

Testimony of Bonnie Miller

before the National Council on Disability

Congressional Forum: “Disability in the Budget: Why It Matters”

Good afternoon. I would like to thank Jonathan Young, Chairman of the National Council On Disability, Council Members, and the House of Representatives for allowing use of this hearing room and for the opportunity to speak with you today regarding home and community-based services and how they have made a difference in my daughter’s life and mine.

My daughter, Karrie, is a wonderful young woman who 35 years ago was diagnosed with what then was referred to as mental retardation. Many medical doctors, teachers, and psychologists told us that she would never be like other children and that she would be limited in what she could do. As parents, my husband and I never looked at her with that diagnosis. To us, she was our beautiful baby girl who had great difficulties in many areas. We, from the beginning, believed in her and that she had the right to live an everyday life like any other child. We provided her with the opportunities that other children were afforded: dancing lessons, girl scouts, swimming lessons, birthday parties with other children her age; and we taught her the responsibilities of working, giving back to the community, and strong family and community values. Today she is working and volunteering in the community.

When Karrie graduated from school at the age of 21, it was like she fell off the face of the earth. Karrie is a people person, she wants to work, loves being in the community, loves helping others. She wanted to work, connect with others, and be a part of society just like any other person. Karrie was one of many people on a waiting list. When we were told that she was going to receive home and community-based waiver services we were overjoyed. We asked what type of services Karrie could get with her funding and were told that there was nothing for her but a sheltered workshop. That was not where Karrie wanted to be. None of this mattered because 10 days prior to Karrie receiving home and community-based waiver funding, the county pulled her from the “waiver slot” she was to receive and gave it to someone else who they stated needed it more. We were devastated!

Karrie at the age of 21 did not want to go to a babysitter during the day while my husband and I went to work, but that was our only alternative if I was to continue to work. Karrie had no funding for services and even if she did, the services that were available to her would not meet her needs. A babysitter was our only option. She would cry daily and I would go to work crying every day until we finally decided that I needed

to quit my job. We went from a two paycheck family to a one paycheck family and having to fully care for our daughter 24-hours-a-day without any assistance. Karrie requires 24 hours/7 days a week support and as parents, we were the only ones providing her this care.

After I quit my job, Karrie and I became very involved with the state of Pennsylvania's Office of Developmental Programs and I became a member of their advisory committee.

From attending meetings and sitting on committees I learned about the waivers and began to advocate for Karrie to get her services. Karrie finally received home and community-based waiver service funding. After going to a traditional workshop for one month to be evaluated she became depressed and began to have severe behavioral problems. The workshop was continually informing me that Karrie was kicking, hitting, not listening to them and not doing what they wanted her to do. My husband and I took Karrie to counseling where she was diagnosed with bipolar disorder and prescribed numerous medications. We also held many meetings with the service provider to structure and set up a program that would fit Karrie. After counseling and meetings, I knew that I needed to play a stronger role in setting up and structuring Karrie's services, including interviewing, selecting, and hiring staff, locating places for her to volunteer, locating paid employment opportunities and connecting her with the community.

Having 24 years of experience with my daughter I believed that I was more qualified and knowledgeable to set up the type of services that were more beneficial for her. However, the provider agency did not want to work with me. Knowing my rights under home and community-based waiver services, and that the money follows Karrie for her services, I worked with the state to set up participant directed services where I could use the funding to hire, manage and train Karrie's support staff. That was 10 years ago and now my daughter has a life of her choosing and the staff that we have chosen have been with her 3, 5, 8, and 10 years.

Karrie has three part-time jobs. She receives a paycheck and that has in turn reduced her social security income (SSI) payments because she is now a productive, tax paying member of the community. She also has a volunteer position at a local church camp. At 35 years of age, Karrie now has her own life. Her medications have been significantly reduced which has also significantly reduced the cost to Medicaid.

My life has drastically changed too. I am now working full-time and paying taxes. I advocate for individuals and families, assisting them in using home and community-based waiver funds and in self-directing their services. I have helped individuals that have minimal to severe needs use the home and community-based waiver funding to acquire volunteer and paid positions in local fire companies, pizza shops, camps, food

pantries, thrift shops, churches, and nursing homes. In particular, one individual, with guidance from his staff (hired through home and community-based waiver funding), documented the construction of the local airport's runway project. The airport was so impressed with his pictures and documentation of the project that they arranged for a feature story on the local news. Many individuals like Karrie are learning a sense of independence and becoming a part of the community and workforce.

When individuals and families are given the opportunity to use home and community-based waiver funding, we are able to provide more services than if traditional services had directed the funds. In doing this, I have spent less money for services for Karrie than the state and federal government would have otherwise spent on more traditional services such as a sheltered workshop or group home.

Fifty-eight percent (58%) of all individuals receiving home and community-based waiver services are living with their families. When we factor in the individuals who are on waiting lists for services, we can say that most people with developmental disabilities are living with their families. By working with individuals and families and allowing them to direct their own services, individuals with disabilities will receive the services of their choice, based on their needs, and the cost of those services to government will be significantly reduced.

Karrie was devastated, traumatized, had severe behavioral problems, was on many medications, and was not sleeping at all during the night, when she was assigned to traditional services. In the beginning, neither she nor I had any say in the setup and structure of her services. Karrie is now a happy, content, productive young woman who does not have to be medicated or restricted because she now controls and directs her services through home and community-based waiver funding. This would not be possible if we did not have the flexibility and freedom to direct Karrie's services ourselves. Karrie is receiving all the services she needs now and I have established a working budget that she is able to stay within.

We are in a time when cutting costs is real and must be done. However, the cuts should never be on the backs of individuals who are the most vulnerable, or put their health and safety at risk. I believe we need to acknowledge that by allowing individuals and their families to self-direct the home and community-based waiver funding for their services, we can cut costs without putting the individual's health, safety and quality of life at risk, allowing individuals to live an everyday life. While not every family can do this, many can.

Families can support their sons and daughters. Many families can design and direct their services, saving the government money. We can cut the budget without causing

individuals and families to suffer by providing participant directed services using home and community-based waiver funds. It can be done! And it must be done or there will be a serious cost to people with disabilities, their families, and for government.