00;00;09;18 - 00;00;35;24

Brandi Williamson

I have been on an airplane run for 11 years and it snows. And then I hit turbulence. And then I flew for many hours and I got ready to land. And then I had a malfunction. And the plane down land, I had to take back off again. Every time I feel like I'm ready for safe landing, I hit turbulence.

00;00;40;20 - 00;01;08;07

Courtney Ringstaff

Welcome to Adjusting the Sails, a podcast for parents, caregivers and service providers for children with disabilities. I'm your host, Courtney Ring Staff, and this is my co-host, Melina Danko.

Melina Danko

Hi, everyone. We are so glad you've joined us.

00;01;08;23 - 00;01;40;18

Courtney Ringstaff

Melina is the assistant director of communications and marketing at the Center for Excellence in Disabilities and the project director of the West Virginia Family two Family Health Information Center.

I'm a social worker in Morgantown, West Virginia, and I've created this podcast to be a platform for parents. Caregivers and service providers can come together, exchange information, educate one another, and find support and connection through the relatable topic discussions. We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

00;01;41;06 - 00;02;07;24

Brandi Williamson

My name is Brady Williamson and I am a parent network specialist with the CDC. But I'm also a parent to a child with a disability. A span of bifida. I found out that my daughter had spinal bifida when I was 23 weeks pregnant. She was my third child. I really didn't have a whole lot of concerns during my pregnancy, so I thought at 13 weeks I had found out that she was a female.

00;02;07;25 - 00;02;35;24

Brandi Williamson

So my anatomy scan pushed a little longer due to the weather and things like that. So at around 23 weeks was technically when we did the the anatomy scan. When I was in the ultrasound. The lady continue to look at the screen and just make some measurements. And I felt something was wrong. But during that timeframe, you know, of course, she maintained composure and tried to make sure that I was okay.

00;02;36;02 - 00;03;12;20

Brandi Williamson

She had went to get the doctor and when she did, I instantly knew something was wrong. And so he comes in and they send me downstairs to the maternal fetal medicine to where I could have a indepth better ultrasound. It was my first time being down there because my children are kind of carry babies kind of low. So I just thought it was typical ultrasound and they gave me the prescription and I go downstairs to have the better ultrasound.

00;03;13;09 - 00;03;53;16

Brandi Williamson

And on the prescription it had a diagnostic code of elements on, and I did not know what that was. So I was sitting in the waiting room alone and decided to Google an app on Google. I found that lemons on mint, spinal bifida, everything negative from spinal bifida came with me reading Google. So I had the ultrasound and the doctor came in, was very short, very rude, and was like, Your child has an open neural tube defect and there's not very many options.

00;03;53;19 - 00;04;23;10

Brandi Williamson

One is being aborted to you can have fetal surgery. There's only a few places that does it, but you're also at the timeframe where there's a cutoff. So probably not even sure that you qualify. You probably would rather consider abortion. And he left. I was very emotional with. No, I felt like there was no hope. You know, you're telling me to abort my child, which was not an option for me.

00;04;23;18 - 00;04;52;16

Brandi Williamson

And I just felt like I wasn't given even the places that did the fetal surgery to see if I could even qualify. And so my doctor upstairs, my O.B., called and had me to come back upstairs. It was after hours and offered me great support and consoled me and held me while I cried and explained that we would get through this and we would call.

00;04;52;16 - 00;05;20;23

Brandi Williamson

Cincinnati Children's Hospital was one that did the fetal surgery and Philadelphia was one that did it, and there was one in Texas. And so he did tell me that we were on a time crunch and that we would need to act quickly. So I said, okay. He explained that having fetal surgery is a new way to correct things in the womb.

00;05;20;23 - 00;05;47;21

Brandi Williamson

I said that the child would have a better quality of life walking and bowels and bladder, so that was a good thing for us. I was very excited. However, I was still kinda iffy on everything. I just found out, you know, an hour prior that my child has a birth defect that I didn't know anything about. And now everything else has been thrown at me full force.

00;05;48;19 - 00;06;15;27

Brandi Williamson

And they connected me with Cincinnati and the fetal care. And we received a call from them. We did a lot of questioning over the phone. Then we found out at the last question that we did not qualify for fetal surgery. Again, my world was flipped upside down. I felt that my body had failed her, that I had failed her.

00;06;15;27 - 00;06;47;11

Brandi Williamson

Now, the only hope that we had of getting her a better life was now shot because of of a stipulation on meeting the criteria. So we still agreed to go to Cincinnati Children's for all the fetal clear testing, the fetal MRI and so forth. We went through three days of testing and met the team and what span of effort to looks like and how our lives would probably be affected.

00;06;47;11 - 00;07;20;28

Brandi Williamson

And you know what? We should expect long term and things that potentially could help us later on in life. So they discussed like a VP shot for hydrocephalus. They discussed Casper Graham for Bowers and Bladder. They discussed wheelchairs and braces for her legs. And I was very overwhelmed. I had just received that diagnosis a week prior to that.

