

Senate Finance Committee

May 28, 2019

Chairman Matt Dolan

Ranking Member Vernon Sykes

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.

I am 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 who provided me with information about 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 and programs for Steven, 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, to the best of my knowledge, the services offered in Ohio were 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. They existed in my home state, but I had never been given the information about all available programs, both public and private..

In the meantime, I related this story to my brother who shared it with a friend of his in Athens, Ohio. Because of her own experience with a niece, she made a call to the Heinzerling Foundation in Columbus, and soon Steven and I had an appointment to tour Heinzerling's intermediate care facility. 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, ranked 3rd in the nation, and no one outside of the Columbus area seemed to know about it. The information was available, but it 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 best version of himself that he can be. The cleanliness, care, opportunities for participating in programs and in the community are excellent. My voice is always heard, and answers and solutions are just a phone call away.

When my son was born, the estimated age of survival was 21-30 years. Today, he is thriving and looks forward to a long and happy life because of the loving care he receives from the Heinzerling Community. There are many solutions and services available for every sort of physical and mental developmental challenge. **ICFs may not be for everyone, but they are the best and only choice for some people.** People who require full time, complex care must not be under-represented. Our most fragile citizens require the most care, and their families must be provided with information about intermediate care facilities in our state along with all other services, both public and private, in order to make a truly informed choice.

It took me ten years and thousands of miles to find the perfect care, the perfect home, and the perfect life plan for my son, Steven, right here in Columbus, Ohio -- only 2 ½ hours from my home town. **How is it possible that such a journey had to happen?** 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, a parent of a developmentally disabled person who requires full time care, could not make an informed choice about the best care for my child.**

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 **the Informed Choice Amendment to House Bill #166** 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