

Testimony SB2276  
House Human Services Committee

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Chairman Representative Weisz and Members of the House Human Services Committee.

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.

First, I would like to formally introduce myself. My name is Brittany Zappone. I have two beautiful children; my son who is 8 and my daughter who is 6. Both have special needs, stemming from one traumatic event: My daughter was violently shaken at 2 months old.

Over the last several years, things have gotten very complex and hard to navigate. Keeping a job was impossible as, due to her medical complexity, she was admitted frequently to the pediatric intensive care unit in Fargo. I had nowhere near the income I had previously when I was working.

My daughter's medical complexity and the lack of available and trained staff out there really made it difficult to work. She's nonverbal, 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. If my staff member was ever out sick or needed a day off, I had to cover and leave work to do so. Keeping employment was a must as we could not make it without an income, and we do not qualify for any assistance besides Medicaid.

Since the injury, she has had to fight every single day to survive. Her seizures have gotten worse, and they were not responding to the interventions. She was life flighted to her epilepsy team in St. Paul MN. After getting home, she had multiple medication changes and very little improvement. I went to work, knowing that my daughter may not get better. I struggled every day when I had to leave her. I checked in often and struggled daily to keep focused on the tasks for work. Her condition is getting worse. The seizures are still breaking through and the doctors have run out of options. I never thought that I would be making end of life decisions for my six-year-old child. It breaks my heart that I was not be able to take the entire journey with her. I had to continue to work to keep a roof over our heads and food on the table as there was no other option. A few weeks ago, my daughter transitioned to hospice services. I am officially on unpaid leave (FMLA) at my current job. When it comes down to it, we will always sacrifice to take care of those we love, but we should not have to choose like this. She continues a remarkable fight each day and has lived longer than most adults at this stage.

Due to these recent changes, we will not be able to use these proposed services if the bill passes. I do hope that this will help the next family, and that they will not have to fight as much as we have for adequate care. The children referenced in this bill are remarkable children who deserve to have the same care as any other child without significant needs. 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 a yes, a do pass on SB 2276. Families are in crisis; we need help now.





