

Chapter 1: February 2020 to November 13, 2020, Madison WI

Our son started going to speech therapy at around 2 years old. He could only say the word this or point at something.

He did 12 weeks of therapy and there was no improvement. His SLP advised us to get him checked for Autism Spectrum Disorder.

At this point, I was not sure what to think. It was not something that fit in with our plans.

The day we took him to the appointment for his diagnosis, I was nervous, but I thought he was fine and it was just a scare. A child was crying in the hallway and our son was in a room with a glass door. He looked at the child confused about why they were crying because he did not understand this other child's emotions.

That was the first sign the Dr. saw that our son was on the spectrum.

They take him to do more observing and my

husband and I wait in a private room. We were talking about the "what ifs".

They brought him into the same room. They said he is behind by 2 years and should be able to talk more than he did then.

The milestones have not been met. I am about to cry at this point. The Dr. said based on their information that our child has Autism Spectrum Disorder.

The Dr said it is a good thing to catch early because there is support to help with medical bills and items needed for basic sensory needs.

Both my husband and I are crying with our world turned upside down! This was not part of our plan. This point and on we both agreed we would start a different journey.

Chapter 2: Talk to family

We were both shaken up and in shock. My Twin sister and her son are both on the spectrum, they recently got diagnosed around this time. She kept

on saying it to us and thought we understood how she felt. She said she didn't know how to say certain things and her brain works differently.

I only knew at this time that my son could not communicate with us, he did not like to eat all the foods given to him and he was behind in learning and potty training.

I have worked for clinics that take medical assistance. I worked for the WI Medicaid client for two years before I left to be a full-time mom. I have heard of programs that helped with Autism so I started there. I looked up Katie Beckett on the DHS website and started applying. This took a lot of paperwork and 3 months.

The DHS website had information about CLTS. This stands for Children's Longterm Disability Support. I did not know how helpful they would be. I signed up through their program as well.

Chapter 3: ABA and Hope

January of the next year came around and we got our Medicaid acceptance letter. The SLP said ABA therapy would help him after we updated her about his diagnosis. What I knew of ABA was it was play-based and on one. He got into Caraval Autism on the east side of Madison. We had our first orientation to talk about our goals and concerns. I saw a room for occupational therapy. Kids with Autism need to get their wiggles out to focus on learning. Seeing this room helped us prepare for sensory needs at home. Within 2 months, our son was doing much better!

He was in ABA from January 2020 to February 2023. He graduated ABA at age 6 just after his birthday. We were worried because he is not potty trained, How will he cope in kindergarten? February 2023 is when he fully integrated into kindergarten with his own IEP. That is known as an individual education plan. He started halfway through three years but he caught up and graduated kindergarten with his classmates!

From January 2019 until public school. He needed an asafee home so we asked CLTS for back backyard fence, sensory items from Amazon.com, Angel Sense Device tracker. He received toys, a trampoline, and a sensory swing door alert because he's a runner.

This is just a summary but CLTS saved our family.

Chapter 4: The present

Medicaid covered ABA therapy 40 hours a week therapy-related medical bills, and dental bills. We received respite care hours for my sister to help out.

We may have cried in that private office when he got diagnosed and for years we felt alone.

Respite care is still hard to find. I stayed home for 5 years and I was finally able to go back to work in June of 2022 at the same company with

Medicaid except my role changed from member to

provider support and I just kept on moving up ever since.

Conclusion: Summary

Without my experience and knowledge of the DHS and systems, I have learned we would have a harder time. There were times that our son got so mad and frustrated because he did not know how to communicate with us. We just hugged and cried for hours! When we took him to the park and did not know to ask him to play, it broke my heart! He followed the kids around and tried to copy them.

It's a hard path and you don't need to do it alone like we were. That is why my husband started Help for Neurodiverse Kids Corporation.

If you need an advocate, a friend, or resources we are here for you!

