

Hello. I am Karen Axmacher. I am Amy Axmacher's Mom and Legal Guardian. I am here today to testify in support of the Informed Choice Amendment which will require County Boards of DD to provide individuals, parents and legal guardians information about all of the service options available, even before they might need these services.

Amy will be 38 years old in about one month. While she is nearly 38, she functions at about a nine month old level, in our opinion. Amy has Rett Syndrome, named after Dr. Rett. Rett Syndrome is a Degenerative Neurological Disorder, primarily affecting only girls. Rett Syndrome falls on the Autism Spectrum and is extremely devastating. Rett Syndrome Girls progress normally until about 13 months old. Then, whatever skills she has accomplished, are lost. Because Rett Syndrome is degenerative, Amy's health will continue to decline. She cannot walk nor talk; she needs 100% care with toileting, bathing, feeding, etc. She is given medicines and formula by nurses via her feeding button in her stomach.



Once Amy was out of high school, she attended a day program run by the Butler County Board of DD for approximately 1-2 years. At this facility, called The Enrichment Center, we became concerned with Amy's care there. After numerous meetings and attempts to address the issues, we felt it was necessary to remove Amy from the day program. Amy continued to live at home, with Mom and Dad; and, one Nurse five days per week. On Monday through Friday, Amy saw and socialized with us three; and, on weekends, she had only Mom and Dad.

Obviously, raising and caring for Amy for 35 years in our home, was extremely difficult and challenging. Because Amy could not walk, even taking her to Doctor and Dentist appointments was difficult. NONE of Amy's Case Managers from the Waiver Program, NOR the Butler County DD Managers, whom we stayed in contract with, EVER mentioned other options. Amy's Neurologist, Dr. David Franz from Cinti. Children's Hospital, suggested we check out the Brookside Home in Mason, Ohio. After researching this home and others, which we found out about from other acquaintances and contacting random nursing homes, we decided to make Brookside Amy's Home. Amy has now lived at Brookside for 2 1/2 years. In

May of 2016, when Amy was 35 years old, we first heard the acronym ICF. We sent an e-mail to our Case Manager asking what ICF meant. We never received a reply. At some point, a Brookside employee said the words, ICF. Of course, we were subsequently informed by a Brookside employee what ICF meant.

Amy absolutely loves Brookside. In addition to the great personal and medical care she receives there – she has skilled nursing care 24/7 -- she actually Has Friends. This is remarkable and a First!! This may not sound like much, but believe me, this is Huge. Amy gets to socialize all of the time. She has Friends and while we read to her, some of her friends will sit with her and everyone laughs and smiles with each other. Amy recognizes and smiles at her roommates. One friend at Brookside, who is blind, shared her bracelet with Amy when they were sitting next to each other. Again, Remarkable.

In summary, Amy is very happy at Brookside Extended Care in Mason. She now gets to have friends, to socialize, her behavior has improved and she has excellent care. While we miss her, we know that she is much happier than ever before; and, at times, we feel guilty for not having provided such a good home choice for her sooner.

Thank You for the opportunity to share our experience with you.