

Testimony of Mona Tremblay, Parent of twin sons with a diagnosis of autism, CT Family Support Network Northeast Regional Coordinator, Family-to-Family Health Information Specialist-NE and Regional Medical Home Initiative Coordinator-NE

Monday, March 16, 2009

Government Administrations 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 Administrations and Elections Committee. Thank you for taking public testimony today, on several proposed bills which will negatively impact families like mine, and those I attempt to support.

I am in my 8th year of professional child and family advocacy; specifically on behalf of children with disabilities and/or special health care needs, and their families. Having nearly 30 years of experience working in the field of developmental disabilities, as well as “living the life,” with my twin sons, both diagnosed with autism, I am nothing if passionate about the population of children and families I speak for today. Like the “Hair Club for Men,” commercial, I am not just a CEO, but I’m also a customer!

The bills before you, if passed, will either enable or disable CT’s most vulnerable and disempowered constituent families. Your charge is enormously serious and your deliberations so incredibly important to real children and real families, living with “larger than life,” unthinkable challenges. In an economy which presents a struggle for the “typical, average American family,” try to imagine coupling the dire economic state of affairs, with tending to the unrelenting needs of children who require an inordinate amount of special care and constant attention. In a, day by day, oftentimes hour by hour, continuum of phone calls, necessary medical appointments, therapies, insurance disparities, educational insufficiencies, and a litany of social injustices, these children and families dealing with life-long special health care needs and disabilities, need help and hope in navigating a frightening world of service delivery; and that’s on a good day.

My personal, biggest frustration comes when a family contacts me, needing specialized programs or services that don’t exist. Where are these families to turn? You see; I have been there. In truth, it is only because of a once “innovative”, DDS Home and Community-Based Waiver, that I am in a position to work outside the home and support my sons, in our home, within our community. Prior to that, I could barely get through the day, let alone provide important testimony to the CT Legislature. Now I have time to “pay it forward,” by carefully and respectfully listening to the

personal stories of parents who are all but broken, and who have no idea where to begin in locating appropriate programs and services for their children.

For nearly the past decade, The CT Family Support Council (slated for termination in H.B. No. 6375) and a parent staff of statewide Network Coordinators, have worked tirelessly to take these concerns from the kitchen table to the policy table. Most of us take calls daily; oftentimes in the evening or on weekends, to accommodate parents' overburdened schedules. We advise; often based on experience, we share what we know to be true, we inform parents about available programs, and most importantly; we listen. We take our charge incredibly seriously, and thankfully, we are not alone in our crusade. We come together monthly, partnering with all the critical agencies and commissions responsible for meeting the needs of our specially challenged families. We work as a team as we try to unravel current barriers for families. We are sensitive to individual needs as well as disturbing gaps or trends, and I am happy to report: the partnership works.

We are undeniably stronger and more successful every year because of our collaboration with key professional partners which include The Commission on Children (also in jeopardy with the passage of the same bill, as well as S.B. No. 840). This faithful and long-standing partner at the advocacy and policy table, provides us with legal expertise, uncompromising diligence, creative problem solving, and years of collective experience in advocating for all children. The Office of the Healthcare Advocate (S.B. No. 840), and The Office of the Child Advocate (S.B. No. 839) have contributed incalculable policy expertise, heartfelt partnership, critical advice and support, a passion for justice, and a tenacity of spirit and collaboration, that I propose, is unparalleled in the majority of similar "agents of change," in this country. Each of these entities slated for elimination is responsive to a fault, and collectively, we brainstorm ideas; often thinking "outside the box." We will not waver in our determination; always searching for answers that will be responsive to meet the growing needs of literally hundreds of families, one family at a time.

So having said all of this, how will you proceed in these difficult deliberations in the days and weeks ahead? If I have done my job well, you will know and understand that all of the aforementioned entities slated for elimination, are anything but dispensable. Do we provide functions and services that are obsolete? Hardly. Do we recognize the indomitable challenges you face, in balancing an impossible State Budget? Completely.

Thank you for this time and attention on one of many long days during this busy legislative session. May you, your families, and loved ones, experience good health always, and may your policy decisions and voting privileges concerning those not as fortunate, reflect the compassion, decency, and integrity that placed you in the honorable seats from which govern. May God bless you all.

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