00;00;10;18 - 00;00;31;18

Courtney Ringstaff

I don't know where Truett begins and the autism ends all the time. And so for that reason, I don't necessarily feel like I need to justify his behavior with this diagnosis or give everyone that we encounter an explanation.

00;00;37;00 - 00;00;48;21

Courtney Ringstaff

Welcome to adjusting the sales. 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.

00;00;49;00 - 00;00;51;23

Melina Danko

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

00;00;52;01 - 00;01;22;05

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 and working multiple ways, 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 connections through the relatable topic discussions.

00;01;22;29 - 00;01;31;27

Courtney Ringstaff

We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sales.

00;01;37;06 - 00;01;59;20

Courtney Ringstaff

My name is Courtney Ring Staff, host of Adjusting the Sales. Some listeners of the podcast had reached out to me and asked if I could share my personal story. As a parent whose child was diagnosed with autism because they'd been listening and didn't realize that I was a parent until there was a certain episode that I mentioned it.

00;01;59;20 - 00;02;24;00

Courtney Ringstaff

It was the Autistic Experience episode with Cortland Leslie. I hadn't really talked about it on my end because the podcast started before we got the diagnosis for my son, and so it just never seemed like the right time. And then also I wanted the platform to be for other parents and other families. It was hard for me to look at my own self and my own story through that same lens of like, you have a story, you should tell it.

00;02;24;00 - 00;02;41;20

Courtney Ringstaff

It can help someone else. It might help you feel more validated in your experience. Those are the reasons I want families to come share, but I just didn't feel the same way about myself. I think it's just different when you're thinking about your own personal story in your own personal journey. When she mentioned that to me kind of was like, Oh yeah, obviously, of course I should share that.

00;02;41;20 - 00;03;01;18

Courtney Ringstaff

I don't even include that. I'm a parent myself. In our intro, I just say that I'm a social worker and that this is the program I work for, and that's why we started the podcast. But I am also a parent. And so if it's going to help, some of our listeners feel a little bit of connection and really stability with me as a host, then I definitely want to share my story as well.

00;03;02;06 - 00;03;22;14

Courtney Ringstaff

We're very much still in the throes of the beginning of our story. We've come a long way, but we have a whole lot longer to go to. It just got his diagnosis like a year ago. So I don't have like a beginning, an end like some of our stories do because I feel like our story is still so ongoing.

00;03;23;00 - 00;03;51;25

Courtney Ringstaff

I will at least share where we are up to this point and what has been challenging for us and what's really helped us along the way. And so I hope that that can just help some of our listeners as well. My story starts with COVID, so I was pregnant and due in March of 2020. My boss at the time actually told me to leave and go home and not to come back because we were having the COVID outbreak and it was just days before the world shut down and she was like, Courtney, you're very, very pregnant.

00;03;51;25 - 00;04;16;03

Courtney Ringstaff

You should just stay home and just not come back to work. Just take your maternity leave early. And that was on the 23rd of March. And then I ended up having to do it on the 25th of March. So just two days before everything kind of shut down when we got to the hospital. It was funny. I always tell people that it felt like we were like in a zombie apocalypse because the parking lot was completely empty and we were there for a scheduled induction.

00;04;16;03 - 00;04;35;21

Courtney Ringstaff

So we knew we were going to be there at midnight and there were some security guards and maybe nurses. I don't really know who the staff was, but they met us in the parking lot in like hazmat suits and like did a screening like it asked us a bunch of questions and then escorted us in straight to the room and no one was allowed to visit us and we weren't allowed to leave the room at that time.

00;04;35;21 - 00;04;51;20

Courtney Ringstaff

It was so early that we weren't wearing masks or anything that was even before masks and things like that were recommended. So we were just kind of supposed to stay in there and kind of quarantine to our own room tour. It was born on March 25th. We weren't even there a full day before he was born, labor went pretty quickly for me.

00;04;51;27 - 00;05;15;14

Courtney Ringstaff

My water broke on its own and it was a pretty easy labor. There were no complications after he was born, they took him back for his newborn hearing, screaming. He did fail the hearing screening. And when he failed, I remember them coming back into the into the room with him and they said, well, he failed his screening. And I got emotional and I cried and I said, he's not going to ever hear us.

00;05;15;14 - 00;05;31;03

Courtney Ringstaff

I thought I thought that meant he was deaf. My husband was like, it's okay, we'll just learn sign language. It's not a big deal. And I was like, Oh, okay, yeah, you're right. We will be able to communicate. It'll be fine. And then the doctor was like, No, lots of newborns fail their first hearing screening because their heads are just so full fluid.

00;05;31;19 - 00;05;52;18

Courtney Ringstaff

We'll do this again in a few months and we'll go from there. So everything was fine with him as an infant as far as we knew. I mean, we didn't see any differences. We were home, we were quarantined. So no one was meeting him like no one met him for the first several months of his life. We didn't notice any differences in his hearing.

00;05;52;28 - 00;06;18;12

Courtney Ringstaff

I figured everything was fine. Like if we would clap our hands or if our dog would bark, he would turn his head. And then in September, when I was six months old, we were able to go back in for another hearing screening. And I think typically they actually do a screening sooner than that if they failed our newborn screening, but because it was COVID and because they were just trying to limit newborns coming into clinics, we didn't see anybody until he was six months old.

00;06;18;22 - 00;06;37;22

Courtney Ringstaff

My husband took him back that time for his six month hearing screening and he failed it again. But this time he was like super squirmy and he was just not really complying with the test. So they told us he's probably fine. Like they asked him, you know, does he turn his head with you? Clap? Does he turn his head when the dog barks?

00;06;38;05 - 00;06;56;19

Courtney Ringstaff

And we said, yes, he does. And so they said, okay, well, it's probably just because we can't get a good reading. He's just moving around too much. So if you have any other concerns, you can bring him back at another time. But for now, like, we're not really concerned and we weren't concerned because like I said, we knew he could hear us at some capacity.

00;06;56;19 - 00;07;15;28

Courtney Ringstaff

We knew we could get his attention. But I also, looking back, think I used to be able to my husband's a contractor and he was doing a lot of renovations around our house at this time because we were stuck during COVID. And so I remember thinking like, Man, Pruitt can sleep right through the hammering and the drills and saws.

