



State of Connecticut  
GENERAL ASSEMBLY



Commission on Children

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**Submitted to the Committee on Insurance and Real Estate  
Connecticut General Assembly  
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**Proposed Bill No. 6152, An Act Concerning a Catastrophic Cost Pool for Medical Expenses**

Senator Crisco, Representative Fontana and members of the Committee:

My name is Elizabeth Brown and I am the Legislative Director for the Connecticut Commission on Children. I appear before you today to speak in support of an important bill (Proposed Bill No. 6152) to improve the lives of children with special health care needs and their families in Connecticut.

Connecticut is home to a large and increasing number of children with special health care needs – children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require an unusual level of health and related services.

According to the 2005-2006 National Survey of Children with Special Health Care Needs, supported by the U.S. Department of Health and Human Services:

- Nearly one in six Connecticut children (16.0 percent, 133,073 children) have special health care needs, an increase from 13.9 percent in 2001. The Connecticut rate is higher than the overall U.S. rate (13.9 percent).
- More than one-third of insured Connecticut children with special health care needs have inadequate insurance (34.4 percent), slightly worse than the overall U.S. rate (33.1 percent).

Many children with special health care needs in Connecticut have chronic medical conditions that require complex and costly long-term care. Nearly one in five (18.7 percent) children with special needs have a condition that frequently affects their activities; 13.2 percent missed 11 or more days of school due to illness.

Their families – which are evenly split across all income ranges – make sacrifices every day.

Nearly one in six (15.7 percent) Connecticut children with special health care needs have conditions that cause financial problems for the family. Some are forced to give up their savings, jobs, homes, and their time with their other children, in order to take care of their child with special needs.

- One in five (21.9 percent) children with special health care needs in Connecticut have conditions that cause family members to cut back or stop working.
- One in five (22.1 percent) Connecticut children with special health care needs have families who pay more than \$1000 out of pocket in medical expenses per year for the child. Some of these families spend ten or a hundred times that amount on medical and non-medical costs related to the child's illness.

In a series of Connecticut summits and roundtable meetings on children with special health care needs in 2006, it became evident that Connecticut's system for health care coverage, access, and family support does not meet the needs of these children and their families.

The resulting report by the Office of the Child Advocate, *Children with Special Health Care Needs: A Plan of Action* (2007), presented an alarming picture of the challenges facing these children and their families. The quality of their health care, accommodation, legal representation, and services is frequently substandard and inconsistent.

Access to health care services that respond to special health care needs is a crucial issue for many families. A large number (42.8 percent) of Connecticut children with special health care needs are underinsured (34.4 percent) or uninsured (8.4 percent), according to the 2005-2006 survey.

The Child Advocate also reported that Connecticut's fractured state systems under-perform, there is no single point of entry for information or support services, and children with special needs too often receive poor-quality services. In some cases, the deficiencies of services to children with disabilities and chronic medical conditions have resulted in tragedy. The death of Leeana C. in April 2004 occurred at a group home where licensed nurses were not adequately trained to deal with her physical needs.

Those of us involved with the 2006 summits proposed many solutions, including improvements in health care coverage and access to services, home and community-based services, workforce development, and oversight and accountability.

Proposed Bill 6152 is intended to address the problem facing families when insurance coverage fails to cover expensive medical expenses. The concept is to assist adults and children who have exhausted the limits in their insurance policies.

The Commission on Children applauds this effort, which is related to the catastrophic relief fund proposed last year. Each proposal – whether a cost pool or a relief fund – is a strategy that would help families burdened by enormous health-related debt.

Families whose children face serious illnesses and injuries often encounter enormous debt. When children have a serious accident, injury or chronic medical condition, the cost of caring for

the child can be thousands of dollars per month, far beyond what insurance will cover. Working, tax-paying parents quickly accrue debt that erodes the family's savings and destroys credit ratings.

Here is the story of one Connecticut parent who asked us to share her story with you:

My name is Laura...My son was in and out of hospitals from May 24<sup>th</sup>, 2006 to August 29, 2006 due to an infection of the shunt system in his brain. The longest he was home was for ten days. My son actually had to be transferred to NYC for his care.

