

Family-Provided Health Care for Children With Special Health Care Needs

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abstract

BACKGROUND AND OBJECTIVES: Many children with special health care needs (CSHCN) receive health care at home from family members, but the extent of this care is poorly quantified. This study's goals were to create a profile of CSHCN who receive family-provided health care and to quantify the extent of such care.

METHODS: We analyzed data from the 2009–2010 National Survey of Children with Special Health Care Needs, a nationally representative sample of 40 242 parents/guardians of CSHCN. Outcomes included sociodemographic characteristics of CSHCN and their households, time spent by family members providing health care at home to CSHCN, and the total economic cost of such care. Caregiving hours were assessed at (1) the cost of hiring an alternative caregiver (the “replacement cost” approach), and (2) caregiver wages (the “foregone earnings” approach).

RESULTS: Approximately 5.6 million US CSHCN received 1.5 billion hours annually of family-provided health care. Replacement with a home health aide would have cost an estimated \$35.7 billion or \$6400 per child per year in 2015 dollars (\$11.6 billion or \$2100 per child per year at minimum wage). The associated foregone earnings were \$17.6 billion or \$3200 per child per year. CSHCN most likely to receive the greatest amount of family-provided health care at home were ages 0 to 5 years, were Hispanic, lived below the federal poverty level, had no parents/guardians who had finished high school, had both public and private insurance, and had severe conditions/problems.

CONCLUSIONS: US families provide a significant quantity of health care at home to CSHCN, representing a substantial economic cost.



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WHAT'S KNOWN ON THIS SUBJECT: Many children with special health care needs receive health care at home from family members, but no studies systematically document the volume and cost of this care, which are likely to be substantial.

WHAT THIS STUDY ADDS: Each year, American families provide 1.5 billion hours of health care at home to children with special health care needs. The economic cost of this care is in the tens of billions of dollars.

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Starting with Medicare's 1966 push for home health alternatives,¹ the health care system has increasingly asked family members to care for the chronically ill at home in an effort to improve patient quality of life and contain inpatient costs.²⁻⁶ Concomitantly, technological advances have helped move interventions from the inpatient to home setting.⁴ Family members now perform medical tasks in the home that extend well beyond what were perceived as familial responsibilities several decades ago,^{7,8} from maintaining and operating medical devices (eg, ventilators) to administering nontechnological interventions (eg, physical therapy).

Providing health care at home, however, is time intensive for family members.⁹ Time spent delivering care is time that could be spent attending to other family responsibilities, employment obligations, and leisure activities. Family-provided health care can result in employment disruptions, financial distress, social isolation, marital dissatisfaction, and reduced quality of life for families of children with special health care needs (CSHCN).^{8,10-14} A better understanding of this care could inform efforts to support families of CSHCN. Unlike services from home health agencies, however, family-provided health care operates in the "informal" economy and is unpaid. Consequently, no records systematically document the volume and cost of care provided. In this study, we use nationally representative survey data to estimate these figures.

METHODS

Dataset and Definition of CSHCN

We used the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), a nationally representative, household-level telephone survey. A random sample of

196 159 US households was screened for the presence of CSHCN, defined as children ≤ 18 years identified by parents/guardians (hereafter referred to as parents) as having "one or more chronic physical, behavioral, or emotional conditions who also require health and related services of a type or amount beyond that required by children generally." Eligible parents were asked about the child's health care needs, access, and use. If multiple children in the home met criteria, one was randomly selected. The dataset contained 40 242 interviews with parents of CSHCN. Interview-level survey weights were assigned to ensure that the sample was nationally representative. Additional details appear elsewhere.¹⁵

Variables

Variables included characteristics of the household (income, highest parental education level, state of residence, and if any family members experienced financial problems, reduced work hours, stopped work, or avoided changing jobs because of the child's condition) and child (age, sex, race/ethnicity, insurance status, continuity and adequacy of coverage, 20 current health conditions, and school days missed due to illness). We characterized respondents' assessment of the extent to which the child's condition(s)/problem(s) limited doing things other children do as never, sometimes, or consistent and/or great¹⁵; severity was also indicated by the number of CSHCN screening criteria met.¹⁶ Presence of government-mandated paid family leave was based on state of residence.⁷ Outcomes were analyzed based on nonmissing responses. For explanatory variables (eg, age), an unknown category (response of "don't know" or "refused," or incomplete survey) was included.