00;07;15;28 - 00;07;34;00

Courtney Ringstaff

He doesn't even care about that. Like, I remember thinking I could just cover his ears and we'd sleep right through it, and now we know it's because he really couldn't hear it. It was very muffled. But at the time I just thought, he's a really good sleeper. And, you know, I just didn't I didn't think about it as being a concern because if we were trying to get his attention, we could we could get a response from him.

00;07;34;20 - 00;08;04;07

Courtney Ringstaff

So then October ish of 2020, that same year, I was sitting in a staffing meeting with my previous job where I worked in foster care, and we had a child who was just within a few weeks of Pruitt's age. They were almost exactly the same age. And my social worker was telling me about this child on her caseload and that she only said like one or two words and that they had some concerns of her speech delay and that they were going to put in a birth to three referral.

00;08;04;20 - 00;08;22;07

Courtney Ringstaff

And I remember like looking at that child's age and then looking like thinking in my head, trauma is literally just a few weeks older or younger. I can't remember, but they're like the same age. And he also doesn't say any words. And so that's when it started to kind of dawn on me that maybe true. It also has a speech delay.

00;08;23;01 - 00;08;39;00

Courtney Ringstaff

I had been kind of in denial about that. I remember one time AJ said to me, my husband said to me, I would have thought that we would have been hearing Pruitt say Mommy and daddy. But now you know Mama and Dada. And I was like, Oh, no, you know, all kids kind of develop at their own pace, which they do.

00;08;39;14 - 00;08;59;09

Courtney Ringstaff

But by now, he was almost a year old and was still not really babbling. And I was like, No, he's fine. You know, he'll he'll get around to that. I just brushed it off. And then in that staffing meeting, when I'm sitting there giving my social worker recommendations, I'm saying, yeah, we need to put in a three referral.

00;08;59;09 - 00;09;20;06

Courtney Ringstaff

And, you know, she should be doing this. These are the milestones. It dawned on me that like, I didn't even look at my own child through that same lens. And I was like, Man, okay, maybe we also need to do a birth of three referral for my son. And ironically, that same social worker, she also worked for Ruby, and so she walked me through the process.

00;09;20;06 - 00;09;43;10

Courtney Ringstaff

I had never personally applied for emergency three services before and so she gave me the ages and stages questionnaire and I filled that out and realized that there were a lot of things that he was not yet doing and it looked like he was going to qualify for services. So in November of that year, he did finally have his birth free evaluation and he did qualify for services on the basis of his speech.

00;09;43;10 - 00;10;05;25

Courtney Ringstaff

DeLay. But they wanted to rule out his speech delay being the result of auditory issues. And so we again, were going to get testing for his hearing. And I told him at the time his history with all of the hearing screenings and told them that, you know, we don't have any concerns about hearing, but I did anyway go.

00;10;06;02 - 00;10;26;22

Courtney Ringstaff

And so this time when he failed it, they sent us on and they actually could see that there was a lot of fluid. So that same fluid that his newborn, I guess, just never drains correctly because of the shape of his ear canal drum, your drums and canals and so he did need to have tubes put in in order to hear.

00;10;26;28 - 00;10;54;04

Courtney Ringstaff

And it was it was like a chant. So they knew, like put the tubes in and hopefully that would correct the problem. But if it did not correct the problem, then we were going to have to look at other options. But we got tubes in his ears in March of 2022 and the tubes corrected the issue immediately. So as soon as the tubes were put in, they were able to test while he was still under and see that he could actually hear.

00;10;54;19 - 00;11;12;16

Courtney Ringstaff

And so they told us at that time that his hearing was equivalent to him laying in a bathtub of water so he could hear like the loud noises we would make to a degree. But it was very muffled. But yes, if it's a dog was barking, he could hear something. If we were yelling his name or trying to get us attention, he could hear us.

00;11;12;20 - 00;11;32;18

Courtney Ringstaff

He wasn't like repeating what we said because of that. Like it was so muffled. And then our reverse two three experience really started. And by now, providers were mostly coming back into the home. And because of its age, I opted for the providers that would come to the home like they had the choice to either be virtual or in person.

00;11;33;00 - 00;11;49;17

Courtney Ringstaff

And even though there was the risk of contamination and things, I went ahead and wanted it to be in person because he was so young. So I just didn't think that he would get much out of virtual therapies. So I was connected to some therapists who would come to the home and they also would go into the community with us.

00;11;49;17 - 00;12;12;05

Courtney Ringstaff

So there were some times where we like met at the park or there was a splash pad in Fairmont that we would meet at and they would do some services there. They were not yet allowed to go into the daycares or schools. That did come later for him. My experience with Britta three was mostly positive, definitely positive. Overall, the first OT we were connected with didn't click super well.

00;12;12;10 - 00;12;31;11

Courtney Ringstaff

I just felt like over shared her personal life with us honestly. And so I think for some families that might be like some rapport building, but for us it was kind of like, okay, you're here, you've been here for a long time. Can we get to the therapy part? And so our coordinator was really quick when I reached out to her and said, Is it possible that we could find another O.T.?

00;12;31;11 - 00;12;52;03

Courtney Ringstaff

And so we were able to kind of make some changes to our team as we saw best and as was the best fit. We were connected with one speech therapist and we really liked her. I feel like speech therapy was hard in the beginning because all the providers wearing masks and so the kids weren't seeing them enunciate. They weren't seeing their lips move.

00;12;52;03 - 00;13;09;28

Courtney Ringstaff

And so sometimes he would be trying to repeat a sound that he thought he was hearing, but it actually wasn't the way he was hearing it because he wasn't seeing their mouth move. He still pronounces things, some things differently or kind of odd, like for like the word Cheeto, he says, like rhino, I don't know. You know what?

00;13;09;29 - 00;13;27;08

Courtney Ringstaff

That's connected, but he really does. He is the kind of kid who really watches your mouth when you talk. And so I wonder if that had something to do with why we weren't progressing super quickly in the beginning, because he was really trying to look at your mouth and their mouth was covered. So I was really involved in the speech therapy at that time.

00;13;27;14 - 00;13;42;28

Courtney Ringstaff

They would say the word, I would keep saying it to him so that my mouth was like exposed and he could really see it. One day our speech therapist didn't come back and didn't respond to my text messages. I don't know what happened. I had reached out to our care coordinator and said, I haven't seen our speech therapist and we love her.

