00;00;09;27 - 00;00;16;27

Sheila Harman

Vacations are exactly what you make, whether it's camping in your backyard or going to the all inclusives.

00;00;17;05 - 00;00;38;06

Brandy Brown

Try to see the vacation through your child's eyes. That would be my my best advice is to take off your adult hat and you're out your dark glasses and see it through a child's eyes and how they would see that and live that experience.

00;00;40;22 - 00;00;52;13

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.

00;00;52;23 - 00;00;55;16

Melina Danko

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

00;00;56;03 - 00;01;07;16

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;09;20 - 00;01;36;21

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 connection through the relatable topic discussions. We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

00;01;41;28 - 00;02;08;11

Sheila Harman

I'm Sheila Harmon. I had four children, three special needs kiddos and I'm also a travel agent for a magical vacation planner. We have everything from non-verbal autism to feeding tubes at our house. I adopted all four children, and that's one of the reasons that I became a travel agent was to help other families with children, a special needs take vacations.

00;02;08;11 - 00;02;12;29

Sheila Harman

Because if we can go to Disney, I think I could help everybody go to Disney.

00;02;14;13 - 00;02;40;15

Brandy Brown

Everyone, I'm Dr. Brandy Brown. I am an occupational therapist by trade. I have over 15 years of experience as an occupational therapist, but I am also a mom of a child with special health care needs. My youngest son has cerebral palsy, cortical vision impairment and a lot of sensory issues. So we've been on many a family vacation and it has been a journey, so to speak, and a learning experience as well.

00;02;41;07 - 00;02;45;00

Brandy Brown

So I'm here to hopefully help some of you figure it all out.

00;02;45;19 - 00;03;16;06

Sandy Corbett

Hello. My name is Sandy Corbett and I am a licensed independent clinical social worker and I was recently employed by the Center for Excellence in Disabilities as a positive behavior support specialist. And my clinical background, it spans 15 years of direct practice. My interest in this area is my best friend has a son who is now in his twenties and he has cerebral palsy.

00;03;16;06 - 00;03;28;21

Sandy Corbett

And we have just worked together, vacationed together. We spent holidays together and that guy has captured our hearts. So thank you for asking me to join the panel today.

00;03;29;08 - 00;03;49;15

Courtney Ringstaff

Thank you. And thank you all for being here. We very much appreciate you joining us and being willing to come and talk about this topic, because I really feel like so many families don't know what types of vacations they can take. And they might be scared, too, to try to navigate that. It's expensive to do that if it's not going to be successful or if it's not going to be enjoyable by the whole family.

00;03;49;26 - 00;04;07;11

Courtney Ringstaff

And so just to kind of kick off the summer season, I really wanted there to be some kind of discussion for our listeners about vacation, how to take them, how to enjoy them, how to prepare for them, and what types of supports to put in place when you're on them so that it is enjoyable for the whole family.

00;04;07;24 - 00;04;36;22

Courtney Ringstaff

And so in doing research on this topic and in preparation for the episode, I did kind of separate disabilities into my head into two categories, and that would be physical disabilities. So disabilities that require equipment, you know, accessibility issues and then disabilities that are more sensory or behavioral. In my mind, that's kind of where families might have a child or just a person that they're taking on vacation with them.

00;04;36;22 - 00;04;59;25

Courtney Ringstaff

It doesn't have to be a child. It can be an adult that might struggle with the thought or the plan of going on vacation. Marlene and I put our minds together and we really came up with this strong team of panelists to come and discuss some of these topics. Let's just start this conversation by what are some common family concerns that have been brought to you as a professional or maybe even as a fellow parent to a child with a disability?

00;04;59;28 - 00;05;04;20

Courtney Ringstaff

What if? What are some concerns that you've come across working with other families about going on vacation?

00;05;05;14 - 00;05;32;26

Sheila Harman

I know for me, when my daughter got her feeding tube, it was scary because we had never dealt with feeding tubes at all. We didn't know what all it incorporated and even the care. So even taking a vacation to Tennessee was was hard to even think about because just the thoughts of what if it clogs, what if it, you know, falls out?

