Mr. Chairman and committee, thank you for receiving my testimony today. I testify today in support of the Informed Choice Amendment.

My family's story gives evidence that some individuals with developmental disabilities (DD) who benefit from community services most of their life, may need an ICF to provide care for increasing medical needs late in life.

I am the sister and former guardian of Jon Larsen who passed away on March 20, 2018 at the age of 49. Jon died from complications from Alzheimer's disease which commonly afflicts individuals with Down Syndrome.

Jon's story includes care in a community-based nursing home that failed to understand his disabilities and pushed him away from their services.

Growing up and for much of his adulthood, Jon was ambulatory, independent with self-care and was a verbal communicator. He had a delightful sense of humor and a talent for socially including others.

Jon was born in a time before individuals like him were integrated into public education. He attended a County Board school until the age of 21. He lived in his family home through age 30 and did not receive waiver services while living there. At 30, he moved to a group home on a waiver and lived in waiver group homes through the age of 47. Jon loved visiting his family and his family loved spending time with him.

As an adult, Jon accessed the full continuum of employment services, participating in day- programming and sheltered workshops, enclave employment, and competitive employment at different periods in his life when those various options were the appropriate fit for him.

In 2011 at the age of 43, Jon began to show signs of cognitive decline. At that point, I became his legal guardian. Jon experienced ongoing decline and in 2015 was given a diagnosis of dementia by his doctor.

His group home rallied to provide additional support for Jon which worked well for an additional year. They went so far as to state that they felt they would be able to continue to accommodate for him throughout his decline and lifespan. Neither his home nor his County Board SSA fully explained ICF options at that time or provided a comprehensive list of ICF facilities. Jon was happy at his home and I really wanted him to be able to stay there. I didn't really have any sense of "back up plan", I was just getting through each week and providing as much support to Jon and his care givers as I could.

In February 2016, Jon was hospitalized due to suspected seizure activity and loss of ambulation. Neurological testing confirmed advanced dementia. Upon discharge, Jon was transferred o a nursing home for rehabilitation to restore ambulation which Jon lost suddenly prior to hospitalization.

Jon exhausted his rehabilitation resources without regaining his skills and it was time to discuss long-term placement. Jon was now totally dependent for eating, self-care, ambulation and tasks of daily living. His communication skills, once conversational, had decreased to vocalizations and a few words.

A meeting with the County Board SSA and Jon's caregivers was held to discuss care options.

Jon's group home communicated that they could not allow him to return, due to a bureaucratic issue that did not allow them to hire trained nursing assistants. Jon would have limited access to the agency's nurse. Again, no one had expressed this concern earlier or provided information on alternatives such as ICF's.

Jon's nursing home reluctantly agreed to keep Jon temporarily, but began to apply pressure for him to find an alternative placement.

Jon was undesirable to them because:

- His higher reimbursement rate for rehabilitation was no longer available and the nursing home would experience less financial gain from his care.
- Jon vocalized frequently and sometimes at a loud volume. They wanted to sedate him during the day with medication. Jon had a legal right not to be "chemically restrained". The nursing home did accept my decisions regarding medications, but after that pressed harder for alternative placement.
- Jon was 47 years-old at that time which meant the nursing home was out of compliance for day activities standards for persons under 60 and would have been required to improve day activity options.

Despite the nursing home's insistence that Jon needed to find another placement, the social worker provided no referral suggestions or information at this meeting.

Jon's SSA did mention ICF's after the meeting. Jon's SSA toured two small ICFs with me, but neither facility had adequate skilled nursing for Jon's needs, and both required residents to travel to work or attend off-site day programs during the week that were not a fit for Jon. Stillwater, a large ICF in Montgomery County that specialized in people with DD who had complex medical needs was not mentioned.

Some weeks later, the social worker at Jon's nursing home gave me a general list of skilled nursing facilities for adults. Stillwater was on that list. I contacted them and was surprised to learn that they were an Intermediate Care Facility for adults with DD. I was to find out that Jon's SSA assumed I knew about Stillwater, because as a child, Jon attended the school that was next to Stillwater. I was aware of Stillwater but mistakenly thought they served children, not adults.

Jon was placed on a waiting list for Stillwater and was accepted but had to wait an additional 5 months for a bed to open. Those five months were stressful and difficult for Jon and his family.

Upon Jon's acceptance at Stillwater, I was required to attend a meeting with the superintendent of the Greene County Board of DD, the county of his nursing home. I was participating in what is called pre-admissions counseling, a policy established in July 2015 by the state legislature to ensure guardians were informed of their residential options prior to accepting an ICF admission. What a frustrating irony! I was getting counseled about options other than ICF's but never got fully counseled about ICF's when it was needed.

On April 7, 2017, Jon was admitted to Stillwater. It was like a "world of comfort" opened for Jon, our mother and me.

- Stillwater's doctor and psychiatrist carefully monitored Jon's medications and never once suggested medication for sedation. Jon's vocalizations were not considered to be a problem at Stillwater.
- Stillwater had nurses on staff 24 hours a day and the nursing staff and caregivers were exceptional and experienced with developmental disabilities.

- Jon was able to attend a day program which was connected to Stillwater by a breezeway. His days were filled with meaningful activities that met his skill levels.
- Despite the dementia, it was obvious that Jon felt more accepted and relaxed at Stillwater, and that he enjoyed the day program he attended.

Jon lived at a this large ICF in Dayton, Ohio for one year prior to his passing.

In conclusion:

I believe in a continuum of services for persons with disabilities and families need to be informed of all options. Everyone in this world benefits from a range of opportunities and services across their lifetime. People with disabilities are no different in that regard.

There is a growing population of aging individuals with disabilities. Nursing homes will need to make significant changes in their attitudes and services if they are to accept and accommodate individuals with developmental disabilities in a respectful and comprehensive manner. Based on my family's experience, nursing homes are not even trying to meet this standard. Stillwater, a large, comprehensive ICF met this standard and did it with a lot of love.

I urge you to support the Informed Choice Amendment and to support a continuum of care that includes Intermediate Care Facilities.