00;07;20;28 - 00;08;03;06

Brandi Williamson

My child was having a disability and I didn't know anything about it. And now I'm being told all these medical terms and I didn't know what life would look like for us. So we move forward to 25 weeks where I was having some significant blood pressure issues and I was in the hospital. We had a plan that I was going to deliver at Cincinnati because they felt with her lesion where her back was open of spinal bifida, that it would just be safer and she would be there for her team of doctors and everything on standby.

00;08;04;09 - 00;08;32;20

Brandi Williamson

And that didn't happen. I delivered at the AMC Women's and Children in Charleston at 25 weeks. She was £1 of me, four ounces and 11 inches long. She had a 6% chance of survival rate, and it was very unknown if she would survive even given birth. Once she was born, she sustained and was able to be put on a ventilator.

00;08;33;10 - 00;09;12;13

Brandi Williamson

And we were told, you know, she's very critically ill. We still made the decision to go to Cincinnati. They were trying to find other hospitals that could accommodate us. That was closer, but no one was willing to take her. Due to her size and needing the closure and those and the things that was going on with her. So at 25 weeks, she was transported to Cincinnati alone because I had just had an emergency C-section and I wasn't allowed to go with her during those times of transport.

00;09;12;24 - 00;09;34;26

Brandi Williamson

She was non stable. She was transported very critically, medically ill. And they let me know that she may not make it to Cincinnati. Upon arrival, she made it to Cincinnati safely, and they began to work on her and stabilize her.

00;09;37;13 - 00;10;03;28

Brandi Williamson

At three days old, she was stable enough that she had a small window to have her back closed for her spinal bifida. I left the agency and I drove straight to Cincinnati, where my child was getting ready to undergo her back closure surgery. Before that closure, she had function of her legs and her feet and her bowel and her bladders.

00;10;04;08 - 00;10;29;20

Brandi Williamson

So they were very amazed that she had function when she wasn't supposed to have pooping as little as she was. She was not able or stable enough to go to the O.R. room to have surgery. So her neurosurgeon decided that we had a small window and he was going to take the window to correct her the best way he could.

00;10;30;12 - 00;10;58;19

Brandi Williamson

So he created a surgery suite in the neck U and she is still the first baby to have a split up after closure in the neck. It was a very scary situation and the things were unknown and she was so small that her sac that she was born with had to be put back into her back. She was very little again, only weighing a pound.

00;10;59;04 - 00;11;22;15

Brandi Williamson

So they didn't want to do any more damage to the nerve endings and the things that were entitled to that to make sure she was okay. When they opened the sac up, it was one that they had never seen before. They had told me, typically these shocks have the nerves and the roots of the nerves and things. And that's what controls a lot of the physical movement in the legs and the bowels and the bladder.

00;11;23;01 - 00;11;55;02

Brandi Williamson

The her sac was more bone and cartilage, and they really just didn't know what to do with it because it was very unique and odd. But they made her move and placed the sac back into the back and stitched her up. And we continue to monitor closely and during those first few days, we were told, you know, that she had hydrocephalus and that she would need a shot, that we would need to make that decision pretty soon because, you know, it could cause her lifetime deficits.

00;11;55;03 - 00;12;22;01

Brandi Williamson

We continue to watch a monitor and she stabilized out to where she didn't require shunt. It was often monitored every week with ultrasounds of her head, but she didn't require a shot. So we just continue to monitor that during our Nikki's stay. We were in the Nick you for 19 weeks and I had two other children at home.

00;12;22;15 - 00;12;53;25

Brandi Williamson

So I moved myself in to the Ronald McDonald House and then later into a townhouse that I was able to stay in and provide her with all the time care and be at the hospital when they needed me to be there during that time frame. My other two children were staying with their grandparent and then my husband began to stay with them as well on Alternate.

00;12;54;09 - 00;13;27;16

Brandi Williamson

But that still left me not coming home. I think in 19 weeks I only came home maybe three times and it was very challenging for my family income wise. It was very challenging being away from my other children and trying to reassure them that I still love them as well. And then also having to learn because I didn't know anything about Spanish before that and be an advocate because I knew that she depended on me.

00;13;28;21 - 00;13;51;09

Brandi Williamson

So it was all a learning curve for all of us involved. Spanish Before the babies are typically cast, they use a cath program for their urine and at three days old they introduced a cath program to us that our brown bladders was working. So I refused it and asked for us to wait a little longer to see if that would be needed.

00;13;52;05 - 00;14;26;21

Brandi Williamson

At two months old, they introduced the cath program to us again, but still yet her bowel and bladders and pressures in her kidneys were still working and we still had not had a UTR. When stop after the babies are born, they typically put them on an antibiotic just in case for UTIs. And she had been on that antibiotic since birth and I felt like she has not had one and I felt like we could wing down and take her off of that.

00;14;27;09 - 00;14;50;23

Brandi Williamson

And they were not very accepting of that decision or of me bringing that to them as a discussion because she had spinal bifida, so she needed to be on an antibiotic, she needed to be protected, but her scans and her tests showed otherwise. It showed that her kidneys were working, her bladder was working, things were working like they should.

