

Madam Chair Lee and Members of the Human Services Committee,

My name is Toby Lunstad, this is my husband Shawn and our youngest daughter Addilynn who is 8 years old. Our family lives in Mandan in District 31.

We are here to testify in support of Senate Bill 2276 for an Act to create and enact a new section to chapter 50 – 24.1 of the North Dakota Century Code relating to legally responsible individuals providing Medicaid waiver services.

Passage of this bill would create a pathway for legally responsible individuals to be paid to provide services to meet the extraordinary care needs of their loved one. This is an option in North Dakota's HCBS Aging and Disabled Waiver, it is not possible in our children's waivers nor the Individuals with Intellectual Disabilities/Developmental Disability Waiver.

Addilynn has a rare disease, meaning only 1 in 2,000 individuals are affected. She has variant on a gene called CACNA1A, which controls communication between brain cells. Her variant is ultra-rare because she is the only one in the world with it.

Addilynn has several CACNA1A-related disorders including a form of epilepsy that doesn't respond well to medications, being high risk for hemiplegic migraines, and global developmental delay. At 8 years of age, Addilynn has been hospitalized more days than we can count and receives care above and beyond what is expected for a typically developing 8 year old. She receives this care insure her health and welfare needs are met and to avoid institutionalization.

The list of care Addilynn receives is long. As her rare disease has changed and progressed, we have learned how to meet her needs from her therapists, nurses, different medical specialists, pharmacists, and dieticians. The care Addilynn receives includes:

- Medication preparation to insure accurate dosage and frequency, administration of medications via her feeding tube, and monitoring for side effects
- Completion of skilled home programming prescribed by her physical therapist, occupational therapist, and speech therapist
- Repositioning and incontinence management to maintain skin integrity
- Wound care for her feeding tube site as well as miscellaneous incisions after surgeries
- Adaptation of leisure activities to allow her to "just be a kid"
- Weighing and preparation of meals to insure her calorie needs are being met daily. Addilynn eats orally and via her feeding tube, so each meal is calculated to insure her calorie needs are met, as well as facilitating oral motor skills to maximize her safety during eating.
- Calculating fluid intake at regular intervals through the day based on her oral intake and what needs to be given via her feeding tube to insure her hydration goals are met.
- Complete assistance with bathing, dressing, eating, transfers, mobility, and toileting needs.
- Emergency medical interventions including application of oxygen mask, administration of emergency medications during a seizure or hemiplegic migraine, and monitoring of vital signs during an emergency
- Constant 1:1 monitoring for seizures

- Overnight monitoring and checks when alarms sound due to Addilynn’s risk of SUDEP (sudden unexplained death of epilepsy)

Due to her disability, Addilynn is eligible for the Individuals with Intellectual Disabilities/Developmental Disabilities Home and Community Based Medicaid Waiver (known from this point forward as the DD Waiver). Addilynn receives in-home supports, case management, equipment and supplies, environmental modifications, and medical care including specialist appointments and medications from the DD Waiver.

I worked full-time until 2020, when Addilynn’s health took a turn for the worse and we realized that her developmental and medical needs were not being met by in-home support staff despite repeated efforts of training and education of staff and agency management. We experienced staff sleeping during their shifts, being more engaged in their phones or a book than Addilynn, improper set up of feeding tube equipment, unsafe transfer techniques, and staff taking pictures and being on social media in our home. We attempted to hire in-home support staff using self-directed services, but were unable to recruit staff that were willing to provide all of the cares listed above...everyone was intimidated by Addilynn’s medical, physical, and developmental needs. We lost my employer paid health, dental, and vision benefits and now pay nearly double for a private health insurance plan, my husband has to work longer hours, and it is difficult to be a one-income family given the state of our economy.

In the 3 years since I have been home with Addilynn full-time, we have seen tremendous gains in Addilynn’s function in the midst of setbacks. She is clearly thriving from continuity of care from someone who has the knowledge and skills to care for her. She has had two unexpected surgeries and recovered well. We were able to postpone a complex surgery on her hips for 2 years because I was able to consistently complete her home exercise program...a program that was not being completed when we had in-home support staff caring for Addilynn. Family, friends, and her medical care team have noticed that Addilynn is blossoming with the consistent, quality care that she has been receiving since I left my full-time job.



As I stated before, Addilynn is on the DD Waiver. She also qualifies for an institutional level of care. According to slide 77 in the North Dakota Developmental Disabilities Study completed by Alvarez & Marsal, North Dakota’s share of DD waiver spending for individuals to live in institutions is 29%. This is significantly higher than national figures of 19%. Given our experience with trying to find qualified caregivers for Addilynn and the changes our family has made in order

for me to be home full-time with her, I was not surprised to learn that North Dakota spending is higher than the nation in this area. Some families have to turn to institutionalization because they have no other options to care for their loved one. I believe SB 2276 has the potential to reduce spending in this area of the DD waiver because paying families to provide care is much less expensive than paying for institutional care. Paying families as service providers would reduce the need for institutionalization and would keep the family unit intact.

I am Addilynn's mom. I am also her service provider because I consistently provide services that a non-legally responsible adult would be paid to do. This is why our family respectfully requests a "Do Pass" from each of you on Senate Bill 2276 and for it to be implemented July 1, 2023. Please give families in North Dakota the option to be paid as service providers for the extraordinary cares they provide on a daily basis. Thank you for your time and I will answer any questions you may have.



Sincerely,

Shawn, Toby, and Addilynn Lunstad

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