

My name is Lisa Kroh.

Our address is rural New Salem. We live 17 miles west of New Salem on a farm. We are in the Glen Ullin voting district.



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.

Our Story

In our family we have 6 children, 5 boys and 1 girl. Ages 15, 13, 11, 7, The last 2 are twin boys 5 years old. 2 of our children have disabilities, only one receives services. His name is Benat. I stay home and my husband works full-time and is also a full-time student.



Back – Lisa, DeLainis, Wes, August
Front – Benat, Henry, Fritz, Gordon

Benat was born premature at 33 weeks and is a twin. 7/13/2017



Within minutes after birth, we were told he had a heart defect and was flown to Mayo Clinic in Rochester, MN within 24 hours after birth. We were told he has a bicuspid aortic valve with severe stenosis of his aorta. At 10 days old he had open heart surgery. Luckily, he got to come home after only 4 weeks in the hospital. We were told that the fix was only temporary and by age 2 will more than likely have to have another surgery.



Wes with Benat at Mayo.
9 days before surgery.



10 days olds.
2 hours after surgery.



Dr. Said, the one who
saved his life.

At 6 months old he was having issues and ended up back at Mayo for a balloonoplasty to open aorta. Which helped his situation and will allow him to grow and get stronger.



Mayo allowed Henry to go as moral support.

He has also been diagnosed with visual issues (CVI), autism, speech delay, eating issues (a lack of wanting to eat or drink without being continually prompted to eat) and physical/mental processing delay. However, when tasks are learned it is evident that he is capable of things that are unimaginable to doctors given certain medical conditions and diagnosis that he has.

From the beginning of birth all I heard from doctors was “I’m sorry.” With no answers.

So, I set out to make him the best he could be. He wouldn’t eat and they were talking feeding tubes. He was losing weight. They said he had rib flare and wanted to put him in an abdominal binder. I said the kid is starving. I did not listen to them and started to get him to eat. I fixed the problem. That was year 1. 2018



Benat can hold his own bottle Feb 2019

They said he would probably be in a wheelchair for the rest of his life. Having 6 kids and one possibly in a wheelchair and multiply trips to MN for appointments we bought an actual bus with wheelchair access. Although where were preparing for a future with a wheelchair, I could not give up. New Salem school is not really handicap accessible therefore he has no choice he has to learn to walk. He had therapy at Sanford PT 30-minute sessions once a week. Sanford did allow me to attend his sessions. So, I got to see what to work on and how they did weight shifting. I felt weight shifting sessions a waste of time. I live on a farm 45 minutes from Bismarck. That is 1.5 hours round trip for a 30-minute weight shifting session. So, we quit. We were blessed to have got amazing advice from Cathy PT at BECEP as we got access to a stander, and eventually were able to use a gate trainer then a walker. I was on my hands and knees at home every day moving those little legs because a wheelchair wasn’t going to be an option in New Salem school. He is now walking without a walker or assistance. I programed his brain though words and movements and I TAUGHT HIM TO WALK. That was year 2. 2019



We call this “Benat’s Bus”.



Awesome Zippie adaptive stroller.



Old school stander



Learning to sit



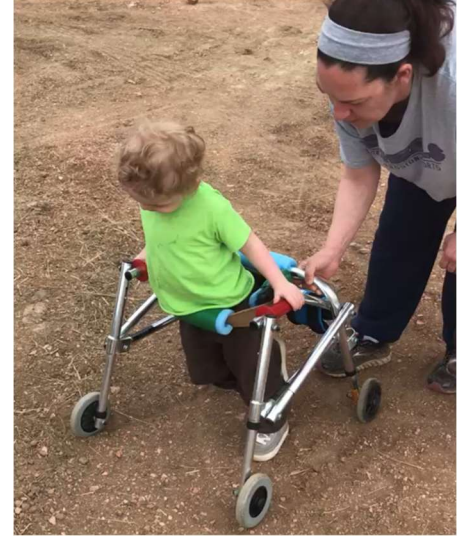
Brand new stander, thanks to BCBS and tons of appointments and referrals.