Time Spent on Family-Provided Health Care

The survey asked about time family members spent providing health

care for their child: "Many families provide health care at home such as changing bandages, care of feeding or breathing equipment, and giving medication and therapies. Do you or any other family members provide health care at home for [said child]?"¹⁵ If necessary, the survey provided additional clarification: "Please base your answers on the last several weeks," and, "Only include care related to the child's condition."¹⁵ Respondents who answered "yes" were asked, "How many hours per week do you or other family members spend providing this kind of care?" Additional clarification included: "It is fine to provide an average number of hours per week based on several weeks. Please give your best estimate," and "Only include care related to the child's condition."¹⁵ A respondent could report multiple conditions.

In the public data set that we analyzed for this paper, responses above 10 hours per week were reported in intervals of 11 to 20 and 21+ hours. To estimate average hours per week, we used 15.5 (the midpoint) for the 11 to 20 interval and 21 for the 21+ interval. In a sensitivity analysis with maximally conservative estimates, we used 11 for the 11 to 20 interval. The survey differentiated between time spent providing health care at home and time spent coordinating health care outside the home with analogous questions for the number of hours family members spent arranging, scheduling, or organizing health care. The survey also covered financial problems and effects on employment.

Cost of Family-Provided Health Care

We estimated the cost of family-provided health care using 2 approaches.^{17,18} The "replacement cost" approach estimated what it would cost to obtain a similar amount of skilled or unskilled labor from the market. Skilled and unskilled labor were estimated by assigning

caregiving hours the average cost of hiring a home health aide and the minimum wage in 2010, respectively, in the family's state of residence.¹⁸⁻²⁰

The "foregone earnings" approach estimated wages lost due to caregiving by assigning caregiving hours the median hourly earnings rate, adjusted for labor force participation and rates of full- and part-time work based on data from the US Bureau of Labor Statistics' 2010 Current Population Survey.²¹ Because labor market activity varies with demographics, we performed a supplementary analysis stratified by race/ethnicity, as described in the Supplemental Information.

Monetary values are reported in 2015 US dollars (USD), applying the appropriate consumer price index.

Statistical Analyses

Logistic regression was used to analyze caregiving, whereas linear regression was used to analyze hours spent caregiving. Procedures for complex survey data were used to produce representative estimates and to perform valid statistical inference; hypothesis tests were based on probabilities of 0.025 in each tail. All analyses were with Stata, version 14 (Stata Corp, College Station, TX). This study was deemed exempt by the Boston Children's Hospital Institutional Review Board.

RESULTS

Profile of CSHCN and Family-Provided Health Care

The percentage of CSHCN receiving family-provided health care was 49.7% (Table 1). The CSHCN most likely to receive any care were 0 to 5 years old (61.5% vs 39.9% for those 12-17 years old; $P < .001$), identified as other race (53.2% vs 48.3% of non-Hispanic white children; $P < .001$), and lived below the federal poverty level (FPL) (52.8% vs 44.0% of those 400% of the FPL; $P < .001$).

Those most likely to receive any care also described their condition as always or greatly affecting daily activities (57.2% vs 42.1% of those for whom daily activities were never affected; $P < .001$), met 4 to 5 CSHCN screening criteria (62.6% vs 45.3% of those meeting 1 criterion; $P < .001$), and had both public and private health insurance (55.7% vs 45.4% of those with only private coverage; $P < .001$); additional details appear in Supplemental Table 6. Fourteen of 20 specific health conditions were associated with a greater likelihood of receiving family health care relative to not having the condition (Table 2).

TIME SPENT ON FAMILY-PROVIDED HEALTH CARE FOR CSHCN

On average, CSHCN with family-provided health care received 5.1 hours of care per week for a total of 1.5 billion hours nationally. Our conservative sensitivity analysis estimated an average of 4.9 hours of care per week. Conditions with the highest average amount of care included muscular dystrophy (13.8 h/wk); cerebral palsy (14.4 h/wk); cystic fibrosis (12.9 h/wk); intellectual disability or mental retardation (11.2 h/wk); and head injury, concussion, or traumatic brain injury (11.9 h/wk) (Table 2). Parents who spent time coordinating health care outside the home averaged 3.9 hours per week on those activities.

