

Support SB 2276

January 24, 2023

Chair Lee and members of the Senate Human Services Committee, my name is Tessa Miller and I live in district 34 in Mandan with my husband and two sons. SB2276 would affect families positively by allowing a legally responsible adult to get reimbursement through a medical waiver for the extraordinary medical needs of a child. This allows parents to care for their medically complex children while being financially stable. This option, families providing care, is much less of a financial burden to the state of North Dakota than residential placement. Which in some instances can be the only option for families that cannot lose that caregivers income coming into the home.

I'd like to share a little of our family's story with you. My 8-year-old son, Asher, has severe autism and is nonverbal along with other diagnosis including ADHD, OCD, and anxiety. Asher attends school in Mandan Monday through Friday with limited hours Monday, Wednesday, and Friday. In addition to school, he attends occupational and speech therapy weekly for one hour and ABA therapy (applied behavior analysis) for nine and a half hours weekly. He is on the North Dakota DD Medicaid Waiver which pays for these therapies and for respite care. Asher is approved for 38 hours of respite care per month though his waiver, but we only use approximately 17 hours per week due to staffing shortages and high turnover rate.

I am extremely fortunate that Asher qualifies for all these therapies, especially ABA therapy, because it teaches him coping skills in order to thrive in our world. This supplies him time with qualified professionals while out of my care or not in school. Autism is the only diagnosis that qualifies for this specialized therapy.

Due to the complex scheduling needs of my son, I was a stay-at-home mom for a while. Eventually, I was able to find a job in my field that allowed me to work part time with a flexible schedule to do pickups and drop offs for Asher. Eventually, that job and my son's schedule also conflicted. Fortunately, I had the resources and support to open my own small business to gain income while working a flexible 20 hours per week. If I was unable to open my business, I cannot imagine an employer that would be able to give me the flexibility I need to get Asher to and from his therapy sessions and school. It would also be impossible for me to work full-time.

Having a child with special needs adds a lot of stress to the already stressful job of parenting. According to Boston University (bu.edu), "The burden of stress is great for those with special needs. A recent study found that mothers of adolescents and adults with autism had levels of stress hormones comparable to soldiers in combat". As parents we do what we can to alleviate some of that stress including respite for the child, seeing a therapist, or attending support groups. What should not be factoring in on these families' hardships is the financial strain. These parents have no choice but to stay home and care for their child with complex medical needs or their high behavioral outbursts because there are just not enough qualified professionals to fill the gap. Add onto that the high percentage of those in rural areas in our state that have no service providers available to them.

In closing, please consider passing this bill to support North Dakota's children with disabilities by proving them with the most qualified person to care for them. This would give their parent or guardian the financial support they need to supply the services to them while keeping the child in the home. Thank you for your time.

Sincerely,

Tessa Miller

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