Appropriations Committee Testimony on H.B. 5044
Marina Derman, Westport

Senator Bye, Representative Walker, and members of the Appropriations Committee – I thank you for making time today to hear our concerns. I am here today **in opposition to bill H.B. 5044**, because of the inadequate budget for DDS, particularly in the area of Community Residential Services.

My husband and I have two sons, both of whom have autism and intellectual disabilities.

Today I'll talk about my son Kyle, who is 22. Like many students with autism, he spent time in Birth-To-Three, then eighteen years in the school system, about ten of those years outplaced by our school district to costly private special education schools. All of that support, and his hard work, allowed him to progress enough to attend the Chapel Haven School, a residential school in New Haven which teaches people with disabilities the life skills they need to live independently in the community. Already he is doing things that we never thought he would do – taking care of his own apartment, working at several jobs, independently navigating the New Haven bus system and the Metro North train system, budgeting his own money and shopping for his own food, and, on a Friday night getting a pizza with some of his friends. These are miracles, and they are only possible because of the sum of the years of systematic teaching, starting in Birth-to-Three all the way to Chapel Haven. Now he has a life with dignity.

Now, Kyle has one more year at Chapel Haven . . . and then what will happen? Because of the DDS funding crisis, Kyle, even as a Priority 1 on the Residential Waiting List, has little hope of receiving a residential placement. Do we waste 20 years of skill-building and growth, only to throw it all away and have him move back into our house? Will he give up a life of dignity and self-sufficiency, and return to a child-like existence in his parents' home? I say that if Kyle graduates from Chapel Haven, and then *through lack of residential funding* has to come home to his parents' house in the suburbs of Westport – that would be <u>unconscionable</u>. It would do Kyle a disservice – Kyle, who spent years learning to function as an independent member of society. And it would do a disservice to the taxpayers of CT, who invested in his education all along the way, only to see it thrown away at the end.

My story is not unique. The Residential Waiting List continues to stagnate at about 2,000 people, with priority going to emergencies and with no funding available beyond that. Families endure year after year – all of us getting older, and faced with the stated DDS policy that our child's only hope of getting a residential placement is for us to die.

The budget cuts to DDS, which total $60 million since 2012, with another $59 million proposed in the current budget bill, have left services reduced in <u>all</u> areas.

Now, there is also a waiting list for Day services. There is a waiting list to get into BSP (Behavioral Support Program – formerly VSP), the program that serves the most behaviorally challenging of our children. There, families are in crisis with children who are aggressive and self-injurious, and the door has been closed to their entering the program that could help them. Respite services have been cut. And this year's new graduates already have planned delays built into the start of their services.

This is a desperate situation for our families. I heard the Governor speak last week at a Town Hall, and his general response to people asking for funding to be preserved was, "Do you want your taxes raised? No? Well, in the absence of a revenue source, I have to cut. Shared sacrifice." I argue that our population has sacrificed enough. This is a matter of setting priorities – and making sure that less essential efforts are set aside in order to take care of our vulnerable citizens, who have no other options to take care of themselves.