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CATALYST CENTER
IMPROVING FINANCING OF CARE
for Children & Youth
WITH SPECIAL HEALTH CARE NEEDS

Payer of Last Resort:

Medical Debt and Financial Hardship among Families Raising Children and Youth with Special Health Care Needs

Federal Mandate: Adequate Financing

Federal law calls for the establishment of state systems of care for children and youth with special health care needs and their families in every state and territory of the U.S. by the year 2010.[1] That objective is incorporated into both the 2010 Health Objectives for the Nation and the President's New Freedom Initiative; the former a broad document defining a health agenda for the nation and the latter, a comprehensive plan for community inclusion of individuals of all ages who have disabilities. One component of a state system of care is adequate financing, required to assure insurance coverage and other disability-related living costs.

The Catalyst Center was established in 2004 to address adequate financing of care as part of the broad Healthy People 2010/New Freedom Initiative (NFI) agenda. Funding for the Catalyst Center comes from the federal Maternal and Child Health Bureau. The mandate of the Catalyst Center is to provide leadership and support to the efforts of stakeholders at the federal, state and local levels in assuring adequate financing of care for children and youth with special health care needs.

Why Focus on Financing?

The mandate of the Catalyst Center presumes that financing of care for children with special health care needs is an issue in need of attention. For those engaged in the daily care of children with special health care needs: parents, medical providers, care coordinators, special educators and other direct caregivers, that presumption comes as no surprise.

Boston University School of Public Health ♦ Health and Disability Working Group
Albany Street, Boston, MA 02118 ♦ Tel: 617-638-1930 ♦ Fax: 617-638-1931 ♦ http://www.hdwg.org/catalyst/index.php

For others, however, and most specifically for policymakers who decide how public dollars will be spent and private health services will be structured and regulated, it may not be so clear that there are gaps in the financing system that urgently call for attention.

In fact, the mandate of the Catalyst Center challenges widely-held beliefs that current public and private benefits do a good job of serving any family that has a valid claim with regard to a child's special needs. Yes, there is recognition in health policy literature that the cost of health care for children with special health care needs is higher on average than the cost of care for other children.[2,3] There is also broad recognition that among children with special health care needs, a small group incur exceptional costs: many times those associated with the care of other children. [2,4] What has not been widely reported, and is therefore less well known, is that existing public and private investments may be inadequate or, in some cases, misplaced, leaving families with huge financial burdens and some children, at some times, critically underserved.

Skeptics on this issue point to programs that provide benefits and services that are designed specifically to help children with special health care needs or their families.[5] Supplemental Security Income (SSI), special education, special Medicaid waiver programs, and the state-based Title V Children with Special Health Care Needs program – are the programs most often cited. Indeed, these programs are crucial to families.[6] But they offer specific benefits to limited numbers of children – depending sometimes on diagnosis, sometimes on family income and sometimes on geographic proximity – leaving large numbers of families with unmet needs and many with substantial financial hardship.[4]

The Family Experience

Research on financial hardship for families of children with special health care needs has been limited, but evidence does exist. Once it is linked to a qualitative understanding of the day-to-day challenges encountered by families, several things become clear:

1. Financial hardship is common among families of children and youth with special health care needs;

2. Financial hardship is associated with severity of disability but is *not* unique to families of children with complex medical needs or even especially high medical costs;
3. It is arrived at by three distinct but often interconnected pathways: the cost of services related to special health care needs, higher “routine” expenses, and the loss of employment income.

There is further evidence which suggests that financial hardship itself may affect family well-being in several domains, leading to social as well as financial stress, and may ultimately lead to the break-up of some families.