00;05;32;26 - 00;05;56;05

Sheila Harman

You know, what if what if something happens? She actually throws up a lot, too. So that was another concern with her just throwing up there. Like what? What would happen, you know, if something would get stained. But we we actually talked to a lot of our therapists that comes in for our oldest daughter. And we still are in contact with like birth the three therapist.

00;05;56;05 - 00;06;27;07

Sheila Harman

And they, you know, they're like, this can happen. So I started researching doctor's offices, hospitals, ers just to know where they were when we went. So in case something like that would happen and even with my clients, I've had clients, their children had had catheters. So, you know, they wanted to send that equipment down to the resort at Disney or if they flew, get it down there so they didn't have to pay baggage fees and things like that.

00;06;27;07 - 00;07;00;05

Sheila Harman

So that was that was probably one of the biggest concerns for me. And then hearing, you know, different things from clients, you know, medications that needed to be refrigerated, you know, is there storage in the resort large enough for that? A week's worth of medication. So that's where I come in to play. And I call the resort or I do research myself and let them know, hey, you can take this and this is probably how you would get it down there.

00;07;00;19 - 00;07;18;00

Sheila Harman

Talk to your doctors. And, you know, we have a wheelchair, too. So we've never flown with the children with the wheelchair, but, you know, just the storage and will it fit through the doorway type thing is usually what I hear and I run into as a parent.

00;07;18;24 - 00;07;35;15

Brandy Brown

And I know for me, you hit on it there a little bit, Sheila, when you said, well, the wheelchair fit through the doorway, a lot of the concerns with whether they're adults or children that use wheelchairs that I've had with a family members as well as clients that I've served, as you know, will it fit through the doorway?

00;07;35;15 - 00;07;54;15

Brandy Brown

What if I have to go to the bathroom? How do I navigate that? Will the wheelchair fit in that as the individual needs help getting on and off of the toilet? Is there room for the caregiver in that same space to be able to do that? We ran into issues. I went on vacation and with my adoptive grandfather who had a stroke and was in a wheelchair.

00;07;54;15 - 00;08;17;27

Brandy Brown

And we went to a restaurant and we had to go to the bathroom and it wasn't handicapped accessible. And my grandma adopted grandma as well call her could not she couldn't get in there to assist him. So I had to kind of talk him through like, how are you going to get on and off the toilet without grab bars in a bathroom that's not accessible and a toilet that was built in the 1930s that's pretty much sitting on the floor.

00;08;18;05 - 00;08;39;01

Brandy Brown

You know, it's it's not built up like the one you have at home. At home. He's independent mostly. But it was it was rough. And had I not been there or someone been there to be able to assist him, there's no way she could have gotten him. So that was one of the big concerns that a lot of families had as far as as the wheelchair goes, is is it going to sit is there going to be room?

00;08;39;01 - 00;09;02;06

Brandy Brown

Can we fly with that? How do we get to the plane? How do we get off of the plane? All of those things. And then from, you know, the sensory aspects, my child has a lot of sensory issues and sensory needs and behavioral issues. And I know just me personally, even though I am an OTA, I feel like sometimes as a professional you forget that you learn stuff as a professional because it's your kid, right?

00;09;02;06 - 00;09;18;06

Brandy Brown

And so as a professional that went out the window because it was my son figuring out how do I deal with his behaviors in public when we're at Disney and he's smacking his head off of a metal pole because that's what he does. When everybody is looking at me, how do I manage that behavior? What do I do with that?

00;09;18;06 - 00;09;38;19

Brandy Brown

How do I minimize his outburst? Those are a lot of the concerns, the trips, the length of time, car rides. How do I survive a 18 hour? All right. With a kid that, you know is going to need to get out and do things? So those are some of the ones that I commonly hear or I have experienced.

