

Thank you to the Public Health Committee for hearing our thoughts on Senate Bill 294 today.

I am a parent and grandparent and have been up here in Hartford testifying for 3 years now. My husband and I are the custodial grandparents of Matthew, a wonderful 25-year old young man with intellectual and developmental disabilities. He has been waiting and continues to wait for residential placement and a home with his peers. As pointed out to other legislators, the caregivers will soon need caregivers.

I want to wholeheartedly thank all the legislators who have been so patient with us as we try to explain what our life is like to them. Thank you to Sen. Bye, Rep. Hampton, Rep Case and all the members of the ID Caucus who have fought so hard to bring our loved ones out of the shadows. Sen. Fasano, Rep. Staneski, Rep. Ferraro, Rep. Demicco, Rep. Betts, Rep. Srinivasan, and many others have been meeting with us in true bi-partisanship to help us formulate a foundation for our work in the future. , Bill 294 is a result of this effort and it is a good beginning. I would like to suggest several amendments to this bill that would serve as a solid foundation for moving forward.

First, and foremost, for 3 years we have been here in Hartford talking about the infamous "Wait List". Section 1, Part 3 of this bill talks about this list, or these lists. In order for the Wait List

to be a viable tool in beginning to formulate a plan to help our loved ones, the numbers have to be validated. The Wait List as it stands now is inaccurate and the numbers old. There are people on the list who do not want residential placements, and there are people on the list who are designated Priority 2 or 3 who want/need residential placements now. There is confusion as to who should be on the "Wait List" and what the "Wait List" is for. In order for any future work to be accomplished, we need a census taken to establish a baseline. How can anything be appropriated and a plan made if you don't know who or how many are being planned for? Every DDS client has a caseworker. Caseworkers should be doing a census to establish correct numbers. There is no fiscal note to this bill, as caseworkers have to be, and should be, in touch with their clients at least once a year. A census is needed, and would build an accurate foundation to move forward.

The Residential "Wait List" and Day Services are not the same thing. The "Wait List" should consist of all people who want/need residential placement and the Priority Status is a means of showing how soon a person needs/wants placement. Priority Status relates only to a person's status on the "Wait List."

A person should not be taken off the "Wait List" or put on another list if they accept day services as a band aid until

residential placement occurs. This point has become very confusing with mixed messages given from DDS about this practice.

Requiring DDS to update this list every 3 years will not maintain an accurate picture of the ID Community. New York has recently proposed a bill that would require updates every 6 months.

We ask that Section 3 be stricken from this bill unless and until the meaning and ramifications can be ascertained.

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