program coding problem. On page 11 in the section "Prevalence of Special Health Care Needs," the first sentence should have read as follows: "An estimated 11.7 million US children (16.2%) younger than 18 years had a special health care need in 2000."

On page 12 in the section "Use of Health Services," the second sentence should have read as follows: "Specifically, CSHCN had about 3.4 times the number of hospitalizations (86 vs 27 discharges per 1000; $P < .01$) and spent about 7 times as many days in hospitals as other children (552 vs 90 days per 1000; $P < .01$)."

On page 12 in the section "Expenditures for Health Services," the first sentence should have read as follows: "Total health care expenditures averaged \$2335 for CSHCN, more than 3 times the average of \$652 for children without special health care needs ($P < .01$) (Table 3)." In the same paragraph, the third sentence should have read as follows: "For example, CSHCN had about 5 times higher hospital care expenses (\$552 vs \$116; $P < .01$), more than double the amount of physician services expenses (\$412 vs \$160; $P < .01$), and 6 times greater nonphysician services expenses than children without special health care needs (\$146 vs \$25; $P < .01$)."

On page 14 in the left column, the second to last sentence of the first paragraph should have read as follows: "When financial burden was expressed as a share of income, children in households with incomes less than 200% of the FPL spent about 159% more of their family's income on health care (95% CI, 95%-242%) and those living in households with incomes between 200% and 400% of the FPL spent about 55% (95% CI, 15%-108%) more than their counterparts in households with incomes at or above 400% of the FPL."

On page 15, the first 2 sentences of the first paragraph should have read as follows: "Altogether, CSHCN constitute 16.2% of the child population but 37.3% of total health care expenditures. Excluding dental care expenses, CSHCN accounted for 45.5% of total medical care costs for children in 2000."

A corrected set of tables can be obtained by emailing Paul W. Newacheck, DrPH, at pauln@itsa.ucsf.edu.