00;00;09;22 - 00;00;36;03

Whitney Price

When you are hit with that diagnosis, emotional support is the first thing that you need. Your life is completely changed. The story that you thought you were going to have is now being told in a completely different language on an island, on your own. And that is exactly what it felt like.

00;00;40;25 - 00;01;08;16

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.

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.

00;01;08;29 - 00;01;36;03

Courtney Ringstaff

I am a licensed 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 connections 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;40;22 - 00;02;12;17

Whitney Price

My name is Whitney Price. I am the founder of On Parents Connect. I have a little boy on the spectrum. He is five. He's almost six. And during the pandemic, when we were shut down, we started to notice some more differences or milestones that weren't met. And fortunately, we had had a person come out and evaluate him at the daycare center that he was at, and they had told us that he might qualify for birth to three services.

00;02;13;00 - 00;02;34;05

Whitney Price

I had no idea what that meant. At the time. I didn't realize that that was going to be services provided free to him by the state. And I didn't know why he qualified. I knew he was a little bit speech delayed, but I didn't realize that it was enough to be considered a developmental delay at the time. So fast forward to March.

00;02;34;06 - 00;02;58;11

Whitney Price

Everyone is shut down. I'm having him with me full time at this point. 24 seven and we actually spent 120 days together in our homes, weren't allowed out, couldn't go see anyone. No one could come in. And it was just my husband, myself and my son. And during that time, we really started to notice that there were more delays than we realize were there.

00;02;58;11 - 00;03;30;14

Whitney Price

We knew that the speech wasn't there, but we also realized that he wasn't responding to his name. Eye contact was a little iffy, and we started noticing a lot of hand flapping, toe walking and things that could point to autism or other typical toddler behaviors. So that's where Birth two three came in. I had a lot of time on my hands, so I called the birth two, three representatives and spoke with her about what the options were going to be.

00;03;30;19 - 00;03;52;14

Whitney Price

Because I knew if we were going to have all of this time at home, how was I going to utilize it? How was I going to keep anxiety together during the pandemic, but also be able to say, okay, the silver lining is you can focus 100% on your son. So we ended up getting an occupational therapist, a speech therapist and a behavioral therapist.

00;03;52;24 - 00;04;20;07

Whitney Price

Unfortunately, they were all virtual, but the great thing was this was all so new to us, but also at the point in time where he could do a lot of different evaluations on him. So they were able to track that. He only had five words at the time where the milestones should have been met and just kind of get a game plan together of where he should be and how we were going to get him there.

00;04;21;04 - 00;04;46;27

Whitney Price

During that time, we also started seeing some new behaviors. We started seeing a lot more physical behaviors hitting, biting, scratching, more aggressive behaviors, which was very new to us because, like I said, we're home during the pandemic. It's just the three of us. And there was no reason for those behaviors to be happening, or at least we thought of it that way.

00;04;47;07 - 00;05;21;29

Whitney Price

So during that time, we had him evaluated further and they had their psychology just come out. And then he was diagnosed with autism. And Connor didn't have the typical signs for autism. He made great eye contact at the time. He was starting to respond to his name and we were up to 15 words at one point. And then we had a complete what's known as a regression where all of those skills go away and Connor had had tubes before.

00;05;22;01 - 00;05;40;05

Whitney Price

So this was something where we thought, okay, maybe the tubes fell out. We weren't able to just go see a doctor at the time. And we thought, okay, well, maybe there's a potential that he's deaf. There was no hearing test that we're going to be able to be performed on him to where we would know for certain. Okay, he definitely can't hear.

00;05;40;05 - 00;06;03;07

Whitney Price

And everything was just up in the air in question. So what we did first was we took him back to WVU medicine, had a second set of tubes put in, waited, and no words came back. So the words that we had were completely gone, said Mama, dada, binky, a several words that he would constantly say. And we thought, okay, well, at least we're moving up.

00;06;03;16 - 00;06;29;22

Whitney Price

Maybe the speech will eventually come and it was completely gone. He was mute for three months before he started developing that speech again. And not just the speech, there was a lot more physical activity that was happening. Hand slapping. Stimming is when it's typically called more. They have just constant, repetitive motions. So for Connor, it was a lot of hand motion hands, gestures, flapping.

00;06;30;04 - 00;06;56;06

Whitney Price

He is a jumper, so the constant movement for our son never ended. As a parent, you start to question, okay, and my not doing enough, you know, you're constantly questioning, am I not only doing enough, but where do we go from here? So thank God that we had the therapists and the teachers from birth to three to kind of guide us in the right direction.

00;06;56;21 - 00;07;19;11

Whitney Price

First, we started with an occupational therapist evaluation. The first one that he did, he said, and this was all virtual because of the pandemic. He said, I don't think your son has autism. I think he might be deaf. So then we started immediately with a speech therapist on sign language thinking, okay, this child could potentially be deaf, get the tubes, let's get another hearing test, which he passed.

00;07;19;11 - 00;07;42;10

Whitney Price

So we knew that he wasn't deaf at that point. But for the autism screening with the occupational therapist, he did not believe that Connor had autism. He didn't meet enough of the criteria. A couple of months later, we're starting to see these new behaviors. The regression was still there, so that is when they sent their birth to three psychology out to have a full evaluation.