1. Financial hardship is common among families of children and youth with special health care needs.

The first national U.S. survey of families of children with special health care needs was conducted from 2000 to 2002. The National Survey of CSHCN (National Survey of CSHCN) 2001 is currently the best source of quantitative data we have about the lives of families of children with special health care needs. It posed several questions to respondents about family hardship: not enough to explore the topic in detail, but enough to indicate unmet need.[7]

A sizable proportion – more than 11% – of families reported spending over $1,000 per year on out-of-pocket costs for their child’s special health care needs to National Survey of CSHCN interviewers. That translates into more than a million families nationwide. A subset of those families – 1.6% of all families of children with special health care needs – spent over $5,000.[8] Even if expenses for each of these families was just above the cut-off for their expenditure category,* that adds up to $878 million for families spending between $1,001 and $5,000 and $761 million for families spending over $5,000 in 2001. That means the low-end estimate of total expenditures by these two groups of families is over $1.6 billion. If we add in expenditures by the large majority of families of children with special health care needs who incurred out-of-pocket expenses in the hundreds of dollars, it adds up to billions of dollars in any given year.

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* This would mean, for example, that every single family who reported spending over $5,000 spent exactly $5,001.

To help grasp just how much the aggregate burden on families amounts to, see **Table 1,** showing reported family out-of-pocket expenditures by state. Note that these figures reflect expenditures reported by families for the prior year when they were surveyed in 2001. The trend up to and since 2001 has been towards an increased share of national health care expenditures borne by consumers; so current figures for family out-of-pocket costs would be significantly higher than those shown here.[9]

That would be particularly true for families of children with most intensive health care needs. A study which looked at a large sample of privately insured children and youth with special health care needs, found that family out-of-pocket costs for co-payments and deductibles increased 35.3% over two years for children with single, minor chronic conditions, compared to 51% for families of children with multi-system or critical conditions.[10]

Table 1. Estimated cumulative expenditures among families reporting greater than $1,000 in expenses by state.†

State	Number of families of CSHCN (weighted est.)	Cum. out-of-pocket expense if mean expense = $1,000 ($)	Cum. out-of-pocket expense if mean expense = $2,000 ($)	Cum. out-of-pocket expense if mean expense = $5,000 ($)
Alabama	13,380	13,380,000	26,760,000	669,000,000
Alaska	2,947	2,947,000	5,894,000	14,735,000
Arizona	13,044	13,044,000	26,088,000	65,220,000
Arkansas	9,359	9,359,000	18,718,000	46,795,000
California	112,088	112,088,000	224,176,000	560,440,000
Colorado	22,642	22,642,000	45,284,000	113,210,000
Connecticut	14,382	14,382,000	28,764,000	71,910,000
Delaware	2,434	2,434,000	4,868,000	12,170,000
Dist. of Columbia	1,702	1,702,000	3,404,000	8,510,000
Florida	60,514	60,514,000	121,028,000	302,570,000
Georgia	33,770	33,770,000	67,540,000	168,850,000
Hawaii	2,629	2,629,000	5,258,000	13,145,000
Idaho	6,051	6,051,000	12,102,000	30,255,000
Illinois	38,806	38,806,000	77,612,000	194,030,000
Indiana	26,200	26,200,000	52,400,000	131,000,000
Iowa	8,446	8,446,000	16,892,000	42,230,000
Kansas	12,833	12,833,000	25,666,000	64,165,000
Kentucky	16,444	16,444,000	32,888,000	82,220,000
Louisiana	19,558	19,558,000	39,116,000	97,790,000

Table 1. cont'd.

