

Hello, my name is Matthew Ferderer.
My wife and I live in Mandan in voting district 34.

We are 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 was raised on a dairy farm just west of Mandan. This upbringing prepared me to handle many life situations with more ease than the average person. As a lot of North Dakotans know, farmers must wear many hats in order to be successful. You must be a veterinarian, an electrician, a mechanic, a welder, an equipment operator, a plumber, an accountant, a businessman, an agronomist and work 100 hours a week. The list goes on and on and you must constantly improve your abilities in this ever-changing world. The same is true for parents of special need children. You have to be a doctor, a nurse, a phlebotomist, an occupational therapist, a physical therapist, a speech pathologist, a nutritionist, a respiratory therapist, a psychologist, a pharmacist. You must specialize in GI and IR and learn everything there is to know about heart transplants and rejection and worry about sickness and infections constantly. And at the end of the day, the transplant surgeon's voice echoes in our mind. He said to us, "that is a good heart, it will last her 30 years." 30 years! Sometimes we look at each other and say we will bury her someday. We should be enjoying these days but the guilt of not working with her so that she can develop and be the best that she can be and the fear of taking her out in public because she is immunosuppressed and could get sick and have to take another antibiotic and risk heart rejection. Things that most parents don't have to worry about. Raising a child is a feat of its own, but nothing can prepare you for a child with special health needs. A person could never understand unless you have gone through it yourself. We are wearing more hats now than ever and our backs are tired. Most of the time we feel so numb that it is hard to think of the future. We also have another child that we are trying to raise to be the best he can be. The hand we have been dealt has limited us. It has affected our marriage, our bank account, our jobs, our mental and physical health, our relationships with family and friends, opportunities and ultimately our livelihood. I am not standing up here asking for sympathy from anyone in the room but rather empathy. I am just trying to paint a picture so that maybe you can understand. That being said, we wouldn't change it for the world. Our little Elliott brings us many challenges, but also so much joy. We love her in indescribable ways.

My wife and I have worked hard to get to where we are at in life. We planned to have our son and we planned to have our daughter, but we could never have planned for what has happened in the last 2.5 years. We enjoy our jobs. We enjoy what we do with our money that we have rightfully earned. We have had to drain resources we worked hard for due to all the time we have had to take off work unpaid for appointments, therapies, hospital admissions but most of all when we don't have staff to care for her. She deserves to have opportunities to participate in therapies that will dramatically help her abilities, but they are so expensive, not covered by insurance and we as parents obviously have to be with her to participate. This bill would allow us to help fill the gap of no paychecks while we travel for these therapies. Changing this legislation would help us and so many other families in similar situations.

I am not a political person, but I do stand up for what I believe in and for others that need help. This bill just makes sense.

We were told that she had a heart condition at her 20 week ultrasound. At 36 weeks, my wife relocated to Minneapolis as she would have to deliver there. Our daughter, Elliott, was born with an extremely rare heart defect. She was diagnosed with pulmonary atresia and intact ventricular septum with severe hypoplastic right ventricle complete RV-dependent coronary circulation with bilateral atresia of coronary ostia. Shortly after her birth she underwent surgery that involved atrial septectomy, BT shunt and aorto-tricuspid RV shunting. These are medical terms that moms and dads shouldn't need to know, unless you're a pediatric cardiac doctor. Elliott has traveled a very long road in her short life already. The first two open heart surgeries allowed her to survive until transplant. She received a heart transplant at the age of 2 months old. It is very difficult to put the emotions into words, but that day came with several complications. Elliott spent the first 8 months of her life in the hospital. Because of how long Elliott was inpatient, sedated with medications, intubated and immobile along with the complications from surgeries (mainly right after the heart transplant) she suffered seizures and two strokes. The second stroke was more substantial, and the left side of her brain was hit hard. She has right sided hemiparesis as a result, which means she can't move her right arm or leg as effectively as her left. She has also been diagnosed with Cerebral Palsy because of the stroke. Another complication from the day of her transplant was that she lost blood flow to her right foot. Her toes and her heel on her right foot turned black and eventually self-amputated. She does not eat or drink enough orally, so she gets her nutrition via a GJ tube. She has PT, OT and speech therapy that come to our home daily and often several therapists each day. She takes meds twice a day to suppress her immune system in order to prevent rejection of the heart. We could write a book on our journey so far. My wife and I have fought until we are numb so that Elliott has a fighting chance at life and so that she has the best possible outcome.

Now imagine struggling to balance work, other children at home, finances, meds, therapy schedules, medical supplies, sports schedules, marriage, a social life; while constantly worrying if your son or daughter is getting the care she needs. We have gone through several caregivers. Some just don't show up, some show up but obviously don't care, most can only work very limited hours, one we even had to let go because she was intoxicated while caring for our daughter. It is very difficult to find quality caregivers that care about Elliott and impossible to find someone that cares about her as much as her parents. Elliott has special needs. A simple illness can severely threaten her life. Completing PT exercises, OT exercises, range of motion, speech, feeding therapy, g tube feedings; these are just a few of the things in Elliott's daily schedule. Her daily care takes specialized training and medical knowledge/experience. Because Elliott is immunosuppressed and has these special needs, we cannot take her to a daycare. There are countless days, weeks, and months where my wife or I need to stay home from work because there is simply no staff. We have no PTO. We don't get paid. We cannot afford to have one parent stay home as we both have essential roles in the workforce and need paychecks and benefits to provide for both of our children. Allowing us as parents to be paid when we must stay home from work due to not having staff would alleviate so much stress. It would also give us the option to stay home more often and possibly full-time if we ever chose that. Most importantly it would give Elliott the best care possible. We are her parents, and we are already providing all these cares. We are the experts and best people for the job. A stranger can get paid to take care of our daughter, but we can't. The funds are already approved and allocated to Elliott and her care.

Having a child with a disability is hard. We shouldn't have to choose between leaving her at home in someone else's care versus going to work to pay the bills. The right solution is to let Moms and Dads have the option to stay home and care for their child and be paid. That solution has the best outcome for everyone involved.

Kris is a program coordinator at HIT Incorporated. She has been there for 12 years. Her extensive knowledge has helped us navigate this process with our daughter. She oversees plans for individuals with developmental disabilities. She lives it day in and day out; caring for her clients and their families. She not only does it for employment, but she lives it.

I am the Service Manager for Titan Machinery in Bismarck. My company has been more than helpful in our situation. I manage 7 people and take care of a statewide community of customers. My customers include farmers, ranchers, and construction contractors.

We both excel in our careers. We enjoy our careers. We, as everyone, strive to live the American dream. Help others, live a meaningful life and enjoy life. If this bill passes it would make that possible for the minority of people now struggling with unforeseen and unchangeable circumstances.

Thank you for your time serving our state and for listening to our 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.