00;13;42;28 - 00;14;00;22

Courtney Ringstaff

I don't know what happened. And I still to this day don't know what happened, but they were really quick to replace her and get us a new speech therapist and that one stuck with us through the end. And so, again, even when you have like little hiccups and bumps in the road, I felt like as a team overall they were really quick to problem solve and get someone else out to us when things had come up.

00;14;00;26 - 00;14;23;04

Courtney Ringstaff

So I was grateful for that. During all this, during all this birth to three, like navigating the birth of a three service, I found out I was pregnant and technically we had been trying for my daughter. It took us a couple of years, like almost two years to get pregnant with Truett. So when we started talking about having another baby, we thought it would probably take us a while.

00;14;23;07 - 00;14;46;01

Courtney Ringstaff

So we were like, Let's go ahead and just start planning out our timeline, kind of tracking ovulation and all those kinds of things that we had to do with Truett. But we ended up getting pregnant like immediately. Like as soon as we started trying, we got pregnant and looking back, if I could rewind, I would probably have spaced them out a little bit more if I would have known that we were going to go through this with it.

00;14;46;01 - 00;15;06;27

Courtney Ringstaff

Because I feel like sometimes I didn't give my daughter and her infancy as much attention as I could because I was also trying to focus on getting through it. His diagnosis and his evaluations and like coordinating all his stuff. Like I felt like my time was so split that I really didn't get to give either one of them the attention they needed in that time.

00;15;07;04 - 00;15;22;05

Courtney Ringstaff

But because Emmie was literally an infant and was just sleeping all the time, I felt like my ten year old was mostly on through it and I look back in her infancy. It's kind of like a blur and that's kind of sad, so I wish I would have spaced them out a little bit until we kind of had a handle on these services.

00;15;22;05 - 00;15;45;02

Courtney Ringstaff

Or maybe he was even out of birth to three, so she was born in May of 22 through it, loved her from the second that she was there. I was so nervous because it was always such a mommy's boy and we were just like the Three Musketeers, you know, me and my husband. And through it we were just always together or very close.

00;15;45;19 - 00;16;06;20

Courtney Ringstaff

We've gone through all of this stuff together and like AJ had been very involved in all the doctor's appointments and all of the birth of three appointments. He he tried to come to every single one of the birth to three appointments, even if he was leaving work early. And so I was concerned that would be really jealous. When we brought me into the room, my sister had cut through it while we went to the hospital to have Emmie.

00;16;06;28 - 00;16;24;04

Courtney Ringstaff

They didn't come to the hospital to see us because COVID protocol was still in place, even though it was like two years later, there were still no visitors allowed. We brought him home and brought her in and I went and sat down with it and was trying to explain to him, you know, all the baby that was in Mommy's belly is now here.

00;16;24;04 - 00;16;51;16

Courtney Ringstaff

We have her. We brought her home. And as soon as I brought her in, he was just infatuated and he wanted to hold her. He was kissing all over her face like he loved her. There was no jealousy like that was very much his baby. I think bringing her into our family helped him in some ways, kind of mature a little bit, learn some new words and some new skills for sure, because we were doing all of those things with her, like all of the same mama, mama and, you know, trying to get her to repeat us and babbling.

00;16;51;16 - 00;17;08;01

Courtney Ringstaff

And Terrell was doing it. And that's one of the first times that he was talking as while we were trying to get me to talk. And so now he could hear and I guess I hadn't thought about doing it that way because he was a toddler. So I wasn't getting down to being like, Ooh, mama, mama to him.

00;17;08;01 - 00;17;25;24

Courtney Ringstaff

I was doing that to her. But he was he was repeating it and picking up on it and he was repeating it to her, trying to get her to say it to him like he was teaching her and not like he was saying it, you know, for the first time. So I think that bringing her to the family kind of helped him in some ways, too, because he definitely, definitely loved her and loved interacting with her.

00;17;26;09 - 00;17;58;02

Courtney Ringstaff

And then in June of 2022, just about four weeks after I had my daughter, I started my job at the city. And I took the job because I had always had an interest in working with people with disabilities and families that had children with disabilities. That's where my professional background started in 2014. That was my first job and I even was with the city as a student and a trainee twice for two separate years.

00;17;58;11 - 00;18;19;10

Courtney Ringstaff

And so even though I had left and gone into foster care and adoption for a couple of years, after I finished up maternity leave, I went back to the city and started working with the Parts for Parents program. And so that was all before we got any other diagnoses with him. At this time, I just thought that he was a kid with a speech delay because of a hearing impairment.

00;18;19;28 - 00;18;56;28

Courtney Ringstaff

I started to notice, though, some differences in interests behavior. There are a couple things that I'll mention that like really kind of made me question if he might have something more going on than just a hearing impairment. And so that started in like July and or August of 2022. So just a few months after starting out the said and I feel fortunate, like I feel like the timing of things is really crazy because I was in a place at work every single day where I was surrounded by professionals who see people and see kids with disabilities all day, every day.

00;18;57;07 - 00;19;12;04

Courtney Ringstaff

And so when he would do something that I felt like was kind of different or maybe not typical for a child his age, I would like run down the hallway and be like, Hey, Cassie Truitt did this today or he did this this weekend. What do you think that means? Do you think that this is concerning or or whatever?

00;19;12;04 - 00;19;33;16

Courtney Ringstaff

And I felt fortunate to have, like, contacts that I could trust to kind of bounce ideas off of, because it was really hard for me to put my social worker hat on when I was looking at him. For some reason, it's like I would be able to justify everything that he was doing and play it off as like, Oh, well, my dad was weird too.

00;19;33;26 - 00;19;54;09

Courtney Ringstaff

Or I don't like to make eye contact either. Like, I could just I could just justify the characteristics that I was seeing of autism with all these other things. And so I needed someone from the outside to say, Yeah, that might be strange, or Yeah, you're right. You know, just because he does that doesn't mean anything. Some of the things he was doing was like he would never point to anything.

00;19;54;09 - 00;20;21;02

Courtney Ringstaff

And other kids was like, they are pointing to everything because they're two years old and they want me to see what they're pointing at. So other kids are pointing at everything and I could not get him to point at anything he was interested in. Even if he needed something, he would he would take my hand and lead me to it and then just kind of put my hand merit and wait for me to figure it out, walk to the refrigerator and kind of stand by it and maybe hold his cup or something and wait for me to figure out that he needed his water cup refilled.