00;09;38;19 - 00;10;02;26

Sheila Harman

Have you ever had sleepless nights at a hotel because your child didn't really feel like they belonged there in that hotel room? Because everything's just out of the norm? That is probably the biggest thing that we dealt with is, you know, we would go for doctor's appointments and have hospital stays. A lot of behavioral of. Let me just touch this.

00;10;02;26 - 00;10;03;29

Sheila Harman

Let me rip this.

00;10;05;11 - 00;10;06;04

Brandy Brown

Yeah, absolutely.

00;10;06;13 - 00;10;12;26

Sheila Harman

My therapist was phenomenal at helping us get through that. And we still have issues with that sometimes.

00;10;14;11 - 00;10;37;05

Brandy Brown

Yeah, my my son was the same way when we went to Disney. He has always slept with a noise machine. It has to be a certain noise machine with a specific noise. No other noise machine will work the batteries went dead and we couldn't get them for one night. But then there was so much excess noise because we were on we were in an accessible room, but we were on the bottom floor because there you know, usually on the bottom floor.

00;10;37;05 - 00;11;02;05

Brandy Brown

Right. But the issue with it was he's so sensitive, hearing wise, that he heard every single noise and if the air would kick on, he would scream. And it was our first vacation, like big vacation with him. He was two at the time. And yes, it was very sleepless, sleepless nights because, you know, with the textures and he needed his stuff as he blanket and he needed that noise, but he needed quiet outside of that.

00;11;02;05 - 00;11;28;07

Brandy Brown

And he wasn't in his room with his stuff that he was used to. And then I don't know if Sheila or Sandy, if any of you have experienced it, but I know even just clothing, swimming trunks, those types of things where the texture is different than what he would typically where we never really thought like, hey, because we went to Disney in May, we should probably put these on and see how this goes.

00;11;28;07 - 00;11;45;11

Brandy Brown

Or like the pull ups when they get wet, you're a little bit different when they're dry. So that's another thing that didn't really plan for, but definitely came up as something that created a little bit of, you know, me and having to navigate on on our house and try to make things work. So.

00;11;46;29 - 00;12;11;13

Melina Danko

So, Brandie, I really like those specific things that you said about like the pull up getting wet or the way that the swimming trunks feel. Those are things. I think that a lot of parents that are listening will resonate with and think, Oh, wow, I never thought of that. And so in that case, then what would be some of those recommendations that you would have for families as they start planning to help?

00;12;11;28 - 00;12;19;10

Melina Danko

Think of what are those things that might be easier to overcome if we plan in advance?

00;12;21;06 - 00;12;48;10

Sandy Corbett

Well, I think first and foremost, it's give yourself some grace as parents. In addition to that, as far as helping your kiddo, it's the rehearsal. And of course, as I'm listening to you, Brandi, I'm thinking of the pull up. That is something that I think many parents would forget if I were sitting with a parent, having this conversation, talking more about, let's go through the day and what are some of the obstacles that you could encounter?

00;12;48;17 - 00;13;17;21

Sandy Corbett

And let's talk about bedtime. Let's talk about mealtime and how different it's going to be. And you really slice that very, very thin that we can take a look at each thing and then practice as much as you can when you mentioned Disney. So, you know, looking at as many YouTube videos as you can find on what that looks like for you, taking your child to Disney for the first time.

00;13;18;07 - 00;13;42;21

Sandy Corbett

You know, Disney is one of those top vacation spots. However, perhaps that's not practical for you at this time. And keeping those understanding that lowering the expectation and really celebrating the small things, I think as I'm listening to the two of you, by the way. Wow, you're amazing.

00;13;44;08 - 00;14;11;16

Brandy Brown

Thank you. I think also, as you said, lowering expectations, but I think setting boundaries as well. I know when we travel, we often travel with other family members or friends or go to friends houses. And I think oftentimes they don't live our lives with our children. And so, you know, establishing those boundaries, I remember being, you know, on vacation with my parents and my mom is one of those very much like me.