State	Number of families of CSHCN (weighted est.)	Cum. out-of-pocket expense if mean expense = $1,000 ($)	Cum. out-of-pocket expense if mean expense = $2,000 ($)	Cum. out-of-pocket expense if mean expense = $5,000 ($)
Maine	4,605	4,605,000	9,210,000	23,025,000
Maryland	22,722	22,722,000	45,444,000	113,610,000
Massachusetts	13,630	13,630,000	27,260,000	68,150,000
Michigan	29,707	29,707,000	59,414,000	148,535,000
Minnesota	18,199	18,199,000	36,398,000	90,995,000
Mississippi	10,774	10,774,000	21,548,000	53,870,000
Missouri	22,120	22,120,000	44,240,000	110,600,000
Montana	4,005	4,005,000	8,010,000	20,025,000
Nebraska	7,025	7,025,000	14,050,000	35,125,000
Nevada	8,254	8,254,000	16,508,000	41,270,000
New Hampshire	5,284	5,284,000	10,568,000	26,420,000
New Jersey	34,247	34,247,000	68,494,000	171,235,000
New Mexico	4,920	4,920,000	9,840,000	24,600,000
New York	45,528	45,528,000	91,056,000	227,640,000
North Carolina	34,679	34,679,000	69,358,000	173,395,000
North Dakota	2,693	2,693,000	5,386,000	13,465,000
Ohio	43,953	43,953,000	87,906,000	219,765,000
Oklahoma	17,410	17,410,000	34,820,000	87,050,000
Oregon	13,216	13,216,000	26,432,000	66,080,000
Pennsylvania	35,937	35,937,000	71,874,000	179,685,000
Rhode Island	1,798	1,798,000	3,596,000	8,990,000
South Carolina	19,123	19,123,000	38,246,000	95,615,000
South Dakota	2,954	2,954,000	5,908,000	14,770,000
Tennessee	23,560	23,560,000	47,120,000	117,800,000
Texas	91,730	91,730,000	183,460,000	458,650,000
Utah	12,248	12,248,000	24,496,000	61,240,000
Vermont	2,274	2,274,000	4,548,000	11,370,000
Virginia	25,951	25,951,000	51,902,000	129,755,000
Washington	24,092	24,092,000	48,184,000	120,460,000
West Virginia	6,269	6,269,000	12,538,000	31,345,000
Wisconsin	19,470	19,470,000	38,940,000	97,350,000
Wyoming	2,711	2,711,000	5,422,000	13,555,000

[†] These figures are estimates based on the number of families in each state who reported out of pocket expenses over $1,000 in the 2001 National Survey of CSHCN. We don't know the actual mean expenditure among these families, so we have provided estimates which reflect what the cumulative cost *would* be, if the mean were $1,000, $2,000 or $5,000 per family.

Of course, if you are wealthy, an expenditure of $1,000 or even $5,000 may not be that hard to absorb. Since out-of-pocket expenses may or may not result in real hardship for a given family depending on that family's income and its other expenses, the National Survey of CSHCN also asked whether respondent families experienced financial problems related to a child's condition. Over 20% of families reported that they did experience financial problems. Even though lower income families reported spending less on average than did higher income families in response to the question about out-of-pocket expenses, lower income families were more likely than others to report financial problems related to a child's special health care needs. **Table 2** presents information on families' experience of financial problems in each state from the National Survey of CSHCN.

The most telling finding of the National Survey of CSHCN related to family finances, however, concerned not the expenses of having a child with special health care needs, but the impact on family income. Almost one-third of families reported that having a child with special health care needs affected the employment of someone in the family: 17% reported that they had cut back on work; 13% that they had quit work entirely to provide care for their children.

Findings of another survey, which was not specifically targeted to families of children and youth with special health care needs, bear out the findings from the National Survey of CSHCN. Preliminary Catalyst Center analysis of data from the National Longitudinal Survey of Youth (NLSY), a survey aimed at tracking labor force participation of Americans from adolescence onward, indicates that having a child with a disability significantly reduces the number of weeks that a mother works and lowers her hourly pay by about 6% and overall labor income by about 12% when she does work. Overall family income, including income earned by the mother of a child with special health care needs or her husband if she is married, is about 9% lower than income of other mothers. This reduced income, along with increased expenses, significantly reduces the probability that the family of a child with special health care needs has positive net worth and reduces net family assets by almost $40,000.[11]

Table 2. Percentage of families who experience financial hardship by state.

