

Senate Human Services Committee
Senate Bill 2276 – February 7, 2023
Testimony in Support of SB 2276

Chair Lee, and members of the Senate Human Services Committee, my name is Kellie Hamre, and I reside in District 27. I am writing you on behalf of my daughter, who is 9 years old and was born with Down syndrome and a congenital heart defect. I am writing in support of SB 2276 relating to legally responsible individuals providing Medicaid waiver services.

Upon my daughter's prenatal diagnosis of Down syndrome and a congenital heart defect, my family immediately entered a world we were unprepared for. When she was four months old, we traveled to Minneapolis to get her heart repaired. What was supposed to be a straightforward repair, resulted in complications that sent us down a different path. After her first surgery, while still inpatient, she struggled with medication regulation and went into heart failure and pulmonary hypertensive crisis. The stitches on her mitral valve ruptured and the unregulated blood flow was backing up into her kidneys and lungs causing her to struggle to breathe. Fast forward through 69 days inpatient, a second open heart surgery, 14+ days on a ventilator, feeding tube, and countless meds we went home. At home, she needed 13 medications multiple times a day, was on a narcotic wean, ate only through a feeding tube, and required home oxygen. She had lost all the basic skills she entered the hospital with and was now extremely medically fragile.

At her first doctor appointment post discharge, we discussed options on care. I will never forget her doctor saying that right now my daughter needed me. She needed her mother more than anything. My husband and I wholeheartedly agreed, knowing that financially going from a two income household to a single income household would not be easy. I took an unpaid leave of absence from my job to focus on her recovery.

At this time, we were living in Moorhead, MN and I was able to utilize funding through the Minnesota Department of Human Services so I could be my daughter's in-home caregiver. Being required to hire an outside caregiver, a stranger, to provide in-home support for her would have put her at increased risk of illness, reduced her continuity of care, and created an environment of many unknowns. Thanks to the funding available in Minnesota, I was able to put my focus on where it was needed most. My daughter's recovery.

When we moved to North Dakota, I was thankful for the numerous supports the state had in place for her. However, a critical piece missing is the ability to hire a legally responsible individual for her.

Thankfully, my daughter is now a thriving 9-year-old. My husband and I firmly believe that is due to me being able to fully focus on her as her in-home caregiver during that critical time in her life, an essential support our neighboring state provides.

I often think of other families navigating similar paths as ours in North Dakota and the challenges they face. Staffing shortages are real and a challenge that isn't going away. Stability and consistency are key to so many individuals with a disability. The ability to hire a legally responsible individual will have a life changing impact on families making our community and state an even better place to live.

Please support SB 2276.

Respectfully,

Kellie Hamre

Parent of a child with a disability

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