

Chairman Weisz and Members of the Human Services Committee,

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 legally responsible individuals providing Medicaid waiver services. This Act 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 Home and Community Based Services (HCBS) Aging and Disabled Waiver, it is not possible in our children's waivers or the Individuals with Intellectual Disabilities/Developmental Disability Waiver (also known as the DD Waiver).



Addilynn has a rare disease. In the United States, the definition of a rare disease is one that affects less than 200,000 individuals. She has variant on a gene called CACNA1A, which controls communication between brain cells. Her specific variant is ultra-rare because she is the only one in the world with it.

The variant on Addilynn's CACNA1A gene has changed how her brain cells communicate, causing several CACNA1A-related disorders including a form of epilepsy that doesn't respond well to medications, being a high risk for hemiplegic migraines, and global developmental delay. At 8 years of age, Addilynn has been hospitalized for more days than we can count and receives care above and beyond what is expected for a typically developing 8-year-old. She started showing developmental delays at 6 months and since the age of 3, she has experienced 4 life-threatening neurological events that have significantly changed her life and the care she requires. Each of these events come with waves of grief, anger, and frustration...But we continue to make sure she receives the care needed to ensure her health and welfare needs are met, to avoid institutionalization, and to keep our family together.

Due to her disability, Addilynn is on the DD Waiver and receives in-home supports, case management, equipment and supplies, environmental modifications, and medical care including specialist appointments and medications.

As Addilynn's rare disease has changed and progressed, we have learned how to meet her needs from her therapists, nurses, different medical specialists, pharmacists, and dieticians. Our days are filled with meeting her extraordinary needs.

If Addilynn is doing well, I complete two medication passes per day. Her medications are given via her feeding tube. This involves accurate measurement of liquid medications and dissolving medications in syringes. I constantly monitor her for side effects of her medications. If she is feeling ill, the frequency of medication passes and the preparation increases.

If she experiences a medical emergency such as a seizure or hemiplegic migraine, I swipe her vagal nerve stimulator (device implanted in her chest to help with seizure management), administer emergency medications, monitor vital signs, and give her oxygen to hopefully stop the seizure or hemiplegic migraine. A seizure or hemiplegic migraine can occur at any time, without warning.

Illness, lack of sleep, or stress can also trigger a neurological event. She is monitored 24 hours a day, 7 days a week and requires 1:1 care so we can assess and intervene at a moment's notice. Addilynn also has a high risk of SUDEP or sudden unexplained death of epilepsy, so throughout the night, I check her if alarms sound, reposition her for safety and skin integrity, and attend to neurological emergencies if they occur.

Addilynn requires complete assistance with bathing, dressing, transfers, mobility, and toileting needs. I reposition her and complete incontinence management to maintain her skin integrity. I complete wound care of her feeding tube site and any other miscellaneous incisions after surgeries. She uses a wheelchair to get from place to place and a communication device to let us know her wants, needs, and feelings.

Addilynn eats and drinks orally and using her feeding tube. She does not independently scoop her food with utensils and bring it to her mouth, so I assist her during every meal. She has a calorie goal to meet each day prescribed by her dietician. Aside from cooking her meals and feeding her, I also weigh and calculate what she will eat orally and what will be given through her feeding tube. Each meal has the goal to increase her oral motor skills, decrease food aversions, and meet her calorie needs.

Addilynn also has a hydration goal she must meet each day that is prescribed by her dietician. Since she drinks both orally and with her feeding tube, I am constantly calculating and adjusting how much fluid is given through the tube to make sure she meets this goal. She does not independently reach for or hold her water bottle, so I assist with this as well.

Addilynn's days are also filled with school and various medical appointments, skilled home programming prescribed by her physical therapist, occupational therapist, and speech therapist, and adapted play and leisure activities so she can experience as much fun and independence as possible.

The extraordinary, specialized cares I just described are cares that a non-legally responsible adult would be paid to complete for Addilynn. These are all cares that I have trained staff to complete for her. We do the same work, except the non-legally responsible adult is paid, thereby supporting their family and contributing to the economy...and I am not.

Up until February of 2020, I worked as an occupational therapist and manager. Addilynn's health took a turn for the worse and we realized that her developmental, physical, 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 extraordinary cares I have described ...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 works longer hours, and while our family is intact, we have less time to make memories with our daughter whose future is uncertain.

Addilynn has in-home support service hours authorized under the DD waiver that are not being utilized both because of the quality of staff available and because of the workforce shortage. I am frustrated knowing that the cares I provide to Addilynn are valued enough for a non-legally responsible adult to be paid to provide them...but I cannot be paid for the same cares despite the fact

that I am a highly trained, compassionate caregiver to Addilynn who is wholly invested in her future and well-being.

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.

Individuals with all different levels of care are struggling to receive the in-home support services they have been authorized. I have read testimony that direct service provider agencies have a turnover rate of 47% and that they are unable to fill authorized service hours. In previous testimony, it was stated that 13 million dollars of authorized service hours were unused. This is not because individuals didn't need them...it was because there was no one to fulfill these hours. This situation is not going to improve unless SB 2276 passes and legally responsible adults are able to be paid to fill the gaps in the workforce. Passage of SB 2276 would free up demand for those individuals whose care plan states that a non-legally responsible adult is the best person to provide in-home supports. It would give parent caregivers who have been out of the workforce, a place in the workforce. We are all doing the same work.

According to the Kaiser Family Foundation study titled *Ongoing Impacts of the Pandemic on Medicaid Home & Community-Based Services (HCBS) Programs: Findings from a 50-State Survey* published November 2022, every state is experiencing workforce shortages of direct care workers. The study states and I quote "As the pandemic persisted, HCBS workforce shortages contributed to provider closures. Most states (44) reported a permanent closure of at least one Medicaid HCBS provider during the pandemic, up from 30 states in 2021. This trend suggests that even as the broader economy returns to normal, HCBS providers continue to struggle." This study also reports that 48 states allow legally responsible individuals to be paid caregiver, which is up from 36 states in 2020. Both the workforce shortage and the paying legally responsible individuals are nationwide issues that states need to address. (link to the study below)

[Ongoing Impacts of the Pandemic on Medicaid Home & Community-Based Services \(HCBS\) Programs: Findings from a 50-State Survey | KFF](#)

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%, which is significantly higher than national figures of 19%. 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.

Link to the full A&M study and report

[North Dakota Developmental Disabilities Study \(ndlegis.gov\)](http://ndlegis.gov)

I am Addilynn's mom. I am also her service provider because I consistently provide the extraordinary care 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. Please give families in North Dakota the option to be paid as service providers for the extraordinary cares they provide to their loved one. Thank you for your time and I will answer any questions you may have.

Sincerely,

Shawn, Toby, and Addilynn Lunstad

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