

House Finance Subcommittee on HHS

Barbara Fox Testimony

April 8, 2019

My name is Barbara Fox, mother and guardian of Kevin Fox who is 17 years old. I am testifying today in support of the Informed Choice amendment which families with disabled children have proposed to the operating budget. First, I would like to tell you about Kevin...

-He is 17 years old. He can walk (not a straight line). He can eat food with his mouth, so does not need a "G-tube". He can breathe on his own and can use a toilet for almost all of his bathroom needs (small miracle here that was one of the hardest things I ever had to do).

-Despite the best efforts of Cleveland Clinic specialist, over 20 medicines, diets or devices tried, he has 5-10 seizures a day that knock him to the ground. He wears a protective helmet to reduce most head injuries with these seizures.

(Show picture with helmet)

-He does not speak, get dressed by himself, or use the restroom by himself. He will never read or tie his shoes or say "Mommy" or "Daddy". He has severe autism and a great degree of mental/intellectual disability with no fear of putting his hand into a hot oven to get food or to running into the street. He needs 24/7 care. He is considered "medically fragile".

We cared for Kevin in our home in Shaker Heights for his first 3.5 years before getting on the Ohio Home Care Waiver which provided morning and afternoon nursing and aide help in our house in Shaker Heights. From the time Kevin was age 3.5 - 10, we managed at home but barely.....aides coming in and out of our household, daily seizures, frequent hospitalizations, PT, OT, Speech therapy appointments, doctor appointments, specialist appointments, hospitalizations, trying to raise a 2nd healthy child, husband often traveling out of the country with no relatives within 500 miles. The aides and nurses were helpful for the mornings and afternoons they showed up, but there were frequent no-shows and no care was granted for the 10 hours that Kevin was supposedly "asleep" at night. As a well-educated upper middle-class couple (husband was physician so I could stay home), we BARELY existed. By the time Kevin was 11, in 2012, we are at a point of desperation and exhaustion. Our marriage was barely hanging on, I was underweight, our younger son had countless weeknight sleepovers at the neighbor's house when Kevin had ER visits when my husband was out of town. At this desperate time, I called the Cuyahoga County Board of DD to ask what could be done. I will never forget sitting in my kitchen on the phone in early 2012, calling our Cuyahoga County Board of DD. I explained that Kevin was getting out of his room at night and roaming the house. We had locks so he could not leave the house, but he was getting downstairs to the kitchen standing on kitchen table and island and not being supervised at night. The State Home Care Waiver refused to give night time care, so I needed something else. I was floored by the response I got, which was essentially, "we can help you find some place for your son to live when he is 18. Call us back in 7 years!!!!"

I spent 48 hours being crushed by this response and then realized there must be more help available. I set out to research what was available somewhere...if not in my area then somewhere. I had heard of Hattie Larrilham and called them. I was disappointed to learn they did not have residential services for mobile children. However, they gave me two very useful bit of information. One was the term "ICF Intermediate Care Facility" and the other was the name Rose Mary Center for Children, an ICF 25 minutes away from our house. I contacted the Social Worker at Rose-Mary Center in mid-2012 and arranged for a tour. The 40-bed facility was old and in need of major aesthetic changes, but this was a great fit for Kevin!! It had a warm water therapy pool, long hallways to practice his tricycle ridings in the winter and a fenced in playground with very soft playground flooring. There was a large gym with a giant bounce house, an on-site Nurse (LPN) 24/7, a dentist and eye doctor that came 2x a year, an in-house Physical Therapist, an in-house industrial kitchen and cook. We asked the Rose Mary Social Worker to place Kevin on the waiting list and I remained in touch monthly. After a few months (in Jan 2013), Kevin did a 2-night 3-day respite stay there (a test drive). Both parties found that satisfactory, so we now desperately waited for an opening. At this point, I had no further contact with the County Board. We waited at home for an opening at Rose-Mary. Kevin's safety continued to be compromised, so I again asked Ohio Home Care for more nighttime care and explained the unsafe nature of Kevin walking around the house at night. Ohio Home Care/Carestar got Department of Child and Family Services involved. DFS alerted CCBDD to the situation and I do believe CCBDD did come in at the very end to ask Rose-Mary Center to put Kevin to the top of the waiting list. It was if I had to find the gift, assemble it, wrap it and then CCBDD came in at the end to sign the card. No one every mentioned ICF as an option to us and the clear message was "we can help you out when your loved one turns 18."

Thank God, as a well-educated, empowered, upper middle class, resourceful stay-at-home mom I was able to dig and navigate my way out of this desperate situation on my own. What happens to the 19-year old single mom in this situation? What happens to the widowed attorney who works 70-hours a week and does not have the time to do hours of research? What happens to educated but grieving friend who suddenly finds herself guardian to a disabled child whose parents have just been killed and/or incarcerated? *Who is telling them ALL OF THEIR OPTIONS? I realize that voluntarily putting your child in a large care facility seems unthinkable to many. It is not until you live through this painful reality that you can see what a great relief, comfort and life-saver these ICF places are. To neglect to mention them, hide them or minimize them is like turning you back on a drowning family that needs help.*

Call to Action: Please support this bill that would require families to be notified about the option for residential care in an ICF for their loved one. Also, when you hear stories about large ICFs, please make sure you are hearing from parents who use them. The mid-larger sized ICFs are essential for the hundreds of constituents in your districts who have severely and profoundly disabled children like ours. They are so often forgotten, made invisible or pushed to the margins, please do not do that here.

