

Appropriations Committee Testimony on S.B. 294
Marina Derman, Westport

Senator Gerratana, Representative Ritter, and members of the Public Health Committee – I thank you for making time today to hear us. I am here today **in support of bill S.B 294**, but would like to recommend some modifications.

My husband and I have two sons, both of whom have autism and intellectual disabilities. One of my sons is lucky enough to be placed in a group home, but the other is a Priority 1 on the residential waiting list. So I here today before you, know something about this problem and caring deeply about it.

Before talking about the bill, let me tell you something about special needs families. We are a terrible constituency. Our children are exhausting. Some of us literally cannot get out of the house. Others of us spend every free moment driving our kids to speech therapy, social skills therapy, occupational therapy, physical therapy . . . the list goes on and on. For some, even a bit of free time must be used taking care of their own needs, and they can't manage to drive to Hartford. Some of us have children who are violent, aggressive, and self-injurious. We are so buried in the challenges of our own lives, that it is hard to put our heads up and know that these legislative changes are even occurring. And some of us have trouble getting caregivers who can step in and give us a break. So for all of these reasons, the very people who most desperately need this bill are those who are unable to come to here to speak to you. So please, hear me and know that I'm speaking for my friend Nancy, and Valerie, and Lori, and Avery back home, who aren't able to be here for a whole day, as much as they would if they could.

On to the bill itself – this bill is a vital first step in solving the problem of the DDS waiting lists – the residential waiting list (which has been around for years) and the newer waiting list for day services, for in-home supports, for respite, and to

get into the BSP (formerly VSP) program. There are those who say we don't need a bill like this. I say, how can you solve a problem if you haven't analyzed it?

The information DDS currently has on the needs of its families is outdated and inaccurate. We speak to families every day who have never been asked whether they want to put their child on the residential waiting list. And we know that some families who were offered residential placements several years back actually wanted in-home supports, rather than an actual out-of-home placement.

So the first step to understanding the actual needs would be a census of all families – easily done since there is an annual Individual Planning (IP) meeting. Find out what their needs are, and what the timing is of those needs. And then update this list annually, because things change – our kids change, our situations as caregivers change.

Please consider the following suggestions for amendments to this bill:

1. Consider each waiting list as its own entity. The residential waiting list is one list (not broken into the “waiting list” and “planning list” as it is now). The list for in-home supports and services is a list. The waiting list for day programs is a list
2. As I mentioned, update this analysis annually.
3. Please consider including wording so that family members can be more informed about the status of their loved one on the waiting list(s), and the process (including PRAT reviews and LON paperwork) that led to that status.

Thank you again for considering this important bill.

