

My name is Jane Hampton and I have a son who will be 25 this month. His name is Jake and he has both autism and intellectual disability. I am here to support increased appropriations for DDS services, in particular to continue to fund existing needs and add funding to fill unmet needs of hundreds of families.

Jake first got on the waiting list when he was ten years old. I was told if I ever wanted housing I should put him on the waiting list. I was not interested in housing for my child, I was thinking ahead for his future. He's been on the waiting list for 15 years, he started out a Priority 3 and there he remains, despite the needs of a 25 year old man being so much different than the ten year old boy.

Since then, Jake has grown and increased in some of his skills, while others remain significantly delayed. His speech and language improved as did his motor abilities. He walks, talks, breathes, eats, showers on his own. For many this would be viewed as a blessing. But these physical abilities can be a curse when they belong to a young man whose judgment is impaired and threatens his safety. He has in his life gotten up in the middle of the night to use the bathroom, flooded the bathroom and the floor below and went back to bed, he didn't recognize the urgency of doing something or telling someone. Another time he woke up at night and disassembled the new gas adapter for the fireplace, an active gas line taken apart while the family slept. He's opened the door to strangers and invited them into the house, while adults were available to do it, he didn't recognize the danger. Fortunately he sleeps through the night most of the time, but the random nature of these serious events put us at risk at any unpredictable time, and sometimes makes sleep impossible.

I am the primary caregiver and I work 30 hours a week, work is my respite. If I am not at work I have the responsibility of my son, period. DDS provides respite 3 weekends a year. His father will take him a fraction of the time, but has threatened to discontinue this. For some reason, in DDS data collection, my needs don't count, only my age and my ability to not abuse or neglect. Most social service supports are provided based upon the needs of the individual needing the service, not their parent's ability to provide. My only choice right now is to continue to do what I've been doing or abandon him in a hospital. Not much of a life choice. I am willing to work with the department, but even if I can afford to pay his rent, it is his need for adult support that is the costly support.

Jake needs to learn to function as part of a household away from me. My sheer presence creates a need in him to be dependent. I don't foster that, I don't want that, I haven't been able to affect a change in that for his whole life. I firmly believe, however, that with a highly trained residential staff person, Jake's ability to do some things more independently would grow. If the right efforts were spent early in his life, he could probably reduce his dependence upon staff for the long term, result is overall reduction of cost. But as long as he lives with me, this isn't changing. Please, please, please fund the Department of Developmental Disabilities so that they can ascertain the real level of needs of our loved ones and their families and provide for our unmet needs. If we invest the time, money and effort now in creating a system that works for the individuals being served, and the staff that provides for them, our overall cost may be reduced.

Respectfully Submitted,  
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