State	Yes, financial hardship due to child's health (%)	Weighted estimate, number of families of CSHCN
National Average	**20.9**	**1,935,536**
Alabama	23.7	35,866
Alaska	21.3	4,334
Arizona	18.3	27,910
Arkansas	24.9	24,054
California	19.2	183,608
Colorado	20.4	26,290
Connecticut	17.6	20,867
Delaware	16.3	4,890
Dist. of Columbia	17.6	2,711
Florida	25.9	124,141
Georgia	21.9	61,688
Hawaii	13.4	4,299
Idaho	27.6	11,877
Illinois	22.0	82,521
Indiana	20.8	46,330
Iowa	19.4	17,319
Kansas	24.4	25,698
Kentucky	20.8	32,274
Louisiana	22.0	41,930
Maine	17.2	7,931
Maryland	16.3	33,828
Massachusetts	15.3	33,782
Michigan	16.1	57,492
Minnesota	19.5	31,355
Mississippi	26.8	26,174
Missouri	19.6	41,716
Montana	26.6	7,094
Nebraska	20.0	11,358
Nevada	21.9	12,805
New Hampshire	20.6	9,593
New Jersey	18.9	49,865
New Mexico	22.0	12,478
New York	19.4	107,281
North Carolina	21.8	59,938
North Dakota	24.0	4,705
Ohio	21.3	85,333
Oklahoma	23.1	29,772

Table 2, cont'd

State	Yes, financial hardship due to child's health (%)	Weighted estimate, number of families of CSHCN
Oregon	24.2	27,348
Pennsylvania	17.8	66,657
Rhode Island	14.8	5,195
South Carolina	25.3	33,686
South Dakota	20.4	4,607
Tennessee	24.3	47,807
Texas	24.1	173,639
Utah	22.3	17,682
Vermont	21.1	4,825
Virginia	21.4	57,481
Washington	20.8	43,520
West Virginia	22.0	14,476
Wisconsin	18.0	33,087
Wyoming	27.8	4,417

National Survey of Children with Special Health Care Needs, 2001.

2. Financial hardship is felt by families with a range of attributes.

The National Survey of CSHCN revealed important patterns in out-of-pocket expenses. Better off families were more likely to be in the highest spending group, while lower income families were most likely to be in the lowest spending group. Families in two middle-income quartiles spent less, on average, than wealthier families and more, on average, than families with lower incomes. This may seem intuitively reasonable since better off families had more to spend. But that is not the whole story.

First, as noted above, lower income families were more likely to report hardship due to out-of-pocket costs than better off families. This is consistent with results from a 2000 study based on a different national survey, which indicated that while high income families spent more, on average, than low income families, families with incomes below 200% of the federal poverty level were 11 times more likely than higher income families to spend more than 5% of total family income on out-of-pocket costs.[12] Furthermore, families of children who were uninsured, who are generally less well-off than other families, were even more likely than high-income families to have out-of-pocket costs above $1,000. Fully 20% of families of uninsured children and youth with special health care needs reported costs at this level and 42.5% of families without insurance reported hardship due to the cost of their children's care.

Severity of a child's condition as reported by a parent respondent is another predictor of out-of-pocket expenses. This was not limited to children with a high need for medical services per se. Families whose children had cognitive or behavioral conditions which parents defined as severe, as well those with physical disability, reported higher than average levels of expenditure. The next section explores the types of expenditures that may confront families whose children have disabilities that are associated with high costs that are not strictly medical.

Table 3 shows the percentages of families of children with special health care needs experiencing financial hardship by income, insurance status, and the severity of their children's conditions.

Table 3. Experience of financial hardship by family attributes.

	"No" Financial Problems (%)	"Yes" Financial Problems (%)
By Income Level (FPL = Federal Poverty Level)		
0-99% FPL	71.5	28.5
100-199% FPL	70.6	29.4
200-399% FPL	78.5	21.5
400% or greater FPL	88.0	12.0
By Insurance Status		
currently insured	80.3	19.7
currently NOT insured	57.5	42.5
By Severity of Child's Health Condition		
Mild (0-2)	91.4	8.6
Moderate (3-6)	79.0	21.0
Severe (7-8)	64.0	36.0
Most Severe (9-10)	58.6	41.4

National Survey of Children with Special Health Care Needs, 2001.

These data indicate that patterns of hardship are complex. They reflect a range of interacting group and individual attributes of children and families. What that means for policy makers and others concerned with the well-being of children and families, beyond the general point that hardship is widespread, is that preconceptions about who is likely to experience hardship may be misleading. Families living in different circumstances, with children who have a range of different conditions, may encounter significant financial challenges.

