

Tiffany Peterson

Lincoln, ND

Voting 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.

My eight-year-old son Cooper, along with families like mine are the reason I implore you to vote yes on Senate Bill No 2276. At ten months old Cooper was diagnosed with a brain tumor that has fingered its way through many parts of his brain. This resulted in complete blindness at about 14 months old, seizures, hydrocephalus requiring shunting of three of the four ventricles in his brain, speech issues, an abnormal gait, excess growth hormone, precocious (early) puberty, thyroid hormone imbalance, etc. About two years ago, Cooper was also diagnosed with small tumors and lesions on his spine and some of the spinal nerves, as well as scoliosis that will most likely require bracing soon and possibly surgery further down the road.

At the time of his brain tumor diagnosis, Cooper was also diagnosed with a genetic disorder called Neurofibromatosis, type 1 (NF1). This is a disorder that causes tumors to be formed throughout the body, along with other medical problems. Many NF tumors are benign, but others are considered cancerous. Cooper has been on one form of chemotherapy or another for his brain tumors for seven of the last eight years. The manifestation of NF1 in people varies from mild to very severe, sometimes ending in early death. There is no way to predict the future with this disorder, but we do know that Cooper will continue to have numerous health problems and medical appointments, likely more surgeries, and will never be able to live independently.

I am so thankful that Cooper qualified for a Developmental Disabilities Waiver shortly after his diagnosis, therefore qualifying us for in home caregivers. This saved me from having to quit my job as a nurse and kept my family from incurring even more unexpected debt than we have over the last eight years. As thankful as I am for the in-home caregivers, this has also been very wearing and hard on our family. This is in part due to their lack of experience, the frequent turnover, and the sheer number of people who have come through our home. After eight years of caregivers, I would guess that we have had nearly fifty different caregivers through the agency we contract with -some have been there for one shift, others have been there for a couple of years, sharing Cooper's schedule with other caregivers. Some caregivers are absolutely AMAZING, but others are not. For some this is due to the lack of adequate time to provide them with needed training, but for others it is a lack of desire or ability to learn what is needed. Much of the training ends up in the hands of the caregivers already working with Cooper. Just like the game of telephone though, once a message goes through so many people, the message gets lost and becomes something completely different.

Nobody ever wants to think of having to ask to be paid to take care of their own child, and I'm sure some may think of this bill as doing just that. However, after all my family has been through in the last eight years, Senate Bill No 2276 is a beacon of hope for us, a family that has been "JUST SURVIVING" for so long. In addition to Cooper, I have a son named Owen who is 10 years old and has seen and heard more things than any child his age should have had to, and missed out on more time with his parents than any child his age should have to. If this bill had existed about five years ago when we put 17,000 medical miles on our car, probably spent more time in medical facilities than at home, and Cooper had at least 14 brain surgeries in 12 months, I could have been home with both of my boys when they needed me the most. Instead, I was back to work just days after each of Cooper's brain surgeries – just surviving, trying to make enough money to keep us afloat, and spending just enough time at work to keep me from losing my job– FMLA only takes you so far. That year, Owen spent a lot of time with grandparents, aunts, and uncles that we could leave him with on our way to Minneapolis where most of Cooper's medical care is. Then, as soon as we came home, often after traumatic and emergent trips, my husband and I

were right back to work and Owen was right back to daycare, when one of us should have been home looking after our children – one who was experiencing the emotional trauma of continuously being uprooted and not being able to understand what was going on; the other going through a physical and emotional trauma over and over again.

If Senate Bill 2276 passes, it has great potential to improve the mental wellbeing of my entire family, it will allow me to provide the best care for both of my children, help Cooper’s development of new skills and retaining of old ones because of the consistency I can provide, and would significantly help my family financially. After eight years of taking so much time off of work without pay, we are always coming from behind, and never able to get ahead. Senate Bill No 2276 may even help us step out of the role of “JUST SURVIVING” to “THRIVING”.

I Thank you for your time serving our state and for hearing my testimony. So many families like mine are in crisis, and we need help now. I urge you to vote yes on Senate Bill No 2276 and for it to go into effect July 1, 2023.

I welcome any questions you may have for me.

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