00;20;21;02 - 00;20;47;07

Courtney Ringstaff

Like, or he would try to do it himself, but he would never just point to it. So no pointing. And I couldn't get him to point out things either. If we were like looking at a book or watching something, I would say 0.2, the tiger or something, and he just wouldn't do it. And I didn't know if that was his speech delay because he really didn't understand requests or demands or if that was something more.

00;20;47;16 - 00;21;06;25

Courtney Ringstaff

Then also he was not answering to his name. I could be an inch from his face and he could be looking at something or watching TV or looking out the window. And I would just keep saying his name and he would just never turn his head to my voice saying his name. It's like it's like he didn't realize that it's the social norm to acknowledge someone when they're talking to you.

00;21;07;06 - 00;21;26;18

Courtney Ringstaff

And I know that he knew his name. And by now and we're talking about he'd had tubes in his ears now for six months. So we know for sure he could hear us. It's just it's like it was very selective when he would when he would acknowledge that he was being addressed or being talked to. And then he was not engaging with his peers.

00;21;26;18 - 00;21;53;12

Courtney Ringstaff

And by now, his peers were still doing a little bit of parallel play in school, but they were, for the most part, like starting to play things together, like pretend together. And so I didn't even realize this because his sister was still so young, but his teacher actually brought it to my attention that he was one of the only kids who, like if everybody else was playing in the play kitchen at daycare, like he didn't really care to, he didn't really care to participate.

00;21;53;12 - 00;22;08;17

Courtney Ringstaff

And when all the other kids were doing, he would be like on the outskirts of the kitchen, kind of doing his own thing. There were just some of those kinds of things where he wasn't really interested in what his peers were doing and didn't understand that there's like a social cue or a social norm to like participate in this.

00;22;08;17 - 00;22;36;15

Courtney Ringstaff

Unless he was like physically being like hand over hand. This is how we play with them by the teacher, otherwise he just wouldn't care to engage. Had this time he was obviously getting birth to three, but I decided to look into getting outpatient services as well because the speech delay was so significant at one time. I want to say the first evaluation, it was like a 60% delay for for receptive speech and like a 40% delay for expressive speech.

00;22;36;15 - 00;22;57;21

Courtney Ringstaff

So both was very delayed. And I started looking into that and quickly learned that even as someone who has pretty good insurance, it is super expensive to have outpatient services because you're insurance, first of all, only starts to pay once you meet your deductible and then once you meet your deductible, they only cover like 30 appointments and then you have to pick up the cost again.

00;22;57;21 - 00;23;20;29

Courtney Ringstaff

So if he's going weekly, that didn't give us much time. It was going to be expensive for us. And I was kind of complaining about that one day we were going to do it, but I was kind of just complaining about it. And Kathy Miller is the feeding and swallowing director and she is the speech therapist. She also sees patients outside of the clinic who come in for feeding and therapy and speech therapy.

00;23;20;29 - 00;23;42;20

Courtney Ringstaff

There at the center, Cassie was like, if you don't mind for the students to observe, we could schedule him for early Thursday morning before work. You could bring him in and the students could work with him doing speech and occupational therapy. And I would be here and showing them what to do and it would just kind of be a learning experience for them, but also could be beneficial for you.

00;23;42;20 - 00;24;06;04

Courtney Ringstaff

And I was definitely on board with that, so I was bringing him in at like 745 like every Thursday morning and letting him work with the students. I really enjoyed his time there. He called her Miss Kathy and that became part of his routine. So I was really fortunate for that. And for the students that participated, it seemed like sometimes there would be like one or two students, but then sometimes there was like five or six students.

00;24;06;04 - 00;24;29;15

Courtney Ringstaff

Some of them would be observing and some of them would be like working with him directly. And then he sometimes also saw Dr. Bird, Amy, Bert, and she is the occupation therapist. She's also with the feeding clinic. But she also sees some patients there at the center outside of the feeding clinic. And so I was fortunate to have both of them there because I asked them a ton of questions and really trusted what they had to say.

00;24;29;15 - 00;24;54;19

Courtney Ringstaff

And so guidance that they gave me with him. But they agreed after they started seeing him for speech and occupational therapy, they agreed that there were some things that we could we could all sit down and go back and forth about whether or not it looks like autism. But none of us are diagnostician. And they kind of just convinced me that, yeah, you should probably go ahead and have him evaluated.

00;24;54;19 - 00;25;19;08

Courtney Ringstaff

And I, I agreed with that. Obviously, I'm the one who had a concern and brought it to their attention in the first place. And so I appreciated that they were, you know, willing to tell me that and to be honest with me like that and say, yeah, you should probably get him tested or evaluated. So we added a psychologist to our two, three team and she actually scheduled him and we actually did our evaluation after work.

00;25;19;08 - 00;25;39;08

Courtney Ringstaff

One day there at the side, we used the classroom that he was he's used to for occupational and speech therapy. So she came there and observed him playing in that space with me. At the end of that evaluation. It lasted almost 2 hours, I think like an hour and 45 minutes or so. And it was it was kind of rough because it was at the end of the day after school.

00;25;39;08 - 00;25;54;19

Courtney Ringstaff

And he was tired and I was a forgetful mom and I forgot a diaper. So he a pet himself and I had to take his diaper off and he didn't have another diaper to put on. I just put a shorts on and he'd be himself again. And this time, of course, it got all over his shorts and so he was mad because the shorts were wet.

00;25;54;19 - 00;26;09;20

Courtney Ringstaff

And I was trying to like air shorts out and it just seemed like such a hot mess of an evaluation. I thought personally, like from the autism side, I thought he was doing fine. I felt like he was playing with me and he was bringing me toys and he was talking to me a little bit, saying like one word every now and then.

00;26;09;22 - 00;26;35;04

Courtney Ringstaff

At that time, he probably had like ten and ten or 20 words that he was using. So I thought things were going well. I really thought she was going to say, you know, no, I don't see autism here, but I definitely see a kid who's mad about peeing his pants. He really wanted to, like, run up and down the hallway, but I just kind of thought that was like normal toddler stuff because it's a long hallway and he sees it and he's just like, Oh, I can't wait to run down that whole long hallway and have my mom chase after me.

