

Testimony in Support of SB 2276
2023 Legislative Session
March 6, 2023

Senator Robin Weisz and Members of the Human Service Committee,

My name is Amy Thom and our family resides in Bismarck, ND in District 8. I am testifying in support of Senate Bill No. 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.

Our daughter Em was born with Sturge Weber Syndrome in 2013. As a result of this diagnosis she experiences life threatening seizures (which has resulted in numerous hospitalization stays), has global developmental delays, has a port wine stain which needs regular laser treatment, has had countless eye surgeries related to glaucoma, and has undergone proton beam radiation therapy for retinal detachments. She has low muscle tone, which has resulted in recent bilateral hip surgeries. She has also struggled with her immune system which lowers her seizure threshold level. In spite of how hard she has had to fight, she has the gentlest personality and is such a joy in our lives.

Because of her health struggles, and at the recommendation of our doctors not to do daycare, I resigned from my professional job as a Master Level Social Worker 7.5 years ago. I became her full-time caregiver at home. I have been trained and educated on how to best provide her care from Occupational Therapists, Physical Therapists, Speech Therapist, Pharmacists, and Physicians. She is our miracle and has thrived in our home setting.

As time went on and we had more children, I needed more respite services as our daughter continues to need 24 hour care. She needs complete assistance with feeding, drinking, medication administration, dressing, bathing, and incontinence care. She also needs 1:1 assistance with walking, and continuous safety monitoring due to her seizure activity, which also requires overnight monitoring. Her other needs include all the other typical cares; meal prep, laundry, cleaning, playtime, and all the other activities that simply help her to be a kid.

We have always used the self-directed portion of the respite waiver. My husband and I wanted the ability to hire and know exactly who would be coming into our home environment. As time has gone on, it has been more and more difficult to find high quality respite providers that can meet our daughter's level of care. We have been very blessed to have had a family member from out-of-state move back part-time to fill in

those respite care gaps for us and provide respite care, as we have been unable to find full-time respite caregivers.

If this bill is passed it would give our family the opportunity to continue to meet our goals of keeping Em in our home. My husband and I would have more flexibility to work together to meet our daughter's needs, instead of relying on an outside individual to do these very personal care needs for her as she ages. It is our deepest wish and prayer that we could be together more as a family unit to continue to make sure Em has the highest quality of life possible as well as meet the needs of our other children.

While I was working in Nebraska during college years, I was able to intern and meet countless families who were on NE Medicaid Aging and Disabled Waiver Programs. The ability for family members to provide and be paid for direct 1:1 care instead of hiring outside facilities or individuals to come into their home was such a beautiful process. Their quality of life, ability to maintain cultural practices, and to honor their family unit was so very evident. It was one of my career highlights because it exemplified my own set of values, which is the importance of the family unit. Little did I know that someday I would be one of those caregivers here in North Dakota. My only wish is that our waiver program could financially support family members who are providing extraordinary care to help keep the cohesiveness of the family unit intact.

That is why I am asking each one of you to please consider a "Do Pass" on Senate Bill 2276.

Thank you for your time.

Sincerely,
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