

Maran Blair

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Voting district Morton

I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

I am a single Mom and choose to quit working after my maternity leave so I could take care of Keegan due to him being medically fragile and his medical complexities. Keegan was born with arthrogryposis, hypotonia, microcephaly, clubfoot, a brain abnormality, and many others. The brain abnormality has caused him to have epilepsy. He got a feeding tube surgery at about a week old. He also got a trach surgery about 8 months ago due to breathing issues.

When we wake up in the morning I have to suction him a lot due to build up of secretions when he's sleeping. This can cause him to gag as well. I also give him 6 different medications in the morning and 5 at night. Every day I have to clean his trach mask he uses at night that hooks up to a humidifier machine, fill the humidifier, get out a new HME for his trach during the day, do trach cares, make formula, fill feeding bag, and homeschooling. The humidity for his trach is because since he can't breathe out of his mouth and nose so the humidity provides moisture for his throat. Every week Keegan also has 3 days of therapies consisting of 5 appointments total, this does not include the school coming into the home to provide homebound school services. My Mom and I also do a trach change every week. I choose to homeschool Keegan due to all his medical complexities and being medical fragile. His pediatrician wrote a letter strongly advising to homeschool Keegan due to these issues.

Having this bill passed would financially help to supply Keegan's

needs plus bills and not having to go without things we need. It would also help get adoptive equipment that would make Keegan thrive as adoptive equipment is expensive and a lot is not paid through Medicaid such as an adoptive carrier, special swim gear, a floor play chair that is supportive, and many others.

Thank you for your time serving our state and for reading my testimony. I urge you to vote yes on Senate Bill No. 2276 and for it to go into effect July 1, 2023. Families are in crisis, we need help now.

Maran Blair

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