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My name is Caroline Lahrmann. I am here with a group of families in support of the Informed Choice amendment that will ensure DD families receive full information about all Medicaid services when they seek help from their local County Boards of DD. My husband Bill and I are parents of three children, Henry and Elizabeth, 19, who are twins with profound disabilities. Our oldest son Will was three when they were born.



Henry, Elizabeth and Will enjoying
Heinzerling's Sensory Garden.

As Director Davis testified, the County Boards serve as the point of contact for families. That's because the State has contracted with them to serve as the local Medicaid administrator. All state agents serving Medicaid recipients have an obligation under federal law to inform the public seeking care of service options.¹ Additionally, central to Medicaid is the very American principle of Free Choice of Provider² – meaning Medicaid beneficiaries have the right to receive services from any qualified and willing provider of care. For individuals with DD, that may mean any agency provider, independent provider, or Intermediate Care Facility. So, federal law makes clear, Medicaid applicants are to be given information about services and beneficiaries are to have choice.

Families have found that all choices are not being provided when they seek help from their County Boards. Parents have the best understanding of their children's needs and are the most motivated to ensure children live happy, healthy lives. As such, getting full information into the hands of parents will ensure the best outcomes for children.

To give you a window into the state of mind and the circumstances of a DD family, let me share our experience. Henry and Elizabeth were born with profound neurological damage. As babies, this meant dramatic developmental delay, a rare intractable seizure disorder, and difficulty swallowing. Today as adults, they function at an infant's level. They had countless seizures and received multiple medications and injections a day. For a period, we had to take their blood pressures twice a day, test their urine, and take stool samples. Feeding was very difficult and they expressed discomfort frequently, causing sleepless nights. Juggling these responsibilities and the care of our

¹ Pursuant to 42 C.F.R. § 435.905(a) & (b), the state has a legal obligation to provide information, in plain language and in a manner that is accessible and timely, concerning: "(1) The eligibility requirements;" "(2) **Available Medicaid services;**"¹ and "(3) The rights and responsibilities of applicants and recipients."

² Pursuant to 42 CFR § 431.51(b)(1) "...a beneficiary may obtain Medicaid services from any institution, agency, pharmacy, person, or organization that is (i) Qualified to furnish the services; and (ii) Willing to furnish them to that particular beneficiary."

three-year-old was overwhelming. We were also managing tremendous grief and worry about our children and about our future as a family.

When we met with the County Board, it did not occur to me that they would hide a care option from a struggling family. We were told about waiver services and put on a wait list. We were not told about the ICF option.

Finally, my husband took family medical leave. His goal was to find a permanent solution and then return to work. I was in charge of the children. He was in charge of the solution and making meals. Later, I would find out that when he went to the grocery store, he would take cat naps in Kroger's parking lot.

Fortunately, before Bill left for leave, a colleague mentioned that there were care centers for people like our children – a ray of hope. We did not know where they were or what they were called, but something existed. Bill took to the yellow pages. Through phone calls and referrals, he found Heinzerling, an ICF that cares for 200 of Ohio's most difficult to care for people. Heinzerling's original mission was to care for medically challenged babies like ours. And, it was just 10 miles from our home. Why didn't the County Board tell us about Heinzerling?

I will never forget the day the Heinzerling social worker and nurse came to our home to meet our children. It was like a world of hope and healing opened up to us. Finally, there were people that spoke our same language. They knew exactly the care needs and the pressure we were under.

Governor DeWine has named April the Month of the Young Child in honor of Early Intervention. I urge this Committee to understand that for children with severe and profound needs, in many cases the ICF is the best form of Early Intervention. I attach to my testimony pages from the CMS website that explain the ICF option, and I highlight the description of the active treatment component (Exhibit page 2). It is active treatment that enables ICF residents to make milestones. The ICF made a dramatic difference in my children's health. I urge the state of Ohio and the County Boards to recognize the importance of ICFs to early intervention and inform parents of this life-saving option, at the same time parents learn about waiver services. Then, simply let parents weigh their options and decide what's best for their child.

The year our twins were born the movie *Cast Away* came out, It's about a man whose plane crashes and he ends up alone on a deserted island. One night, our neighbors watched our children so Bill and I could get out of the house. We went to see *Cast Away*. It was difficult for me to watch because it hit too close to home. We lived in a lovely community, but our family was on a veritable island. When we found Heinzerling, our children, our family were connected to the community again – we were rescued from our island. By only sharing community services, the County Boards are consigning many families to islands.

I urge you to support the Informed Choice amendment. Families deserve to know their options so they truly have Free Choice of Provider. For some, their choice will be Home and Community Based Services. For others, their choice will be an ICF. Many will

access both care options at some point in their lifetimes. What families choose should not be anyone else's concern, because no one else walks in their shoes.

Thank you,
Caroline Lahrmann



Happy at Home
Henry and Elizabeth taking a stroll
at Heinzerling.



Visiting the Columbus Zoo
with Mom & Dad