Among care recipients, 11.7% received ≥ 21 hours of family-provided health care per week (Table 3). CSHCN most likely to receive such care were 0 to 5 years old (14.9%), identified as Hispanic (19.1%), and lived below the FPL (20.0% vs 5.1% of those 400% of the FPL; $P < .001$). Those most likely to receive such care also had conditions/problems that consistently or greatly affected daily activities (26.9%), met 4 to 5 CSHCN screening criteria (28.8%), had no parents who had finished high

school (23.0%), had both public and private insurance (22.2%), and lived in a state with a paid family leave program (16.9%). The conditions of children most likely to receive this level of care included cystic fibrosis (odds ratio [OR] = 5.427), muscular dystrophy (OR = 4.111), diabetes (OR = 3.355), and cerebral palsy (OR = 2.563) (Table 4). Among CSHCN with generally less time-intensive conditions (eg, asthma) who received this level of care, nearly 90% also reported more time-intensive conditions (eg, cystic fibrosis).

Cost of Family-Provided Health Care for CSHCN

The annual replacement cost of family-provided health care at home for CSHCN in the United States was estimated at \$35.7 billion and \$11.9 billion based on skilled and unskilled labor, respectively (Table 5). Purchasing an equivalent amount of care from home health agencies or from people earning the minimum wage would have cost families \$6400 or \$2100 per child per year, respectively. In states with paid family leave at the time of data collection (California and New Jersey), replacement cost (based on skilled labor) was estimated at \$4.1 billion. Under the foregone earnings approach, the annual national cost associated with 5.1 hours per week of family-provided health care at home for CSHCN was estimated at \$17.6 billion (\$3200 per child per year.) Foregone earnings from the supplementary analysis stratified by race/ethnicity were estimated at \$16.3 billion.

Nationally, caregivers reported higher rates than non-caregivers of experiencing financial problems, reducing work hours, stopping work, or avoiding changing jobs out of concern about health insurance as a direct result of the child's condition (26.9% vs 16.3% experiencing financial problems, 21.8% vs 13.1% reducing work hours, 20.3% vs

TABLE 1 Characteristics of CSHCN Receiving Family-Provided Health Care at Home

Child and Family Characteristics	Estimated No. of CSHCN	Percent Receiving Family-Provided Health Care at Home	<i>P</i>
Total	11 203 616	49.7	Not applicable
Age			
0–5 y	2 329 117	61.5	<.001
6–11 y	4 331 510	53.6	<.001
12–17 y	4 542 990	39.9	Reference group
Race/ethnicity			
White	6 640 248	48.3	Reference group
Hispanic	1 876 944	51.6	.023
Black	1 807 323	51.0	.055
Other	879 102	53.2	.005
Impact of child's condition on daily activities			
Never	3 841 359	42.1	Reference group
Sometimes	4 304 223	51.2	<.001
Consistent and/or great	3 024 109	57.2	<.001
Unknown	33 923	39.9	.772
No. of qualifying CSHCN criteria			
1	5 782 714	45.3	Reference group
2	2 299 766	50.0	<.001
3	1 547 702	52.0	<.001
4 or 5	1 573 432	62.6	<.001
Household income status (% of FPL)			
0%–99%	2 492 229	52.8	Reference group
100%–199%	2 448 219	53.6	.596
200%–399%	3 192 814	49.6	.016
≥400%	3 070 355	44.0	<.001
Highest parental education level			
Less than high school	1 245 769	48.5	Reference group
High school graduate	2 228 585	51.9	.109
More than high school	7 729 262	49.2	.718
Insurance status			
Private only	5 672 715	45.4	Reference group
Public only	3 883 880	54.5	<.001
Both private and public	888 572	55.7	<.001
Uninsured	388 228	48.8	.237
Unknown	370 221	50.7	.050
Paid family leave available in state at time of survey			
No	9 907 315	49.9	Reference group
Yes	1 296 300	47.6	.235

Total number of CSHCN from US Department of Health and Human Services²²; other counts calculated by multiplying the total number by proportions. All race categories are for non-Hispanic responders. The unknown category includes responses of "don't know" or "refused," as well as incomplete surveys.