00;14;51;10 - 00;15;14;20

Brandi Williamson

So I advocated and had a care conference, one of many that I called discussing that I wanted the antibiotic stopped for her bladder, and with the care conference they listened to my concerns and we stopped the antibiotic and was also introduced at that time that if I stopped the antibiotic that I would really need to consider starting to cash.

00;15;15;14 - 00;15;46;21

Brandi Williamson

And I did not consider that it was an option. But again, her scans, her bladders and kidneys were working. So I always said, we'll cross that bridge when we get there. And we wasn't there. So we continue to manage her urine output and continue to do scans for her urine and bladder and kidneys and everything remained well. So we was often told we need to do a cath program, we need to start Cath and we need to learn how to Cath before we bring her home.

00;15;47;03 - 00;16;15;05

Brandi Williamson

We need to Cath and the only reason that they could give me is because she has spinal bifida. There was no medical reason other than a diagnosis. We didn't have high pressures in the kidneys. We didn't have urine reflux, we didn't have no urine output. We didn't have incontinence going excessively. We didn't have excessive UTIs. We only had a diagnosis of, Oh, she has spinal bifida.

00;16;15;05 - 00;16;41;08

Brandi Williamson

During those days of me being told that she had spinal bifida and trying to make me cash really changed how I saw things. I wasn't a first time mom. It was my third time being a mom, but it was my first time being a mom to a child with a disability. And I felt very overpowered by the medical world and they were very, very predominant.

00;16;41;09 - 00;17;18;13

Brandi Williamson

You know, they their knowledge and you're supposed to follow what they recommend and they're the doctors. But my mom get said otherwise. And so I followed my mom gut and I advocated and we did not start a cath program and Nick you stay was very much of a rollercoaster ride. So not only did I have a child with a disability, I had a micro preemie that was born weighing £1, and that alone carries a whole nother list of problems.

00;17;18;24 - 00;17;48;14

Brandi Williamson

We had chronic lung disease due to her being born so early and being on a ventilator. We had a PDA in the heart. That's a flap that goes from the heart to the lungs. We had brain bleeds. We had our OP where that affects the vision. Nutrition issues, not gaining enough weight, bowel issues. I mean, anything that could be related to a preemie, we had it on top of everything else.

00;17;48;26 - 00;18;07;28

Brandi Williamson

So our journey was a little rough, to say the least. I continue to stand strong and just fund advocacy and things that I felt that she needed or if like they changed her calories in the nick you to make her gain weight but then it would cause her to have bowel issues. I would have to ask them, can we fortify that?

00;18;07;28 - 00;18;32;18

Brandi Williamson

Can we reformulate that? Because spinal before the children have issues with their bowels and bladder anyways. So we had to decide was it an increase of calories or was it actually due to her spinal bifida and during those times of me happened to say things like, can we recheck that? Or three, four or five that? A lot of times they referred back to she has found a before.

00;18;33;05 - 00;19;00;23

Brandi Williamson

So this is just part of her spinal bifida and you'll learn it. But then when we would change back the formula to decrease the calories, then the so called symptoms of spinal bifida would diminish. And so I didn't feel that it was funny before the related, I felt that it was preemie related. There wasn't a lot of resources for me because the type of spinal bifida she has is very rare.

00;19;00;23 - 00;19;23;27

Brandi Williamson

There wasn't much support. Even Google wasn't even a help. Even though I was told not to Google, there wasn't any research on Google. The parent library at Cincinnati is amazing and has all the resources for all your child's disability and everything that you need to know. And they have such a nice layout out of your appointment complex and what things will look like.

00;19;24;17 - 00;19;50;13

Brandi Williamson

But it didn't look like that with us. And so I found myself feeling very hopeless at Tom's because it was like, Well, let's try this, or We really don't know, so we'll see how this goes. And that's not what you want to hear. Do you want to hear someone very sure of their situation? You want to be confident in your doctors and in your team, but we're all walk on this journey together.

00;19;50;13 - 00;20;13;18

Brandi Williamson

And I learned that I found a lot of respect from the doctors who would say, what do you think? You know, what is your suggestions, mom? You know, she's she's and they went for us, too. So, you know, would you have any suggestions for that? So I thought included, I felt like I didn't have a Ph.D., but I was learning my child very well.

00;20;14;04 - 00;20;37;01

Brandi Williamson

I was learning things that worked and didn't work. I was learning things I in like her oxygen saturation and like when it when she would drop her oxygen saturation, she was a color changer. I was a monitor watcher. I watched all the monitors daylight to dark and I watched the numbers, watched everything, always check a match, heart, getting their results, feeling anxious.

00;20;37;01 - 00;21;06;25

Brandi Williamson

With every scan that came through. But I learned that my child was different in many ways, so the monitor could read that she was had a O2 saturation of, you know, 85. But if she wasn't changing colors, that probably was not a true oxygen reading. And I had to learn that that monitor was a visual. It wasn't really who she was.

00;21;06;25 - 00;21;32;28

Brandi Williamson

Even though I was consumed by the numbers on that monitor because she was one and in all the cases she was beating the odds. So the monitor just was there because it had to be like it was just a god for them. We also experienced, you know, like I had said with the PDA and the PDA is a flap that goes from the heart to the lungs.