00;14;11;19 - 00;14;30;09

Brandy Brown

It all out and go, go, go. I want to get everything I can for the money that I spent to be here. So we're going to go from 7 a.m. up for breakfast, 11 p.m. down at night and you know and she's my mom is sometimes it's hard for people to set those boundaries with families or family or friends.

00;14;30;09 - 00;14;46;05

Brandy Brown

And I finally got to the point where my mom was like, I don't know why your son is so grumpy. He never acts like this. This is ridiculous. And I was like, Well, we didn't sleep the night before we came here. He's been up all day. He's completely out of his routine. And you're dragging him all over like so.

00;14;46;08 - 00;15;00;05

Brandy Brown

Yes, he's going to be super grumpy and super irritable and not the way you want. So this is how the rest of the trip is going to go. Y'all are going to do what you're going to do. And I'm going to take him back and we're going to put him down for a nap. And then, you know, and that's what we did from that point onward.

00;15;00;05 - 00;15;23;11

Brandy Brown

And she really wasn't offended. She just was like, I didn't even think of that because in her mind, she doesn't see my son as a child that has, you know, extra needs. She just sees him as her grandson, which is great. But on the flip side, it makes it challenging because she almost expects him to do things that, you know, he can't do or he can't tolerate.

00;15;24;01 - 00;15;46;26

Brandy Brown

So that that's one of the things I think when you set expectations, I think also setting those boundaries, you know, and whether that's even with with your family, you know, together with the older brother who wants to go, you know, my older son likes to do more kind of higher sensory like riding the really fast rollercoasters and doing all of the things that my younger son can't tolerate.

00;15;46;26 - 00;16;10;25

Brandy Brown

So setting those boundaries with him as well and saying, you know, well, I can go do this with you, but then I have to go do this with your brother or your dad can do that with you. And then we will. We'll switch off whoever those caregivers may be. But I feel like that's important. And it's, you know, for parents to know that it's okay to say no and it's okay to to say this is what we're going to do because this is what works for us.

00;16;11;20 - 00;16;35;25

Sheila Harman

The waiting in line part is also hard. And I've learned to think outside of the box because even at Disney and Universal, they do the passes where you don't have to wait as long. But sometimes there is that, you know, 20 minute wait or a 15 minute wait and, you know, you learn to count things, look for colors, you know, have car.

00;16;35;25 - 00;16;57;13

Sheila Harman

Do you have fidgets? You know, the bubble lines and snacks like you, you just learn to think got out of the box to help them with that. You know, 15 minutes and 20 minutes is nothing to us, but it's a lifetime, it seems like, for the kiddos that they can't take the waiting. And so I've been known to pull bubbles out of my purse.

00;16;57;13 - 00;17;00;05

Sheila Harman

And you.

00;17;00;05 - 00;17;16;24

Brandy Brown

Yeah, that's that's one of the things that we always recommend or I always recommend as an occupational therapist is that you have your your bag of tricks with you, you know, you know, your child, you know what things work for them. So anything that's portable, that's packable that you can take with you, that you have that with you.

00;17;16;24 - 00;17;38;13

Brandy Brown

My son is very sensory seeking. He loves what we call have you work. So like pushing things heavy, pulling things heavy, having something kind of have you seen it? You can imagine carrying a backpack and the weight of that backpack on your shoulders. That's really calming to him. So oftentimes I will make him carry his own sensory bag and his own backpack and he helps me load it with all of his favorite things.

00;17;38;13 - 00;18;03;08

Brandy Brown

So something we practice before we go on vacation now where he just knows, like if I say, Hey, we're going to go to my mom's house this weekend, that's not even a vacation, but it's a trip because it's 3 hours away. He literally will go and he has my backpacks ready to use from and we'll go and we'll be like, I'm going to take this bag today and then he'll load it with all the things that he wants to take to entertain himself with, and then, you know, I let him pick out his snacks and and all of that stuff and that really helps.

