

Testimony SB2276 - Senate Human Services

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ND District 32

Senator Chairwoman Lee and Members of the Human Service Committee.

My name is Brittany Zappone. I have two beautiful children; my son who is 7 and my daughter who is 6.

I am testifying in support of Bill No. SB 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.

Both of my children have special needs, stemming from one traumatic event. Our story was that of a pretty typical household until November of 2016 when our lives were turned upside down and we were soon to navigate a new world completely different from the one we had known. My daughter was in pain and wholly unresponsive. She was life flighted to the only pediatric neurosurgeon in North Dakota. As the minutes and hours turned into several days, we fought to grasp even the slightest concept of what was happening and wondered if the next test or surgery would finally reveal an answer. My daughter was violently shaken. We didn't get the diagnosis right away, but when the news came, I still remember my exact reaction. I was shattered and broken. After the diagnosis, there came interviews and a ton of other new challenges. We are immensely thankful for the ongoing family support we have through Family Voices of ND. They have been there to support us from the start and have truly made it a little easier to process.

Over the last several years, things have only gotten more complex and harder to navigate. In the beginning, I had to quit my full-time job to care for the children. I also had to find a way to utilize all the resources I knew nothing about, navigate the judicial system for a divorce, and somehow move to a new city with services for the children. I truly hit rock bottom but was always supported by those who walked this journey with us. A lot of those being therapists, doctors, friends, and agencies as I did not have family support. Throughout this time, I needed to also find a way

to get her to specialists in Fargo. Due to her medical complexity, she was admitted frequently to the pediatric intensive care unit as they tried to find a medical plan that worked for her. Travel was never a cost that was covered and often left me with hard choices as I did not have an income that could even begin to cover the needs. I had a small portion of TANF but that was nowhere near the income I had previously when I was working.

My daughter transitioned out of early intervention services and qualified for the DD waiver, however when we moved to Bismarck to be closer to specialists, the lack of available and trained staff really made it difficult to work. Daycare facilities aren't trained for medically complex children and can't provide the one-on-one skilled care her condition demands, making that a non-option for her as well. She was in school half days a few days a week. I started to volunteer at her school until a position opened. I slowly made it to full time over the years and only decided to take it as she was supposed to attend school full days in kindergarten. The only reason I still have this job is because my supervisors truly understand my daughter's needs and, when I need to take her to doctors out of state or for an extended hospital stay, they are flexible enough to allow me to make up some time outside of normal hours if needed. I truly am lucky and extremely blessed that I have found this job as most would not be this understanding and flexible, but I do also fear that soon it may cause issues as my daughters' health continues to significantly decline.

With the agencies we did have for respite, it was difficult to find someone to care for her as her needs are complex and require not only someone who understands the medical knowledge, but someone who can find what she wants by her expressions, as she is nonverbal. She has a G-tube, Cecostomy tube, and a VP shunt. She is non ambulatory and has been diagnosed with global developmental delay. The medical complications alone would take me hours to explain. A few of them include encephalomalacia (softening or damage to brain tissues), epilepsy, severe scoliosis, CVI (cortical visual impairment), and cerebral palsy. I found it very difficult to find people and often would cover the shifts myself as the staff was not reliable. As of right now, I have one staff for her, and the availability doesn't allow us to use our current budget. If my staff member is ever out sick or needs a day off, I, again, must cover and leave work to do so. Keeping employment is a must as we cannot

make it without an income, and we do not qualify for any assistance besides Medicaid.

My daughter has had a medical journey that none of us could possibly imagine. Since the injury she has had to fight every single day to survive. She has undergone over 25 surgeries with 10 of them being major brain surgeries. She does therapy every day of the week, sees multiple specialists, and has been attending school full time. Unfortunately, we have run into the issues of the schools not being able to provide her with the proper care and I have missed work to be home with her. She was previously at a special education program for three years, after she transitioned to general education it was a mess. Unfortunately, we've run out of time trying to fix concerns at the school.

On December 29th last year her seizures started to get worse, and they were not responding to the interventions. I administered the rescue medication that I have never had to use and called EMS. She continued to have seizures and was life flighted to her epilepsy team in St. Paul MN. No one could have ever prepared us for the outcome of that visit. Due to issues with formula we had to make the decision to either stay and add one issue to another or try our best to treat outpatient. She was already in pain; I could not knowingly put her through even more problems. I ultimately made the decision to bring her home.

Doctoring out of state is difficult and due to insurance, we have had to make several decisions like this and have had to transfer her knowing very well that she may not survive the trip while actively having seizures. Thankfully those times she did, but, looking back, we know that it was truly a higher power that made sure she did.

Since being home, things have been a roller coaster. She has had multiple medication changes and very little improvement. My fiancé and I are thankfully able to adjust our schedules, but, again, this is only because our employers know the situation. We've been very lucky in that regard. Our staff covers 2-3 hours a day, basically the gap between when his shift starts and mine ends. This has taken a huge toll on my family. Not only do we have limited time together, but the kids also have been struggling as we are never together as a family unit. Unfortunately,

we still cannot make it without both of us bringing in a full-time income. I go to work, knowing that my daughter may not get better. I struggle every day when I have to leave her with my fiancé, who does his absolute best but cannot legally make decisions or calls. I check in often and am struggling daily to keep focused on the tasks for work.

Her condition is getting worse, and the seizures are still breaking through. The doctors have run out of options besides medications that will ultimately sedate her. I always knew that it was a miracle that she survived the injury and that most do not survive. The life expectancy for children with shaken baby syndrome is rarely in their teens, but I never thought that I would be making end of life decisions for my six-year-old child and have them in place so soon. The doctors are trying to slow the progression, but they will never be able to stop it. Her condition will continue to get worse, and it breaks my heart that I will not be able to take the entire journey with her. I will have to continue to work to keep a roof over our heads and food on the table as there is no other option.

I do not know whether we will be able to use these proposed services if the bill passes or not, as our time with her is truly unknown. I do, however, hope that these services will help those in similar shoes if we are no longer able to.

No one should ever have to choose between work and being with their child during the last stages of their condition to provide the quality of care that comes from the lived experience of a parent.

Thank you for your time serving our state and for listening/reading my testimony. I urge you to vote yes on Bill No. SB 2276. Families are in crisis; we need help now.

Thank you for your time and consideration.

Brittany Zappone





