Jeanne Milstein
Child Advocate

STATE OF CONNECTICUT

OFFICE OF THE CHILD ADVOCATE
18-20 TRINITY STREET, HARTFORD, CONNECTICUT 06106

TESTIMONY OF JEANNE MILSTEIN, CHILD ADVOCATE, BEFORE THE HUMAN SERVICES COMMITTEE

February 15, 2007

Good morning Senator Harris, Representative Villano, and members of the Committee. My name is Jeanne Milstein and I am the Child Advocate for the State of Connecticut. I appreciate the opportunity to testify **in support of Proposed Senate Bill No. 246, An Act Concerning Home and Community-Based Services for Families with Special Needs Children.**

Before I say anything more, I ask you to change the title of this bill to refer to families with **children** with special health care needs. So often we refer to children as a diagnosis or a set of needs – special needs children, foster children, cognitively limited children. Using children-first language keeps the focus on the children, whose needs may be unique, but who still hope to grow and develop like any child.

SB No. 246 is vital to ensuring that hard working families with children who have special health care needs can keep their families together and take care of their children at home. While Connecticut has committed tremendous resources to deinstitutionalizing adults with disabilities, it seems we have forgotten about the children. Sadly, children with special health care needs continue to be at the highest risk of institutionalization.

What it is like for families? Let me share with you what families have shared with me. When you have a child with special health care needs, you experience the joys of parenting just like other parents. You also have a great deal of care to provide. Your child may need around-the-clock care, requiring you to be alert throughout the night, for example, to clean a tracheotomy or to help your child change sleeping positions or go to the bathroom. Your child may require specialized equipment for mobility, eating, or speaking. Your child may require specialized transportation. Your older child may need diapers or specialized formulas. You stretch yourself thin, function on less sleep than most people, and do your best to meet the needs of the rest of your family. You can't go to the doctor to address your own health needs because you need someone with specific skills to care for your child in your absence. Your insurance doesn't cover respite services.

You work hard. You pay taxes. You have insurance. You struggle to pay the mortgage or rent on your home each month. And every day, you are faced with expenses not covered by your private insurance – like formula or diapers for older children. You are told that you have

Phone: (860) 566-2106, (800) 994-0939 Fax: (860) 566-2251
oca@po.state.ct.us
An Affirmative Action/Equal Opportunity Employer

exceeded caps for covered services, like physical therapy or speech therapy. You need help with providing overnight care to your child but your insurance doesn't cover overnight nursing care. You look to the state for assistance and find that there are five state departments you must navigate to get services. If you earn over 300% of the poverty level, you are not eligible for Medicaid, with few exceptions. You can apply for the Katie Becket Waiver to access Medicaid coverage and wait three years for one of the only 180 funded slots to come available. You have few options. . You and your spouse can get divorced and live separately so you'll be eligible for Medicaid. If the family can afford to live on one salary, one spouse can quit working. Or, as many families have done in desperation, you can give custody of your child to the Department of Children and Families (DCF).

Sadly, children who are institutionalized in settings regulated and funded by the state are not receiving adequate care. Since 2001, my office has documented evidence about the substandard care often provided to children with special health care needs, particularly those in state care. You may recall in April 2004, Leeana C. died. Leeana was just turning three years old when the DCF removed her from her home because of a lack of home care providers. DCF placed her in a large group home where the licensed practical nurses did not know how to manage her tracheotomy (Department of Children and Families, 2005) and there was no oversight of the capacity of her caregivers. Her tracheotomy became obstructed with mucous and she died.

The investigation into the circumstances of the death of this little girl and other investigations we are involved in regarding the care and treatment of children with complex health and developmental needs leaves us with some alarming conclusions:

- Children with special health care needs are often subjected to substandard care and protection across all disciplines, including all levels of health care, legal representation, and education.
- DCF has no established system of professional oversight for the health care of children with disabilities or complex medical conditions placed in their care.
- Education, recreation, socialization and religious activities are consistently lacking in residential programs for children with special health care needs. Some children are literally living in industrial parks with no outdoor space for fresh air or play.

Connecticut can do better than this.

In too many cases, institutionalization could be avoided or cut short with the availability of health insurance that covers extended hours of home nursing care, respite, or other family supports. By adopting a few simple measures, Connecticut can help families meet the needs of their children at home. It is the most humane, family-centered, child-centered, and cost-effective[1] thing to do.

My office will be releasing a report within the next week, entitled "Children With Special Health Care Needs: A Plan of Action." This report explains in detail the many options Connecticut has to provide necessary insurance while maximizing federal dollars. It would take

[1] The cost of institutional care can range from $500.00/day in some state facilities to over $1000/day in private facilities.

too long to detail all of the options here, but I urge you to read it and take each option under consideration in the coming years in order to maximize all available subsidies from the federal government. As part of a large collaborative addressing these issues, my office is recommending just two options this year in order to increase coverage with minimal administrative burden: (1) fully fund the Katie Becket waiver[2] for the 200 slots already authorized and (2) amend the state Medicaid plan to take advantage of the Medicaid buy-in option in the Family Opportunity Act. By fully funding the Katie Becket waiver, we would add 20 slots to this program, helping to reduce the very long waiting list. By applying for the Medicaid buy-in option in the Family Opportunity Act[3], we would provide families with an alternative waiver program, which has two benefits. First, only families with the most severe needs would find it necessary to obtain a Katie Becket waiver, thus freeing up slots. Second, it allows families to purchase Medicaid coverage, using a sliding scale based on income, enabling families to meet the needs of their children at home. The investment in subsidized health care coverage falls far short of the financial liability of taking a child into state care, not to mention the profound effects on the life of a child removed from family and community.

The current system of supports and services for children with special health care needs acts as a powerful force against family preservation. It is critical that Connecticut act now to improve the quality of care, enhance services available in the community, demand accountability for existing programs, capture and invest federal revenue, and ensure coordination of services and supports.

Thank you for the opportunity to testify. I would be happy to answer any questions.

---

[2] Katie Becket is a Medicaid waiver program that pays for the cost of care provided in the home for persons who would otherwise be institutionalized.

[3] The Medicaid buy-in option under the Family Opportunity Act allows families of children with disabilities to purchase Medicaid coverage for such children. There are no income limits on this option, although the federal government will only match Medicaid expenditures for families whose income is below 300% of the poverty level. A child would need to meet SSI-defined criteria for disability. Parents are required to participate in employer-sponsored health insurance when available and where the employer pays at least 50% of the premium. A uniform sliding scale Medicaid premium would be established by the state based upon family income with parameters: no more than 5% of family income where income is less than 200% of poverty level and no more than 7.5% of family income where family income is greater than 200% of the poverty level. States may opt to reduce Medicaid premiums to reflect premiums paid on employer-sponsored insurance. The state may also pay the employer-sponsored insurance premium and/or waive the Medicaid premium where "undue hardship" is noted. The buy-in option affords a flexible use of Medicaid coverage as a supplement to underinsured families and gives children access to comprehensive health care in a home setting. There is a 50% federal match.