00;07;43;06 - 00;08;15;29

Whitney Price

He hadn't seen my son, hadn't seen anybody else during that time. Everybody was just virtual for aa2 and a half year old. To keep any type of constant communication through an iPad or an iPhone was just next to impossible. So when they were finally allowed to come back in the homes, we had the psychologist with us and it was about a three hour evaluation asking all kinds of different questions, playing with him, watching how he interacts with us, with toys, with her.

00;08;16;26 - 00;08;36;15

Whitney Price

And honestly, during the evaluation, he knew all of his colors could point to all the numbers up to ten and was able to do all the animal sounds. And we had worked so hard with him, but I thought, there's no way he has autism. He's too advanced. He just has such a speech delay. That's all that it is.

00;08;37;02 - 00;08;59;07

Whitney Price

Maybe he was deaf for a period of time and we're just catching up and we thought there was just no way. I mean, she was just writing so much information down, complementing what he knew and we thought, okay, she's just probably thinking we're ignorant first time parents and we're in the pandemic. Every child must be behind. No one's able to interact at the time.

00;08;59;07 - 00;09;26;17

Whitney Price

So this is probably our new normal and we'll figure it out later. And after the evaluation, after she watched him play, watched him interact, she said, Has anyone talk to you about autism? And we said a little bit. I said, Well, I'm the one that thought maybe that there was a chance. What do all these scores mean? We're going through all of this speech delay and we're going through the delay with social emotional skills.

00;09;26;17 - 00;09;52;23

Whitney Price

We knew that that was there, but what's all this mean? And she said, I believe your son has autism. Here's what I think you should do. And it was just more therapies and it was more intensive therapies. ABA was mentioned. We didn't know what the heck ABA was at the time. When you get that new diagnosis, I think every mother and even every father knows that it could be a potential their nose and it's a possibility.

00;09;52;23 - 00;10;18;21

Whitney Price

And most of us had to fight to get that diagnosis. But they're still in the back of your mind, that glimmer of hope that you could be wrong. And for that brief moment of time, you are praying to God that you were absolutely wrong and then you find out you're not. So I think so much of our anxiety stems when I talk to these new parents that are just newly diagnosed, that all of these emotions happen.

00;10;19;03 - 00;10;47;13

Whitney Price

There's nowhere to go. There's no support. They're wondering what the heck to do. They're given this diagnosis. And then you're typically told, keep them in occupational, keep them in speech, try to do behavior as these behaviors grow and develop. Try ABA therapy, which none of us have at our disposal. So you're hit with all of those emotions at the same time you're also beating yourself up.

00;10;47;21 - 00;11;15;14

Whitney Price

You're going to doctor Google and saying, Did I cause this was it because of our genetics? Was there some environmental issue that we didn't know about? Is there a lead in or what? I mean, there's so many rabbit holes that you start to spiral in. And I went down that path for months. We went back to work. Eventually we took advantage of birth to three.

00;11;15;14 - 00;11;49;19

Whitney Price

We had five people on our team at one point and we drilled as much therapy in that little boy as he could handle. And every single day that therapy with him on top of coming home. And I feel like so much of him lost an opportunity to be a little boy because we were so concerned with what the future was going to look like, that we just every minute that we were with him had to involve some type of learning which affects how you are as a parent, know you're not able to just relax and play and look and be little.

00;11;50;05 - 00;12;23;15

Whitney Price

You're so worried and concerned about where you scale out on that graph of milestones being hit that you're trying to catch up. And that's all that it was for me for the first probably year and a half that Connor had that diagnosis. So skipping ahead to finally getting him into an ABA therapy, we were blessed. The speech therapist that we have at the time knew of a new therapy center that was opening up that happened to be right beside where I worked.

00;12;23;15 - 00;12;48;22

Whitney Price

And she said, call and get him in. So I did. It ended up being such a huge blessing for us and Connor is still in full time. ABA therapy right now. He is at a different center out of Marietta, Ohio, and they have the school for autism. He goes Monday through Thursday from 10 to 3 and will continue all summer doing that.

00;12;48;22 - 00;13;10;25

Whitney Price

And then during the school he will be transitioned to their school side and be given a registered behavioral technician that is overseen by a CPA who will be able to come up with a plan that fits every individual child's needs. But during that time, emotional support wasn't really there. My husband and I, more or less, we're on an island.

00;13;10;25 - 00;13;37;16

Whitney Price

We live in Parkersburg. At the time, we we both worked in the auto industry. He works as a general manager for Aster Auto Group. At the time I worked as a finance manager for Metheny's Auto Group. So 50 hour plus workweeks, including driving our son back and forth between therapies and when you were hit with that diagnosis, emotional support is the first thing that you need.

00;13;38;06 - 00;14;11;13

Whitney Price

Yes. You need the therapies. Yes, your child needs the education. But for the parent, your life has completely changed the story that you thought you were going to have is now being told in a completely different language on an island on your own, and that is exactly what it felt like. And we had moved here several years ago without any family support for our jobs and with not having any family or close friends around us.

00;14;11;13 - 00;14;42;02

Whitney Price

I felt like I needed to start a parent group just where Connor was going to therapy. They were growing as a therapy center. One of the main reasons I wanted to start that was to tell people about the other resources in the state that they could qualify for, but also because we just wanted to have a nice community of parents come together and be able to get to know each other better, have separate playdates and socialize our children.

