

My name is Peggy Embardo. I am here today to speak in support of HB 5534, An Act Concerning the Provision of Services to Individuals with Intellectual Disabilities, because I believe it will make a difference in my son's life, my life, and the lives of families like mine. I am the mother of a 25 year old son who was diagnosed with autism at age 2. Robert is a sweet, loving big teddy bear of a person and I love him more than life itself. I am proud of him, and if you meet me in the supermarket I will tell you how well he's doing, and how much he's able to do. But that's a mother's love talking. The other side of the picture is darker. My 6 foot, 320 pound son can only speak a few words and you wouldn't understand what he meant if he said them to you. His communications skills are limited at best. He knows how to do some tasks at home, but if asked to do them with different words than he is used to, he looks at you blankly, because he doesn't understand, although he really wants to help. I won't leave him alone in the house, because he doesn't have the judgment skills to make the right decisions in an emergency. He loves to eat, and doesn't know there are times to stop. He doesn't know how to cook or use the microwave.

In short, he inhabits the body of a man, but his skills come a lot closer to toddler level. And like a toddler, he needs supervision, all of the time. He needs to live with people who know his limitations and who always have an ear alert to any signs of trouble. He needs to be given snacks of fruit instead of potato chips. He needs his meals prepared. He needs help with shaving and needs to be told to get out of the shower. He needs to live in a place where this kind of supervision is always available to him.

When he was little, when I first contacted what was then known as DMR, I was told that when he was grown, he would be transitioned from his family home to a group home, where he would spend his adult life. That was a scary thought for us when he was 6. But we had no idea that the future would actually be much scarier. Because the future is now. DMR has become DDS and DDS has been telling families like mine that there is virtually no chance that our children will have a place to live outside our homes until we die. The message isn't delivered so bleakly. I hear statements that say traditional ways of care, such as group homes, are obsolete because they limit peoples choice and freedom to live their daily lives the way they see fit. I'm told that technology exists to supervise adults with disabilities so that a person can live alone in his own apartment safely.

But that isn't an option for a person who functions at Robert's level of ability. He needs live people, aware of what he's doing and what he should be doing, every day of his life. He attends respite centers run by DDS and I can see that this living model works really well for him. I would love to transition him to a residence that looks like this. I would love to see him settled.

He gets the supervision he needs living with me. I am glad I've always been able to keep a roof over his head, and that we live like a happy family. But, in reality, he is only one short step away from needing residential care on an emergency basis. His dad died 8 years ago, and he has no siblings. There is no one besides me to take care of him. I'm getting older and while I'm still healthy, any disaster can strike me at any time. I certainly didn't expect my husband to die at 57, but when he did, I realized it could happen to me as well, and then Robert would be sunk. The way the system works today, only if I die will Robert get a residential placement. He'd lose his mother and his home on the same day. He doesn't

have the words to express how this will feel. So I'll say them for him. It is unconscionable that society can allow that to happen to someone so needy.

A society is judged by how it cares for its weakest members. Please support this bill, with its measurable goals to increase residential care options, so that the State of Connecticut will be known for its humanity and compassion for all members of society, not just the successful ones.

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