

Speech to the Joint Committee on Health Care during the September 4, 2008 meeting

Thank you for the opportunity to speak today. My name is Dana Kavanagh and I am a Case Manager with Ability Unleashed. I have been involved with people with Developmental Disabilities and their families for several years, in capacities ranging from close personal relationships to professional. I have worked in roles ranging from Personal Care Attendant in the community for teens that use the DD Waiver to providing telephone and online information & resource support and now as a Case Manager.

The agency I work for, Ability Unleashed has been providing Case Management and Service Facilitation, serving Northern Virginia down into Fredericksburg and Richmond, for 6 years now. I want to address one issue today on behalf of not only the DD Waiver clients Ability Unleashed services, but on behalf of people with Developmental Disabilities and their families waiting for services all over the Commonwealth. That issue is DD Waiver slots.

Before I get into the issue of DD Waiver slots, I want to express, based on Terry Smith's presentation and the questions that came up afterward, that a person cannot even apply for the DD Waiver until they are 5 years and 9 months old. After they apply, are screened and determined to meet the eligibility requirements, they are placed on the Waiting List, where they will wait for an average of 5 years – closer to 6. Why do they wait so long? They wait because of the issue I have come here to discuss – the issue of DD Waiver slot allocation.

The DD Waiver did not receive any slots this year. That's correct – zero. We did ask for them, but we were denied. Over the history of the DD Waiver, precious few slots have been allotted each year, and EVERY year the MR Waiver receives many, many more slots than the DD Waiver. I am not here today to try to compete with the MR Waiver in any way. I am here today to advocate for the people with Developmental Disabilities and their families who have been waiting, and waiting, and waiting for services. And I have to let you know that our clients wait on pins and needles for the news of "how many slots." When I have to tell them that the DD Waiver was allotted ZERO slots this year, of course they say "Well, I saw an email that or I heard from a friend that or I read in the paper that the MR Waiver got 600 slots..Why didn't we get anything? How come those 600 slots couldn't be shared somehow? How is this fair?" I honestly have no answer to give them.

Let me give you an example of someone who recently got the DD Waiver last fall and what it meant to him and his family. He is a 25 year old young man who suffered from a traumatic brain injury at the age of 18 when he was getting ready to go off to college. He now uses a power wheelchair. He requires assistance with everything – eating, bathing, dressing, getting in & out of bed, communication, etc. He has no cognitive impairments; his body just simply will not do what he wants. He lived in a nursing home for 5 years because his family could not provide the type of 24 hour care that he requires. They needed daily personal care support. In addition, his family's home is not accessible in any way for his wheelchair. It takes 3 people to get his wheelchair out of the house with him in it. He can never be left alone. There is no way for him to get out, let alone access a bedroom, take a bath, cook meals and so on. The family would also need a van with a lift on it for his power wheelchair. So this young man stayed in a nursing home and waited. He got a slot last fall. He is now living in his home with his family

with daily personal care support and respite support. The family is now hoping to find providers who will accept the DD Waiver and modify his home.

By contrast, we have another client – a young man who has Autism – who calls our office on a very regular basis. In fact, there are times when he will call every day, sometimes multiple times a day. And that's OK. We understand he's calling out of desperation. He lives with his parents, but he imagines living on his own someday. He wants to be able to get out into the community. He knows that he has to learn to do his own shopping, banking, and manage his own medical appointments and prescriptions. He wants a job, and he wants to enjoy social outings with peers. What does he need from the DD Waiver? He needs a personal care assistant, In-Home Residential Support, supported employment, and a computer – which is Assistive Technology – to help him coordinate and manage his life. This young man has also waited almost 6 years for a slot. But his number didn't come up this year, almost – he is in the top 50 but not quite. So here he is – a young man with hopes, dreams, ability, all kinds of potential and plenty of desire and motivations – sitting, waiting, calling, begging, pleading... "When can it be my turn? When can I get the stuff I need?" When I explain the situation, he says, "Well, can I at least have a computer? Do you think they would at least give me a computer to practice? Can I practice living an independent normal life?"

So I am here today to ask you, when you aware slots from this point forward, PLEASE keep in mind that people with Developmental Disabilities need services, too. They need slots, too. I am asking for the two young men I just described to you – one who finally got a DD Waiver slot and one who still waits. And I am asking for all those they represent who sit and wait, too.

Thank you for this opportunity and for inviting me to speak.