10.0% stopping work, and 21.3% vs 14.2% avoiding job changes; all $P < .001$). These effects were greater for caregivers whose children had more severe conditions; for example, financial problems were reported for 43.9% of children whose conditions/problems limited their daily activities consistently or a great deal versus 16.2% for children whose daily activities were never affected ($P < .001$).

DISCUSSION

Although caring for CSHCN is often rewarding, an extensive literature

has addressed the psychosocial, health, and employment challenges experienced by family members.^{24–30} This study examined the time that families spend providing health care at home to CSHCN and estimated the economic costs of family-provided health care.

Using data from the 2009–2010 NS-CSHCN, we found that 5.6 million of 11.2 million CSHCN in the United States received an average of 5.1 hours of family-provided health care per week for a yearly total of 1.5 billion hours of care. Although families of children without special

health care needs certainly spend time caring for their children, almost 12% of CSHCN received ≥21 hours of family health care each week. Under the replacement cost approach, the annual national cost of this care was estimated at \$11.9 to \$35.7 billion, depending on the ratio of skilled versus unskilled labor needed. Under the foregone earnings approach, the annual cost of this care was estimated at \$17.6 billion. The difference between these estimates reflects the fact that the imputed hourly wages of family caregivers was higher than state-mandated minimum wages but lower than the

cost of hiring a home health aide. These estimates suggest that the magnitude of caregiving for CSHCN is substantial and that if families were to stop or significantly reduce the amount of care they provided, major gaps in health care would be exposed.

It may be informative to compare our findings with the cost of family care for a high-need population at the opposite end of the age spectrum. The annual national replacement cost of informal caregiving for older individuals with dementia was estimated at \$106 billion in 2010 US dollars (USD)¹⁷ (\$114 billion in 2015 USD), and the replacement costs of informal caregiving for older individuals generally were estimated at \$221 to \$624 billion, depending on the ratio of skilled versus unskilled labor required.¹⁸ The estimated annual replacement cost per older person with dementia is \$30 839 in 2010 USD.¹⁷ Informal caregiving for dementia differs from informal caregiving for CSHCN in ways that make a direct comparison of the costs difficult. In this study, we focus on the provision of health care tasks, such as changing bandages and maintaining breathing equipment. The dementia estimates presented above, in contrast, focus on assistance with activities of daily living (eg, bathing, dressing, grooming, shopping, laundry). Therefore, the tasks captured in the dementia studies reflect baseline societal expectations of parents that were explicitly excluded from the NS-CSHCN. Had these tasks been included, the CSHCN cost estimates would be much higher.

CSHCN have 3 times the health care expenditures, including out-of-pocket costs, of other children.^{31,32} Moreover, caregiving can take a physical, psychological, and financial toll and is associated with increased stress, morbidity, and mortality.³³⁻³⁵ In caregivers of children with cerebral palsy, greater caregiving demands have been associated with poorer caregiver physical health