Our family traveled back and forth to the hospitals. My husband stayed with him at night and I went early in the morning. This was a difficult task in itself considering we have four other children. I needed to take FMLA. Our family not only lost income but spend a considerable amount of money on gas, food, hotels, parking and child care. Overall this cost approximately \$20,000. Although one person in the family is not working you still need to pay the mortgage then you do what you have to. Most of the money needed was put on a credit card. As one can imagine a loss of income like this snowballs and takes years to recover. We are still trying to recoup this loss.

For many families, their ability to work is compromised by their child's illness or injury. The stress of caring for the child – plus the stress of medical debt itself – can interfere with an employee's work attendance and performance and destabilize a business.

The Commission recommends that the committee determine whether a cost pool or a relief fund is the best approach to meet the needs of families in this situation. We urge you to examine the examples of Massachusetts and New Jersey, which have successfully implemented successful catastrophic relief funds.

Since its creation in 1989, the New Jersey fund has awarded more than \$108 million to over 4500 families. Here are three examples of families served by the fund:

- ❖ A family purchased a specialized, modified van for their son, who is now 15 years old. He was born with a neurological disorder of the brain and nervous system and must use a wheel chair for mobility as well as requiring assistance with all activities of daily living. In order to enable their son to access their home with the wheel chair, his family purchased a portable ramp to transport the wheel chair into the home. Although insured, the family realized that these types of expenses were not covered by insurance but would be considered by the New Jersey fund, which assisted this family with an award of over \$25,000.
- ❖ A mother was insured when her daughter, now 15, required spinal surgery for her curvature of the spine. She was left with uncovered expenses due to out-of-network providers and expenses not covered by her insurance plan. The New Jersey fund relieved her of a \$28,081 debt.
- ❖ A couple had to modify their home to care for the needs of their daughter, now 17 years old. The girl has cerebral palsy, a seizure disorder, very poor vision and requires total care for all activities of daily living. She uses a wheelchair for mobility. The family

modified their home for ease of care and accessibility and also purchased a modified vehicle to accommodate her wheelchair. The New Jersey fund awarded the family \$41,307 for home and vehicle modifications and other expenses not covered by insurance.

The range of services that are covered by a catastrophic illness relief fund is broad. Here are the categories of eligible health services by frequency in applications approved by the New Jersey fund in FY 2007:

**New Jersey Catastrophic Illness in Children Relief Fund**

*Category of Eligible Health Service Frequency (FY 07):*

Transportation 58 %	Hospital, Out of State 15 %
Physician Services 56 %	Ancillary Services 10 %
Health Insurance Premium 47 %	Temporary Shelter 7 %
Pharmacy 42 %	Home Health Care 6 %
Specialized Pediatric Ambulatory Care 31 %	Specialty Hospital, In State 4 %
Home Modification 26 %	Specialty Hosp., out of State 3 %
Hospital, In State 25 %	Telephone 3 %
Durable Medical Equip. 21 %	Long Term Care <1 %
Disposable Med. Supplies 18 %	Funeral Expenses <1 %
	Experimental Services 0%

The New Jersey fund serves families from all income ranges, which demonstrates that medical crises affect children regardless of economic background. In FY 2007, 28 percent of the families awarded had an income of \$80,000 or above; 15 percent had an income below \$20,000.

Some form of insurance covered the majority of New Jersey families eligible for assistance regardless of employment status. More than 89 percent of the families served in FY 2007 were insured and still had extraordinary out-of-pocket expenses incurred in the care of a child.

When it comes to the debt that families accrue as a result of a child's serious medical condition, Connecticut families deserve health insurance coverage that meets their needs. The catastrophic cost pool in Proposed Bill 6152 or a catastrophic relief fund will not solve the health insurance issues that place families in dire financial trouble. But it can serve as a vital safety net that will help these families climb out of debt, become productive workers again, relieve their stress, and focus their personal attention where it is most needed – on their children.

Thank you for your consideration of the Commission's views on this important bill.