Senate Finance Committee

May 28th 2019

Chairman Matt Dolan

Ranking Member Vernon Sykes

   Thank you for giving us time today to tell you our family story.

  My name is Pete Billington.  My wife Karen and I are the parents of a  disabled daughter Kerry,  now 35 years old.  I am here to encourage you to support our the Informed Choice amendment, giving families informed choices when confronting their  disabled  Childs lifetime future.

Kerry has been a resident of the ICF Home Hattie Larlham Home for Disabled Children for over 31 years.  This wonderful  Home  has been a Godsend for both Kerry and our family.  Kerry’s life began as a struggle,  and is now a life of the highest quality our society can offer a child with her complications.

Kerry was born with severe brain damage and at the time uncontrollable seizures.  From day one on,  we were two young parents with a healthy older brother,  but an unknown situation new to us and without direction.

Kerry came home in a medically fragile situation.  She would have 20-50 seizures a day and was looked after by us as best we could.  Many nights were spent in the Rainbow Children emergency ward with doctors looking over Kerry,  putting IV drips with any medicine they hoped might control her shaking.

  This was our life for the first three years with Kerry.  Endless nights and days in doctors’ offices,  not sure when or where to take her.

  Karen reached out to our local DD office in Cuyahoga county..and the advice at the time was a day service preschool where she could go 4-5 hours a day by bus in her wheel chair, to begin a life, and give us some short respite to work and care for her brother age 5 .

  We were never directly informed by the Cuyahoga DD office  or encourage to pursue any other avenue at the time.  This preschool was their option.

  We only heard about the wonderful Hattie Larlham Home at a party,  when a concerned friend,  with a friend involved with Hattie,  made us aware of this  other option for our child.

  After a year at service at United Cerebral Palsy of Cleveland  (also suggested by our friends at a party,  )  we called Hattie Larlham for a interview and a chance for a two week stay over by Kerry to see how life would be for her…and our family.

  At his stage we had a new born little brother, and life was as hectic as you can imagine.

  Let me stress this now…Kerry is at an extreme level of profound disabilities.   My daughter Kerry is an 8 month old trapped in a 35 year old body.  She does not speak, walk or able to let those around her know what might be uncomfortable, or  actually  pain.

  She has all  her   seizure medicines  given through a tube  surgically planted in her stomach.  All her life sustaining liquids are also give through her stomach tube 5-7 times a day by a nurse on staff 24 hours a day

  Kerry is totally dependent on those around her for all her life supporting needs. Shower, diapers, feeding and entertaining.

  This ICF home at Hattie has given my family a life of normalcy we never would have been able to achieve.  Kerry’s brothers were able to grow up in home where they could both have complete parents attention,  but also love their sister Kerry without ever feeling she deprived them of life’s opportunities

I must point out that  statistics show that 75% of parents with children of  disabilities end up in a divorce,  mostly from the pressures and strain of having this child at home, needing 24 hour a day attention.

This ICF  Home for the Intellectually  Disabled has give Karen and I 43 years of marriage, blessed with being able to visit Kerry every day and feed her lunch or dinner,  with a Barney movie on  where  smiles and laughs abound .

  I ask that you vote for our Informed choice amendment when asked.  We are only seeking that individuals and their parents and guardians are informed of all options-community services and Intermediate Care Facility services-so that they can choose the option that best addresses the needs of their loved one and family.

    Thank you for this opportunity to speak today

Peter B Billington