00;14;42;12 - 00;15;02;24

Whitney Price

But more than anything, just being able to meet other families that were like ours. Because when you were given that diagnosis, it's tough to explain to other families you're going through behaviors with your child that really no one else understands. You're going into work late because of a meltdown that could last anywhere between a half hour and an hour.

00;15;03;07 - 00;15;35;29

Whitney Price

And not having people surrounding you in that circle can be so isolating. And you take that home to your child and you're expected to be able to handle a full time job and be able to patiently parent a child that is neurodivergent, maybe non-speaking, maybe communicates with the device. All of that stress will eat away at a parent, and then you're expected to try to manage another divergent child.

00;15;35;29 - 00;16;00;13

Whitney Price

And it's just it's just too hard. So that is where unpleasant parents connect with more. Going back even further, one of the best things that came out of Curtis three was the education on West Virginia waiver. And I'll touch on that just briefly. West Virginia, a waiver gives the child Medicaid for the life that they are in. West Virginia.

00;16;01;07 - 00;16;30;08

Whitney Price

Even if you have a primary insurance, you may not realize why Medicaid is so important. But if you have a child like mine who is in speech, occupational, behavioral and ABA therapy, all of those have co-pays associated with them. So at one point we were paying a mortgage payment weekly for Connor's therapies and not everything was covered. You are also capped at a certain limitation for these therapies.

00;16;30;15 - 00;16;52;10

Whitney Price

So some primary insurance companies might only give you 15 occupational sessions a year. My kid needs a weekly or sometimes two or three times a week. Same with ABA. It's one of the most, if not the most expensive therapy out there. We were paying $50 a day to get him in there. So all of these expenses add up.

00;16;52;17 - 00;17;14;17

Whitney Price

And if you are able to get on Medicaid, it's going to pay those co-pays for you. It's going to pay that deductible for you. West Virginia waiver provides us with respite care for 17 and a half hours a week. We had to have a sitter. You have to have somebody else in your environment that can help you care for your child because it is overwhelming.

00;17;14;19 - 00;17;45;20

Whitney Price

You're not just caring for a neurotypical child that when I say it is a 24 seven job, we have cameras throughout our home because we can't take our eyes off of our son for a moment. He has tendencies like pica, which is putting an edible things in his mouth that he doesn't know he's not supposed to do. He has tendencies to not know what is dangerous, so he will put his hand on a hot stove.

00;17;46;00 - 00;18;09;19

Whitney Price

Has no idea he's elopement. He is constantly in a fight or flight mode. So if he hears a sound that's startling, or if he sees an open door, he's going to dart out not knowing that he's not supposed to do that. So he needs 24 hour assistance. And he also has had issues with sleep. So he might wake up at one in the morning and be up the rest of the night.

00;18;10;07 - 00;18;37;13

Whitney Price

So it's imperative to have that respite care and waiver can provide that. So it was imperative for us to educate that for other parents in our group and also at the school to let them know, hey, you don't need to financially struggle. We were there for a long time and it doesn't matter how much you've won the lottery, you can have a great job and financially struggle to get these children the therapies that they need.

00;18;37;27 - 00;19;07;26

Whitney Price

So, yes, some waitlist is very difficult because it can be up to 2 to 3 years until that child receives a spot. And while you're on the waitlist, there's CSP, which is another program for children with disabilities to be able to get that Medicaid. We do a lot within our group. We do a lot of outreach programs. But my mission in that group is to let other parents know that there is help out there within our state.

00;19;07;26 - 00;19;31;23

Whitney Price

And even though the resources might not be a true back door, we don't all have to struggle financially because the last thing that a parent needs to worry about is financially struggling to get the child the support that they need that they're already fighting to get. We don't have a ton of therapies out there. It doesn't matter where in West Virginia you're at, you're going to be on some type of waitlist.

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Whitney Price

So at least within this support group, we have other providers in it, we have a therapist, we have our first three group. And our mission and goal is just to be able to give you those resources wherever you are at. So we are based out of Wood County, but we have so much outreach within the surrounding counties in the Mid-Ohio Valley that we should be able to point any parent in the right direction.

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Whitney Price

We have grown so much over the past year. It's been pretty amazing. We went from just a tiny table of ten people at my son's therapy center to now having over 200 members and having active events each month. We do get togethers with the parents and the group is primarily for the parents because I believe if we can't get the parents, the emotional and the mental support that they need, they're not going to be able to properly parent their children that are leading the support 24/7.

00;20;40;18 - 00;21;06;18

Whitney Price

It's exhausting. So you have to have some type of emotional and mental state of mind to be able to go into this and give it your all because it's it's absolutely draining. I have a good friend. Her little girl has Down syndrome. Her story is absolutely amazing. They had no idea that her daughter was going to have Down syndrome until she was born.

00;21;07;04 - 00;21;29;15

Whitney Price

And she left her job to care for her daughter and her family. And through that, she created a planner for special needs. And she also has a foundation called The Glory Days. And she and I went to high school together and we had connected. And she was one of the first people that I reached out to when my son was diagnosed.

