

Monday, March 16, 2006

Testimony Before the Government Administration & Elections Committee

**HB 6375** AN ACT CONCERNING REVIEW AND TERMINATION OF CERTAIN BOARDS AND COMMISSIONS

**SB 839** AN ACT CONCERNING MERGERS AND CONSOLIDATIONS OF VARIOUS STATE AGENCIES

**SB 840** AN ACT CONCERNING THE ELIMINATION OF CONSUMER COUNCIL, THE OFFICE OF THE HEALTHCARE ADVOCATE, THE OFFICE OF OMBUDSMAN FOR PROPERTY RIGHTS AND CERTAIN LEGISLATION COMMISSIONS

Good Morning, Senator Slossberg, Representative Spallone and esteemed members of the Government Administration & Elections Committee,

Thank you for the opportunity to submit testimony on some very important proposed bills.

My name is Alice B. Buttwell. I am a resident of New Milford, CT. I am a parent and guardian of a 20-year old son with multiple, complex special health care needs. I work for the Family Support Network as the Northwest Coordinator. I am also employed as a Family Support Consultant with the Northwest Medical Home Initiative for Children and Adolescents with Special Care Needs/St. Mary's Hospital.

**I am writing to you that I am strongly against any proposal to shut down the Office of the Healthcare Advocate.** On a personal basis, the Office of the Healthcare Advocate (OHA) helped me with a very complex dental situation for my son who had been placed out-of-state by Dept. of Children & Families (DCF). The OHA helped me navigate quickly and smoothly a few times through working with Dept. of Social Services staff, the insurance carrier and the numerous complexities with New Hampshire providers in getting Medicaid pre-approval for my son, and for trying to work with DCF and my son's former appointed guardian. Their expertise helped to save costly dental bills, as well as keep on a timely

schedule in getting long overdue evaluation and dental work done that had been ignored by others responsible for his care. Their office is a small staff who are diligent, professional, compassionate and timely for all the workload they handle across the entire state who work tirelessly to help children and families. On a professional basis, I have referred parents of children with special care needs with multiple, complex insurance issues to the Office of the Healthcare Advocate. And all have shared the same recognition and respect for the work that all the staff in the Office of the Healthcare do for CT citizens. I urge you to keep in mind that parents and caregivers of children with disabilities of all ages from birth throughout a lifespan need the help, support, knowledge compassion and expertise of each staff in this office. Caregivers many times don't have the time, energy, stamina to deal with nor no how to handle complex situations and mechanisms of insurance carriers. Most spend their time dealing with necessary and direct care of their loved one on a full-time basis with little to no time nor respite for themselves. Many primary caretakers are unemployed or underemployed, and the ones who are working full-time struggle to take care of their own basic needs in addition to their family member and others in the family. With that said, their child, no matter how old, will require throughout each lifespan the ability to deal with medical and dental issues with insurance companies, many times with life-threatening or preventative complicated situations.

The parents/caregivers are exhausted, stretched to the limit with caregiving, short-term & long-term self-education, training, learning, actively involved in ongoing new associated arenas related to raising and caring for their child/ren each on **an individualized basis directly related to each child that continues to change, many times not routine**, navigating through a very complex system of care in medical, education, personal, community matters on specific & general information, rights, laws, special education, therapies, medical appointments, medication management, etc. all with little to no respite or relief, and many who have other children, or no other family or as a single parent. Or with the onset or ongoing care of an older or an elder family member who is in another stage of life where caregivers may have to deal with more grieving or newer onset of disorders, sometimes barely able to navigate through complicated and forever changing systems and policies and procedures in the insurance arenas from a longer time or greater intense management of direct caregiving, some in addition to other major life responsibilities. It has been said that there are 30% of CT

caregivers who are unemployed or underemployed and stating here again, many are primary, full-time caregivers, whether or not they are employed, underemployed or unemployed. So their time is priceless and limiting with unpredictable and changing priorities each and every day with little help or relief over and above their caregiving responsibilities. Paperwork alone can be voluminous to read, file or take action related to complexities of the medical field in dealing with sensitive and critical matters in the ever-changing policies, procedures, laws, rights and ambiguities of language in health insurance matters. **That is why we have the expertise of each individual at the Office of the Healthcare Advocate who can step in, evaluate each individual's situation, and help deal on behalf of each family, in a professional, objective, timely and expert manner in such complex preventative, life-threatening, new or ongoing medical matter that needs a professional team to resolve and troubleshoot objectively. In addition they most likely also have more resources than the family involved in such a healthcare matter that requires such a specialized, legal healthcare advocate.** Please urge the Governor to keep our Office of Healthcare Advocate. They have done an outstanding job in our state on behalf of vulnerable people from all walks of life with troubleshooting complicated medical and dental insurance issues and concerns. This Office has not only been cost-effective and cost-efficient in its own right as a state agency, it has saved time, money, healthcare and lives of numerous vulnerable citizens in CT who NEED this assistance and advocacy where it is necessary in helping them as a caregiver in the prevention and treatment of their own family member as well, while also making their lives a little to a lot less stressful and more productive, including giving them a gift of a little more time - that is so precious living as a primary unpaid caregiver in this state with little supports or services in their homes.

I'd like to turn now to the Commission on Children who serves on our CT Family Support Council (CTFSC).

I am **STRONGLY OPPOSED** to closing The Commission on Children (COC). COC has served on the CTFSC and is a vital link of support and collaboration with our Council on the work we do to help children with special healthcare needs and their families.

As a unique agency since 1985, COC brings representatives of the three legislative, executive and judicial government branches together with representatives of the private sector to promote public policies in the best interests of all children. A few of their numerous initiatives that are all about children helped to promote and

strengthen the father's role in the family unit with their child/ren and that of the grandparent's role in absence of the parent/s.

And all of these initiatives lend itself to outreach in all communities across the state for the parents, fathers and grandparents who cannot make it to the LOB but can share and be included by being able to view all of these humanistic and educational programs on television or viewing CT-N, letting these families know that they are not alone and that this is what they can do in parent engagement to help their children or learn and educate themselves on what programs are out there for their children. All of these programs help to increase and promote awareness on various topics to parents in the best interest of their child/ren. It also gives them the opportunity to share and give back when they are able, and participate more positively in the lives of the children.

COC's legislative agenda focuses on improving basic services for children and their families while also reducing unnecessary expenditures and streamlining procedures in these difficult times. Continued dedication and commitment of their high-quality, diversified staff are in constant visibility by their research, policy, presence, and work in the testimonies that they bring to the legislative hearings, proactive forums, and all the preventative and active engagement programs on behalf of children. Their website ([www.cga.ct.gov/coc/](http://www.cga.ct.gov/coc/)) is truly a testimonial to their history of all that COC staff has done, and continues to do, to work in the best interests of our children. It should **NOT** go unnoticed but instead **read and reviewed** for all of the specific topics they proactively engage in on policy and legislation, health & safety, education, and parent engagement.

On behalf of all of our children and their families in CT, please **do NOT** close the CT Commission on Children but instead keep it in operation to continue in all the necessary work that it does.

Respectfully submitted,

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