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CATALYST
CENTER

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

Relief Funds:
A Safety Net for Children and Youth with Special Health Care Needs

What is a Relief Fund?

Relief Funds function as a payer of last resort for families who struggle financially to meet the health care needs of their children. Operating under the principle that all children should have access to the care they need and families should have protection against extraordinarily high costs of care, Relief Funds pay for services that are not covered by private insurance, Medicaid, or any other public or private programs.

There are many reasons that families struggle with excessive expenses for children with special health care needs. A child may not have health insurance, or may have lost coverage temporarily due to changes in the family employment situation or changes in eligibility for publicly funded health care. However, many of the children and families served through Relief Funds do have health care coverage, through either Medicaid or private insurance. Those with private insurance often encounter financial hardship when their maximum benefit levels are exceeded, or when co-payments or deductibles become excessive. And for all families, regardless of the source of their insurance coverage, there are many health care-related expenses that insurance does not cover. These include vehicle and home modifications, out-of-town or state travel and lodging when a child needs care at a specialty hospital, and adaptive equipment that is necessary for the child to play or learn with peers.

Some states allocate a portion of their Title V block grant, or their state or county public health budget, to pay for services for children and youth with special health care needs (CYSHCN) that are not covered by health insurance in much the same way that Relief Funds do. However, the amount of funding available for this relief is usually quite limited and often subject to changing economic

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circumstances in the state or county. Relief Funds are generally financed through other avenues and offer more enhanced capacity to provide financial relief to families.

How do Relief Funds help families and children?

Under the worst of circumstances, catastrophic illnesses can push families into bankruptcy. In fact, medical bills are the leading cause of personal bankruptcy in the United States.[1] Nearly every study on individuals or families who experience medical debt has found that this debt leads people to go without needed health care services.[2-4]

Extraordinary health care expenses can force families to make choices that pit paying for a child's care against paying for food and housing for the family as a whole. Under these pressures, some families have no choice but to accept inferior medical care. The financial stresses of balancing the bills, trying to pay for uncovered health care-related expenditures while trying to meet the basic needs of the family, and the pressure to take time off from work or not work at all in order to make sure a child's health care needs are met puts a huge strain on families. It is no secret that these stresses contribute to marital conflict and the divorce rate, and that this places additional burden on custodial parents, siblings and the child with special health care needs.

Relief Funds function as a safety net for families – they provide relief for families who struggle with the financial responsibilities for a child's health problems.

How do Relief Funds work?

Relief Funds can be established through legislation or through private donations and bequests. In three states that operate these funds, Michigan (MI), New Jersey (NJ), and Massachusetts (MA), the funds are administered by the state Departments of Health or Human Services and are governed by a Commission or advised by an Advisory Group. The Funds all serve a diverse group of families in terms of income levels, employment status and children's health care needs.

Michigan's Children with Special Needs Fund is the oldest of the three funds. It was established in 1944 by one of the founders of Dow Chemical Company, who donated a gift of Dow Chemical stock to support services for children with special needs. Since that time other individuals, businesses and organizations have contributed to the fund through gifts and bequests. In the early years, the fund provided services such as artificial limbs and eyeglasses for children with vision impairments. More recently, it helped to finance a Parent Participation Program to encourage more active involvement of parents of children with special health care needs in the development of family-centered systems of care.

The two Relief Funds in New Jersey and Massachusetts were established through legislation that levies a $1 per employee tax on employers who contribute to the state Unemployment Compensation fund. The New Jersey Catastrophic Illness in Children Relief Fund was started in 1989 through legislation that calls for the Fund to work with Special Child Health Services, and the Commission that administers it to pay for case management units across the state that provide information, referral and assistance to families in understanding and utilizing health insurance at the local level. "Catastrophic" condition is defined as any condition for which the out-of-pocket expenditures on the part of the family exceed a certain percentage of the family's annual gross income

Since its inception, the majority of families helped by New Jersey's Relief Fund have been employed; in FY2005, the average income was $65,287. Most – 87% in FY2005 – also had insurance, but all still experienced catastrophic uncovered medical expenses. The majority of the Fund's expenditures (80%) go to provide non-covered services, while most of the remaining funds cover expenses that exceed benefits provided by private insurance companies.

The Massachusetts Catastrophic Illness in Children Relief Fund was established by legislation in 2000. The fund is managed by the State Treasurer's Office and administered by an eleven-person independent Commission, including seven public members appointed by the Governor and the Attorney General, and four ex-officio members. The Massachusetts Department of Public Health provides staff support to the Commission. Most of the children who have received assistance from the Fund come from low-income families with health insurance coverage. In FY2005, new applicants to the Fund documented medical and related expenses that represented, on average, 51% of the family's income.[5]

Table 1. Relief Funds: Details on the State Models

These three programs have had an important impact, helping relieve some of the burden on families of CYSHCN who have to make choices between going into debt or forgoing recommended care for their children.

