

Testimony of Karen Zrenda, CT FAMILY SUPPORT COUNCIL
5 Dogwood Dr., Old Lyme, CT 06371 (860) 271-3808
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Government Administration and Elections Committee

Commenting on:

**H. B. No. 6375 AN ACT CONCERNING REVIEW AND TERMINATION OF CERTAIN
BOARDS AND COMMISSIONS.**

**S. B. No. 839 AN ACT CONCERNING MERGERS AND CONSOLIDATIONS OF VARIOUS
STATE AGENCIES.**

**S. B. No. 840 AN ACT CONCERNING THE ELIMINATION OF THE OFFICE OF CONSUMER
COUNSEL, THE OFFICE OF THE HEALTHCARE ADVOCATE, THE OFFICE OF
OMBUDSMAN FOR PROPERTY RIGHTS AND CERTAIN LEGISLATIVE COMMISSIONS**

Senator Slossberg, Representative Spallone and esteemed members of the Government Administration and Elections Committee. Thank you for the opportunity to give testimony today the very important proposed bills named above. My name is Karen Zrenda and I am a governor-appointed parent member and co-chair of the Connecticut Family Support Council.

H.B. No. 6375 would eliminate the **Connecticut Family Support Council** as an unnecessary and obsolete entity. I disagree. Over the years without the benefit of a budget allocation since its inception, the Council has become a major state resource to state lawmakers, families raising children with disabilities and many state agencies that struggle to determine how best to support families. The Family Support Council has steadily improved the knowledge and understanding among lawmakers of what families raising children with disabilities and complex medical conditions are experiencing. The FSC has partnered with state agencies and the legislature to identify gaps in services and have proposed and advocated for solutions. For example, several years ago members of the FSC applied for and were granted federal grant funds to create a network across the state to provide information, support and education to Connecticut families caring for a child with special health care needs. This network still exists today and operates six regional networks across the state – assisting hundreds of families to access and navigate across systems including health care, education, and communities. The Family Support Council is made up of family members of children with special health care needs and disabilities and state agencies and is an unparalleled resource in our state, not only to families but to the state agencies. I urge you to **preserve the Family Support Council** as a necessary and far from obsolete state entity.

S. B. 840, the **Commission on Children** would be eliminated. Please do not support this. The Commission is a member of the Family Support Council and has been a very active and dedicated resource for the work we do. For example, last year they sponsored a phenomenal forum here at the LOB on bullying – drawing over 250 people. Most recently, they sponsored the forum on the Federal Stimulus Package and its possible affects on issues directly related to children and families. There is no other resource like the Commission on Children in this state. Their ability to conduct rapid and thorough research keeps Connecticut's citizens and it government informed about the circumstances of children and families as well as cutting edge solutions to problems families face. The Commission on Children has provided significant resources on poverty, obesity, violence and health care when those issues were only starting to be recognized for the problems they represent in children's lives. I do appreciate that we are in very difficult economic times, but these are the times that children are most at risk, especially children with disabilities or complex medical conditions. Losing the Commission on Children would represent a loss of a critical resources and CT's ability to access a great many other resources we can not do without at this time. I urge you to **preserve the Commission on Children**.

S. B. No. 839 and S. B. No. 840 eliminate the **Offices of the Child Advocate and the Health Care Advocate**. Both of those agencies have been dedicated partners with the Family Support Council. In addition to the work they have done for individual families in need of assistance, like the Commission on Children their staff have been remarkably helpful to our members in carrying out our mission. They provide up-to-date information about state and federal policy and help us tremendously translating information directly to families. At our most recent meeting of the Family Support Council, a Network coordinator expressed the fear that if the Health Care Advocate of Child Advocate were to be eliminated, she would not have anyone to call for help with these families. It is crucial that these agencies remain viable and available to families, that they remain independent to ensure their ability to maintain objectivity and freedom to examine complaints when children are not served as they should be. Furthermore, these two agencies do their work with a great deal of expertise, not only in the fields of child welfare, juvenile justice and health care and but also in the laws, ethics and standards that drive those fields and in the investigational techniques required to get fair and accurate accounting of the facts. Children with disabilities or complex medical conditions are at great risk for neglect from public systems.

Families of children with disabilities and chronic health care needs have extraordinary challenges in obtaining the health care and services and providers needed for their children. Their hope often comes in the way of having a place to turn when the systems fail them time and time again. Those places – in Connecticut – are usually the Office of the Health Care Advocate or the Office of the Child Advocate. Families are not turned away; they listen, they advocate and get the responses that no other agency can do for us.

I work in a children's hospital that deals with the most complex situations; staff and families both know intimately of these two state entities because of the success families have experienced in maximizing insurance benefits and the expertise and professionalism we encounter when dealing with the **Child Advocate's office and the Health Care Advocates office**. Eliminating these organizations will result in more children living in institutions; more children going without their needed medications and therapies; more children placed in foster care; more families resorting to bankruptcy and divorce to get what their children need. This would be a huge step backwards in our state. **Please preserve** these two vital resources as well as their independence to advocate for children and families.

I certainly appreciate the grave challenge before you but I believe you'll find the Family Support Council – which has no budget allocation, the Commission on Children, the Office of the Child Advocate and the Office of the Health Care Advocate are all agencies that cost the state little and represent significant resources and in the big picture, savings for the state of Connecticut. Thank you for your time and attention.