

Paula Ennis
Voting district 33

I am testifying in support of 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 Grandma to Asher Ennis born on 09/02/2022 and diagnosed with CF on 09/13/2022 who resides in Gwinner, ND
Mother Nicole Ennis.

Becoming a parent for the first time is scary, Nicole faced not only this new scary world but also during a pandemic, and then finding out Asher now has Cystic Fibrosis. This leads to a lot of stress, education, heartbreak, but also a blessing because she still has a beautiful baby boy. We all work every day to ensure one thing: that our children outlive us. Unfortunately, we can never be sure of that, can we? But no parent can. Tragedies happen, and with CF they happen ALOT!

Gwinner is a very small community with limited services, and there is currently one daycare and they do not have the staff to accommodate a baby with CF

One downfall of all the treatments a baby with CF is that your average teenage babysitter is unable to babysit, it takes someone that knows how to do all the treatments necessary for Asher to help prevent early organ damage and help Asher to live a longer, healthier life.

Daycare providers are spending more time with our children than we are.

09/19/2022 Asher was seen at Sanford coordinated treatment center in Fargo. The Doctor explained to Nicole she would need to stay home with Asher for an additional 12 weeks after a short term disability and recommended Asher not to go to daycare until at least one year of age.

Nicole was denied FMLA at her place of employment for 4.5 years due to the fact she had not worked enough hours in 2022

They also explained that she would have to go back to work at 6 weeks with no FMLA for any of Ashers Dr. Visits so unfortunately Nicole had to resign at her place of employment.

I ask you to please consider paying the parents of Cystic Fibrosis especially in ND and vote in favor of bill 2276

Thank you for your time
Paula Ennis