

# WITNESS INFORMATION FORM

Please complete the Witness Information Form before testifying:

Date: 4-8-19

Name: Peter B. Billington

Are you representing: Yourself yes Organization yes

Organization (If Applicable): DISABILITY ADVOCACY ALLIANCE

Position/Title: \_\_\_\_\_

Address: 220 MURWOOD DR.

City: MORELAND HILLS State: OHIO Zip: 44022

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Do you wish to be added to the committee notice email distribution list? Yes  No

Business before the committee

Legislation (Bill/Resolution Number): AMENDMENTS FOR INFORMED CHOICE OF

Specific Issue: AMENDMENTS TO UNIFORM INFORMED CHOICES DD SERVICES

Are you testifying as a: Proponent  Opponent \_\_\_\_\_ Interested Party FOR FAMILIES OF DD

Will you have a written statement, visual aids, or other material to distribute?  Yes  No

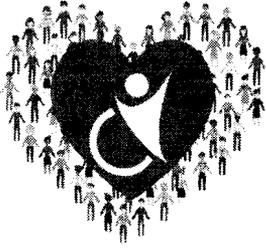
(If yes, please send an electronic version of the documents, if possible, to the Chair's office prior to committee. You may also submit hard copies to the Chair's staff prior to committee.)

How much time will your testimony require? 3-5 minutes

Please provide a brief statement on your position:

We are asking State Senate + House to support our  
Amendment to Families Informed Choice of DD Services.  
See Following Page 2

Please be advised that this form and any materials (written or otherwise) submitted or presented to this committee are records that may be requested by the public and may be published online.



# Disability Advocacy Alliance

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## **Legislative Amendments for Informed Choice of DD Services**

Families and Guardians of individuals with intellectual and developmental disabilities propose the following amendments to enable individuals and families to act with Informed Choice when seeking services from their County Board of Developmental Disabilities.

1. When individuals and their families inquire about DD services or before they are placed on a wait list for services, require County Boards to:
  - Inform individuals and families about the different types of services available, including Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs) and Home and Community Based “Waiver” Services (HCBS).
  - Give families an educational pamphlet about ICF and HCBS services prepared by the Department of Developmental Disabilities (DODD).
  - Direct families to a list of ICF and HCBS providers on the DODD website and provide contact information for ICF providers in the home county and contiguous counties.
2. Require DODD to include ICF providers on the list of DD service providers that is maintained on the DODD website. DODD is also required to provide a link on its website to the educational pamphlet referenced above that describes ICF and HCBS services.
3. Require County Boards to provide a link on their websites to DODD’s educational pamphlet describing ICF and HCBS services and to DODD’s list of ICF and HCBS providers. County Boards shall include ICFs along with any listing of HCBS programs, services, and providers on their websites.
4. State that an individual with DD who is eligible for ICF services has the right to obtain ICF services from any qualified and willing provider. (Ohio Revised Code presently recognizes free choice of provider for HCBS services.)
5. State that an individual who is eligible for HCBS and ICF services has the right to choose whether to receive ICF or HCBS services.

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 the Informed Choice amendment, giving families informed choices when confronting their disabled Child's 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. There were many endless nights and days in doctors' offices, never 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 encouraged 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 also 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 given 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. Her bathing, 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 given 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