

March 8, 2023  
Testimony in Favor of SB2276

Chairman Weisz and members of the House Human Services Committee,

My name is Katynka Morrisette and my family lives in Bismarck , ND, in District 7. My husband, Joe, and I have 3 medically complex children who are on the Medically Fragile Waiver. I am writing to you to ask for your support of SB 2276, that allows a legally responsible individual to be paid for the extraordinary cares they provide in the home to their child that requires care far beyond what a typically developing child their age would require.

Due to our children's metabolic condition they require constant supervision, multiple blood glucose checks and ketone level checks per day, medications and nutritional supplements given via g-tube around the clock, care for their implanted medical ports and medication to be administered in that central line, regular infusions, breathing treatments and chest percussion vest therapy, as well as intervention and assistance with multiple daily living tasks.

No two days in our home look the same, with my living room becoming a space for rescue medication, IV poles, feeding pumps, scales, syringes, formula bags, heating blankets, and emesis bags at a moments notice. We try all possible intervention when our kids are in metabolic crisis, to avoid a lengthy and costly hospital stay. Too much physical activity, too little sleep, a common cold, a late dose of cornstarch in their tube, or an unsafe food being given can all trigger a crisis with life threatening hypoglycemia or acidosis.

With our waiver we are authorized for in home support and care, but due to staff shortages we have not had those hours fulfilled in months. I have contacted or interviewed now 39 potential employees in the last 6 months. We have been able to staff a mere 5 hours a week, some weeks. Those hours are filled by a previous employee who is now advancing in her education and professional career.

People are taking other jobs that offer benefits or more pay, they just don't feel like working many hours and want something easier, or they do not give me a response at all and don't show up for the interview. This is the reality of the workforce crisis we are in. Even if we found somebody willing to fulfill these hours, it is hard to get someone trained to do this level of care and mistakes have been made by previous staff. My husband and I have spent many hours being trained by their teams of specialists on how to give them the safest care and keep them in our home, some of those extraordinary cares would have to be performed by a Registered Nurse but as the legally responsible individuals we are able to do them.

With this bill you would allow the legally responsible adult that is giving these extraordinary cares the ability to be compensated for the care we are authorized for and not receiving, as well as making us a part of the workforce that so many of us have been forced to leave due to staff shortages not allowing us to work outside the home. This would also free up staff from agencies that have been giving some coverage to the higher level of need children who qualify for this service option, and allow them to provide better coverage for the families who this service option is not considered in the best interest of the child's needs per the child's DDPM on annual assessment.

In these months without staff in our home, I have no longer been able to keep my employment outside of our home. While this has been a sacrifice for our family, we have also been able to see improvements in their stability and wellbeing. We believe this is because the best quality of care for these children often comes from the parents who work closely with teams of doctors

and therapists and are fully invested in the health and care of their child and child's best interest.

We are not asking to be paid to be parents, we are asking for the compensation that would be given and has been authorized to be given to a total stranger coming into my home and performing these tasks, but only after spending weeks being trained by me. No amount of training can substitute for the years of "on the job" experience in managing my child's medical conditions.

I wanted to be able to testify in person today, but without in home staff support for our kids and the extensive cares required, I am unable to leave them with an untrained caregiver or drop-in daycare on a good day, let alone when one is sick.

I kindly ask that you give a DO PASS recommendation on SB2276 so that families are not faced with hard decisions like placing their child in an institutional setting. Keeping families together, children in their own communities, and increasing health outcomes when care is being compensated for and given by a loved one should be a priority in this state.

Thank you for your time and DO PASS recommendation,

Katynka Morrissette