



# STATE OF CONNECTICUT

OFFICE OF PROTECTION AND ADVOCACY FOR  
PERSONS WITH DISABILITIES  
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Testimony of the Office of Protection and Advocacy for Persons with Disabilities  
Before the Children's Committee  
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Good morning and thank you for this opportunity to comment on two of the bills on your agenda today. The first of these is **Raised Bill No. 1324, AN ACT CONCERNING HEALTH CARE ACCESS, QUALITY AND FAMILY SUPPORT FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS**. This bill fleshes out the concepts presented in Proposed Bill No. 331, which the Committee reviewed at its February 6, 2007 hearing. In essence, it would transform the functions and structure of the State's existing Family Support Council into a Special Health Care Needs Partnership, complete with an Oversight Council and Family Support Network. The Partnership would be charged with coordinating health care services for children with significant health care needs so as to improve quality, accessibility and accountability of those services, and to ensure that they are delivered in ways that are genuinely relevant to family needs. Guidance for the Partnership would be provided by the Oversight Council, which would be made up of agency representatives, legislators, and family members. The family representatives (or advocates) would comprise a majority of the Council membership, and one of them would serve as co-chair along with one of the legislators. Importantly, the Family Support Network, which is a wonderful outgrowth of the existing Family Support Council but is not currently recognized in Statute, would be formally recognized and made permanent.

A little history might illustrate why this proposed Partnership is needed. In 1994, our Office enthusiastically joined with several other advocacy groups to support legislation establishing the Connecticut Family Support Council. The original goal was to improve the "family friendliness" with which various agencies implemented programs that benefited children with significant needs. We recognized that all children, including children with significant disabilities, had a right to grow up as members of a family. But, we also saw that too often families had tremendous difficulty accessing and navigating through service delivery systems - difficulty that contributed significantly to the family's stress level, and sometimes resulted in families falling apart. In the 12 years since it was established, the Family Support Council has highlighted a number of issues and problems for policymakers, has co-sponsored several influential "think tank" initiatives, conducted surveys, produced useful reports, and has been a significant catalyst for change. One of its most significant contributions has been the development of a Family Support Network which is comprised of regional family groups, led by part-time parent coordinators. The network directly advises and assists families to find resources, solve individual problems and become active in efforts to speak out and improve things for their children.

So if it is so wonderful, why change it? Well, despite the reports, recommendations and family-to family guidance, many of the same frustrations that originally led to creation of the Family Support Council still persist - too many families raising children with significant health care needs still report that services and programs that are supposed to help their children are fragmented, difficult to access and filled with Catch-22 dilemmas. Every time our Office holds a public forum to get input on our priorities, several new parents come forward and relate their experiences of groping for help - which they may or may not have ultimately obtained from the particular agency or program to which they had applied. But, their consistent complaint is that they were never informed about some of the other programs that they later discovered, usually on their own, could also have helped. Twelve years of talking about the need for better coordination hasn't changed the realities facing these families. These families are trying to do the right thing - to raise their kids with disabilities as members of their families and communities. Instead of doing the human service shuffle, we should do a better job of helping them. The problem is one of coordination, but the central issue is accountability. This proposal would create some real oversight of what will, absent that oversight, likely remain a fragmented, wasteful system of disconnected programs administered by different agencies, each of which has its own, usually different priorities.

Its time for the next evolution in family support. This proposal would increase the strength of family voices advocating for better coordination of services, improve accountability, and formally recognize the value of the Family Support Network in educating and advising families that are raising kids with special health care needs.

I urge you to pursue this proposal and to develop and adopt the comprehensive legislation it contemplates.

The next bill I would like to comment on is **Raised Bill No. 7141, AN ACT CONCERNING HEALTH CARE ACCESS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS THROUGH THE FAMILY OPPORTUNITY ACT AND THE CHILDREN'S HEALTH INSURANCE PLAN WAIVER**. This bill would direct DSS to make modifications to the State's Medicaid plan in order to: 1) Take advantage of the recently enacted federal Family Opportunity Act, which provides for a sliding scale Medicaid buy-in program for children whose family incomes exceed usual eligibility limits; and, 2) to apply for a waiver that would allow coverage for certain in-home services under the HUSKY Plus program.

This promising proposal is rooted in the grim financial realities facing families raising children with significant health care needs. By definition, these children have greater needs for health care and rehabilitation services than do typically developing children. The higher levels of need often translates into a very considerable demand on the financial resources of their families, often to the point of where the family lives on the brink of bankruptcy, with more than a few actually crossing into that territory. Although one might assume that families that have health insurance coverage through their employers' plans are in somewhat better shape, these days there are so many limitations in coverage, deductibles and exclusions associated with health insurance plans, that even these families are also continually facing major financial demands. One result is

that some families operating at the lower ends of the income spectrum choose to limit their incomes in order not to lose their eligibility for Medicaid; others simply collapse under the weight of fiscal pressure, and their children may wind up being placed into State custody.

The Family Opportunity Act follows a highly successful approach established for workers with disabilities who, like these families, faced significant costs associated with their higher need for health care along with extreme difficulty finding and paying for private insurance that covered the types of services they most needed. The solution was a sliding-scale Medicaid buy-in program. That program removed a major disincentive that had kept many people with disabilities from pursuing employment: the prospect of losing Medicaid health insurance coverage. And, just as that program is paying dividends by enabling many adults with disabilities to become productive, tax-paying workers, the Medicaid buy-in permitted under the Family Opportunity Act would benefit families raising children with significant health care needs, and, at the same time, serve the State's long term policy interests. Families would experience better access to relevant health care services, and could increase their incomes up to 300 % of the federal poverty level without jeopardizing their health insurance coverage. The State would also reap benefits because kids with good coverage stay healthier, hospitals and providers would get paid (reducing uncompensated care), and families that can pay their bills and earn more income experience less stress and are more likely to stay together and be able to raise their children by themselves. It's a win-win that is well worth pursuing.

The other provision of the bill is also important. Most in-home services - the kind of routine health care services that are most needed by kids with significant health care needs - are not available to Husky-B participants. Because this limitation is a function of federal law, the state would need to seek a waiver in order to provide these services.

I thank you for your attention and urge you to support these measures. If there are any questions, I will try to answer them.