

My name is Lorie Burger and 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. This is my husband, Mark, and loving brother-in-law to Jon. We testify today in support of the Informed Choice Amendment as our family's story exemplifies the importance of providing information on service options to families so they can engage in planning.

As both a sibling and a career speech/language pathologist I have a broad-based perspective on supporting individuals with disabilities.

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 served by the Montgomery County Board of DD much of his life, attending the 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 into an 8-bed group home on a waiver.

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. We were to find that Jon would also need the full continuum of residential supports.

At the age of 43, Jon began to show signs of cognitive decline. I petitioned to become his guardian with the support of our mother. Jon transferred to a four-person group home, again with a waiver, so I could be nearer to Jon as I knew he would need my assistance. Jon experienced ongoing decline and in 2015 was given a diagnosis of dementia by his doctor. His group home and County Board SSA communicated that they would adapt to care for Jon throughout his life and made no mention of ICF options.

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

Jon exhausted his rehabilitation stay without regaining his skills and it was time to find a long-term placement. Jon was now totally dependent for eating, self-care, ambulation and tasks of daily living. A meeting with the County Board SSA and Jon's caregivers was held to discuss care options. The nursing home reluctantly agreed to keep Jon temporarily, but communicated concern that they were not equipped to care for someone with significant medical needs in combination with intellectual and developmental disabilities. They communicated that he did not "fit in" with their other residents. They felt Jon vocalized too often and too loudly. Jon was asked to find an alternative placement.

Jon's group home representative stated that their agency did not have the necessary supports for Jon's increasing medical difficulties and communicated bureaucratic difficulties in hiring the level of care needed for Jon to return to his group home. They were not willing to take him back.

An ICF option was not mentioned to me during the meeting but was suggested by Jon's SSA 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, which I did because as a child I remember Jon attending the school that was next to Stillwater, but mistakenly thought Stillwater only served children, not adults.

Jon was placed on a waiting list for Stillwater and was accepted for admission 5 months later. Jon's nursing home continued to give him basic care but was no longer responding to him in a dynamic manner, with the exception of a few key staff who did all they could for him.

Upon Jon's acceptance at Stillwater, I was called in for 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.

During the pre-admission counseling, the ICF option was fully explained and choice was communicated. But where was that counseling early on, when Jon and I could have benefitted most from it? Why were ICF's not mentioned until late in the process and then did not include the full range of ICF types? Why didn't I, as guardian, understand all Jon's options. Jon had many loving caregivers in his life, and I was only one of them. Accepting and planning for Jon's progressive terminal disease was difficult for all of us.

I know that no one intentionally withheld ICF information from me, but collectively Jon's lead caregivers did not fully explain Jon's residential options due to innocent assumptions, lack of information about ICF's themselves and/or the absence of a clear process for informing families about ICF options.

On April 7, 2017, Jon was admitted to Stillwater. It was like a "world of comfort" opened up for Jon, our mother and me. Jon's caregivers at Stillwater and the Northview day program which is next door, gave Jon the fullest life possible during the time he spent there. 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.

Jon needed a large comprehensive ICF toward the end of his life.

There is a growing population of aging individuals with disabilities. The ICF option - that specializes specifically on the needs of the developmentally disabled - should be shared with families so they can plan, and their loved ones can benefit from appropriate supports when they need them.



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