00;21;32;28 - 00;21;58;04

Brandi Williamson

Someone you have a full term baby. When they take that first gasp of air, it closes and hers did not where she was so early and it was causing her lungs to be profusely wet and we couldn't get her off. Oxygen support at all because of that. And I had to make a decision 5050 that was my statistics and it wasn't a you have to do it.

00;21;58;04 - 00;22;20;16

Brandi Williamson

This is a parental choice. We think that it may help, but we really don't know if it will or not. And so I had to make a parallel choice of a 5050 to place a PDA plug into her heart in hopes that it would close her PDA, her PDA was very large. It was the size of her aorta.

00;22;20;29 - 00;22;53;04

Brandi Williamson

And with that being said, I made the decision to place the device. And instantly, within 24 hours, I significantly regretted my decision. She did not adjust very well to the device during the next 72 hours of the device be in place for some of the scariest times of my life. My child coded 17 times and 24 hours. My child coded 16 times in 12 hours.

00;22;53;27 - 00;23;24;17

Brandi Williamson

She coded again on day three. We coded again more than than documentation can count on day three. They had called my family in things were very very scary. She was very sick and I didn't know in the hospital what that meant. I didn't know that when they told me prior to the surgery that, you know, she may get sick, I thought they meant a fever.

00;23;24;17 - 00;23;47;27

Brandi Williamson

I thought they meant throwing up. I thought she just would be sick like a normal kid, even though I don't like to use the word normal. Just a typical cold, no sick. Typically in those terms mean it's going to get really rough. And for us it got really rough. My family was called in on day four, giving us 24 hours to live.

00;23;49;01 - 00;24;09;08

Brandi Williamson

Her kidneys were not working. Her lungs were not working. Her heart was failing. She had more pressure built up on the brain because the body was just shut and down. She was not stable to go anywhere because I was trying to find anywhere in the United States that would take her, because I felt like that was my only option of saving this child.

00;24;09;23 - 00;24;39;14

Brandi Williamson

You know, California, Texas somewhere, you know, somebody was something to help her. And I was told she's not stable. And I realized that when they would go to listen to her with a stethoscope and she would clamp the vent and code, I realized that when they would go to her to turn her and she was already on a paralytic and she was so sick that when they would turn her, she would bottom out and code.

00;24;40;06 - 00;25;04;24

Brandi Williamson

I realized in that moment that I was completely out of control when all the doctors had came in and I was standing by the incubator and by her open bed, you know, watching the doctors perform tricks, compressions, while her body turned lifeless, gray and heart rate of nothing, you know, we drop down to nothing. And I stood there watching all that unfold.

00;25;05;20 - 00;25;36;21

Brandi Williamson

We had came so far to take such a setback. We had overcame so, so much. And I put my faith in God and I had to just fully rely on him at that time. And that moment we were on every device, every pump of a pump, everything that could keep this child alive besides an echo machine was keeping this child alive.

00;25;36;21 - 00;26;05;02

Brandi Williamson

I had came to terms that I was giving up in a sense, because she couldn't take no more. She was lifeless. Her body was for out. Lifesaving measures were hard. She was she was were out. So I had came to terms that I need to figure out what my next step is and how do I want to approach this.

00;26;05;02 - 00;26;24;21

Brandi Williamson

I just slowly remember during that time putting a lot of faith in tears. I never left to make you in seven. In three days I never left the AQ you. I never slept, I never ate. They actually took me off of the ACU floor to make it something to drink because I was so weak that I was just.

00;26;24;21 - 00;26;53;17

Brandi Williamson

I was sick myself, but I just could not leave her at that moment. But things started to change. Intervention started to happen, and we started seeing slight improvement on day five and any improvement was better than what we had just been through when that happened, I began to kick back into advocate mom mode and I felt like I was stronger than ever before that we had a purpose.

00;26;53;17 - 00;27;21;01

Brandi Williamson

We needed to tell somebody our story. We made it over the hump. We wasn't supposed to make it, and we did. So at that point, things did start to change. And I started calling care conferences, you know, every shift. What's our plan? What's next? You know, and obviously you want the instant answers now and you want all this trauma that you just experienced to wake up and it just be over.

00;27;21;02 - 00;27;48;26

Brandi Williamson

Like it's over, like, oh, here, here's a happy baby. That wasn't the case. But I did start advocating for, you know, let's lower the paralytic, you know, let's see how she does lowering, you know, the paralytic medication. Then they did echo and she was diagnosed with pulmonary hypertension. And that was truly what was causing most of our problem was the pulmonary hypertension.

00;27;49;10 - 00;28;16;07

Brandi Williamson

And they did a repeat echo and the pulmonary hypertension was gone. It was no longer present or or at even shown a case of pulmonary hypertension. So with that being said, I asked to start lowering other medications. You know, the the heart failure medications, the kidney failure medications. And they they did were very respectful to my wishes. But, you know, medically, we had to do things at a slow rate.

