

Good Afternoon

I am testifying today in response to the 5 year plan which DDS has published. Here is the one line in the 30 page report which I want to address

“As there are more individuals requesting residential supports than appropriations will allow the department to support, DDS maintains a waiting list for these services.”

I want to tell you what those seemingly neutral words actually mean. Robert, my only child, is 27. His diagnosis is autism, and his disabilities resulting from that are severe. He uses single words to express concrete needs (bread, pretzel), has no sense of safety, doesn't realize that sometimes he must stop eating, can't make reasonable food choices. He lives largely in the present, which means that it's really difficult, if not impossible, to change behavior that needs to be changed.

I've read that it takes a village to raise a child. That is especially true with mine. Providing 24 hour support and supervision for an adult is not a job for one person alone. No one has that much energy. I can keep my son safe, and I can keep him happy, but not usually both at the same time.

All families who have children with disabilities are facing challenges they never expected to face. I am eternally grateful that my son did not present his father and me with challenges we couldn't handle, that would have forced the state to provide help to keep us all safe. But now it feels as if we did too good a job. If we had been less able to handle him when he was still a teenager, he might not be living with me today. Now he's grown up, and his father has died, and I'm getting older. I won't always be able to manage him. But even more importantly, I want to see him settled. He's always going to need a high level of supervision. When I'm dead, he isn't going to get some of the cool, high tech specialized placements that DDS is touting as a solution to the residential care problem, because they aren't a solution for him.

He isn't enough of an emergency to get assistance, even though he has been on the waiting list since before his father died 11 years ago. I'm his only caregiver. I can't trust him to cross the street, or handle any household emergency. Caring for him requires the same commitment that caring for a newborn baby demands. But he is 6 feet tall, and I am not the young mother I was once. It is my nightmare to be the little old lady with osteoporosis, barely able to negotiate the supermarket, but being there with my strapping son at my side, asking me for more bagels.

And someday I'm going to die too and there will be no one to care for him except DDS. And they won't know how to care for him because they won't be familiar with him, in spite of my best efforts. Robert deserves better, and so does his peer group—other adults whose disabilities get in the way of them surviving on their own.

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