Gate trainer



BECEP walker

1st time outside with walker not stroller

Through people giving us guidance and our hard work, he now walks. Benat and I did that!

Benat was considered nonverbal. No one can understand him or figure out what he wants except me and some respite workers. He screams, hits, throws things and cries. Or I should say no one has patience to pay attention to what he is trying to communicate. So, year 3 we work on sign language and the use of an iPad as a talker with an app used for communication, which we purchased out of pocket. We started at Sanford therapy however our awesome SLP quit. So again, on my own. That was year 3. 2020

This brings us to education. This is my new challenge. IEP and the school system. I was hoping that they could give me guidance on how to educate my son. We spent 1 year traveling 2 times a week for 1-hour sessions. So, 2 hours weekly for IEP therapy only. Not enrolled in school. I was not allowed to go into session. I have no idea what is going on. I have no ideas what to work on with him. I called an IEP meeting and explained that they have him for 2 hours a week and I have him for 166 hours a week. We need things to work on. Also, when we leave school, he is crying and is crabby for a least 5 hours, possibly the rest of the day. Again, I have no idea what they did to upset him he was nonverbal. The year of regression. That was year 4. 2021

I don't even want to cover my struggles with putting him in head start and the New Salem school system after all the work I have done and the past year that just happened with them. I will make 2 comments though. This is the year my personal health took a turn for the worse due to the stress they caused and the severe regression we experienced. I literally started losing my hair and is a year I wish to forget. That is year 5. 2022



IEP in corner instead of being taught to work with peers.



Sitting with aide on lap instead of floor with peers.



In corner with aide instead of with peers.



Twin brother Henry in same class.



My hair loss due to stress.

This year 2023 is focus on speech and homeschooling education. No one wants to use the talker! I have to teach him to talk! I found Amazing Erin at Little Light Therapy in Bismarck and with her help (2 – 1 hour session weekly) we have been accomplishing unimaginable things. She just told me the other day that he was only saying more and all done by sign language in July 2021.

Benat is not going to school this year with his twin Henry to kindergarten due to past issues with the school system. He is currently however attending IEP therapies that I have determined very important. Such as vision and PT. However, I do anticipate serious problems in the very near future. Meaning today at 11am at my IEP meeting in New Salem.

My Daily Life:

Mondays, Thursdays, Fridays

5:45am – wake up kids, Potty training Benat, Benat seizure meds and applesauce cocktail (sweetened applesauce, miralax, muscle milk, cinnamon, graham crackers) help kids get ready for school.

6:45am – Bus picks up kids for school. Start laundry, vacuum, pick up house, work on morning dishes. Benat assists me with all these tasks. Some days we take the time for him to do them by himself with assistance. Takes forever!

8:00am – We go to learning room. I have set up a room in my house designated to Benat's learning and therapies only. I have purchased mats, swings, wedges, therapy items, and school supplies out of pocket to help me with my son over the years.

9:30am – snack time/breakfast – takes him roughly 45 minutes with the use of tablet playing Blippi or Jack Hartmann to eat a bowl of cereal and drink a glass a milk through a straw with continual reminding to eat and drink. If he does not have a tablet he will not eat.

10:15am – learning room

11:30am – free time

12:15am – Lunch (peanut butter and jelly with chips and cheese, glass of milk with straw)

1pm – Benat's Nap time. I take dogs outside and tend to rabbits and chickens.

2pm – Finish house chores I didn't get done in the morning.

3pm – wake up Benat. He is usually very crabby, lots of screaming, very mean for 45 minutes no matter what I try.

3:45-4pm – kids come home from school.

4pm – unpack backpacks, remind kids to get chores done, schoolwork all while Benat is at my side.

5pm – start to make dinner. We have a family dinner every night. All while Benat is at my side.

5:45pm – family dinner. I feed Benat and make sure that he eats. Again, can take 45 minutes+ for him to finish a meal. Often, I end up not eating.

6:30pm – family playtime

7pm – Bath time

7:30pm – Meds and TV time

8pm – Bedtime. Benat usually falls asleep around 8:45-9pm.