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Whitney Price

And I said, I know that that we have different diagnosis and I'm going to be in a lot of therapy. Can I buy one of your planners? And we ended up talking on the phone. I broke down to her several times and I said, I have no idea what life's going to look like now. I don't know where to go.

00;21;47;11 - 00;22;04;28

Whitney Price

I don't know who to talk to. And she said, You make sure that you get on West Virginia waiver you apply right now right when he turns three and you get on West Virginia waiver because you don't know what life is going to look like down the road. And they don't really give you enough education on West Virginia waiver.

00;22;04;28 - 00;22;28;19

Whitney Price

But she had her daughter is about a year older than my son. So she had already gone through that process. She had already had those similar emotions to what I was feeling. And thank God she got a hold of me when she did, because when the governor cleared the waitlist, my son was on it and we were able to get that spot because we needed the Medicaid.

00;22;28;19 - 00;22;57;23

Whitney Price

At the time, we had no idea what Medicaid was going to cover. We had no idea how expensive therapies were going to be, and we had no idea where to really turn and get the support. But having someone that was already been there, done that, and created their own little community of support and such an amazing foundation that she has created through her daughter's diagnosis inspired me more than anything to say.

00;22;57;23 - 00;23;18;18

Whitney Price

Okay, well, what else can I do with this group? Where can I take it? What else? Where else are we meeting the outrage? And I am not a type of person that can just go up to you and introduce myself. All of that had to change all of that completely changed with my son's diagnosis. Me having to talk about autism is very natural.

00;23;18;18 - 00;23;44;15

Whitney Price

Now, where at first it was something that I tried to blanket and normalize and say, Well, he probably just has ADHD. It's probably not even autism. It's probably just, you know, everybody's got ADHD. And I feel like it's such a blanket statement over autism that parents use or that providers will use when or to uncomfortable to say what's going on.

00;23;45;08 - 00;24;18;11

Whitney Price

And opening up that conversation for kids that are neurodivergent and for the families that maybe were in denial or aren't sure where their child's going to land on the spectrum, because that is one thing about it, since it is a spectrum, your first thoughts are to go to what you know, which are the popular movies. You've got the popular shows like The Good Doctor, you've got Rainman and you've got now this Ezra that's come out the new movie, and you've even got love on the spectrum.

00;24;18;22 - 00;24;52;19

Whitney Price

All of these went to a side of the spectrum that is low support of AIDS. And then you've got my son who has high support needs, who would have what would be called profound autism. And you start learning that my story might be completely different from the people that I'm watching on television, and that's okay. And then I'm seeing kids that are completely device dependent and carry around an iPad all day that have to point to what they want to eat, what they want to do, how they want to speak.

00;24;52;19 - 00;25;18;24

Whitney Price

And they are completely dependent on someone. 24 seven So how do we create that happy medium? How do we bring both of those together? And I can tell you that we've been in this for nearly four years now. You'd think I'd have enough time to digest all of these emotions. But recently, with the month of April being Autism Month, I thought, This is going to be my month.

00;25;18;24 - 00;25;45;15

Whitney Price

I'm going to celebrate it. I am going to go as much as I can and educate and everyone. Our entire company was brought together. We did Autism Month, Autism Acceptance, Awareness, everything, and it was the hardest month, I swear to God I've ever had in my life because of all of the levels of autism that were brought forth and the projection of autism being just another diagnosis.

00;25;46;08 - 00;26;12;02

Whitney Price

I didn't realize how hard it was going to be for me as a parent to a higher support needed child. And that was just two months ago. So there's so many new emotions that arise every single day that you're kind of forced to deal with, even if you think, well, we had the diagnosis, we know what someone like is going to look like.

00;26;12;16 - 00;26;34;26

Whitney Price

There's always an instance that can come up that completely catches you off guard. The other day we were in the grocery store and we saw another little boy interacting with his dad. He was going to be six and he was talking about going to Disney World for his birthday and this dinosaur party. They got to get the cupcakes.

00;26;34;26 - 00;27;00;18

Whitney Price

They have to get the decorations. What do you want for your birthday? And I'm just thinking, my little boy can't tell you what his birthday is. He has no idea how old he is. We're working on that. He just learned. My name is Connor, but I'm not having birthday parties. They're just with me. And my husband will still decorate a room, will still get a cake, we'll still celebrate.

00;27;00;25 - 00;27;26;12

Whitney Price

He'll get surprises, but they're very spaced out. We can't do all of these surprises at once. It's too overwhelming, it's too sensory, stimulating. And he has a lot of trouble regulating those emotions. So we really space for phase out, make it last a whole month, but it catches you off guard and when you least expect it, you're going, we're probably never going to go to Disney World and that's okay.

00;27;26;12 - 00;27;52;15

Whitney Price

There's so many emotions that you're hit with all these different times. We've had parents that have said they no longer attend the events like Thanksgiving dinner. It's too big, it's too hard of an event. Routines are so embedded with us that when there's a week off from school, we are pulling our hair out thinking, Oh my God, now we've got to reset his little mind all over again and go, Okay, it's 8:00.

00;27;52;15 - 00;28;29;08

Whitney Price

It's time to start getting ready. We've got it in completely. Develop this new routine. We can't stray from that routine for a moment or else we suffer very hard at home. So there's so many emotions that I want to spread awareness about and really give grace to those parents. Because when you have a child with profound autism or any type of a divergent diagnosis, you don't realize that their entire world is going to look very different from your neurotypical world.