00;28;16;07 - 00;28;40;19

Brandi Williamson

We had to do things at a safe rate. Once we started weighing down on everything, she started being responsive, which was unknown if that would happen or not. One of the first times that I remember is they had totally turned the paralytic off and we were in a very low stimulus situation because we didn't want her to, you know, clamp the vent.

00;28;40;19 - 00;29;07;00

Brandi Williamson

We didn't want to upset, you know, didn't want to cause any arousal. But I just walked over and I just said her name, which is Kamya, and she opened her eyes and moved. And so she responded to my voice. And with that, it gave me courage to keep fighting for the next day. And we fought for about seven days of taking everything off.

00;29;08;00 - 00;29;39;00

Brandi Williamson

And by day eight, she was off all medications. She was off all paralytic of morphine, all pain management, of all organ failure meds. And she was off the ventilator. She was now on just oxygen at like two liters, nothing major, and was sustaining and doing very well. With that, though, can the other challenges of the span of after, did her bound bladder take it a day, a major three day?

00;29;39;01 - 00;30;05;15

Brandi Williamson

What about the brain and the hydrocephalus? What about this? And so those things often came back to me as what do we have now? And one of the things that I would, you know, that I say often is during that time frame of her being very, very sick, I was overwhelmed with every doctor. I was overwhelmed with every team that would come in and tell me something.

00;30;05;15 - 00;30;39;09

Brandi Williamson

And it wasn't like they were all on the same page. Nobody had a whole lot of hope besides me. And the team was, medically speaking, that she's probably not going to turn around. But I did have one fellow who came in during this time and was talking to me about wheelchairs and crutches and officials and cash programs. And during that time, I really was bitter.

00;30;39;09 - 00;31;01;19

Brandi Williamson

I was like, Why are you even discussing these things with me when I'm fighting minute to minute to save her life? Like, that's not it's not even okay. And he continued he continued to bring those things up. And I continued to get antsy. I didn't feel like we were on the same page. Quality of life was not where we were at at this point.

00;31;01;19 - 00;31;26;08

Brandi Williamson

We were fighting for her life versus what things she may need. So I came up with a little saying and then HQ and it was, you know, we all know that our organs are our wiring and plumbing of our homes, which are our bodies. We have to have our wiring and plumbing or things don't work. Right. So my little saying was, when her wiring and plumbing is right, then I'll worry about buying accessories later.

00;31;27;03 - 00;32;05;12

Brandi Williamson

And so we often use that statement throughout our next journey because we truly needed to focus on those organs work in order to get her to a say series that we would need two weeks after the significant deficit of her being very medically ill and calling my family and I was able to bring her home to West Virginia, I wasn't sure that I was ready to bring this child home to West Virginia, 6 hours away from Cincinnati, 2 hours away from a children's hospital or a big hospital at that 25 week old baby that is now almost three months old.

00;32;05;12 - 00;32;25;20

Brandi Williamson

And you're just going to turn me loose with this child and expect me to take care of it like I don't have a doctorate degree, I don't have a team, I don't have a call up and like this is not okay. So I had a lot of anxiety of bringing this child home and they were very confident that I was able and well to bring this child home.

00;32;25;20 - 00;32;47;20

Brandi Williamson

And I was not I was not as confident as them. And I did have one nurse tell me it does make me nervous sending her home because she's the only baby that I've ever seen at home. That's a 25 weaker that's not going home with oxygen. So it does make me nervous. So that really didn't call me any of my fears at all.

00;32;47;20 - 00;33;13;18

Brandi Williamson

So during that time frame of us getting ready to bring this child home, she now is on zero support of oxygen. She's now only on stomach medicine for acid reflux. She's now eating from a bottle. She's now having normal bowel movements. We now are not having monitors beeping all the time. We're no longer having scans done every day.

00;33;13;18 - 00;33;38;00

Brandi Williamson

No longer are we have a blood work done and I panic because I can't see what's going on. I can't see a scan, I can't see a set of numbers, I can't see the lab work. And they had to reassure me that she's okay. She's great. She's she's doing exactly what we want her to do. We don't want to keep repeating these scans and poking her if we don't have to.

00;33;38;23 - 00;33;57;20

Brandi Williamson

But my concern was, well, how do you know? How do you know she's okay? Like, we've not this is not an easy road and they kept saying, because she looks amazing and her signs everything looks great. And I still was very adamant that I needed labs on or I need a head CT or I need a head ultrasound.

00;33;58;04 - 00;34;24;27

Brandi Williamson

And they were very adamant that I did not. And we would compromise. We would do one a week, you know, and take care of my fears. And that's what we did. And before we came home, I had called local pediatricians in my area to see where this child was going to go. And I had interviews with these doctors.

00;34;24;27 - 00;34;55;00

Brandi Williamson

I would schedule for them to call me back and I would ask them their areas and their well, how would they handle the situation? And I would ask them, have they ever had a child this size? And I would ask them, you know, series of questions. And I was rejected by a lot of pediatricians because I had so many questions and because they said they felt like I was questioning their their degree or their practice and that if I wasn't comfortable, I didn't need to come there.

