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 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 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. One month in particular we went without nursing coverage for 19 out of 30 nights. This was exhausting as well as unsafe.

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. The concern over how to provide this alternate care for our daughter added to an already overwhelming burden.

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 provided us with the information that we had been seeking. Shortly after this information was provided 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.

We had previously believed that keeping Lauren at home was best for her. It wasn't until after we placed her in an ICF that we realized it was the best place for her. Not only did the ICF provide the medical/nursing support which was required to keep Lauren alive it provided her with a true community for the first time in her life. She lived in an environment with peers and developed relationships that she valued and enjoyed. The move to a facility had a positive effect on the quality of Lauren's life besides being essential for her health and safety. We now realize that Lauren was more isolated from peers and a true community while she lived at home with us. We were still involved in her life with visits 3-4 days a week. If the information about ICF's had been provided when we had originally inquired, we may have discovered this ideal option for Lauren much sooner.

Prior to the admission to the ICF we participated in a preadmission counseling session. My understanding is that it was **mandated** that prior to being admitted to an ICF families had to be informed of all other options to encourage them not to go into the ICF. If the goal is to ensure families are informed of all options in order to best meet the needs of an individual with developmental disabilities, it seems to me that the mandate should be that all options are presented to the families all along not just for the purpose of discouraging placement in an ICF.

The reality is that when an individual with developmental disabilities also has significant medical issues the options to safely provide this care are very limited. I am not sure why ICF's are viewed with such negativity. Our experience was that they can provide a wonderful caring and safe environment.

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** throughout the years of service. They may not access certain forms of care initially, yet they may need them in the future.