00;28;29;26 - 00;29;08;24

Whitney Price

Our sensory days at the museum look very different from a typical day at the museum. All the lights are dim, there's no loud sounds, there's no music playing at the zoo. When they have their sensory days. There are no flashing lights, there are no speakers that are playing. Everything is very quiet and it's very spread out because if you have a child like mine who can't handle more than ten people at once in a room, probably not going to be going to the carnivals or the fairs or the big birthday parties or the mall or Walmart.

00;29;09;06 - 00;29;54;17

Whitney Price

You know, everything is thought out for him every hour is thought out. And that is the hard thing that Neurodivergent parents go through is we can't just throw our child into a scenario of acceptance. That's not how our life works anymore for most of us, and that is something that we have really struggled with, and that is something that I try to mentor new parents that have been newly diagnosed as going through those emotions, handling your own emotions, and creating a new acceptance for your life and your situation looking different and that is difficult.

00;29;54;17 - 00;30;24;18

Whitney Price

Having a new mindset of blocking other people's perceptions out is hard. Unlearning things that you thought were normal is very difficult. You think you're supposed to just be able to take your child to the grocery store? They're supposed to be a good boy. Sit in the cart while you grocery shop and not make a noise if you have a neurodivergent child, I promise you the likelihood of that happening is very slim.

00;30;25;21 - 00;30;46;22

Whitney Price

But I can tell you that your mind will start to shift in a different way as well. So when you hear kids screaming and crying in a grocery store, I no longer think, Oh, that kid just needs to stop. That parent needs to discipline them. I think that could be a kid just like mine or I will not at the mom and solidarity of like I get it.

00;30;47;10 - 00;31;15;07

Whitney Price

No worries I completely get it. Go right ahead. I will say since the diagnosis mine, my mind shift and my husband's mind shift has completely changed. We give so much more grace than we ever did before. I don't think we were ever people that were judgmental by any means. But now that we have been in our shoes, we don't judge anyone.

00;31;15;07 - 00;31;40;28

Whitney Price

We ask to give them grace first, and then we listen to their story. And throughout the autism community, I encourage parents to be the same way because autism is such a huge spectrum. So you do have the kids that are able to go into the classrooms that are extra gifted, that have their own likes and their specialties and their hidden talents.

00;31;41;16 - 00;32;29;05

Whitney Price

And then you have the kids like ours with profound autism who may or may not be an ADA until they completely age out or may have a therapist with them their entire life. So you really do learn to give a lot of grace to people, not just in the autism community, but in the entire disability community. And I think it's so important that we spread the awareness, but we also bring people into our circle of the education and knowing more along the lines of what neurodiverse can look like for every family, because it is such a broad spectrum that it's it's difficult to really educate everyone just beyond the narrow minded research that they've done

00;32;29;05 - 00;32;54;22

Whitney Price

within autism. It's just not enough. So that's something else that we try to help with. The best thing about having people around you that know what you're going through is being able to support each other in a way that no one else can. Even my best friends that have been with me since I was 21 can't give me that type of support.

00;32;55;04 - 00;33;20;26

Whitney Price

They try their best and I know that they love and they support us any way that they can, but it's just not enough. I can't go to them with these types of issues. They don't understand what it's like to sit in an IEP meeting for hours. They won't understand what it's like to have a provider not understand your son, and they won't understand what it's like to not just be able to get a sitter.

00;33;20;26 - 00;33;40;10

Whitney Price

I can't just call anyone up and say, Hey, can you come sit with Connor for a minute? You know, there's no way they won't understand my son. They won't be able to interact with him. We can't. Just like I said, we can't just pick up and go to Walmart. Everything is strategically thought out. Every single hour in our day is thought out.

00;33;40;23 - 00;34;01;00

Whitney Price

And you have to be the type of parent that thinks so far ahead in the future and that's exhausting. You want to talk about creating a fight or flight anxiety for parents have a neurodivergent child that almost and that's another thing my friends do try so hard to pull us in. They'll say, hey, come to the park with us.

00;34;01;10 - 00;34;18;17

Whitney Price

And I'm like, What park? Or You're going to visit fence. How many people are going to be there? Is it one where we're just going to be kind of by ourselves? When are you going like, what time of day do you want to go? Because I have to go at least after he's a and everything is so thought out, we can't just pick up and go.

00;34;18;22 - 00;34;50;08

Whitney Price

We can't just pack a diaper bag. That's another day. We have a diaper bag. He's almost six. Try to relate that to other parents. That's embarrassing. Then you fall back on yourself and you're going to one another. That's really embarrassing to say. And you start that anxiety and that bubble starts to shrink and you start that isolation and it gets so bad that you don't want to talk to anybody about autism you don't want to go and talk to people at work about what you're going through.

00;34;50;08 - 00;35;17;17

Whitney Price

That's embarrassing because then you have people that try to understand, but they also don't know what to say. So they'll say, Well, they'll grow out of it and use that awful stigma as well. How age out eventually and you've you've been living this life for so long that it's it's resentment that starts to happen and all of these other negative emotions.