00;26;35;22 - 00;27;00;02

Courtney Ringstaff

So I just didn't really I didn't really see what she was seeing. And then after the evaluation, she said he meets all the criteria for autism level one. And I remember it was just kind of like, did I hear that correctly? Like I almost was like I had to ask her again to repeat herself. And she had gone on to like continue to say, you know, you can apply for a waiver and you can do these things.

00;27;00;02 - 00;27;14;24

Courtney Ringstaff

And she was trying to like, give me some resources, but I was just like, wait a second, you're telling me to apply for a waiver? But you just told me he had autism level one. Like as a professional, I knew that level one means like very little support needs. And now you're telling me to apply for a waiver?

00;27;14;24 - 00;27;34;05

Courtney Ringstaff

Waiver is designed for very high support needs. So I was confused by that and it made me kind of question like, does she that she see what she needs to see? Does she just tell everyone who gets a diagnosis up to apply for a waiver like it just confused me and then I think I was just going through the stages of grief.

00;27;34;16 - 00;27;51;11

Courtney Ringstaff

I started out with like being in denial about it and being like, No, no, no, she doesn't know. She's talking about like she obviously told me to apply for a waiver. So she has no idea what she's talking about. And then I like moved on to anger and just being mad about the situation, not her, but just like being mad the way it went down.

00;27;51;11 - 00;28;22;01

Courtney Ringstaff

Like he was just tired and he picked himself and like, I just felt like it wasn't a fair evaluation. And then I start to feel sad and I cried a lot. Like I went through all of the stages before I have finally gotten around to acceptance. But four weeks after that evaluation and after that appointment, I continued to question his birth two three team and my team of the occupational therapist and and speech therapist that he was seeing regularly, because I just kept being like, do you guys agree with this?

00;28;22;01 - 00;28;43;18

Courtney Ringstaff

Do you really think that that looks like autism? And and so everyone was kind of encouraging me, you know, for questioning that or if you would feel better about it, get a second opinion, take him for another evaluation. And so I reached out to the in D.C. and I got an application and I was going to make an appointment for the in DC and I actually filled all the paperwork out.

00;28;43;27 - 00;29;10;07

Courtney Ringstaff

It was a large packet that they needed and there was a very long wait list. So he was on the waitlist at some at some point. And I don't know, I guess the more that I thought about things and about him and his diagnosis, I started to think there's no denying that he has a speech delay. At minimum, there probably are also some sensory things going on, which the psychologist had mentioned some sensory things when she diagnosed with autism.

00;29;11;06 - 00;29;33;14

Courtney Ringstaff

And at the time I was like, anybody would be matched. They put themselves, you know, like I just kind of like made excuses in my mind for why things went down the way that they did. But the more I thought about it, I thought I started to kind of come around to that acceptance over the next couple of months because I was thinking like, does it really matter if he has autism level one or level two or or something else?

00;29;33;14 - 00;29;57;20

Courtney Ringstaff

Because he for sure at minimum need speech therapy. And it doesn't matter if he has a diagnosis of autism or not, he definitely needs that. That's obvious. And he was getting a lot at the time. That was also helpful for him. They were doing some different things to help him relax. Sleep was very difficult at this time. I was having to give him melatonin every single night because he could not turn off.

00;29;58;00 - 00;30;19;20

Courtney Ringstaff

He was not falling asleep till three or four in the morning and then we're having to get up for work by like seven. He was not napping at school. Like it's like he could just not shut off his brain attention. And like sitting still to focus on any task was pretty much like not never going to happen. I mean, he he was just so wired up and so energetic all the time.

00;30;20;12 - 00;30;46;05

Courtney Ringstaff

So there were some odd needs there. So I was I was kind of coming around to the idea, like, okay, if I if I don't necessarily agree with autism, what does it hurt to have a diagnosis so that he is able to access these other things because he was getting closer to aging out of birth? Three And I was getting worried that without that diagnosis, he may not be able to start school early and do early preschool, which I knew he was going to need.

00;30;46;15 - 00;31;04;27

Courtney Ringstaff

And so I kind of just started to say, okay, even if he doesn't actually have autism, that's okay, we'll run with it. Because I still had some doubt in my mind, but I thought it'll be helpful for him in the long run to access to services he needs with that diagnosis. And it's going to make it a lot more difficult to question what he needs with that diagnosis than without it.

00;31;05;07 - 00;31;34;09

Courtney Ringstaff

And I've continued to evolve because then some things some things kind of transpired between October of 2022 and March of 2023. When he turned three, in my mind, I was like, Oh, this is the autism, this is what it is. And so now I don't really question it anymore. I don't really doubt it. I think I was like moving through the stages of bargaining and being like, okay, maybe he doesn't really have that, but we can still do this.

00;31;34;09 - 00;31;52;10

Courtney Ringstaff

Like, I literally moved through all those stages of grief, and I have now reached like full acceptance because I see the difference in him and the way he thinks and the way he acts versus his typical peers. But the first thing that happened was we went to his first friend's birthday party and it was a friend from day care and she loved Frozen.

00;31;52;10 - 00;32;06;16

Courtney Ringstaff

So she had like an Elsa Frozen themed birthday, which she loves Elsa, too. So it was it was, you know, he had a good time, but there were lots of activities for the kids in his class and they were probably only like ten kids there. It wasn't, you know, it wasn't a ton of kids. It was just a small daycare class.

00;32;06;29 - 00;32;30;07

Courtney Ringstaff

All the other kids were doing the activities but the nose on off. And then Elsa came and they all wanted to play all of Elsa's games because she was like a pretty princess dressed up and she was so overstimulated and didn't understand the point of the party. He was just like scaling the corners and the walls of the room, like he wanted to get out of there.

00;32;30;07 - 00;32;51;00

Courtney Ringstaff

He was looking for all the doors to run away. He kept going through the to go and trying to dart out the back door. And then he would go to the front door and dart out the front door. He was just not having a good time. I was able to distract him with the birthday cake when I gave that to him, he went and sat in the circle with everybody else and that was the only time that he sat in the circle with the other kids was while he was eating the cake.

00;32;51;00 - 00;33;03;14

Courtney Ringstaff

And then as soon as that cake was gone, he was back up and then scaling the room. Like he just did not want to participate. He did not he didn't really care what the other kids were doing. There was no like sense of this is what everyone else is doing. So I'll just do it too. He just didn't care about that.