3. Financial hardship among families of children and youth with special health care needs is arrived at by three distinct but often interconnected pathways.

Pathway 1: The cost of services related to special health care needs

The first pathway reflects costs that are unique to families of children with special health care needs. These include medications, services, equipment and supplies that may not be covered by insurance or may not be fully covered. Examples which confront some families are over-the-counter medications, which are often non-reimbursable; therapies that extend beyond arbitrary limits built into most private insurance policies; adaptive equipment like special cushions used to prevent dangerous pressure sores for wheelchair users that are often less than fully covered; and wipes for children who are incontinent due to cognitive and/or physical conditions. These are the sorts of expenses that most people (policymakers and the general public) assume are covered by insurance or government programs, but often are not.

Two of the most costly expenses in this category, home and vehicle modifications to accommodate physical disability and maintain children with disability at home may amount to thousands, even tens of thousands, of dollars and are almost never covered by public benefit programs or private insurance. Government sources to meet the needs of families and children in these two areas are especially sparse.

Pathway 2: Higher 'routine' expenses

The second pathway reflects increased expense borne by families of children with special health care needs for items that are required by all families. Most families with typically developing children have no way of knowing that housing, utilities, food, clothing, schooling, and basic health care entail significant and extraordinary costs for families of children with special health care needs. Some of the reasons for these heightened costs are subtle:

- Housing costs are a good example. Aside from the cost of home modifications like installing a wheelchair ramp or remodeling a bathroom to make it accessible, which are uniquely needed by families of children and youth with special health care needs, the family of a child with special health care needs may have added housing costs even if they live in non-adapted housing. They may be limited to a first floor apartment if their child needs heavy equipment. They may need to live near extended family on whom they rely for respite and support, even if that means living in a neighborhood that is beyond their means. Some families have unique safety needs associated with a child's behavioral or cognitive disability.

- Utilities, too, may cost more. Some conditions interfere with the capacity of the body to regulate temperature. The family of a child faced with one of these conditions may incur high heating and cooling bills. Other families face costs for the electricity required to keep life saving equipment going, or the need to have a back up generator in place in case of power failure. Others who live in remote areas may incur high phone bills to stay in touch with medical specialists.

- Even the "ordinary" costs of health care – that is cost of regular doctor visits and the like – may be elevated. A co-payment of $20 per visit, which is quite typical for privately insured families, may not matter much for a family whose child goes to the doctor once or twice a year. By contrast, co-payments may constitute a major burden for a family whose child has five or six doctor visits a month, not uncommon with some serious conditions or when a child has multiple diagnoses. The costs of transportation to and from the doctor and childcare for other children are added burdens when frequent doctor visits are necessary.

Pathway 3: Loss of employment income

The third pathway to financial hardship is reduced income due to reduced employment. A child's need for frequent medical visits is one impediment to employment reported by many parents. The unpredictability of some conditions adds to the challenge for parents; conditions such as sickle cell disease, for example, may involve acute episodes calling for multiple doctor visits interspersed with periods of relative health. Conditions which keep children out of school or day care for prolonged periods also pose challenges.

This category is not limited to children with bouts of what is typically thought of as “illness.” Children with conditions ranging from congenital heart defects to cerebral palsy may require multiple surgeries with post-operative periods at home, making prolonged absences from work almost inevitable and career advancement difficult for parents. Even conditions that do not require ongoing medical intervention can interfere with employment. Parents of children with mental health or behavioral conditions may be frequently interrupted at work to take a child who is acting out or troubled home from school. Again, this may make consistent employment impossible, or may be a barrier to well-paying employment.

The result is that parents cut back hours, take jobs with less responsibility or leave work entirely because of the demands of a child’s care. Of course, these challenges do not affect all parents equally. Common sense would suggest that parents with less flexible jobs or less autonomy on the job are more affected than those with greater freedom.

The Outcomes of Financial Hardship

Financial hardship is, as mentioned above, both an outcome and a cause of other types of stress and hardship for families.