00;35;17;24 - 00;35;41;28

Whitney Price

And then on top of that, you've got to continue your job, be a normal parent, and there's just so much emotion that goes into it. Having a mom that I can call up at any point in time and say, You wouldn't believe what happened and it's happened. And then to is more comforting for me than anything else. I could spend hours with a therapist and she doesn't have a neurodivergent child.

00;35;43;01 - 00;36;07;29

Whitney Price

I'm just getting it out to get it out and I don't know how much that even really helps me if I'm 100% honest. And we do encourage therapy, but at the same time we want to be able to answer those questions. So therapy is important. We do group therapy in our group now. However, what helps is when you have so many other parents in the same room that can go.

00;36;08;00 - 00;36;27;17

Whitney Price

Let me tell you what we did for that. Let me tell you how to reach out to this helped more because I can vent to you all day, but I still have those problems. So for me as a mom, turner, a divergent child, I have to have resources. And as Connor grows and progresses, I need more. I need more and more.

00;36;27;17 - 00;36;55;24

Whitney Price

I need help with potty training. I need help transitioning from the park to home. I need help figuring out what happens if something happens to me or my husband. So there's so many uncomfortable conversations you have to have that having these resources is going to mean the world. And I will tell you that we've had even parents say, at what point do we know that we aren't doing enough for our child and we need help with an institution?

00;36;56;26 - 00;37;22;06

Whitney Price

Those are uncomfortable conversations that you may or may not have to have. Guess what? I've got the resources. I can tell them, Hey, talk to this person. They've been there. Talk to this person. They run this facility. That's our reality. It's uncomfortable. But would you rather be uncomfortable for a short period of time and get the answers that you need or just stay isolated?

00;37;23;04 - 00;37;43;16

Whitney Price

I can tell you from a person that has had that type of isolation for months, it's too dark of a place to try to get out of squash the fear while it's little, before it becomes this huge monster. And that is something else that we try to bring into the group is, hey, if you're having anxiety, let's get it out now.

00;37;43;18 - 00;38;08;23

Whitney Price

Let's all figure out a way to squash it before this becomes something where you're not sleeping at night. Child's already not sleeping. There's so much unknown with what our kids go through. Let's figure it out together before it becomes too big of a problem. So more or less, having those resources is imperative, not just for the kid, but as I said, it's it's for the families.

00;38;08;26 - 00;38;17;14

Whitney Price

There's so much anxiety that goes into this that if you can't get your mind right, how are we supposed to parent these kids?

00;38;19;13 - 00;38;40;11

Courtney Ringstaff

Often we don't talk about dads. And so do you feel that now that you have found this community of other families, that your husband has found some other dads that he can relate to or hang out with or even just to talk to.

00;38;41;03 - 00;39;07;21

Whitney Price

100%? We don't talk about the dads. And my husband is absolutely resilient and he is amazing. And I could talk about him all day and he's the best father to my son. But one of the things that I have admired most about him is how much he's willing to reach out to other fathers and encourage other dads in our group to participate.

00;39;07;21 - 00;39;34;07

Whitney Price

Because we have a huge amount of women in our group, but you know that their husbands are also in it too, and we've encouraged them to come to the events to have those interactions, because the dads tend to be a little bit more reserved, quiet and on their own. But they're going through this too. They're going through the exact same emotions and they need that support also.

00;39;34;15 - 00;40;08;02

Whitney Price

And it's so imperative that he and I together are doing this. He's with me at the meetings. Even if it's all women, he's still there. He is encouraging. I think we had two dads at the last meeting and it was so uplift ing to hear them say, Hey, we appreciate your husband coming. That was awesome. That was awesome that your husband is participating and it is so hard on a marriage to have a neurodivergent child or any child with a disability because one of you has to take a back seat.

00;40;08;02 - 00;40;35;15

Whitney Price

And typically that is the mother. And if you can't do this together, raising kids is hard. Raising kids with disabilities, with the amount of stress and strain that happens. If you can't have a great partnership and marriage, it just won't work out. But he has been amazing and so supportive and so encouraging throughout this entire process and participating.

00;40;35;27 - 00;41;10;23

Whitney Price

We are hoping that it just grows more, of course, but also for the dads, it's nice to have him as an outlet because dads ask questions to dads need the same exact type of support. They may not openly admit that, but it's so helpful to already have another male there that's willing to speak about our journey, what we went through, especially for the new dads, because the fact that a lot of men will be a little bit more in denial or struggle with the diagnosis than the mother will.

00;41;11;20 - 00;41;39;00

Whitney Price

It's helpful to share our story with them because we were both in the in the same type of place. You know, I fought so hard to get Conner evaluated. And even after the first diagnosis, my husband said, Let's get a few more. And then came that acceptance and understanding. Initially, we needed somebody else to tell their story that aligned with ours to say, okay, this is what it is.

00;41;39;11 - 00;42;04;10

Whitney Price

And the acceptance slowly came. But having another male presence there is huge and I admire him so much for participating and really encouraging me throughout this because I don't think I would have left my job of seven years in the business that I was in for 15 and taken the lead to say, Hey, this is worth it. I think we'll create a nonprofit out of it.

00;42;04;10 - 00;42;47;21

Whitney Price

It's needed, it's grown into a passion that I sure as heck didn't think I'd ever have. But he has been my number one fan and encouragement since we started this. So it's been huge. But yes, it's it's amazing to have a strong male presence there to really develop and create this family. Parenting is so difficult. My husband and I were never firm believers in physical disciplining.