TABLE 2 CSHCN Receiving Family-Provided Health Care at Home by Condition

Child Characteristics	Estimated No. of CSHCN	Percent Receiving Family-Provided Health Care at Home	Average No. of Hours per Week Spent Receiving Family-Provided Health Care at Home	OR (95% CI)
CSHCN Condition	11 203 616	49.7	5.1	Not applicable
Allergies	5 423 346	55.9	4.8	1.309 (1.212–1.415)
Anxiety problems	1 829 084	51.8	6.5	1.176 (1.045–1.323)
Arthritis or joint problems	328 768	66.3	9.1	1.703 (1.357–2.136)
Asthma	3 940 587	62.9	4.7	2.246 (2.065–2.443)
Attention deficit disorder	3 216 918	45.4	5.5	0.899 (0.822–0.982)
Autism	846 975	53.2	9.8	1.182 (1.023–1.367)
Behavioral or conduct problems	1 445 649	50.0	7.5	1.055 (0.928–1.199)
Blood problems	169 251	67.7	8.9	1.974 (1.437–2.710)
Cerebral palsy	177 487	71.4	14.4	1.857 (1.372–2.513)
Cystic fibrosis	34 562	93.8	12.9	16.975 (5.428–53.085)
Depression	1 103 974	48.7	7.0	0.879 (0.755–1.024)
Developmental delay	1 881 906	55.0	9.6	1.138 (1.008–1.284)
Diabetes	190 262	62.7	9.3	2.180 (1.629–2.918)
Down syndrome	121 392	62.8	9.5	1.423 (0.975–2.078)
Epilepsy or seizure disorder	348 508	66.2	10.2	1.678 (1.337–2.106)
Head injury, concussion, or traumatic brain injury	160 544	70.2	11.9	1.564 (1.052–2.326)
Heart problems	338 097	57.6	9.1	1.260 (1.022–1.555)
Intellectual disability or mental retardation	618 477	63.9	11.2	1.495 (1.199–1.863)
Migraine or frequent headaches	1 092 620	53.5	6.1	1.006 (0.881–1.149)
Muscular dystrophy	31 455	62.2	13.8	1.261 (0.672–2.368)

Total number of CSHCN from US Department of Health and Human Services²²; other counts calculated by multiplying the total number by proportions reporting currently having the condition. Children could have >1 condition. Average hours of caregiving were calculated among children receiving family-provided health care. ORs obtained from logistic regression of 11+ hours of family health care on binary indicator variables for the 20 health conditions. CI, confidence interval.

and greater psychological distress, cognitive problems, and emotional problems.^{24,27} Similarly, parents of CSHCN are more likely to experience poorer physical and emotional health than parents of other children.^{25,36} Caregiving families also experience financial problems, reduce work hours, and stop work altogether at higher rates than families that do not provide health care to CSHCN,^{24,37} and financial problems and work loss tend to increase with the severity of the child's condition.^{26,29} In a national sample of children with medical complexity, a subset of CSHCN with higher care needs, over half of families reported financial problems

and over half reported that a family member stopped working because of the child's health.³⁰ Likewise, a study of 167 families of children with medical complexity found that nearly one-half reported financial problems, 60% reported that a family member stopped working, and 66% reported that a family member cut back on work because of the child's health.³⁸ These physical, emotional, and financial outcomes, in turn, have been found to negatively affect care, health outcomes, and quality of life for CSHCN.^{14,26,33,39,40}

What can be done to support these families? Increasing access to

TABLE 3 Characteristics of CSHCN Receiving ≥ 21 Hours per Week of Family-Provided Health Care at Home

Child and Family Characteristics	Estimated No. of CSHCN Receiving Family-Provided Health Care at Home	Percent Receiving ≥ 21 h/wk of Family Health Care at Home	<i>P</i>
CSHCN receiving care	5 563 047	11.7	Not applicable
Age			
0–5 y	1 156 501	14.9	<.001
6–11 y	2 150 769	10.3	.490
12–17 y	2 255 778	11.0	Reference group
Race/ethnicity			
White	3 297 151	9.0	Reference group
Hispanic	931 978	19.1	<.001
Black	897 408	12.6	<.001
Other	436 509	13.3	.006
Impact of child's condition on daily activities			
Never	1 907 390	4.1	Reference group
Sometimes	2 137 220	7.1	<.001
Consistent and/or great	1 501 592	24.5	<.001
Unknown	16 844	26.9	<.001
No. of qualifying CSHCN criteria			
1	2 871 350	6.2	Reference group
2	1 141 927	8.3	<.001
3	768 497	13.6	<.001
4 or 5	781 273	28.8	<.001
Household income status (% of FPL)			
0%–99%	1 237 492	20.0	Reference group
100%–199%	1 215 639	13.0	<.001
200%–399%	1 585 361	9.4	<.001
$\geq 400\%$	1 524 555	5.1	<.001
Highest parental education level			
Less than high school	6 185 575	23.0	Reference group
High school graduate	1 106 582	16.2	<.001
More than high school	3 837 890	8.5	<.001
Insurance status			
Private only	2 816 731	5.0	Reference group
Public only	1 928 503	17.7	<.001
Both private and public	441 212	22.2	<.001
Uninsured	192 771	13.1	<.001
Unknown	183 830	7.5	.059
Paid family leave available in state at time of survey			
No	4 919 381	11.0	Reference group
Yes	643 665	16.9	.007

