

Testimony
SB2276
Human Service Committee
03/08/2023

Chairman Weisz and members of the Human Services Committee.

I thank you for all being here today to listen to me on why you should support Bill 2276.

My Name is Jessica Neigum Dargis, and I reside in District 30. I am here on behalf of my daughter Belle who is 4 years old and is developmentally delayed due to being born with an occipital meningocele.

I also work for a developmental disability provider and I'm a local business owner so I can understand the staffing shortage that faces the North Dakota workforce. While all organizations will remain nameless during my testimony, please know that I sit on the executive team at the organization I serve so I know firsthand the staffing struggles that many DD providers are facing and the difficult decisions that are made daily; Many DD providers are having staffing crisis with a turnover ratio of 40-50% which can be proved through Alvarez and Marsal case, please see page 105.

https://ndlegis.gov/files/committees/67-2021/23_5168_02000presentation1230.pdf

Unfortunately, most of the agencies that provide in home supports provide other services such as day programming, residential support, or intermediate care facilities, so when the organization is short staffed and need someone to cover at a location they manage, they often cut family support care first as there is a "back-up" also known as the parent, which doesn't exist in other care settings. Leaving parents caught in the middle of being at work or caring for their child, which in all cases the parent picks their child. Once a parent misses enough work because they don't have adequate care for their child, the parents' employer starts to consider the parent an unreliable employee.

I can respect agencies being short staffed or having sick staff as I hear about it at the agency daily, however as a parent it can be frustrating to find out 20 minutes before work that you will not have care for their child that day.

At some point parents give up their jobs, to ensure their child has continuity of care. While some may suggest daycare, there are very few daycares that will provide care to medically complex children. My daughter Belle attends Bismarck Early Childhood Education Program and receives a 1 to 1 aid while there, most daycares will not provide a 1 to 1 as that is not cost effective to their programs when in most other situations for a 4-year-old they can have 6-8 children or more to 1 teacher or aid. If daycares are willing to provide care, they want to charge the family for that 1 to 1 staff which in most cases negates the point of the parent working as their hourly wages goes to pay for the hourly wage of the staff taking care of their child as public daycares are not certified to bill the state for Medicaid. Which then pushes parents back to using a certified agency that can charge Medicaid yet is short staffed and always cutting care hours.

The state has really left a hole for parents of children with disabilities or special health care needs and forced many to quit their jobs. I am lucky enough that my mother retired after 39 years with the state of ND several of which were served in the Department of Public Instruction and is caring for my daughter.

I don't have to worry about my staff not showing up, because my mother is always there for her and me. However, if something was to happen to my mother, I would likely be without care.

Thank you for your time and consideration in voting in favor of bill 2276

I would like to close with a final thought.

Children are a vulnerable population. **Individuals with disabilities** are a vulnerable population.

Children strive on routine as they understand what is expected of them. **Individuals with disabilities** strive on routine as they are familiar with the process.

So why not provide **Children with disabilities** the stability of a familiar caregiver such as their parent so they can successfully navigate life?

Jessica Neigum Dargis
Parent of a child with a disability
612.695.8150
jess.neigum@gmail.com