

Testimony for SB 2276

I am testifying in support of SB 2276 with regards to changes to the medicaid waiver services and I live in Mandan ND.

I have a unique perspective to the needs of this bill to pass here in ND. My son was born with severe congenital anomalies, for instance, Dextracardia situs solitus (heart on the wrong side of chest but also tilted and backward), Poland Syndrome (left major pectoralis muscle missing), 5 1/2 ribs missing on the left also, 100% GERD that meant every time he ate he inhaled formula into his lungs, He also had 3 holes in his heart 2 VSD 1 ASD, Restrictive Airway and Lung Disease which later became Reactive because of the chronic bronchitis and pneumonia over several years as well as tachycardia. I was a single mother and was told at Duke University Hospital they had never seen this before and that my son had a 2% chance of survival to his first bday and 0% to his 5th bday. I worked 2 and 3 jobs after 2 yrs of being told by our social worker there was no point in getting a job because child care help will only cover up to 1.75 an hour and because my son needed someone with medical experience i could not afford to get care. Finally with the help of our respite care nurse who agreed to help me by watching him for the amount i was allotted a month plus what i could afford outside of that at times i worked two and three jobs in between the constant physical and occupational therapies and many, many dr visits and specialists and hospitalizations which were either here in Bismarck, Fargo or Minneapolis. Going to Minneapolis at least 3 or 4 times a year makes it hard to keep a job when you go thinking it is a 3 or 4 day visit to see all specialists but end up there because of unexpected surgeries and hospital stays at Childrens that would last a couple weeks up to six weeks! Most employers do not understand and neither do landlords so we had to move a lot because I could not pay my rent if I had no income. After 58 surgical procedures, most were prior to age 10, and hundreds of Hospital and clinic visits. I can say my son is now 31, almost 32 yrs old and although his health issues can still cause issues he rents from his best friend as a roommate and works full time. We were lucky in some ways of having a really awesome respite care nurse that helped us and his support care worker who also helped out at times outside of our regular hours.

My unique perspective is the fact that I worked later as a respite and support care person for a couple of years and was a CNA for more than 2 decades. Now we have guardianship of our oldest grandson who is Autistic, Nonverbal, Sensory Disorder, Severe ADHD and Chiari Malformation Type 1 with a 9 mm herniation for which he is having neurosurgery on Feb 9th,2023 in St Paul at Gillette Childrens. We have been extremely lucky with the staff at school from teachers, paras, the principal and secretary and our whole IEP team being behind our grandson from the beginning and are easy to work with. From the principal on down the line they are awesome but above him there is a lot of issues unfortunately. Our grandson receives Speech, Occupational and Physical Therapy at Sanford once a week as well as ABA therapy at Anne Carlsen 3 times a week which he ends up at school a bit later on Mondays and Fridays and he just goes to all therapy on Wednesdays no school. Because I am just getting out of my wheelchair for the first time in over 15 years I was supposed to receive help through respite and support care hours in the amount of close to 280 hrs a month but because of the shortage of staff we have our respite worker pick our grandson up every Wednesday at 10am and she takes

him to Sanford then when he is done at noon she takes him to grab lunch on the way to ABA so that is about 3 hrs once a week that we have that because there are too few workers to the needs that are out there. That is only 12 hrs out of 280 hrs a month. Our respite worker is great with our grandson and yes we have checked other places but they are also shorthanded. Without the support staff or respite and having nobody in the family that can care for your child that could be paid but yet the parent who knows how to care for their child the best not being allowed to and needs to worry about how to pay bills or keep their job if they are lucky enough to get one once you disclose you need to take your child to appts 2,3,6 times a weeks or every other week or even a month you end up stuck. To be scared for your child, not able to pay bills, not able to get child care or respite hours until your child is in school is really hard on families and takes a physical toll on the primary caregiver. I know because once i knew my son was ok and my husband and i married in Dec 2004 i ended up ill but it wasn't until the very beginning of 2007 i ended up in a wheelchair because of the stress and exhaustion everything i went through to make sure my son lived through every surgery and hospitalization and the constant living off 2 or 3 hours sleep every night for years. I know so many single parent families and dual parent families that are sacrificing so much to try to get through these types of issues because of the costs for just basics of rent, food, utilities, phone, car, insurance, etc when they either cannot get a job or cannot keep one because of having a sick child. If a parent was a paid caregiver that would alleviate so many problems for families and quite frankly employers who complain when you are going to be a few minutes late because you need to finish admitting your child to the hospital and even though you are only 5 min late they fire you and complain you just do not want to work which is ABSOLUTELY UNTRUE! There are several states already that do pay the parent as the caregiver and it seems to work well because in many cases the state is not paying for a registered nurse full time to care for many of these children. The cost is less to the state also in how in some cases that extra in a two parent household where one parent is working but they need a second income is the difference between a family on a lot of assistance versus paying them usually less than what you would be paying the professionals to come in and care for the child instead plus all the costs associated with those contracts.

This Bill, SB 2276, not only makes common sense, it is fiscally responsible and is just the right thing to do for the families that are already stressed and scared and worried on a daily basis. It also has a continuation of care that will improve the health and welfare of the child.

Thank You
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