Total number of CSHCN receiving care calculated from Table 1; other counts calculated by multiplying the total number by proportions. All race categories are for non-Hispanic responders. The unknown category includes responses of "don't know" or "refused," as well as incomplete surveys.

medical homes and care coordination is associated with better health outcomes for CSHCN, increased family functioning, reductions in family financial problems, lower out-of-pocket medical costs, and decreases in parental work reductions and/or work loss.^{29,41–44} Literature also suggests that clinicians might be able to help through simpler interventions. Clinicians can optimize care plans for families and help them obtain assistance and support.⁴⁵ Simplifying treatment regimens and making home visits can reduce caregiver hardships.⁴⁶ Mobile device

apps can facilitate care coordination, allow digital communication of care plans, and link patients with local programs that support caregiving.^{45,47} Home health aides can provide respite care, which studies have found beneficial for both caregivers and CSHCN^{48–51}; future NS-CSHCN versions could assess the use of nonfamily caregivers in the home. Families with the most care needs (poor, nonwhite, less educated, and publicly insured) may benefit most from such interventions; however, their ability to effectively access these resources may be limited.

The US Department of Veterans Affairs recently implemented a number of such initiatives for community-based veterans that might apply to families with CSHCN. These include requiring clinical records to indicate all family caregivers, a care plan, and answers to screening questions about caregiving burden (eg, the Zarit Burden Scale⁵²), as well as providing stipends to select family caregivers.^{45,53,54}

Policymakers can mitigate the impact of caregiving by incentivizing

TABLE 4 CSHCN Receiving ≥ 21 Hours per Week of Family-Provided Health Care at Home by Condition

Child Characteristics	Estimated No. of Care Recipients	Percent Receiving ≥ 21 Hours per Week of Family-Provided Health Care at Home	OR (95% CI)
CSHCN receiving care Condition	5 563 047	11.7	Not applicable
Allergies	3 031 204	10.0	0.743 (0.612–0.903)
Anxiety problems	949 677	16.2	0.961 (0.733–1.262)
Arthritis or joint problems	218 119	24.6	1.587 (1.078–2.336)
Asthma	2 478 240	9.4	0.921 (0.751–1.129)
Attention deficit disorder	1 459 176	12.6	0.739 (0.571–0.956)
Autism	452 571	27.8	1.941 (1.415–2.662)
Behavioral or conduct problems	721 880	18.2	1.264 (0.947–1.688)
Blood problems	115 022	23.6	2.253 (1.415–3.586)
Cerebral palsy	126 854	47.2	2.563 (1.630–4.029)
Cystic fibrosis	32 653	30.2	5.427 (2.353–12.514)
Depression	538 373	17.8	1.479 (1.074–2.036)
Developmental delay	1 036 521	27.4	2.411 (1.833–3.171)
Diabetes	119 604	25.1	3.355 (2.207–5.102)
Down syndrome	75 406	25.3	0.939 (0.508–1.737)
Epilepsy or seizure disorder	230 929	31.5	1.249 (0.834–1.870)
Head injury, concussion, or traumatic brain injury	113 537	39.5	2.044 (1.138–3.671)
Heart problems	194 829	26.8	2.353 (1.614–3.432)
Intellectual disability or mental retardation	394 714	36.8	1.783 (1.219–2.608)
Migraine or frequent headaches	587 306	13.6	1.021 (0.758–1.375)
Muscular dystrophy	19 354	52.0	4.111 (1.507–11.215)

Total number of CSHCN receiving care calculated from Table 1; other counts calculated by multiplying the total number by proportions reporting currently having the condition. Children could have >1 condition. ORs obtained from logistic regression of 21+ hours of family health care on binary indicator variables for the 20 health conditions. CI, confidence interval.

