

Senate Finance Subcommittee on Health & Medicaid
Testimony of Caroline A. Lahrmann
May 16, 2019

Chairman Hackett, Ranking Member Thomas and Members of the Committee,

Thank you for this opportunity to testify. My name is Caroline Lahrmann and I am here today in my capacity as a mother and guardian of twins with profound intellectual and developmental disabilities. I testify in support of an amendment to the operating budget, the Informed Choice Amendment, that will ensure that DD families are informed of all service options when they seek help from their County Boards of Developmental Disabilities.

DD families have successfully advocated for the Informed Choice Amendment in the House. Representative Romanchuk submitted our amendment to the operating budget, however, there was a clerical error that caused the wrong version of the amendment to be placed in the Omnibus bill. We are hopeful that the Senate will submit the correct version of the amendment so that the error can be corrected in the reconciliation process. Let me give you background on why the amendment is necessary. We then have several families who will share their stories with you. Additionally, families who were unable to make the trip to Columbus today have submitted written testimony. I hope you will have an opportunity to review this written testimony as well.

The County Boards of DD serve as the face of the DD system for families. That's because the State has designated them 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 principle of Free Choice of Provider² - meaning Medicaid beneficiaries have the right to receive services from any qualified and willing provider of care. For the DD population, this means any Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF) or any provider of home and community based services. So, federal law makes clear, Medicaid applicants are to be given information about services and beneficiaries are to have choice.

On April 8th, 13 DD families from across the state testified to the House Finance Subcommittee on Health & Human Services in support of the Informed Choice amendment. Families testified that they had been in contact with their County Boards for years, but each found the services they needed not because of the County Boards, but in spite of them.

The problem is that County Boards show families only half the menu. A review of county board websites reveals this. Only 11% of county websites affirmatively reference the ICF choice. In contrast, 71% of counties have information about waivers on their websites. While waivers are a fantastic option for many DD constituents, they are not the best option for everyone with disabilities.

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."

ICFs provide 24-hour supervised care and medical oversight, including nursing and therapy services, as well as community integration. ICFs may be the best form of care for many people with severe and profound disabilities and complex medical conditions, yet most DD families will never know this specialized care exists, even though DD constituents are entitled to ICF care under Ohio's Medicaid State Plan and County Boards are required to inform them of it. Instead, the County Boards allow families to struggle for decades rather than inform them of their ICF option.

Considering the challenges of caring for someone with severe and profound disabilities, the policy to not inform families of the ICF option feels cruel. People with profound needs function at the level of an infant or small child their entire lives. They may be quadriplegic, epileptic, tube-fed, and non-verbal. Some individuals may require a ventilator or have a tracheotomy. The health and community integration of the individual with profound disabilities may suffer in a small setting with limited supports. Additionally, the level of care required is emotionally and physically demanding on families. The pressure the persistent care needs places on families can tear them apart and have adverse effects on family members, including the typically developing children in the household.

For these DD families, decisions about services are ultimately health care decisions. Imagine being diagnosed with a serious medical condition, but your treatment professional only shares with you the treatment option that he or she prefers, while hiding an option from you that may be the life-saving care you need. I can speak from experience in this regard. Our twins were born with profound neurological damage and complex medical conditions. Their care needs were overwhelming. When we met with the County Board, the caseworker failed to inform us that Heinzerling, an ICF that specializes in the care of individuals with profound needs, including infants and small children, was just 10 miles from our home. This was the most responsible care option for our children, but the County Board hid it from us. We found Heinzerling simply by luck. A co-worker just happen to mention to my husband that there were specialized facilities for people with DD. So my husband took to the phone book calling different types of care centers until a string of referrals, that led us around the state, ultimately led us to Heinzerling.

When County Boards only provide half the menu, they are in effect, imposing their decision-making upon the parent or guardian, superseding parents that have the most intimate knowledge of their disabled child's condition. This is not how to administer a service system that federal law says is to be based upon beneficiary choice, nor is it any way to honor parental rights or the care needs of a helpless, disabled child.

I urge you to support the Informed Choice amendment. Thank you.

Caroline Lahrmann