

My name is Linda Miller and I am here today to support the Informed Choice Amendment; to make sure ALL families are provided with options, clear directions to how these options can be obtained, and that ALL families will be provided the opportunity to plan a future.

I am a mother of four children. My husband and I managed a middle income working household with both of us employed full time. Our marriage quickly grew into a teenage son and three daughters under the age of five. Our two youngest children were found to have learning disabilities. Our middle daughter was diagnosed and was able to be mainstreamed into the public school system with minimal challenges. Our youngest daughter, Samantha, suffered numerous medical problems that made her a frequent visitor to Cincinnati Children's Hospital. She was eventually diagnosed with Rett Syndrome. Imagine the symptoms of Autism, Cerebral Palsy, Parkinson's, Epilepsy and Anxiety Disorder... all in one little girl. This is Rett Syndrome. Many children with Rett are unable to speak, walk or use their hands and suffer breathing problems, feeding tubes, seizures, anxiety and orthopedic issues.

Our journey started with Children's Hospital who put us in touch with Hamilton County Board of DD where we began early intervention and later enrolled Samantha in Margaret Rost, a County Board school perfectly suited to all of her special needs. Samantha attended Margaret Rost until the age of 22 while we cared for her at home.

While Sam was getting great services at school, I was unknowingly not getting the information I needed to plan for her future after school. Nor I was aware of services that existed to help us pay for the mounting medical bills, and the cost of needed for equipment and home modifications. The bills were tearing my family apart.

At a yearly IEP meeting for school, I raised the issue of our medical expenses. This was the first time I heard the word "waiver," but when I asked for more information I was told, "It doesn't matter because no one is getting one anytime soon." It took years of persistent advocacy on my part to get connected to and a "service facilitator" to be assigned and provide me needed information. It took an additional 10 years to find Samantha had never been placed on the wait list due to a paperwork mistake by the County. In her teenage years, when she was approaching graduation from school, this presented enormous problems as she needed a waiver to attend a day program so that she would have care while I worked. I was also told that Hamilton County DDS does not plan transitions from school to adult programming for students who do not have a waiver. It was suggested that I would have to "advocate for my daughter" to solve the dilemma we had.

How does a parent advocate if service options are not provided to families, rules to the system are hidden, and waiver lists are designed without checks and balances to make sure no child gets left behind?

As graduation approached, I had carefully reviewed all options that I had found; waiver- not available, requested levy funds – told not available and requested emergency status- told we didn't qualify. I called our SSA and explained that in two weeks I was going to have to file Family Medical Leave and pray that a care solution could be found quickly for Samantha. In tears I explained that my baby girl might have to become a ward of the state because I didn't know what else to do. My SSA placed me on hold.

The manger came on the phone. She said she wanted to make sure I was aware that if I did that there was no guarantee she would be placed in state so we could see her. I could hardly recoup from that phone conversation. I left work in a flood of tears, I was sure God had not intended this to be my daughter's future. I had no options left.

Just this year, I learned of the ICF option when I relayed this story to another mother. She wondered why the SSA did not tell me about the ICF option, if only as a short-term solution that would allow me to keep custody of Samantha until we could get a waiver.

After the call with the SSA, I wrote letters to everyone I could think of that could help us; the Governor, ARC of Ohio, DODD and all three county commissioners. A county commissioner replied to my letter and through his help, I received Levy Funds that allowed me to enroll Samantha at Franks Center, a County Board day program.

My daughter once again found a facility and staff that gives her excellent care which meets her needs and provides socialization and community. HCDDS also made possible daily, safe and reliable transportation to and from her workshop.

Since this time, we received a SELF wavier in 2015 and later an I/O waiver. We are now owners of a communication device, wheelchair for the Dog Park, and bath chair for day to day life.

The struggles we faced through Samantha's childhood could have been avoided altogether if the Informed Choice amendment were in place - if we would have learned of all options - waiver and ICF options - when we first contacted the Hamilton County Board of DD. Because the system is so complex and lagging organization, when you do receive care it seems as though it was just by luck. With long waiting lists for service you fear or walking in my family's shoes it makes you not want to speak up to correct things, out of fear you might lose what you finally attained for your loved one. I urge you to support the Informed Choice amendment so parents can plan appropriately for their disabled children's needs. Simply providing accurate and comprehensive information will lessen their burdens, proactive advocate so they can focus on being a parent.