00;33;04;03 - 00;33;25;00

Courtney Ringstaff

And seeing that, I remember coming back to work on Monday and going back down to Cassie. Dr. Miller and just crying because I said for the first time I finally saw him compared to his peers. And that was probably the first time I really saw him in a room full of other kids who didn't appear to me to have a diagnosis of autism.

00;33;25;22 - 00;33;47;29

Courtney Ringstaff

And I got emotional and cried to her because I was like, I didn't realize he was struggling like this to participate or that he was obviously uncomfortable. And so that was the first thing that I noticed. And then by now, he's getting ready to be three years old, and that's when he really started to elope and run from us.

00;33;49;01 - 00;34;10;20

Courtney Ringstaff

And it's scary because I couldn't trust him to get out of the car with anybody other than myself or my husband, because the second he came out of his car seat, he would try to run through the parking lot or run away from us. I would envy the families who could get their kid out, sit them down beside them, get their bags, you know, get their water bottles or whatever, and their kid not run away.

00;34;10;20 - 00;34;30;08

Courtney Ringstaff

But we could not let go of him in a parking lot at all. We couldn't take him to the grocery store without buckling him in to the buggy. And nowhere we ended up having to buy like the safety harness, what some parents say is like a leash. We call it a safety harness because we couldn't take him anywhere, that he wouldn't try to run away from us.

00;34;30;15 - 00;34;47;07

Courtney Ringstaff

It became very much like a game for him. He would like run very far ahead of us and then turn around and kind of laugh and giggle and try to get us to chase him. And so I think it started out as a game and we had no choice but to reinforce it because we had to chase after him.

00;34;47;22 - 00;35;03;19

Courtney Ringstaff

I remember one time we were at like a fall festival kind of event on a on a football field, and I thought, okay, he can run across the football field. I can see him, it's wide open and he won't go to like he he'll have to turn around and come back. He'll have to realize I'm not chasing him.

00;35;04;14 - 00;35;22;17

Courtney Ringstaff

And he ran almost the entire distance of the football field. And then I thought, oh my gosh, there's a parking lot on the other side of that football field. I'm going to have to run after him because he's not coming back. So then I had to take off running across the field to after him and eloping became a huge issue with safety for obvious reasons.

00;35;22;17 - 00;35;41;01

Courtney Ringstaff

You know, one time he did run into traffic. It was like he was trying to escape all the time. Everywhere we were, he was looking for a way to escape. We had to put locks high up on our doors and alarms on our doors in our house, because there was a few times that he would drag a chair or something over and actually stand up and unlock the door and get out.

00;35;41;09 - 00;36;03;21

Courtney Ringstaff

There were two separate times that he was walking down our driveway. Luckily, we caught him before he got into the road or walked through the neighborhood. It was just kind of like sauntering down the driveway on two separate occasions. And so really watching him and keeping things locked up became a full time job. And, you know, I know that that is part of his autism.

00;36;04;04 - 00;36;24;20

Courtney Ringstaff

Other kids who have autism are doing that as well. And so knowing that that he struggles with that and that he tries to run away and I've not really been able to notice a pattern except that he thinks it's fun. It's improved a lot, but it's still it's still not like completely gone. I mean, he still has days.

00;36;25;11 - 00;36;41;29

Courtney Ringstaff

Just a few weeks ago, we got him out of the car. Usually I do live on our main road right now and usually we can get out of a car and I can say Go home and he'll start walking back to the apartment. But for some reason, on this particular day, I went around the car to get out, has to get a sister out, and he decided to turn around and just run back towards the road.

00;36;41;29 - 00;36;59;16

Courtney Ringstaff

And instead of running into the road, he started running down the sidewalk. But then I was having to chase him down the sidewalk and my daughter was standing there in the driveway. She's only two. So she started to walk out into the road. And my luckily my neighbor was mowing grass and he stopped and he went and grabbed me before she got to the road.

00;37;00;02 - 00;37;18;26

Courtney Ringstaff

But I was like, Which one do I chase? And so now I'm like back to, you know, back to holding hands to see if we got a car and how I drag him around with me and hold on to him while I get her out with one hand. I go back to some of those safety measures because I can't obviously have him running away or either of them running into the roads.

00;37;19;06 - 00;37;37;04

Courtney Ringstaff

That still is a concern, even though it's not quite as bad as it used to be. We can go into some spaces now and he understands the concept of why were there like the Splash Park, for example, like before? I would never imagine taking him to one because he would probably not get in the water. He would not stay in the water the whole time.

00;37;37;04 - 00;37;52;09

Courtney Ringstaff

He would be trying to escape. But now he understands that that's fun and he will participate in the activity for the most part. Like I have to still kind of walk around to make sure he stays in that area and remind him, you know, nope, stay on the splash pad, stay on the splash pad. But he will for the most part, stay on the splash pad.

00;37;52;25 - 00;38;13;11

Courtney Ringstaff

But there are still some environments that are just too open, too much like the beach. We live at the beach. And I hate taking him to the beach because even though he loves it and he loves the water, he wants to just run wild and and just run straight lines down the sand and it's too much. I can't chase him and carry the toddler.

00;38;13;11 - 00;38;40;07

Courtney Ringstaff

And so there are just some environments that he still tries to run back in March, in 2023. So shortly after his diagnosis, he understood very little about what we were saying. So I think I mentioned earlier that his speech delay was was he had delays in both receptive and expressive language, but he really didn't understand almost anything of what we were saying to him.

00;38;40;26 - 00;39;06;03

Courtney Ringstaff

So that comes across as very noncompliant to his teachers and to, you know, his day care providers and to other family members who might be giving him directions or telling him not to do things. He really didn't understand anything of what we were saying. He could say some things by now, like he could put one or two words together and, you know, small sentences like, no, I not or I can or things like that, or let me go, things like that.

00;39;06;16 - 00;39;28;10

Courtney Ringstaff

But he could not really understand what I was requesting of him. I could say, you know, now what do you want for dinner or do you want pizza? And even though he loves pizza, he would not. He did not understand what I was asking him without me wording it in ways that I thought he would probably understand because he would pick up on like one main word or me kind of prompting him for an answer.

