

My name is Lisa Freson. I am testifying in support of the Informed Choice amendment so that families can be given all of their service options when they seek services from the County Boards of Developmental Disabilities.

My Daughter Lauren had a brain tumor removed at the age of 2 which left her neurologically impaired. The tumor resection resulted in many neurological deficits and severe developmental delays. She had minimal fine and gross motor function. She lost the ability to walk, talk and swallow. She was completely dependent on others for all aspects of her care. She was ventilator dependent at night and required care 24 hours a day.

23 years ago, in the blink of an eye she went from a typically developing 2-year-old to becoming a child with extremely complex medical issues and intense care demands. We decided that the only choice for us was to bring her home and provide for her needs in our home. We were only able to do this with nursing care for her in our home at night so that we could sleep and provide care for her during the day.

This decision had a huge impact on our family of four and all of our lives. Lauren was the focus of my life almost to the exclusion of everything else. I was not the only one to make extreme sacrifices, her sister and father also sacrificed a normal homelife so that we could provide the intensive care that she needed. Either my husband or I had to be with Lauren at all times unless a nurse was with her. Funding and scheduling nursing care is a monumental feat in itself so suffice it to say that other than night time care one of us was almost always with Lauren which changed our family life completely. There were also numerous times when the nighttime nursing care was not available which meant that I was up all night in addition to providing complex care the next day.

While this was a choice that we made freely and would make again lovingly my husband and I realized that we needed to plan responsibly for her future in case something happened to us, or we became unable to provide her care ourselves.

We had yearly meetings with our county board case worker and we began to inquire about other options for care. **Specifically**, we asked for information about facilities that could care for our daughter if the need were to arise. There was a revolving door of case managers and at one point rather than receiving the information that we were seeking, we received a letter informing us that we were going to be removed from the county board caseload. It took several years of making the same request for information about facilities before we were finally assigned to an exemplary case manager who finally provided us with the information that we had been seeking. **Fortunately**, this information was provided to us because after 20 years of providing care in our home our daughter aged out of the nursing care that had allowed us to keep her in our home. She was still eligible for home nursing care yet she needed to change from a pediatric provider to a provider for adults. Despite exhaustive efforts nursing support for her at home was no longer available. This change in circumstance necessitated the change in service options for her and we placed her in a long-term care facility.

Parents of children with disabilities face profound challenges and must engage in life planning on an ongoing basis. It is paramount that they are aware of **all of their options** not only at the onset of services, but throughout the years of service. They may not access certain forms of care initially, yet they may need them in the future.