3rd Monday of the month is IEP PT at Prairie View Elementary 10:30-11:15am

Tuesdays and Wednesdays

Mornings are the same but no learning time at 8:00am, instead we leave to go to town for therapies and shopping.

Tuesday 9:30am-10:30am Sanford PT in Bismarck then 11:00am chiropractor, lunch (McD or DQ), shopping (Walmart or TSC) then home by 1pm for naptime. This is the only day I get to go to Bismarck/Mandan.

1st Tuesday of the month IEP PT at Brave center 8:30am-9:15am

Wednesday 8-8:45am OT and 8:45-9:15am SLP with Little Lights Therapy from Bismarck but services are at PVE in New Salem, (they travel) then we have to waste 45 minutes which is not easy in New Salem unless you can go to the park. 10am - Vision IEP for 30 minutes. Home by 11am.

Weekends my husband does schoolwork for the past 3 years. So, between tending to Benat and trying to spend time with other kids I am just existing.

Benat does receive Respite. He has received respite care starting with 10 hours weekly 7 months after birth to currently max hours weekly. I was going through agencies here in Bismarck for these services. Poppy's Promise, Easter Seals and was going to attempt trying a 3rd before going self-directed. My issue with the agency's is no one wanted to travel. And when someone did accept the position, they only worked 1 time or she was 70 years old and only came for 8 hours a week. She had a hard time getting up off the floor, where we spend 80% of our time. She came for only 8 hours a week when there was a possibility of 75 hours a week. Then someone was clocking in under wrong client and they sent me a bill. They pay an employee \$13 per hour but charge me \$33.80 per hour. WHAT!?! That is the day I went self-directed.

I find my help through Care.com, posting flyers in New Salem / Glen Ullin and word of mouth. The problems I mainly have is no one wants to travel. The weather prevents people from wanting to travel. Benat can be very challenging and loud. If one kid gets sick in our family, they don't want to work and get sick themselves. I totally understand but that sometimes can take 8-16 weeks to run through a household of 8.

If an employee quits it takes 30+ email to individuals through Care.com and over 3 months to get a response. When I do get a response it's an additional 2 weeks before interview, another 6-8 weeks for paperwork and background checks. I had gals come to interview, fill out paperwork and never hear from them again. I've had gals only work 1 day some 1 week. Most 3 months. I had an employee give me her 2 weeks in July this past year. I was unable to find help until October only for the new hire to work a week or two then have a family emergency and need to take a leave of absence until January. Currently I have 3 respite workers employed, but still can't seem to fulfill hours or have consistency.

I never had to put my kids in daycare because I was fortunate enough to stay home.

Benat should have been in kindergarten this year with his twin brother but due to severe issues with the school system in rural town the past 2 years and the fact that he has certain needs that they can't address, he is not attending school this year and might not be attending in the future. There is nothing but problems in that school for kids with disabilities and if I want Benat to be educated and become productive at all then I am

forced to homeschool, which has been mentioned as an option multiple times during meetings.

Everyone is feeling the financial burdens recently with what is going on in the world. Everyone seems to be affected. I don't feel like I have enough on my plate, so I decided this past summer I'll get a job at a local restaurant (20-minute drive), so we have extra income to help pay for things. I got to work 2 wonderful days. I showed up late 4 hours on the first day and 3 hours late the second day, due to respite not showing up and having to wait for husband to get off work. Then she put her 2 weeks in, so I ended up quitting. It was a sad day for me.

Cost of everything going up, can't afford to travel. I used to travel 4 days a week for Benat's therapies now we are down to 2 days a week. He and I were going to the chiropractor which was helpful to both of us however have now stopped because of financial difficulties. I used to get mental health services but now because of some recent changes to insurance I no longer get that. Our family wears glasses. Kids need eye exams and new glasses. How do we pay for it? Clothes? Food? School lunches? How do we pay for it? The kids want to be in school activities that's extra fuel and expense. Future appointments in MN. We have already refinanced.

My last real solution is for me to work between the hours of 8pm and 5am while the family sleeps. But then when do I get to sleep.

