May 16, 2019

Senate Finance Subcommittee on Medicaid and Health and Human Services
Ohio Statehouse
1 Capitol Square
Columbus, 43221

RE: Bill #166 in support of the Informed Choice Amendment

My name is Margret Gfoeller, and I am the mother of Steven Tomassini. I am testifying today in support of the Informed Choice Amendment that families of developmentally delayed individuals have proposed to the operating budget.

My family is from Fremont, Ohio in Sandusky County. My son, Steven, is a 30-year old man who has been a member of the Heinzerling Community in Columbus, Ohio since August 2009.

It is an easy drive to get here; but the actual *journey* was a long one, both in distance and time.

Steven was born 2 ½ months prematurely; his twin died at birth. Soon after his birth, it became clear that he had many issues that would require the type of care that no average parent can provide for long in an average home. Steven suffers from spastic diplegia cerebral palsy, a form of permanent brain damage affecting reasoning, impaired vision, spinal damage, intellectual and learning disabilities, delayed growth, anxiety, and intense anger outbursts. He functions cognitively at the level of a very verbal 4 – 6 year old; he has a limited reasoning ability and a limited understanding of the thoughts and feelings of others. He cannot transfer or move without assistance, and he requires a wheelchair for regular movement. Daily care for my son includes extensive multiple and overlapping therapies, as well as assistance and health care from a team of medical specialists.

When he was younger and smaller, I could care for him at home, send him to local schools, and drive him to all of his therapies. I remember meeting with local agents who made home visits, as well as meeting with counselors at school and local board offices. The information that I received was for services offered in our area. Unfortunately, I was not made aware of all services offered in other parts of Ohio.

To further complicate the situation, soon I was battling a rare and deadly form of cancer. Every parent of a child with disabilities knows they have to plan for the day when that child will be on his own. I had to make that happen much sooner than I expected. I consulted the resource information I had and asked for more information, but no one really had much to offer. I looked for communities or Intermediate Care Facilities (ICFs), but my son did not qualify for the few that were in our area. So, I had to look outside my home state. Through friends of friends, I discovered a privately run ICF in a rural area on the Eastern Shore of Maryland.

We moved to the Eastern Shore. The residential care and education was excellent, the teachers and staff truly understood my son as a person, and he was happy. When Steven was 19, I could no longer afford to have him stay at the school. I was living in Dover, Delaware and had to bring him home to live with me and attend public school. Because there was not much room for him to move his wheelchair in our house, he felt claustrophobic. His frustration would build to the point of rage, and these rages were directed toward me. I needed help, but I didn’t know where to go. When my sister suggested moving to Colorado to be closer to family, I did. Unfortunately, the funding for those programs was voted down as I was driving us across the country, between snowstorms. Sadly, I didn’t even think about returning to Ohio because what I knew of the services offered was not what Steven needed.

I could not make an informed choice about programs that would meet my child’s exact needs, specifically a residential program that provided education, therapies, and a safe future.

In the meantime, I had related this story to my brother who shared it with a friend of his in Athens, Ohio. Because of her own personal experience, she made a call to the Heinzerling Foundation in Columbus, and soon Steve and I had an appointment to tour the facility and take part in an interview. Before this, **I had never heard of the Heinzerling Foundation** or the Heinzerling Community or the Heinzerling Developmental Center. It has been ranked as one of the premier ICFs in the country, **and no one outside of the Columbus area seemed to know about it. The information had not been shared outside of central Ohio.**

Heinzerling has been the answer to a prayer. Because of them, Steven has everything parents could ever want or hope for their child. Because of the Heinzerling Community, Steven continues to grow and become the vest version of himself that he can be.

It took me ten years and thousands of miles to find the perfect care, the perfect home, and the perfect life plan for Steven right here in Columbus, Ohio only 2 ½ hours from my home town. **How is this possible?** For whatever reason, the information was not available – not to me and not even to the Sandusky County Board of Developmental Disabilities. Because information was not accessible to everyone in every part of the State of Ohio, I could not make an **informed choice.**

Senators, no parent, no family, should have to experience what we have had to go through. I would not wish it on anyone. For this reason, I ask you to support **Bill #166**, **the Informed Choice Amendment**, and spare future families the extraordinary, and unnecessary, detour that took me and my son across the country before we could find that what we needed was right here, at home in Ohio.

Respectfully yours,

Margret R. Gfoeller