

My name is Sommer Jacob, I live in Center, ND, voting District 33.

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.

When my son Bennett was born, was a surprise. He came very unexpectedly after 8 years of infertility, without warning or assistance. He was born prematurely, at 33 weeks, which again surprised us, and scared me. But that was nothing compared to the surprise which followed, just four days later.

After an easy pregnancy and normal results from routine prenatal testing, I was stunned when the doctor came to my hospital room and informed us that he suspected a chromosomal abnormality. I couldn't even comprehend what he was saying, and looked to our NICU nurse, with confusion, asking "What does he mean?" When the words "Down Syndrome" fell from her lips, I could hard believe it. Initially I thought it must be a mistake. After describing some of the typical characteristics of babies with Down Syndrome, it started to sink in. Then I was crushed – devastated, really. We hadn't prepared for that. There were no indications that anything was "wrong." The ultrasound results looked normal and despite my advanced maternal age of 40, I opted out of additional testing because of those findings.

The medical team set forth with genetic testing and shortly thereafter, confirmed, that Bennett did indeed have an abnormality; Trisomy 21. They began looking for the typical health concerns associated with infants with Down Syndrome. The majority of the diagnostic test results were normal. All but those which involved Bennett's tiny little heart.

He was diagnosed with an atrial septal defect (ASD); a hole in the wall between the heart's two upper chambers and ventricular septal defect (VSD); a hole in the wall between the two lower chambers. He would need to have surgery to repair the holes, one of which the cardiac surgeon described as dime sized, on this little golf-ball sized heart -- Open heart surgery at Mayo, in Rochester, MN when he was old enough and strong enough. That would be when he was around 5-6 months old.

Around this time, we were encouraged to pursue coverage for Bennett with the Medicaid waiver program. At that time we had a good income, a fantastic health insurance plan and I didn't think it was really necessary. But after careful consideration, and a lot of handholding, Bennett was approved. I cannot express how incredibly grateful I am that I had the assistance, guidance and expertise of Roxane with Designer Genes and the team at CHI NICU during that time! It was difficult for me to form a coherent thought, never mind navigate the "system" surrounding those in the world of disabilities!

Bennett had a successful surgery and was released from the hospital after just 2 days. We stayed in town an extra night, just because I was nervous about flying home with him, so soon

after surgery. On the flight home from Rochester, we had a layover and connecting flight in Minneapolis. While changing Bennett's diaper, we noticed something didn't look right. His left foot appeared to be abnormally pale and cool to the touch. To keep this brief, I'll skip the details which led us back to Mayo. Bennett ended up on a private flight from Bismarck, back to Rochester, the next day, courtesy of the medical flight team in Bismarck. He had developed a blood clot in his leg. Another brief stay at Mayo and we were given a twice daily routine of injections to dissolve the clot. Something I didn't think I could do, but it's amazing how quickly you get skilled at things you don't think you can do when your child's life depends on it.

It was shortly after that event, I left Bennett's dad. We had a challenging marriage but when I feared for Bennett's safety, for his life, one particularly difficult day, I knew we had to get out. The next 12 months, there was a protection order in place, prohibiting contact with my now ex-husband. He could see Bennett, but it would be through relatives, which he chose to do only a handful of times. During those 12 months, I filed for divorce, sold our marital home, left our mutually owned business and tried to get my feet back on the ground with my other business. My primary income and insurance benefits were all tied into the company we'd created and was then in his hands alone. I was still in a fog, trying to navigate respite care, numerous therapies, checkups and just trying to figure out what was coming next!

I lost my insurance benefits and was so grateful for the Medicaid program so Bennett had coverage. The number of hours for respite care we'd been receiving wasn't enough now that I was raising Bennett entirely on my own. Thankfully we had a great DD program coordinator and I was granted extra hours to cover my work hours and a bit of extra for some "me" time.

I'm still self-employed. I've remarried to a great man that fills in as an awesome father figure to Bennett. His home was in Center, where we eventually moved.

Bennett is doing great in the Hazen school, but is transported there 4 times a week. Most days this isn't an issue. However, there has been times, it has been. And finding reliable, trustworthy, and skilled caregivers for him, is an entirely different challenge.

I work from home most days, even though I have an office in Bismarck. My mom was Bennett's primary caregiver until this past August. When he had to go to preschool at the age of 3, we weren't sure of the hours he'd be going or the hours we'd be approved for respite care. This was my mom's primary income as she had quit her regular job to care for him. My dad took his life two years ago, so she relies on the steady work since she survives on her own income now.

It was a concerning transition for me, to get someone new to watch Bennett during my hours of work, and when he wasn't in school. We've got a great primary respite care worker now, but she has her own family as well. Sometimes there are things that prevent her from being able to work.

The constant care and monitoring Bennett requires can and has seriously affected our family emotionally and financially. For example, my husband works 2 hours away and had to leave work early to assist with the care of Bennett when he was in a hypoglycemic state; a potentially life-threatening condition. Our family lost much needed income much needed income due to my having to leave work early. Additionally, when Bennett is ill (?), I cannot get my work done since Bennett requires one-on-one care during the time when my current respite care worker is not available. Being a sole proprietor, I have no one to cover my work when I am unable to do it.

Bennett's immune system is seriously compromised due to the DS, so he frequently develops coughs and other flu-like symptoms. The school system and the respite care worker are opposed to caring for Bennett when he is ill due to fears of contracting his illness to other children or possibly their families which results in me or my husband staying home from work to care of him. Losing the income due to the frequency of Bennett's illnesses seriously impacts the family finances.

Living in a smaller town lends itself to a very limited supply of qualified respite care workers. When we first moved to Center, I began my quest for respite care workers and did not turn up many candidates. When the one respite care worker I have has a family situation or is ill, I have no backup. This leaves me or my husband in a serious situation not being able to work. This can adversely affect my clients as well as my husband's employer.

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

Name - Email - Phone number