00;39;28;18 - 00;39;50;13

Courtney Ringstaff

So I got into habits of saying, you know, do you want pizza or tacos? Kind of hold my hands up so he could like pick one or the other. And then he was just kind of understanding that I'm asking him pizza on the left hand or taco on the right hand. So not that he's understanding that. I'm asking him what he wants for dinner necessarily, but just that I'm like making him choose a point pizza and tacos.

00;39;50;13 - 00;40;02;27

Courtney Ringstaff

Or I would ask him a yes or no question and he would just kind of stare at me blankly and I would say, Can you say yes or no? And then he would say Yes or no. But I don't I still don't know if he actually meant yes or no or if he was just picking one, because I was giving him those two choices.

00;40;04;13 - 00;40;20;25

Courtney Ringstaff

But he presented really well because he would say something. And so there were some complaints sometimes, not very often, but a handful of times from babysitters or daycare providers that was like, Oh, you know, I gave him directions all day long, but he never followed directions. And I would have to say he doesn't understand what you're asking him to do.

00;40;20;26 - 00;40;41;07

Courtney Ringstaff

You're going to have to do hand over hand to show him what you need or to show him what you're wanting him to do, because he'll he'll convince you that he understands and he'll never, ever do it. So we actually moved to Florida in October of last year, and he started early preschool here, I think is the same type of program.

00;40;41;07 - 00;41;03;02

Courtney Ringstaff

They call it BLEEP. Okay, here, so a different name. But he basically can do preschool twice, just like he could in West Virginia. And he gets speech therapy services now. And I actually have an IP meeting for him next week because they're hoping to actually implement occupational therapy services to help with some of the behaviors and things that he has developed.

00;41;03;19 - 00;41;30;25

Courtney Ringstaff

You know, just as he matures, his needs change. And so we're hoping for some cool down strategies and things like that that we can maybe implement some of the strategies. So we're hoping to start that this the school year. But he receives speech therapy weekly last year he did for 30 minutes every Friday and going to school I think just going to school overall in general has made the most improvement for him.

00;41;32;09 - 00;42;00;14

Courtney Ringstaff

We've had surges in speech and he can pretty much speak in full sentences now, sometimes the words he says are not quite used or he's not pronouncing the words he wants to use completely correctly. And so we have to kind of like try to decipher a little bit what he's talking about. But as far as the school has taught him how to walk and not run away, which like I said, he does still do that a little bit, but walking has made a huge improvement in just walking beside us or holding her hand.

00;42;01;01 - 00;42;19;26

Courtney Ringstaff

And that's because they walk in lines all the time at school. And so they've taught him something called Eagle Walk, which is where he like holds his cheeks out with air and he puts his hands behind his back. And that says Eagle Walk. And so he'll do that at the grocery store or through a parking lot. He'll eagle walk and school has taught him that.

00;42;20;03 - 00;42;40;24

Courtney Ringstaff

Also telling us about what he needs and what he feels. School has really reinforced that. We've seen him like when he gets upset, I'll be like, What do you need, baby? What do you need? And he will tell me I'm hungry or I need ice cold water or whatever it is she met me or whatever. When, before, you know, he would just have a tantrum about it.

00;42;40;24 - 00;42;56;15

Courtney Ringstaff

It's like he couldn't tell me exactly what was wrong or what had happened. And routine has just helped him out tremendously. He really hates it when we don't have school. Like yesterday was a holiday and so we were out of school, but he got up and he went ahead and put a school clothes on and told me he was going to school anyway.

00;42;56;17 - 00;43;14;29

Courtney Ringstaff

He said, No more summer break. And I said, It's not summer break and just it's just one day holiday. And he said, No, I'm going to school. And so he wore his uniform yesterday, all day until we went to the pool. So he really, really likes it. And I think he likes the consistency because he is the kind kid.

00;43;14;29 - 00;43;31;11

Courtney Ringstaff

Every time we get into the car, he starts guessing where we're going. If I drive in the direction of the grocery store, he'll say, Oh, we're going to the grocery store, we're going to the grocery store. Or if I drive in the direction of the gym, we're going to the gym, we're going to work our muscles, we're going to the gym, and if we go past it, then he's like, Where are we going?

00;43;31;11 - 00;43;41;10

Courtney Ringstaff

He wants to know, where are we going? So I try to kind of prepare him for that. It helps to mitigate some behaviors that he has when there's inconsistency or unpredictability.

00;43;42;04 - 00;44;01;06

Melina Danko

Do you still question the diagnosis, like even as he's aging and maturing? And is that still even a factor for you? Because we've talked before personally about like, when should you tell somebody and does that matter? And and those kinds of things. So, yeah. How do you feel about that right now?

00;44;02;00 - 00;44;21;18

Courtney Ringstaff

I still struggle with that. Like when he is having behaviors in public or when someone's talking to him and he is just not understanding and I know he's not understanding. So to step in and try to prompt him for an answer so that he is like more socially accepted by the person, like that happens a lot because people come up, be like, How old are you, buddy?

00;44;21;27 - 00;44;38;26

Courtney Ringstaff

And he has literally within the last few weeks starting to be able to answer that question. Like he just told someone what his name was yesterday. And I was very surprised because they said, What's your name? And he he said, I'm Truett. And I was very surprised because usually I would have to kind of prompt we're very new at that social skill.

00;44;39;03 - 00;45;01;10

Courtney Ringstaff

I do find myself trying to kind of for him or smooth it over with that person so that they don't notice a difference. And I, I tell myself I don't need to do that. And there are times when I don't. But in the times that I don't, it's because we can blame his lack of response on something else.

00;45;01;10 - 00;45;19;16

Courtney Ringstaff

Like he's distracted or he's playing with a toy or he's watching something on TV, and if that's going on, then if he answers the answers and if he doesn't answer, I'm like, Oh, he's distracted because it's like easier to to justify that or to like blame it on that. It's not because he doesn't understand or he doesn't know how to answer you.

00;45;20;01 - 00;45;41;19

Courtney Ringstaff

And so that's still something that we like actively struggle with. I guess I'll say struggle because in my mind I'm always like, Should I jump in? Should I smooth this over so they don't notice a difference? And I just don't have the right answer. I just like, depends on the environment I find myself saying in my head like, they don't need to know that because I want to.

