

Chair Keny-Guyer, Vice Chair Sanchez, Vice Chair Olson, members of the committee, my name is Tiffany Russell. My son Joshua has CP and I am his full time caregiver. I have also worked as a Direct Support Provider in a group home for Bethesda for the past 20 years. I would like to share my personal and professional experiences with options for people with disabilities.

### **Options - As a Parent**

I have a son, Josh, who is 27 and has CP and I provide all of his care. In order for Josh to receive benefits we had lived on the \$12/hour I made after 20 years as DSP at a group home. It was a huge struggle for us. I would have to make sure to keep my income low to keep his benefits. I stepped down and got passed over for jobs just so he could keep his social security. When Josh turned 19 we moved to the brokerage system. Over the years we had at least 3 case managers from 2 agencies and received no services for 5 years because no one told us what options we had and we didn't know what we could spend the money on. It was very frustrating. Josh's current case manager, who is wonderful, was shocked that I wasn't getting paid to do Josh's care and within a month I was being paid to care for him, which is the reason he still lives at home. It's not fair that we didn't know we had those options. We were never told I could be paid to provide his care. I don't know why we weren't told from the beginning, but it's definitely changed our lives. Life has changed dramatically since I have started getting paid for his care. Our bills are always paid, Josh gets to keep his SSI money and for the first time ever we have a savings account. In fact, next month we will be buying a wheelchair van. I will let Josh tell you about that.

### **Josh Russell:**

Without the option of receiving care in home, I would have to live in a group home or assisted living. I can do things living at home that I wouldn't be able to do in a group home like picking my own meals and social outings. Those are things I can't do in those settings. I would hate to be forced into a different situation not knowing that receiving care in home is an option.

### **Choice - As a DSP:**

I've had two clients who were recently literally in tears thinking they are going to get kicked out on the street because they received a 30 day notice in the mail

One client who showed me a letter they got that was a 30 day notice from Bethesda. They had no idea it was even coming. No one called them or met them face to face, they had to be told by a letter. They are only told they have to move into another site by that same agency. They weren't even told that they could go to a different agency, or an Adult Foster Home, another group home or supported living. I had a client who was so worried because she thought that she had to move to Hillsboro, because it was so far. They don't know they have options because no one who knows their story is there to explain it to them.

I have another client who has lived in a home for 5 years, and he has a staff person who he doesn't like. She comes into HIS home every single day. He should know that he doesn't have to deal with that if he doesn't want to. He has the right to move wherever he wants to move, or live with his family if he knew that was an option. If their families knew they could get paid for their care, then what kind of options would that open up? Instead he lived in 17 different foster care homes over three years. These clients have to interview their own foster care homes if they want to move. They have nobody to help them.

Someone, from the moment they got that letter should have said "we may not have the answer, but these are your options...you can live at home, you can live in a group home, you can live in foster care or you can live on your own in supported living" because that's less scary. And they need somebody to guide them through the process.

Not knowing your options is the same as not having any.