00;42;47;25 - 00;43;18;14

Whitney Price

We discussed that before. We wanted to have children, so we knew we weren't going to spank. Had anything of that nature. That was just our personal preference. Now fast forward to a son like ours who has no pain threshold, who has no fear who has no idea really right from wrong when those behaviors happen. We talk about meltdowns for a toddler.

00;43;18;24 - 00;43;47;20

Whitney Price

You think of kids screaming and crying in a grocery store or at the mall, and you think of kids that are just all in their head back throwing a tantrum, say, no, I this, I want this. We talk about a meltdown on the autism world or for our son. We're talking about a child that could scream, cry and, bang a door for up to an hour and a half to 2 hours and have the same repetitive, physical activity until they are redirected or until their mind decides otherwise.

00;43;48;19 - 00;44;21;22

Whitney Price

So for us, I'm learning everything that we knew meant that there was an acceptance, but also I call it the calm strategy, which is I came up with it, which was stressed, calm, caring, attentive, loving mother and I broke it down into ways of, okay, we're going to make sure that he's safe and I'm safe. So in a meltdown with Neurodiverse kids, you could have kids that are self-harming, that are harming you, harming others, or causing self-destruction.

00;44;22;08 - 00;44;49;09

Whitney Price

So for our child, we had to make sure that when those meltdowns happened, we gave space, we were attentive to make sure that he was safe. We were attentive to make sure that we were safe. But we were also very quiet because for him, if you interacted too much, you made it worse. And then also we were on his level, so we would stoop down as low to the ground as possible or meet him where he was at length.

00;44;49;19 - 00;45;20;21

Whitney Price

And if you're in the middle of a store or when you're in public and you're in a situation and most of us have a fight, flight or freeze that kicks in, we also have embarrassment on top of that. So in my group, I try to say, okay, you have to be able to tunnel vision a lot of the time and you have to get where your child is at and you have to meet them with a calm perspective because if you are not calm, they near your emotions and they feed off of your energy.

00;45;21;07 - 00;45;54;06

Whitney Price

So you do really have to unlearn everything that you've been taught. We were from more traditional and strict backgrounds, so my husband and I obviously were taught respect, manners and discipline. And with a child like ours, no communication. And when we were going through a time where words didn't exist, you have to mirror that behavior that you want them to do constantly in the moment that you need to react, you are going to have a setback.

00;45;54;21 - 00;46;18;20

Whitney Price

That is the hardest thing to train yourself and that's the hardest thing to train other parents and get by and with. I can tell you that there were moments where when we were learning all of this and Connor would throw things on the floor, break things, we would constantly sighing go, Oh, Connor, why? And one of Connor's phrases that he picked up was, Oh, Connor, why?

00;46;19;04 - 00;46;48;28

Whitney Price

Nothing breaks your heart more as a parent than hearing your non-verbal child go through the house saying, Oh, Connor, why? Oh, Connor, why? That was hard. And that was something that snapped us back into the reality of, okay, things have to change. We have to start from a place of a little bit of grace and a lot of patience, and they will wear on your patience.

00;46;48;28 - 00;47;10;10

Whitney Price

And it is hard. And there are days that we screw up complete. We there are so many days that we mess this up, but there are so many days where I think we come a long way and we've really pushed ourselves with him. But more than anything, we have helped other people understand that if you don't do this, it's not going to work.

00;47;10;17 - 00;47;32;13

Whitney Price

And if you don't learn to parent this way, it's not going to change because this is how their minds are working, this is how their minds are developing and they are not our typical children. Time out does not work. We just got to the point with Connor where now we can get a timer and he knows. Okay, through all your food on the floor.

00;47;32;13 - 00;47;51;03

Whitney Price

Okay, well, now we have to sit here until the timer goes off, and then you can help pick up the food. And we're talking years of AB therapy to get to that point and he's almost six. So for the kids that are newly diagnosed two and a half to three years, you're pulling your hair out saying what is going on?

00;47;51;03 - 00;48;24;27

Whitney Price

Why won't he sit still? Why is he eloping and preferred activities? Why is he constantly, every time we want him to sit, he's getting up is crying. He won't sit still. He won't sit still in church. He won't go to a normal, traditional classroom. What do I do? I learn what you know, because those situations that happen. Another thing to keep in mind is when you have kids with sensory processing disorder, you don't know if it's a tag in their shirt that's bothering them or our son.

00;48;25;29 - 00;48;46;00

Whitney Price

We didn't know if something that he was wearing was bothering him. We didn't know if there was a light that was fussing. We didn't know if there was a sound that he was hearing that we couldn't hear. We didn't know if he just didn't want to hear a certain song on the radio. There's so many things that were that communication comes into play and we have that communication.

00;48;47;12 - 00;49;12;01

Whitney Price

What do you do? You're just going to have to watch and observe. Your child sickness is the same way. I always struggle with anxiety, but when you have a kid, that's not typical and that can't communicate and they have a fever of 103, you want to talk about anxiety that will take you to places that your mind's never been and then you can't just take them to the doctor, our son.