00;45;41;19 - 00;46;05;03

Courtney Ringstaff

But then I'm like, That's probably too much information and they don't really care to know it anyway. Like, we can just blame his behavior on just like being a kid. I don't have to jump in and say, Oh, he has autism every single time. He doesn't do what a stranger wants him to do, but in my mind, I want to jump in and justify the behavior by saying, Oh, he has autism, but is the autism the reason he's acting weird or is it just because he's four years old and he's weird?

00;46;05;03 - 00;46;32;13

Courtney Ringstaff

I don't I don't know, because kids just do odd things sometimes and they don't always answer in the way that adults want them to or behave the way adults want them to. And so I don't know where Truett it begins on the autism ends all the time. And so for that reason, I don't necessarily feel like I need to justify his behavior with his diagnosis or give everyone that we encounter an explanation of like, hey, just so you know, if things are weird, it's because he has autism.

00;46;32;13 - 00;46;48;04

Courtney Ringstaff

Like, I don't always have to say that, but there has been times when I have said it because he was having terrible meltdowns that I've had to say, like, we really I have to really take it out of this situation. Like we have to go to the car. He has autism. He is not able to regulate right now.

00;46;48;04 - 00;47;04;07

Courtney Ringstaff

Our like there's been times where it's gotten so bad or so out of hand that I have had to tell people why. And then if I'm going to be leaving him with someone, especially, I will make sure that they know. Because if he's running across the parking lot, they're not going to be able to say, Hey, Trip, wait, he's probably going to listen to that.

00;47;04;18 - 00;47;24;08

Courtney Ringstaff

Like they have to know what his needs are related to the disability. And so then I do tell people, but I still struggle a lot with that. And when is the when's it appropriate versus like when is it just me wanting to like, I don't know, make him fit in, I guess, or it make them accept him and accept his behavior by giving a reason for his behavior.

00;47;24;26 - 00;47;29;23

Courtney Ringstaff

So I still struggle with I don't know what the right answer is to that one.

00;47;29;23 - 00;47;56;03

Melina Danko

So there were a couple things that I was kind of noting too, as you were talking, and it was like the second child syndrome, like the blurt, like you kind of set a blur. And so I feel like as parents, because I too have I have two kids. And as a first time parent, I really related to the experiences that you were having because you don't know what's normal behavior.

00;47;56;04 - 00;48;15;25

Melina Danko

You don't know what's normal development. I mean, I think as if you saw a seven year old doing something or even you saw like a five year old doing something, you would know, like, oh, okay. Like that would kind of bring in your head. But an 11 month old versus a 14 month old, you know, you don't necessarily know those kinds of things.

00;48;16;05 - 00;48;42;19

Melina Danko

And so I can remember going into my son's daycare classroom and there was a little girl and the two year room and she was like talking in full on sentences like an adult and then I was really like, Whoa, what's going on? And then, you know, so there were there were things that were, you know, huge kind of eye opening experiences that all of a sudden you're like, Oh, wait a second.

00;48;42;25 - 00;49;07;27

Melina Danko

But I think so many parents will relate to that discussion in your head of I didn't think there was anything wrong. Now, like he is, he is progressing like you're seeing him do things more as a baby. You know, he's starting to do more things on his own. So in your mind, you're like, okay, yep. He's he's capable of being.

00;49;07;27 - 00;49;36;08

Melina Danko

And then also that second child blur. Like when you said that, I thought to myself, well, I feel that way, too. And my first son doesn't have autism. And so then how much of it is that, you know, that weird mom guilt, you know, like, are you having, like, more mom guilt because you feel like Emmie was born when Truett, it was experiencing these things then if he wasn't, you know, and it's like that weird mom guilt that we have no matter what.

00;49;36;08 - 00;49;56;17

Melina Danko

Like, always going to second guess yourself and then you're also always going to justify to. Now I do have two kids now that I have to take care of, and that is hard and they are different. And you know, I can't give my second child all of the same things that I gave my first. And I don't really remember all of it because it was a blur.

00;49;56;24 - 00;50;00;16

Melina Danko

But the first time it was like a core memory because it was all new.

00;50;00;28 - 00;50;01;14

Courtney Ringstaff

Yes.

00;50;02;14 - 00;50;26;02

Melina Danko

So I think that that will be something that really sticks. And I think a lot of people will understand the questioning period, because I experienced that with you and I was in the same boat like, oh, well, he couldn't hear for how many months. Of course, the speech is going to be delayed. He's just learning how to talk.

00;50;26;02 - 00;50;52;15

Melina Danko

You know, he's just now hearing. So it'll catch up and then, you know, hearing, oh, well, that psychologist gave you that evaluation quickly. And yeah, well, that didn't make of course, he was acting differently. He had peed his pants and nobody's going to be comfortable that way. And so I think that that is something that I'll bet a lot of parents probably experience.

00;50;52;15 - 00;50;52;29

Melina Danko

And then.

00;50;53;15 - 00;50;55;13

Courtney Ringstaff

It's so easy to justify.

00;50;55;13 - 00;51;21;29

Melina Danko

Right? Because we talk about your identity as a social worker. We don't. We talk about your identity connecting people to resources. But when you said it yourself, it just didn't click like you just didn't see it in him. And that's until, you know, now you can start to see it and even thinking about, well, nobody's going to want to hear my story, you know, because I'm just so new in it and I don't have.

00;51;22;00 - 00;51;55;02

Melina Danko

But you do. You have now, you know, what, four years of experience going through this. And so a lot of parents that have that infant toddler. Yeah, you know, early pre-K child, they're really going to relate to all of the things that you're you're saying. And so I think that that's really important. And and thank you for doing it because I know it's it's weird and awkward to be interviewing yourself and I'm sure that you're going to like, hate to edit yourself too because you'll pick.

00;51;55;02 - 00;51;55;24

Courtney Ringstaff

Up on the recording.

00;51;55;29 - 00;51;59;15

Melina Danko

But but don't don't because it's it's good.

00;52;01;07 - 00;52;29;15

Courtney Ringstaff

Well, thank you. I appreciate that because it's like I was excited to share my story, but I also was like my story. So it's so little compared to other people who might be big stories with like a lot of advice and words of wisdom to share. My story seems like so little compared to that, but I guess it's come a long way from where I was four years ago, and we've made a lot of progress as a family.

00;52;29;15 - 00;52;45;03

Melina Danko

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