

My name is Dan Jones and I am the father and guardian of Kelly Jones, a 33 year old woman with Cornelia de Lange syndrome who since 1997 has lived at Flat Rock Homes, a 34 bed ICF in northern Ohio.

The syndrome with which Kelly was born severely limits her intellectual functioning. Kelly is non-verbal and unable to live independently, nor can she be employed to perform simple tasks. The cottage Kelly lives in at Flat Rock is a 6 bed-home with five other women on the campus. My wife and I cared for Kelly in our home until she was 13 years old. While living with us, we were able to receive in-home care for Kelly under a waiver from the Cuyahoga County Board of DD. The waiver provided caregivers inside our home for approximately 20-25 hours per week.

When Kelly was 12 years old, we looked for permanent placement for Kelly outside of our home because she needed more intensive supports than we could provide in our home. We learned of the ICF option from our County Board case manager, but it was only by chance. Kelly now enjoys the best, fullest life possible at Flat Rock Homes. She is prone to run and so it gives me great comfort knowing she is on a campus with enough land to keep her away from traffic if that should occur. Because of this characteristic, for Kelly, a community setting would be a restrictive setting for her. Her quality of life would deteriorate. An ICF is the least restrictive environment for Kelly. It gives her optimum freedom and safety. Flat Rock is our choice for Kelly.

While we feel blessed to live in a state that has seen fit to continue to support ICF's as an option for the care of individuals like Kelly, we are fully aware of the efforts by various factions to slowly strangle Ohio-based ICF's ability to not only care for their current residents, but to also prevent those who are still 'standing in line' from hearing about the ICF option. What is unconscionable is that these factions are the same organizations who are chartered and receive taxpayer dollars to protect the interests of Ohio's DD individuals. They have adopted not only a 'one size should fit all' mentality for providing care but they also believe they are empowered to be the 'one voice for all'. They don't speak for Kelly or our family.

As a previous board member at Flat Rock, I can't tell you how many families from our neighboring state of Michigan reached out to Flat Rock's administration asking if there are any open beds for their loved ones. Why? Because the state of Michigan has elected not to support ICF's as an option for the care of their most vulnerable citizens. One size does not fit all. So, in Michigan, many of the most vulnerable citizens go without appropriate supports for their intensive needs. Desperate families are forced to look out of state.

The state of Ohio could choose to set an example to the rest of the country for the highest standard of excellence in how it provides a full spectrum of choice for its most vulnerable citizens. But instead, parents and guardians continue to receive less than optimal counseling on all care options. The ICF option is especially hidden from families. I think back to how naive my wife and I were when we first sought out options for Kelly's care and how lucky we were to find out about Flat Rock. Knowing that parents and guardians of all ages throughout Ohio still face similar challenges is saddening and heartbreaking. They deserve better. Their family members with DD deserve better.

I thank you for your time today and allowing me to provide my testimony. I respectfully ask you to support the Informed Choice Amendment to HB 166.. By passing this Amendment, you will give voice to our daughter, Kelly, our family and all of Ohio's DD citizens, their parents, families and guardians as well.