



State of Connecticut  
GENERAL ASSEMBLY



Commission on Children

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Testimony submitted by:

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Senator Meyer, Representative McMahon and members of the Committee. My name is Thomas Brooks and I am the Director of Policy and Research Analysis for the Connecticut Commission on Children. I appear before you today to speak in support of two important bills (H.B. 5498 and H.B. 5132) that would 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 underperform, 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 Leana 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.

Today we express support for two strategies to begin to address some of these challenges.

## **House Bill No. 5498, An Act Concerning a Catastrophic Illness in Children Relief Program**

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 me to share her story with you today:

*My name is Laura. I am testifying to support the Catastrophic Relief fund. I certainly could have used a fund like this the summer of 2006. 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.

H.B. 5498 would establish a catastrophic relief fund to serve as a safety net for families who have excessive expenses related to a child's medical needs. These funds could be accessed when medical expenses not covered by public or private insurance, or some other source, exceed a certain percentage of a family's income.

This legislation would serve as a much-needed safety net for families who experience a child's medical crisis – whether an unexpected event such as a car accident or a chronic disease – that can financially devastate an otherwise stable working family.

The bill is based on successful models already operating in Massachusetts and New Jersey. 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 illness relief fund proposed in H.B. 5498 will not solve the health insurance issues that place families in dire financial trouble. But it is 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.

The Commission strongly supports H.B. 5498.

### **House Bill No. 5132, An Act Appropriating Funds to the Family Support Council**

Children with special health care needs and their families are in need of state leadership, coordination and easy access to information. The challenges that require vigilant attention by families merit quality assistance from state government and communities.

Improved oversight and accountability – key recommendations that emerged from the 2006 Connecticut summits – are essential to improve our state's response in this area.

However, Connecticut programs that serve these families are split across at least five state departments, as well as other agencies, that do not effectively communicate with one another for planning and policy purposes. Interagency coordination is almost non-existent. There is no effective oversight of services provided to children with special health care needs.

The lack of coordination and leadership results too often in poor care for a vulnerable population. Children with special health care needs who might be better served at home with proper supports end up in a costly hospital setting. There is no single point of entry for information or support. Parents of these vulnerable children are left lacking assistance, resources and options, often at a time of difficult family decisions.

Since 1994, the shining light for these families has been the State Family Support Council, established by state law (CGS § 17a-219c) and consisting primarily of volunteer parents and other family members appointed by state officials. The Council, along with the Family Support Network, has served as the de facto entry point for thousands of families who leave the hospital with a newborn diagnosed with serious health problems, or who seek assistance with medical and non-medical issues related to chronic and severe health problems of their children. The Council has established itself as an invaluable resource for families.

The Council is also intended to play an important policy role in coordinating state efforts on behalf of children with special needs, and to work with state agencies to reform policies and practices for this population. The Council is charged under statute with developing guidelines for services to children with special health care needs and their families; reviewing existing

program policies, procedures and funding mechanisms across five state departments; reporting annually to the Governor on the status of family support services; and other important tasks.

The Council, made up primarily of parents, has no staff to assist it in meeting these statutory responsibilities. Operating without any annual funding from the state, the Council has nonetheless established itself as an important policy voice. However, it is stretched thin without staff support, and its important role is limited. The Council could do much more with funding to meet its statutory responsibilities, and to help the state maximize and coordinate its five-department efforts to serve children with special needs.

The 2007 report by the Child Advocate demonstrated that Connecticut's system for children with special needs is broken. State systems are fractured; there is no single point of entry for information or support services. We need the Family Support Council to be present at the table to help fix that system.

H.B. 5132 would provide funding for one staff member to assist the Family Support Council. We believe this would be a wise investment for the state to make in improved policy coordination and family assistance for the most vulnerable children and families in the state.

Thank you for your consideration of the Commission's views on these important bills.