	Michigan	New Jersey	Massachusetts
Program Name	Children with Special Needs Fund	Catastrophic Illness in Children Relief Fund	Catastrophic Illness in Children Relief Fund
Funding Source	Originally funded by a gift of stock; continues to be funded by private donations and bequests.	A $1 per employee fee charged to all employers who are subject to the NJ Unemployment Compensation Law, which is managed by the State Treasurer.	Employers pay an annual fee of $1 per employee as part of their unemployment health insurance contribution. These funds are deposited into the state's Medical Security Trust Fund and are transferred on a quarterly basis to the Children's Relief Fund once other obligations of the Medical Security Trust Fund are met.
Family Contributions	Yes, based on family size and income, and there are caps on how much the fund will pay for certain items.	May be assessed "family responsibility" if gross annual income exceeds 300% of federal poverty level (FPL).	No family contribution required.
Clinical Eligibility	Child must have one of the 2,700 diagnoses that make him or her eligible for services from the Children's Special Health Care Services Program of the Michigan Department of Health (though does not have to be enrolled in the program).	No specific clinical eligibility; it is not the condition, but the catastrophic nature of the expense that determines eligibility.	No specific clinical eligibility; it is not the condition, but the catastrophic nature of the expense that determines eligibility.
Financial Eligibility	No income eligibility requirement before 2006, now based on family size and income.	Financial eligibility is based on the eligible expenses as a percentage of family income. The expenses for the child's medical condition must exceed 10% of the family's gross annual income up to $100,000, and 15% of any income over $100,000. There is no upper income limit for the family.	The family's out-of-pocket expenses related to the child's medical condition must exceed 10% of the family's gross annual income up to $100,000, and 15% of any portion of the annual family income above $100,000, in a given twelve month period. There is no upper income limit for the family.

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	Michigan	New Jersey	Massachusetts
Age Limit	Under age 21.	Birth through age 21.	Birth through age 21.
Covered Expenses	Changes each year based on funds available, and as public coverage shifts.	Transportation, inpatient and outpatient care; 50% of health insurance premiums; medications; out-of-state hospital care; durable medical equipment and supplies; home modifications; temporary shelter; home health care; vehicle purchase or lease and vehicle modifications; and experimental treatments that receive additional review.	May include: inpatient or outpatient medical care; mental health treatment; occupational, physical and speech therapy; medical equipment and supplies; medication; insurance co-payments and deductibles; Medicaid premiums; medically-related home and vehicle modifications and vehicle purchases (limits apply); home health care; travel-related expenses for out-of-state treatment; funeral expenses; family support when child is hospitalized (fixed per diem amount); childcare for siblings when child is hospitalized (limits apply). Experimental treatment and alternative and complementary medicine may be covered following special review.
Common Use of Funds	Van lifts, therapeutic tricycles, wheelchair ramps and camp scholarships.	Transportation, physician services, health insurance premiums and medications.	Vehicle and home modifications, family support, medical services, equipment, and medications.
Program Limitations	Yes, this changes based on the funds available from year to year.	Does not pay for special education services, elective cosmetic surgery, or modifications to second homes. Seasonal residents are not eligible, but migrant workers who can document their work history are eligible. Annual cap of $100,000 per child. One-time vehicle allowance is capped at $15,000, plus modifications. Home modifications are capped at $25,000/year. Speech, language and hearing services are capped at $3,000/year.	Does not cover treatment in Phase I clinical trials. Only considers expenses going back 24 months from the time of application. Expenses must have already been incurred before request for reimbursement will be considered, although exceptions are made in cases of medical emergency.

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	Michigan	New Jersey	Massachusetts
Enrollment/ Application Process	Families apply directly or through local health departments, a one-page application and documentation that other resources have been exhausted. Families can name a vendor, and the fund will search for the lowest price for an item. If the family vendor is not the lowest price, the family pays the difference. A committee reviews unusual requests and the Fund works with a medical consultant on medically complicated cases.	Outreach through a public information campaign, and program dissemination through volunteer parents, community organizations, churches, employers, and government agencies.	Family submits an application to the fund that includes documentation of expenses, income verification, medical documents and insurance coverage denial.
Decision-Making Body	Parents and family members of children with special needs, health care professionals, general public members	12 Commission members, 5 members ex-officio (Commissioners of NJ Departments of Human Services, Children and Families, Health and Senior Services, Banking and Insurance, and Treasury) and 7 members appointed by the Governor with the advice and consent of the Senate. Two must be providers of health care services for children.	An independent 11-member Commission, consisting of 7 public members recommended by the Attorney General and the Governor, with final appointment made by the Governor, including a representative of the AFL-CIO, and 4 ex-officio members (Commissioners of Public Health and Insurance, Secretary of Health and Human Services, and state Treasurer). A Family Advisor also participates in Commission meetings. Two of the public members must be providers of health care services for children.
Administrative Home	Michigan Department of Health, Children's Special Health Care Services.	NJ Department of Human Services, State Office of the Commission.	MA Department of Public Health.
Annual Expenditures	$500,000 - $1,000,000, based on funds available.	$7.4 million in FY2005, with grants ranging from $280 to $100,000; average award was $26,528.	$1.23 million in FY05
Families Served/Year	250-500	277	186 received reimbursement in FY05

Notes

[1] Himmelstein DU, Warren E, Thorne D. & Woolhandler S. 2005. Market Watch: Illness and injury as contributors to bankruptcy. *Health Affairs – Web Exclusive.*W5: 63-73.

[2] Doty MM et al. August 2005. *Seeing Red: Americans Driven into Debt by Medical Bills*, The Commonwealth Fund.

[3] Pryor C & Prottas J. January 2006. *Playing by the Rules but Losing: How Medical Debt Threatens Kansans' Healthcare Access and Financial Security*, The Access Project.

[4] Pryor C & Gurewich D. February 2004. *Getting Care but Paying the Price: How Medical Debt Leaves Many in Massachusetts Facing Tough Choices*, The Access Project.

[5] *The Catastrophic Illness in Children Relief Fund*. Annual Report: FY 2005. Boston, MA

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About the Catalyst Center

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs is a national center funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration, and is located at the Boston University School of Public Health. The Catalyst Center provides support to the efforts of stakeholders at the federal, state and local levels in assuring adequate health insurance coverage and financing to meet the diverse needs of children and youth with special health care needs and their families.

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