Data from the NLSY, the labor force survey mentioned above, suggest that mothers of children with special health care needs are more likely than others to be raising children alone than other mothers.[10] Findings of the National Survey of Children's Health (NSCH), 2003, confirm this. The NSCH found that children with special health care needs were 26% more likely to be in single mother households than other children.[13] Given the widely accepted link between family financial hardship and divorce, the path from disability to hardship to family break-up is not unexpected. It does, of course, lead to further burden on caregiving parents.

Financial hardship related to a child’s care also has financial implications that affect the lives of all members of families caring for children with special health care needs. Recent reports indicate that costs associated with health needs, whether due to out-of-pocket medical costs or other expenses associated with illness or disability, often turn into credit card debt, as families pay for everything from doctor bills to vehicle modifications on credit.[14] And credit card debt may, of course, limit a family’s capacity to pay for everything else they need, from the purchase of a home to another child’s college tuition. Ultimately, one widely quoted study suggests, medical expenses are associated with 50% of personal bankruptcies in the U.S. The same study identifies debt associated with the medical care for a child as the cause of 13.3% of health-related bankruptcies.[15]

Finally, findings indicate that financial hardship is associated with limitations on families' options for their children's care. We noted above that the National Survey of CSHCN reveals a gradient in how much families spend out-of-pocket on care of their children with special health care needs. Leaving aside the lowest income families, who may qualify for Medicaid or have high expenses because they are uninsured, there is a clear, direct association between family income and absolute level of reported out-of-pocket expenditures. This suggests that better off families are making purchases for their children's care that are beyond the means of poorer families. These better-off families are not necessarily rich: in analyses of the National Survey of CSHCN, the highest income category begins at 400% of the federal poverty level, or about $82,000 for a family of four in 2007.[16] But they are families who have some capacity to purchase (at least on credit) high quality services for their children with special health care needs. The implication is that other children, whose families cannot afford these investments even on credit, must do without.

Breaking the Link between Special Health Care Needs and Financial Hardship

The Catalyst Center agenda is based on the view that we can effectively cut the link between special health care needs in childhood and the accrual of enormous medical debt, without incurring excessive social cost.

The Center's broad agenda can be viewed online at http://www.hdwg.org/catalyst/index.php. Two key components of the agenda that speak most directly to issues of hardship and debt among families of children and youth with special health care needs are:

1. State participation in the Medicaid buy-in option under the Family Opportunity Act. This 2006 federal law gave states the opportunity to make Medicaid coverage available to families of CYSCHN as the primary coverage or as wrap-around coverage for eligible children. Use of this option by states would go far to reducing out-of-pocket costs for families and leveling family capacity to purchase "the best" for their children with special health care needs, regardless of income.

The Catalyst Center Web site offers information and links to resources that will help stakeholders promote the use of this option across the country.

2. Development of state catastrophic relief programs, modeled on such programs in New Jersey, Massachusetts, and Michigan. These programs use special funds, trusts or endowments, to provide special relief to families who incur costs above a defined percentage of income related to care of children and youth with special health care needs. They are flexible, both in terms of the level of funding available to a specific family and the types of cost eligible for relief. For families in states which have such funds, they may mean the difference between economic survival and bankruptcy.

Beyond these two specific program strategies for reducing financial hardship, a broad array of interventions, many reported in the Catalyst Center's *State-at-a-Glance Chartbook on Coverage and Financing for Children and Youth with Special Health Care Needs,* are in place in different states to reduce the burden on families of children and youth with special health care needs. (See the *Chartbook* online at: http://www.hdwg.org/catalyst/Chartbook_Main.php.)

For too long, we have seen innovations like those mentioned here and those in the *Chartbook* piloted, demonstrated, tested, and implemented with small numbers. Recognition of the prevalence and depth of family hardship should be a spur to growing these effective and necessary interventions to scale across the nation.

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[7] Except as noted, results of the National Survey of Children with Special Health Care Needs reported in this paper may be retrieved from http://www.cshcndata.org.

[8] National Survey of Children's Health, 2003. Source: The Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health (www.childhealthdata.org). Special Analysis Produced by CAHMI/DRC Staff for the Catalyst Center, February 2007.

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