00;34;55;10 - 00;35;16;11

Brandi Williamson

So then I felt like I was a difficult parent and I was like, I just don't I don't know what to do. So I found my pediatrician. He was great. I didn't initially have him. I had someone else in his clinic that was a doctor there, and I had him for about a month. And I decided quickly he was not for us.

00;35;16;11 - 00;35;39;19

Brandi Williamson

He just wasn't on his game and I needed him to be on his toes and he was not. So I asked and I was able to switch providers within the building life for us when we came home was scary. I mean, we had a new baby. We had three children. They were they were all under the age of nine.

00;35;39;19 - 00;36;04;18

Brandi Williamson

You know, they were still kind of small this small baby was now in my arms. I didn't have a pulse ox to make sure her oxygen didn't drop. There is a lot of things that were scary. Wake up multiple times there in the night just to make sure she was breathing. So many things that you just take for granted when you bring home a typical child was nothing wrong.

00;36;04;18 - 00;36;31;27

Brandi Williamson

Lung was a child that was a micro preemie. And and hence part of it felt like I was like, I don't know if I can do this. Like, our first year home was not easy. She got sick a lot and those preemie lungs stayed hateful and stayed very upset. And it got to the point to where my doctor would know if I messaged him.

00;36;31;27 - 00;36;51;05

Brandi Williamson

I had a stethoscope and I could listen to her. And fortunately I learned how to listen to the lobes of the long and listen for a sound. And he would call in a steroid when I would message and be like, Hey, you left lobe is sounding a little crackly or, you know, right lobe or, you know, our lungs are not clear.

00;36;51;05 - 00;37;28;16

Brandi Williamson

Like, you know, and if we're wasn't running a fever, he would always let me kind of doctor her myself and give her a steroid and see how we do. But when she ran a fever and still to this day, being 11 years old, she runs extremely high. So when I tell you a fever, we have seen 107 and 108 before on a thermometer and we are talking I rectal temp so it is 100% accurate the first Thomas all those numbers I immediately flipped out and I was packing bags to go to Cincinnati.

00;37;28;16 - 00;38;01;22

Brandi Williamson

I was like, oh my God. Like, something's wrong. And I made a pit stop at my pediatrician's office first, but I was going to Cincinnati and he did all the testing and all the swabs, and it came back. I think she may have had bronchitis at that time or something, and he assured me she was okay. He admitted her to his hospital, but he assured me that for any change he would get me out to Cincinnati a.S.A.P and I had to learn to trust him as well.

00;38;01;25 - 00;38;29;22

Brandi Williamson

And I did not have that because seeing 107 on its anemometer was very unsettling. A typical temperature? No, a baby or any kid. We treat it, but she has hydrocephalus. Could she possibly need a shot? You know, could something in her spine be wrong? Could she have, you know, something more severe that wasn't being caught? So I learned to trust my pediatrician from that day forward.

00;38;29;26 - 00;39;11;24

Brandi Williamson

We have an amazing relationship to this day, life after that, from the time that we brought her home, it started with therapies first two, three appointments every month to Cincinnati. Things were very hectic in my and I had two other children that were in a Christian school that needed help and attention. And you know, those things we get connected with birth to three and I had previously in my college years did internship with birth to three so no one told me about birth to three no providers, no nobody.

00;39;12;06 - 00;39;35;07

Brandi Williamson

I just happened to know about it and was like, We need birth to three. Like we need services. So I did the reach out and did the contact and was able to get contacted my first round of birth to three, every member on my team, they had never even heard of Spinal before. The long list treated. I felt very unsettling.

00;39;35;13 - 00;40;01;19

Brandi Williamson

You've never heard of it, you've not researched it, and you continue to tell me you know nothing about it. You're probably not the person I want all morning. So I got rid of a whole team and then I felt horrible because my child made, these amazing services and we needed all these things. But Mommie Dearest over here gets rid of everybody in the team, including the coordinator.

00;40;02;00 - 00;40;37;15

Brandi Williamson

So I was left to what do I do now? So I contact the coordinator over the coordinator and explained my concerns and she provided me with a new team, which was what we graduated with when we graduated without it at three years old during that timeframe, someone had recommended a outside therapy place. So I reached out to him and I started to see a problem two weeks after she came home, she came home in June and we were probably in therapy by July.

00;40;38;10 - 00;41;16;17

Brandi Williamson

We had done picked up every Thursday. So I live in a really small area and so we drove 2 hours for one hour as therapy and then we got therapy. So then we drove 2 hours for two. Then we got speech and feed therapy, so we drove 2 hours for three. She is currently 11 years old and we still drive 2 hours one way, 4 hours roundtrip for 50 minutes of therapy every single week.

00;41;16;17 - 00;41;37;07

Brandi Williamson

I wouldn't change anything, though, because they've been amazing. They've been my support system, they've been my people. That has helped us get to where we are. They've helped me advocate when I say something wrong, you know, do you see this as well? So my relationship with my therapy team is outstanding. I just wish they were a little closer.

00;41;37;11 - 00;42;06;11

Brandi Williamson

We have made it 11 years and will continue to do so. My family dynamic changed drastically due that because when we first brought her home we had to go to Cincinnati about every month financially, that became very tough. Then I had two other children at home, so I didn't want to travel all the way to Cincinnati by myself.