It's not that I don't want respite help, I need respite, Benat needs respite, but it seems to not be consistent therefore makes it hard for me to be able to have a life, the whole reason for respite. To give me a break. It's seeming impossible for me to have a job. I have asked many times, why can't I be paid for my services helping my son if someone isn't showing up. I have proven time and time again that he is making great gains beyond the doctors' expectations. I am saving a lot of money and paperwork doing things myself. Benat and I have done all the work with guidance along the way. I struggle to get things I need for Benat due to financial difficulties. Things that are not covered by insurance or Medicaid. If I were to get paid that would relieve financial stress and allow Benat the things he needs to become successful instead of waiting 6 months for something to go through the system and be denied. It would also relieve the financial stress of everyday life. Maybe I could leave the house more often because I could pay for fuel.

This past December 2022 at a cardiology appointment we got confirmation that Benat has entered surgery phase meaning every day that goes by his heart is getting worse and as long as he can tolerate it and EHCO show no enlarging or thickening on the left side of heart then we wait. He needs to grow and gain as much weight as possible before surgery. Meaning soon we will be travelling back to Mayo in Rochester, MN to have another open-heart surgery to not fix but replace his aortic valve. I will be talking to the doctor on Feb 3 at 3pm to find out details. Until then we wait unless something changes with him and his heart goes into failure. With that in mind I have no idea what's going to happen, when we are going or how long we will be there when it does because it is going to happen soon. Will the girls that are hired respite still be here when we get back or will I have to start over again looking for help. Could you wait as an employee for a month with no paycheck? I still don't know how we are going to afford to travel and pay for hotel?

With that thought, I want to thank you for your time serving our state and for listening to 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.

Lisa Kroh – imchorty@yahoo.com - (701) 319-0118



Who Am I puzzle 3pc



Learn to hold marker.



Learn to count.



Numbers and Letters



Barn farm animal puzzle.



I can draw a face!



Who Am I Puzzle.



Animal magnets.



Sight words



Color matching with Henry.



Lights board tracing.



Got to visit Henry during Muffins with Moms at school.



Mom and Benat



Independents Day Parade Mandan 2022 - Cloverdale



Safety First.



EEG 2022 I am unable to get screen shot. I've sent many requests so I can compare. No Luck. Pay for it can't see it



Henry and Benat - 2022



Benat and August.



