

Testimony of Lisa Sheppard, Fairfield, CT  
Monday March 16, 2009  
Before the  
Government Administration and Elections Committee  
Commenting on:

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

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

Good morning, Senator Slossberg, Representative Spallone and esteemed members of the Government Administration and Elections Committee. Thank you for the opportunity to give testimony today on some very important proposed bills. My name is Lisa Sheppard and I represent the Connecticut Family Support Network and am part of the CT Family Support Council, I cover and work with families who have children w/ Special Health Care Needs in all of Fairfield County. I am also the parent of a child with a special health care needs. His name is Blake, and he is 11 years old and he has life threatening conditions, autism and seizures. He is my hero and why I do the work that I do today.

H.B. No. 6375 would eliminate the Connecticut Family Support Council as an unnecessary and obsolete entity. I am here to tell you that the Family Support Council is anything but unnecessary or obsolete. The Council has become a major state resource to state lawmakers, families and many state agencies that are otherwise at a loss to determine how best to support families. Since it's inception it is the only state entity with every agency at the table and it is completely non-funded and bipartisan. 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. We have identified shortcomings in state systems, the insurance industry and health care services. We have also developed dynamic remedies for many of those solutions. For example, Council members collaborated to establish a coordinated network across the state to provide information, support and education to Connecticut families caring for a child with special health care needs. Today that network, the Family Support Network, employs six coordinators in six regions around our state serving hundreds of families each year as well as supporting and guiding the case work of the Departments of Children and Families, Developmental Services, Public Health and Social Services. I am one of those coordinators and I service the South West Region of our state. I urge you to preserve the Family Support Council as a necessary state entity that services both family and state.

Also in H.B. No. 6375 the Commission on Children would be eliminated. The Commission is a member of the Family Support Council and has been a very active and dedicated resource for the work we do. There is no other resource like the Commission on Children in the state. Their ability to conduct rapid and thorough research keeps all of Connecticut 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 bullying, obesity, violence and health care when those issues were only starting to be recognized for the problems they represent in children's lives. Losing the Commission on Children would not represent a savings in the budget. It would represent a loss of a critical resource and a connection to a great many other resources we can not do without at this time. I urge you to preserve the Commission on Children.

Next I would like to turn your attention to S. B. No. 839 and S. B. No. 840, specifically in the proposal to 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. The Family Support Network regional coordinators are reporting record numbers of calls for assistance in dealing with health insurance claims or unresponsive state services. At the March 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 most importantly 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 caregivers and public systems. Most people intend to be helpful but we find over and over again that they either just do not understand children with special health care needs or they are at a loss themselves for lack of resources to offer. Subsequently, families find themselves in dire circumstances and only the independent Advocates have the access and authority to bring people together to work out solutions. I urge you to preserve the Office of the Child Advocate and the Health Care Advocate.

For the families I work with including my own little guy it takes a team approach to solving the complicated issues that these families face on a day-to-day basis. Which is why it is so important to keep intact these agencies and commissions. I would urge you to come and meet with the Family Support Council and use these very knowledgeable and talented people to keep you informed on the challenges that your families are going through and ask the questions you need to get answers to before you have to make these hard decisions in the upcoming weeks. In this very challenging time you need to know that when a family gets the devastating diagnosis of a life long disability for their child they go into a financial recession the likes that you have never seen. What we are facing in today's economy is a way of life for families with children who have medical needs...there is no stimulus package for them. When my son was diagnosed I lost my entire life savings caring for his needs and our lives changed forever. I rely on the various agencies, committees and councils I have spoken about today to help me navigate Connecticut's very complicated systems. And, I utilize each to help parents work together for the benefit of their children. And, I choose to work in this field because I didn't want new families who have children with disabilities to go through what I did.

I thank you for your time and attention. I certainly appreciate the grave challenge before you but I promise you that the Family Support Council, 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 even savings for the state of Connecticut.