00;42;07;13 - 00;42;35;13

Brandi Williamson

It was harder to take the other two kids. I didn't have anybody to step up, you know, to always help. So sometimes it became a family trip. Sometimes it didn't, you know, it just kind of what worked also at that time is when the Ronald McDonald House finally moved over to where you could do like a short term stay room versus like, you know, just for chronic patients.

00;42;35;13 - 00;42;55;09

Brandi Williamson

So that began to help us out tremendously. You know, short term, we could stay there for four or five days, you know, and be okay during that time frame to though, I also learned about like the extra resources, like the mode of care that would help with like mileage reimbursement and hotels. If the Ronald McDonald House didn't have anything.

00;42;55;09 - 00;43;23;20

Brandi Williamson

And therapy was actually the one that told me about the monthly incontinence supplies. My husband didn't have a job. He laid off and I couldn't work. He was trying to find a job and I was running with children. Finances got really uncomfortable. We did have a little bit of help from family, but it got really uncomfortable. Very, very much so.

00;43;24;03 - 00;43;45;09

Brandi Williamson

It caused a lot of stress in our home when you're trying to figure out how to buy a formula or, you know, we didn't qualify for work because the formula that she was on was nowhere near to be found here in the state of West Virginia. And they could not order it and it had to come through Cincinnati.

00;43;45;10 - 00;44;17;03

Brandi Williamson

So Cincinnati worked with us was like a waiver application to get us her formula after, you know, we got so far traveling became more intense. Even though she didn't have monitors and things, she wasn't able to crawl. Yes, she was developmentally delayed just typical developmental milestones, even though we were receiving therapy was behind and she caught her weight up very well.

00;44;17;03 - 00;44;38;06

Brandi Williamson

So like she was a chunky baby and so like packing her around with her, we started casting, you know, cereal casting to help us, her legs, you know, packing her around with this cast on was like having three children, you know, it was so heavy and equipment wise, like, she couldn't really use a wheelchair yet, you know? But she was too big for a stroller.

00;44;38;18 - 00;45;04;00

Brandi Williamson

But we made it work. We made we made accommodations. We figured out how to make things. We I drove 8 hours to Richmond, Virginia, to get equipment through an assistive technology department because she needed a stander or because she needed this. And we didn't have the resources. And no one told me that there was anybody else that could help me, you know.

00;45;04;00 - 00;45;29;11

Brandi Williamson

So I did a lot of soul searching and a lot of Google searching and a lot of somebody help me somewhere. And, you know, as she got older, she got to where her appointments were longer in Cincinnati, every three months, every six months, we now visit Cincinnati as needed. And once a year for her main follow ups in the span of before the clinic.

00;45;29;11 - 00;45;54;00

Brandi Williamson

So we've come a long ways today. She's 11 years old. She is very independent. She walks with arm, crutches and affairs for short amount of distance. She uses a wheelchair for long distances. You know, just because it wears her out and her hips and things, she's still not on a task program. She goes independently and she still doesn't have a shot.

00;45;54;06 - 00;46;20;07

Brandi Williamson

So we are still you know, everything is still going good in that direction. I would be lying, though, if I said like if something happens and she gets a headache and she's had it for a few days, if I don't think something else is wrong, if I don't think that because she has kiari as well. So is it the Kerry is she has increased pressures in her head.

00;46;20;12 - 00;46;46;01

Brandi Williamson

She's also had cranial sin and those cysts, ptosis. And that is where the school uses prematurely. And with that being said, we've had it twice, which is typically you only have it once. So when her head hurts, I'm thinking, is her hardware malfunction? Is there something? And they are not wired. Right. So it's constant. It's not a constant with a kid with a non disability.

00;46;46;01 - 00;47;11;15

Brandi Williamson

They get sick, you know, you give Tylenol, you give Motrin. It's all it's a headache when she gets sick. I don't know what it is. So I start from the head to toe. Is it this is it that is it common cold, you know. So I mean, it still factors into her diagnosis. Even though we've came so far, you know, there's still things that can reflect towards that to make it be part of her diagnosis.

00;47;12;06 - 00;47;34;22

Brandi Williamson

She is very smart. She is in regular and special education due to the fact of modifications. I had advocated for that for like when she would have spelling tests with the other kids, like 25 words was just a lot for her. So I asked an IEP if we can modify that to like ten and then, you know, five, right.

00;47;34;22 - 00;48;06;05

Brandi Williamson

Circle the other five, you know, it was just a lot on the fine motor skills, you know, and her learning to do those things. So we have an IEP, her IEP is followed very well. I do advocate very strong on her IEP and it's not always been rainbows and roses with the IEP. It's been a little rough at times, but we've made it through it and she does fairly well in school.

00;48;06;05 - 00;48;38;07

Brandi Williamson

She is in fourth grade. She cheers for Little League and she cheers with a posterior k walker because it has the seat. So you know when she's out there cheer and she can flop her seat down and cheer, she also chairs on a special abilities travel team to which she absolutely loves. We just accommodate and where we are now, a family of six and we include her in every day living everywhere we go.