00;49;12;02 - 00;49;40;26

Whitney Price

We put him in the car. When he's got a fever, he is going to have a meltdown that you wouldn't believe. So then what do you do? You know that that's the place of autism that most people will never understand, and they are lucky for that. But that is situations that you have to completely unlearn and have the unfortunate experiences of knowing what's an emergency and what's not.

00;49;41;28 - 00;50;08;00

Whitney Price

So there's so many different places that our mind has to go that a typical parent could just pack their kid up in the car, take them to Med Express, have them do a couple of swabs and figure out what medication they need. I can't do that. The moment that Connor tired. I know he's getting sick. There's an alarm going off in my mind, going, okay, something could be wrong on medication.

00;50;08;00 - 00;50;33;10

Whitney Price

We can't just give medication. My kid is so sensory that we don't have one type of medication in the house, which is the white clear Advil. If we don't have that, forget it. We found out that he was allergic to red dye out of nowhere. And he was he had been on pink Tylenol. His entire existence. And then we found out the last time that he was sick, kept breaking out in a rash and we didn't know why.

00;50;33;19 - 00;50;57;24

Whitney Price

Had to switch to the dye free. What a nightmare. When you have a temperature of 103 and need that medication in there. My kids go in pink, pink, pink, pink. I can't just throw him in the car and go, no, no, you've got to take this. We're going to the doctor right away. You know, you've got your own set of anxieties on top of an anxious situation.

00;50;58;19 - 00;51;28;13

Whitney Price

So there's just a never ending cycle. And you have to constantly bring yourself out of that. You have to constantly talk to these parents and educate and have that support around us. Say, who's dealt with this before? So for us, when we say unlearning those behaviors, it was years and years of comparing the typical scenario to the untypical scenario.

00;51;28;13 - 00;51;47;11

Whitney Price

That was what we were living in and going through the mix up. And so, okay, that's fine. We just have to make it work. How can we make it work for our kid and throw out any other opinions and worries of what somebody else is going to think? Those have to go away. That acceptance has to be there.

00;51;47;11 - 00;52;16;17

Whitney Price

You have to be able to go, okay, just because I'm doing things different, ignored a side comments. That's hard to because so many people are very absorbed and we're so concerned with social media. I'm concerned over how we parent, what we're going to look like to others authority in this difficult world, telling people, hey, not care about those opinions and comments and negative mindsets.

00;52;17;10 - 00;53;04;00

Whitney Price

That takes years of practice and repetition. So that's something else that we try to really educate on. Another thing that's helped with anxiety for me personally was creating a list on my phone that was labeled times. My anxiety was wrong because every time Connor was sick, I can tell you I spiraled into this awful, awful, awful state of anxiety and depression, not knowing if he was going to be okay, if I was going to be okay, if my job was going to be okay, and then he would be fine or something else would happen with insurance that caused anxiety and things would be fine or, you know, as happened to take Connor to an appointment

00;53;04;00 - 00;53;32;00

Whitney Price

to get a shot or a vaccine, whatever the case was, my anxiety would go through and go through and things would be fine. So when you live in that fight or flight mode for so long and you develop acute stress disorder, you've got to come out of that. So I swear to God, I started just listing every time that I was anxious and it turned out different and I've got to pull it up at least once a week and remind myself how things were fine.

00;53;32;14 - 00;53;54;14

Whitney Price

Oh, we thought he was going to have the stomach flu again. All coded with in the classroom. We're going to get it. He's coughing, sneezing. We're going to get it. Okay. He ended up being fine. You know, just having allergies. If you're in this cycle constantly and you don't remind yourself, hey, it's to be okay, you can go down a really deep rabbit hole and not be able to get out.

00;53;55;03 - 00;54;23;06

Whitney Price

And it's too isolating and embarrassing to just stay down there. So that is something else that we have worked towards is telling people, listen, it can be okay, but you have to constantly work at it. It's like a muscle. It doesn't grow unless you actually train it and really repetitively work with it. That's something else that has really helped me for the last several years is just realizing that the alarm is there and it's never going to go away.

00;54;23;24 - 00;54;54;10

Whitney Price

But redirecting of, you know, is this actually or is it just open ended, intrusive thoughts that are creeping in that I just need to shut up right now and push away until we decide if it's worth thinking about or not, because those intrusive thoughts happen constantly, especially when you're on social media and you know, you've got IEPs, you've got evaluations, intrusive thoughts.

00;54;54;10 - 00;55;17;28

Whitney Price

Just start beeping. You're not doing enough. You're not doing that. You're not doing this. You need medication. You're on the right medication. You're not doing this, you're not doing this. Push them out. Things are going to work out. It's going to be fine. You're going to be fine. He's going to be fine. Our world is just different. It's okay.

00;55;17;28 - 00;55;39;19

Whitney Price

I hope along the way we have a developed a big enough community to where these new parents that are getting diagnosed and freaking out like I was have different stages of parents that they can go to. There's parents with kids that are now working. There's parents with kids that are in college. There's parents with kids in middle school. There's parents that chose to homeschool. We've got such a variety of people that should be able to match your family and someone that's comfortable. Maybe you're not comfortable talking with me and my husband. That's fine. Who do you mesh with? You know, find your people. There's so many of us. There should be one couple that you mesh with that you can call and go to for advice or meet up with. So building a community is so important in this journey.

00;56;11;16 - 00;56;27;04

Melina Danko

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