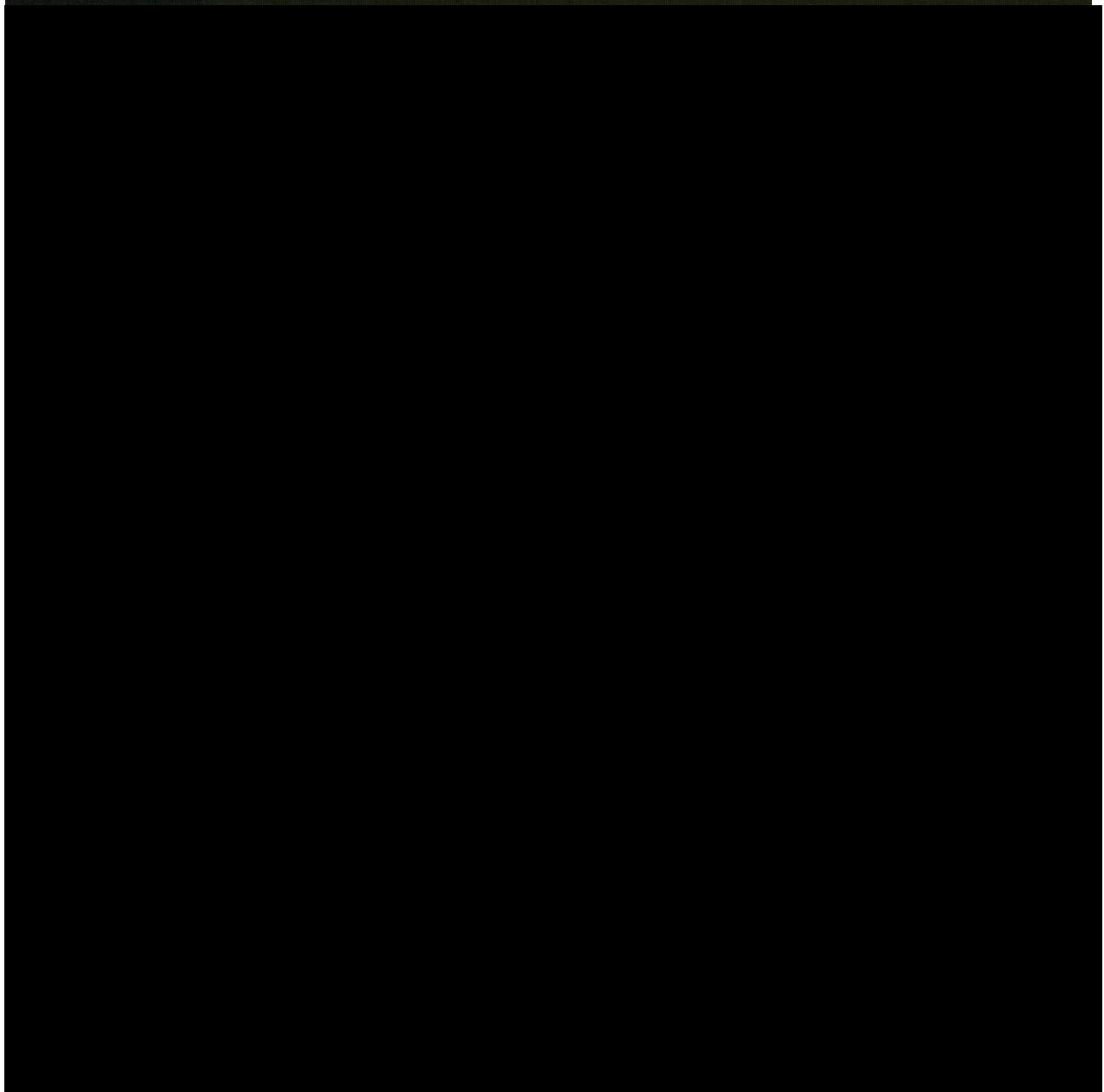
Benat WALKED to Treat or Treat!



1st Day School 2022



Almont Parade August, Benat and Respite (Kyarra)



Hello my name is DeLainis Kroh

I am Benat's older sister. I am also his only sister. My life has changed drastically since Benat was born. My parents are so much more stressed out and are unable to care for their other children the way they used to. They still give us the basic needs for life which are very important. But if they want to spend quality time with certain individuals, they are either rushed or the plans are canceled due to the needs of my brother.

Me and my mother really enjoy spending time with each other. We like to go shopping and go out to eat alone, just me and her. But because of the lack of money, we can't do these things. When we do, she is always worried about Benat and how to pay for it when we go which really stresses her out and makes it hard for her to enjoy anything. The only time we can truly leave is after Benat is put to bed for the night but then all places we wanted to go are closed. This is also when it is dark and dangerous to drive, mom always says she's night blind. I have always tried to make her feel better and calm her down, but it never seems to work.

It has also made my life harder because when my mother is working on something so Benat can have a better life, I step in to watch him. It is extremely hard to entertain any child but for him even five minutes of a single game becomes boring and very quickly you run out of ideas. He also has a very bad habit of throwing various objects. These objects are usually solid objects. He then throws these objects; they either break something, crack something, ruin something, and or actually really hurts somebody. To clarify all those things have actually happened. Recently I have been struggling to play my saxophone. Since my mother played that very saxophone at my age, she helps me and gives me tips on how to play it better. But it is very hard to find a time to practice when she is always leaving to go tend to Benat's needs.

He is always screaming or crying for any reason at all. Like at the dinner table, most nights he refuses to eat for no reason at all. We eat dinner where everyone is present. This makes it hard to enjoy a homemade meal that someone worked really hard to make, when all you can hear is screaming. Since Benat's heart is beginning to fail again he really needs to gain some weight, but he still refuses to eat, which makes my parents even more stressed which also stresses me out. It would make my mine and my parents lives so much easier if we had better help. My mom said if she could go to work to help pay for things, she would but it seems impossible.

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.

DeLainis Kroh [REDACTED]