00;48;38;14 - 00;49;00;24

Brandi Williamson

And if she can't attend like sky zone, you know, that's a place. It's not fun for her. We will take one kid to sky zone and ask her, where would you like to go today or where would you like to go tomorrow? You know, we make sure that we include her in an activity as well. Typically, we just try to do family activities that are all inclusive that she can attend.

00;49;00;24 - 00;49;26;22

Brandi Williamson

But given that one of the kids one day something that she doesn't feel comfortable, we always try to make sure that she has a fun day as well. Financially loss, you know, was rough. It was rough. And then we applied for a waiver and we we were on the wait list and I was part of the lobby and at the Capitol when we had the waitlist to first clear.

00;49;27;07 - 00;49;54;21

Brandi Williamson

And so she got her slot then and that helped us tremendously with even like the goods and services in the waiver, you know, there was $1,000 there that we could use for goods and services that your insurance would not pay for because she did get her disability, the SSA. So we had that and the medical card, but it still doesn't pay for like medical equipment and stuff like that that chairs or the standards or, you know, those things.

00;49;54;21 - 00;50;15;29

Brandi Williamson

It it just doesn't cover that. So the goods and services came in handy for like of the adaptive stroller. We had a bath. She didn't technically need to buy a seat, but we used a our seat for a little while until she got more trunk. Support Safety Reasons. We use goods and services for one time for a shower, for her shower repair so that it would be a little bit more accommodative for her.

00;50;16;12 - 00;50;46;17

Brandi Williamson

So, I mean, the the waiver with the goods and services really was helpful to us financially. She has friends. She's she's very timid, but she does have friends. They treat her amazing. You know, they don't they they just make her part of the clan. They don't treat her any different. And there's always the possibility of another kid bullying her because of this versus that.

00;50;47;04 - 00;51;12;17

Brandi Williamson

There's always a possibility of a parent or an adult, you know, saying things that is not always the best. So I always try to provide education versus being hateful and things. You know, I try to provide the education to the families that have those questions or make those comments or kids. Kids have questions and answer. I'm very respectful and answer them.

00;51;13;00 - 00;51;39;27

Brandi Williamson

You know, it's okay to ask what's wrong with her legs, you know, hey, she doesn't walk as good as you, so she uses braces to help her walk. It's important. It's important that you talk to the kids, their questions, they're just as curious as anybody else. So I feel that it's very important in society just trying to talk to your kids about other kids being with special needs and having different abilities and things that may look different on the outside world.

00;51;41;14 - 00;52;06;23

Brandi Williamson

My advice to other parents is just don't give up. Find your advocacy. Find where you feel strong. If you're not strong, step up. Ask a question. I feel that by me asking the questions I did about the CAT program and why are we cason? I feel like prolonged us from being cast. If we have to be Cat in the future, that's okay.

00;52;07;07 - 00;52;45;29

Brandi Williamson

That right now we're not. I also feel that if you have other children, that's a sibling to a child with special needs to acknowledge them. They might need extra therapy or counseling or extra talking to because it affects them more than you realize. And they they're all trying to handle the emotions, too. So we're all learning together. And the learning curve, a lot of times for us, the family dynamic gets hard because the siblings are accepting there of her, but they want to do certain things.

00;52;45;29 - 00;53;09;07

Brandi Williamson

And a lot of times I'll say we need to see if we can find something else, you know, so that Kamya can be included. That's frustrating for them too. So I do try to make every accommodation for all for children. Sometimes I can't, you know, sometimes I just can't make that accommodation. And that's hard as a parent. That's that's really hard as a parent and a support system.

00;53;10;04 - 00;53;38;04

Brandi Williamson

Find somebody that you can talk to that says, you know, it's okay. Your emotions are fine. You know, I understand you because I didn't have that. I didn't have a support system. I didn't have somebody that I could talk to. You know, one of the things that I was always reminded to anybody, if I would say anything about I'm overwhelmed or these are therapy appointments are getting to me or going to Cincinnati twice a month is getting to me.

00;53;38;16 - 00;54;05;01

Brandi Williamson

Well, just be thankful she's here. I was thankful, but I was still human and I still had to manage a home and still had to try to find work and manage my other children and, you know, keep up with everything. I was very thankful she was here, but I was also living in the reality. It wasn't I wasn't that I was never ungrateful that she was.

00;54;05;01 - 00;54;34;01

Brandi Williamson

It's just this is real. Take a walk in my shoes and you'll see it's not always so easy. You know, we've had multiple surgeries. We're scheduled another surgery. You know, we're constantly chasing that medical world. It does slow down, but it doesn't stop. And that does cause some family issues, trying to manage kids, playing sports and trying to be there for this kid and trying to schedule around it so that you are there for everybody that need you.

00;54;35;00 - 00;54;54;13

Brandi Williamson

So find support the support groups that are offered, you know, through the CD just to be able to hear you out because it gets overwhelming and then your mental health is not good. And so you're not able to care for everyone in your circle. This podcast is.

00;54;54;13 - 00;55;09;10

Melina Danko

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