

Chairman Dever and Members of the Senate Appropriations – Human Resources Division,

My name is Toby Lunstad. I am here today with my husband Shawn and our youngest daughter Addilynn, who is 8 years old. We live in Mandan in District 31. We are here to testify in support of Senate Bill 2276 for an Act relating to paying legally responsible individuals to provide extraordinary cares to their loved one under a new Medicaid waiver service. 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 (referred to as the DD waiver from this point forward).

I am also here as a representative for the many North Dakota families who are providing care to their children that is above and beyond what is expected for a typically developing child of the same age. We provide these extraordinary cares to make sure our children's health and welfare needs are met and to keep our families intact. The alternative would be to split our families and place our loved one in an institution, which unfortunately is an alternative that some families have already chosen.

Addilynn has a variant on a gene called CACNA1A, which controls communication between brain cells. She has several CACNA1A-related disorders including a form of epilepsy that doesn't respond well to medications, prone to hemiplegic migraines, and global developmental delay. Because of her disease, Addilynn is eligible for the DD Waiver and receives in-home supports, case management, equipment and supplies, environmental modifications, and medical care including specialist appointments and medications.

As her disease has changed and progressed, we have learned how to meet her needs from her therapists, nurses, various 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)

While each family's story is their own and unique, we also have a lot in common.

Our children require care above and beyond what is expected for typically developing children of the same age. We have all been taught these cares by the professionals I listed above...and in order for others to care for our children, they would have to be trained in these highly skilled cares. We do not have the ability to take our children to daycare or have a teenage nanny during summer break.

Many of us have experienced a change in our employment status in order to keep our families intact. Some of us have chosen to end our careers. Some of us have been terminated. Others are struggling to maintain the balance of work and care for our children. We constantly feel the pull of our children's care while struggling to keep a source of income for our families. For those of us who have experienced job loss and have spouse or significant other who is working, we endure longer work hours, decreased income, increased cost for health insurance, and less time to together as a family.

We all have authorized service hours that are **not being utilized** due to workforce issues. I have read testimony stating that the turnover rate for agencies providing services is approximately 47% and that they are unable to fulfill the hours authorized to families. If a family chooses to attempt to hire their own staff under self-directed services, they are often unable because of the nature of the work. The workforce does not seem to have an interest in meeting the medical, developmental, and emotional needs of our complex children. Another workforce issue is the quality of staff hired. Families have experienced staff sleeping during their shifts, showing up under the influence, ignoring their children to be on the phone or read a book. Families have witnessed the use of unsafe transfer techniques, improper and unsafe use of adaptive equipment, and experienced medication errors. Families spend an extensive amount of time training staff and working with staff and agencies to make sure their loved one is well-cared for, so these experiences are not the result of lack of training. Many families also experience staff just never showing up for work or abruptly quitting.

We want to keep our families intact and build relationships in the community. We don't want to be faced with the choice to place our loved one in an institution or to pay our bills. We don't want to think about moving out of North Dakota to a state that allows us to be paid to provide these extraordinary cares to our children so we can keep our families intact.

Children and individuals with disabilities thrive on consistency. I left my job in 2020 and 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. 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.

Passage of SB 2276 would provide our loved ones with the consistency they need to grow and be part of their communities. Families would experience less hardship and more time together. Individuals would receive consistent and quality care. Their medical, developmental, and emotional needs would be met on a daily basis. We have been authorized by the state of North Dakota to receive this type of care for our loved ones, however, our loved ones are not receiving this care as authorized. We need to find another way and SB 2276 is that way.

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 and the families I am representing today respectfully request a "Do Pass" from each of you on Senate Bill 2276. 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

tobylunstad@gmail.com

701-595-4386