

Testimony in Support of SB 2276

2023 Legislative Session

February 8, 2023

Madam Chair Lee and Members of the Human Services Committee,

My name is Cari Bousfield and on October 25, 2003 my daughter, Faith came into this world 11 weeks early. She weighed just 2 pounds six ounces. About 3 days after being born an MRI showed she had suffered extensive brain damage due to a loss of oxygen to her brain during my emergency C-section, which was performed at the Mayo Clinic in Rochester, MN. The reason I had her there was because I have a congenital heart condition and my cardiologists had to be present at the time of delivery.

Shortly after birth, my daughter was diagnosed with periventricular leukomalacia (PVL). After a 73-day stay in the NICU, my daughter was able to come home to Watford City. However, at 6 months of age she was diagnosed with spastic quadriplegia, which is the most severe form of cerebral palsy. This began a long journey of extensive medical care, specialists, therapies, and other interventions. Due to her medical needs, we moved to Bismarck in July of 2004. Also because of her medical needs, only one of her parents were able to work outside of the home.

Through the years, Faith required many things to improve her quality of life. Some of these things included:

- Feeding tube and feeding pump
- Orthotics for her feet and splints for her hands
- Manual wheelchair
- Standing table in which to stand in an upright position
- Adaptive toys
- Adjustable bed
- Shower chair system
- Accessible van
- Hoyer lift
- Incontinence supplies

Faith also takes anti-anxiety medication as well as several daily supplements. Also, as part of her cares, I make all of her food in a blender instead of feeding her commercial formula. Her g-tube site requires constant care as well, which includes changing it at home every 6 months.

When Faith was in school, she had trouble making it through the day because she tired very easily. We felt they were not able to adequately meet some of her needs, so we made the decision to homeschool.

During our daughter's younger years, we were able to find some very good respite care workers. Many of them were young ladies in college. Unfortunately, once they were done with college, they either found a different job or moved out of state. It was very stressful not being able to keep good help. This lack in continuity of care was also very stressful for our daughter, who thrived on routine.

In 2020 my husband and I decided to separate and he moved to another city. We later divorced and I became Faith's sole legal guardian. Thankfully, I had been working from home since 2014 and was able

to continue doing that. However, I quickly found that it was very difficult to manage caring for my daughter, homeschooling her, doing all of the day-to-day responsibilities on my own, and trying to find time to work. When a friend of mine heard about my situation she told me she got paid to look after her disabled mother who lived with her. She told me that I should be able to get paid to look after Faith. Upon looking into it, I was told due to the DD Waiver she was on, that would not be a possibility. I asked if there was any way for that to change and the person on the phone told me the only way that would happen was to advocate for it.

As far as supports for Faith, I have one respite care worker who comes 3 hours a week (we qualify for 60 hours a month) to do my daughter's shower, her feeding, in-home therapies, and personal cares, such as getting her dressed, combing her hair, brushing her teeth, and clipping her nails. (Unless she is at her day program, I am the only other person who does all of these things for her). During respite care time, I am usually running errands.

Faith attends her day program 15 hours a week. She also goes to physical therapy, occupational therapy, and speech therapy 3 days a week. I transport her to both her day program and therapy, which means a trip to Mandan and back several times during the week.

Besides personal cares and transportation, part of Faith's cares consist of getting up at least twice during the night to change her diaper or reposition her. Sometimes she needs help every few hours, and even more often when she is sick. This means that when she is at her day program, I sometimes have to make the choice of trying to get some work done or take a nap as to not overextend myself. As I mentioned in the beginning of this testimony I have a congenital heart condition, so I have to be careful not to overdo it. It's really only by the grace of God that I can continue to keep doing what I've been doing.

I understand that by the time this bill goes through, my daughter will be almost 21 years old and hopefully at that time my daughter will be at her day program full-time. I am hoping she might also increase her independence by living in a group home. However, I know firsthand how getting paid as a caregiver in our home would have been of great benefit and would have reduced the amount of stress exponentially. If I can't take advantage of the passage of this bill, I know that there are many families who would get some much-needed relief from it.

I appreciate you taking the time to read this testimony and for considering the passage of SB2276 for families in North Dakota who are in desperate need of any help they can get.



Sincerely,

Cari J. Bousfield

(Faith's mother, service provider, and legal guardian)

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