TABLE 5 Estimates of the Annual National Cost of Family-Provided Health Care at Home for CSHCN (in 2015 USD)

Method	Estimated No. of CSHCN Receiving Family-Provided Health Care	Average No. of Hours per Week (95% CI)	No. of Weeks per Year	Cost per Hour of Caregiving	Annual National Estimate (95% CI)
Unskilled replacement cost	5 563 047	4.9–5.3	52	\$7.88 ^a	\$11.5–\$12.4 billion
Skilled replacement cost	5 563 047	4.9–5.3	52	\$24.14 ^b	\$34.3–\$37.1 billion
Foregone earnings	5 563 047	4.9–5.3	52	\$9.40–\$13.72 ^c	\$16.9–\$18.3 billion

CI, confidence interval.

^a Based on minimum wage in state of residence in 2010 from US Department of Labor,²⁵ inflated to 2015 dollars.

^b Cost of home health aide from the 2010 MetLife Market Survey of Long-Term Care Costs, inflated to 2015 dollars.

^c By race/ethnicity, and derived from US Bureau of Labor Statistics data as described in the Supplemental Material.

employers to increase work schedule flexibility and facilitate time-banking of shared leave among employees.⁴⁵ Paid family leave programs^{55–58} represent another policy option for allowing parents to care for sick children.⁵⁹ We found that the percentage of families providing ≥ 21 hours of care per week for CSHCN in states with these programs was significantly higher than in states without, although this pattern does not necessarily reflect a causal effect of the legislation.

Families with CSHCN may benefit from the access to care and financial protection that the Affordable Care Act (ACA) can provide, but

potentially relevant provisions took effect only after the survey was conducted. The next NS-CSHCN wave, which runs through 2017, will likely enable insight into the effects of the ACA, as well as other recent policies.

Even with the ACA, however, health plans typically do not cover home care provided by family members. Insurance for informal care might be particularly vulnerable to adverse selection (people who most need the insurance are the most likely to buy it) and moral hazard (people who buy the insurance are heavily incentivized to use it), which might rapidly drive up prices. This possibility has been widely noted

in the context of long-term care for adults.⁶⁰ The existing long-term care insurance market is small (and too expensive for all but the wealthiest Americans), suggesting strong adverse selection and moral hazard potential.

This study has several limitations. First, both the replacement cost and foregone earnings approach make a number of assumptions. In the replacement cost method, for instance, caregiving time is assigned the cost of hiring a home health aide or the minimum wage. This method assumes that replacement cost is identical to that of general home health services or unskilled

labor, which may not be the case, depending on the child's needs. In the foregone earnings approach, more disaggregated data on earnings would have been desirable (eg, by both race and ethnicity). Second, neither method captures all costs associated with such care. Studies have shown, for example, that the stress of caregiving for family members increases the risk of a caregiver's own morbidity and mortality.⁶¹⁻⁶³ The costs associated with treating these health issues, however, are not considered in either estimate. Third, the foregone earnings estimate does not account for the possibility that those who provided care may have been more likely to earn relatively low wages. Although others have developed a strategy to account for such selection in the context of elder care,¹⁸ the survey did not include adequate detail for this approach. In future survey waves, additional questions about parental employment (including wages and hours worked) would be informative (as would additional questions about various

caregiving activities.) Fourth, survey data pertaining to caregiving time may be particularly vulnerable to misreporting. Respondents may, for instance, conflate time spent providing health care at home with time spent performing more traditional caregiving duties; the NS-CSHCN did not include the latter category, making it impossible to directly differentiate between these care types in our analyses.

CONCLUSIONS

Our analysis suggests that family-provided health care represents a critical component of the health care system for CSHCN. Overall, US families provide an estimated 1.5 billion hours of health care at home each year to CSHCN, sometimes, especially for children with the most complex conditions, experiencing negative psychosocial, health, and employment effects as a result.^{24-27,29,30,36-38} The annual national economic cost of this care would be an estimated \$12 billion if family hours were replaced with

unskilled labor from outside the home, and an estimated \$36 billion if they were replaced with skilled labor. Clinical interventions and policy responses could mitigate the impact on families.

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ABBREVIATIONS

ACA: Affordable Care Act
CSHCN: children with special health care needs
FPL: federal poverty level
NS-CSHCN: National Survey of Children with Special Health Care Needs
OR: odds ratio
USD: US dollars

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