

Senate Human Services
SB 2276
January 24th, 2023

Senator Lee & Members of the Committee,

My name is Nicki Maddock and I represent myself as a parent of a child with a developmental disability. My son has Duchenne Muscular Dystrophy (DMD) and was diagnosed shortly after his first birthday. As a background of what that means, Weston was given a life limiting disease diagnosis. He will lose mobility and be wheel chair bound by the age of 8-12. His diaphragm and heart will start to weaken in his early teens, requiring ventilation and medication. He will also develop progressive weakness in his upper extremities. Currently, a child with DMD has a life expectancy of 29.

When our son was initially diagnosed, I was working full time as a Medical Technologist in the hospital. Weston had multiple appointments and therapy sessions that required me to be present during the middle of the day, along with clinic days every six months in St. Paul, MN. I had exhausted my paid time off and ended up leaving the field completely to take a part time job with flexibility to be able to meet Weston's needs. This was a significant loss of income for our family, but we felt we had no choice as Weston's safety and health was our main concern. We also had to factor in that Weston has a progressive disease, so his level of care needed was only going to increase.

Due to his progressive rare disease we are currently self-directing our respite hours and utilizing grandparents. We know that if we were to self-direct staff outside our immediate family it would require a significant amount of training on our part. Weston is the only child in Bismarck with DMD to my knowledge. With high turnover rate that currently exists, it would be very difficult to have competent staff taking care of Weston's needs in the appropriate manner. Weston also has a severe speech delay, which has been attributed to his diagnosis. He is unable to communicate through words to us or a caregiver when he is tired or being overworked. Those of us who are consistently in his life understand his needs through non-verbal communication. There is also very real concern that if you don't understand his disease you can do irreversible harm to his body and his muscles. Weston would be unable to voice to us if that was happening through an agency, which would put him in a vulnerable position. He is only going to get bigger and require more physical assistance. As his condition continues to deteriorate, he will lose his ability to feed himself, bathe himself, and perform basic life skills. His grandparents will eventually be unable to provide the care he needs. If this bill were to pass it would allow my husband and I to step into that role to ensure competent staff and keep Weston in our home.

With the reasons stated above my family strongly asks for a "yes" vote for Senate Bill 2276 to ensure we are always able to provide the necessary services for our son, especially as his level of care becomes more significant. Thank you for your time and consideration.

Nicki & JP Maddock
Parents of Weston Maddock
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