00;18;03;08 - 00;18;21;24

Brandy Brown

It gives him some autonomy and some some choice and some power over what he wants to do. But then it also and putting the stuff in the backpack and having that weight there, it provides him with much needed sensory input that he needs. And then having, you know, those textures that he likes, the fidgets that he likes to play with, any of those things.

00;18;21;24 - 00;18;46;22

Brandy Brown

I know that that calm him. We always have like one of my, you know, the ponchos that women can wear. That's almost like a blanket or a fleece blanket. One of those two things always in his backpack. That's the most calming thing for him. So even if I'm waiting in line, whether it's to get into a restaurant or is in an amusement park, if I can't take him off somewhere to put him in a quiet space, we have a wagon, just one of those beach wagons.

00;18;46;22 - 00;19;03;04

Brandy Brown

That's really not meant for kids, but we use it for him anyway, and we just keep that thing with us until we're up to the front and we put him in there or the blanket over it and then he's in his own. We kind of create his own private space. So if there isn't one available, that's another recommendation we have for parents.

00;19;03;04 - 00;19;24;12

Brandy Brown

If you know your kid needs that calm, quiet space, try to find ways to create that. So we do that with the blanket. We have noise canceling headphones. He has his little bag of tricks, his flashlight, and he just he'll go in there and he's like in his own little, little bubble. It works wonders for us. And he loves it and he loves getting to pick out all the stuff every time we go somewhere.

00;19;24;12 - 00;19;28;02

Sheila Harman

So I would like.

00;19;28;02 - 00;19;41;12

Courtney Ringstaff

To discuss empowering parents and letting parents know that it's their right to take their children on vacation if they choose to do so. And just what your experiences with that have been and ways that you feel like you could empower families?

00;19;42;11 - 00;20;07;22

Sandy Corbett

I always try to start with parents from the very beginning and saying, we're going to do this with this curiosity, that it's not going to look the way it looked. Perhaps when you took your first child on vacation. However, you do deserve a vacation and your child deserves a vacation. So really, as both of you, Sheila and Brandi, we're talking about your experiences.

00;20;07;28 - 00;20;34;26

Sandy Corbett

I love how you know what your child needs and what they can tolerate in your building, your own little calming kit when you're on that trip. And again, I love the the piece when you spoke about boundaries, establishing those boundaries with the people that matter and then understanding that there are other people around you, that we can't really affect how they're going to think.

00;20;35;08 - 00;20;50;24

Sandy Corbett

And we go in, we do our best, we do our due diligence. And again, you know, doing that with grace within yourself. So I think that's where I would begin.

00;20;51;21 - 00;21;17;04

Melina Danko

And love that grace within yourself because I think as parents we are always the most critical of ourselves than we would ever be over somebody else. And so having that moment to say, you know what, this is tough, but we're going to get through it. And you know what? If you take a moment and look around other people's kids are having meltdowns, too.

00;21;17;19 - 00;21;43;13

Melina Danko

Other parents out there are melting down, you know, because let's be real vacations aren't all Instagram pictures the whole time. As matter of fact, that's kind of the the reality is you're going to get into an argument with your mom. Your kids are going to melt down. You and your significant other are not going to sleep well in a different space because of whatever reason.

00;21;43;13 - 00;21;52;09

Melina Danko

And so I appreciate that giving grace. I think that that's really important.

00;21;52;09 - 00;22;20;28

Courtney Ringstaff

And since we're talking about parents and empowering parents, what is the advice that you all would have for parents who feel judged or, you know, whose child is acting out and the parent is trying to focus on that child and managing that behavior and helping meeting the unmet need. But then he was also looking around and seeing the eyes and hearing the whispers and things like what is the advice that we have for those families?

00;22;20;28 - 00;22;51;08

Sandy Corbett

I'm I'm trying to imagine myself in that situation, in that moment, remembering that, focusing on my own calm in that moment and zooming in on what my child needs. Again, easy for me to say sitting in this nice air conditioned space in this moment, however, understanding that I love what you said, Melina, when you were talking about All Kids Misbehave, right?

00;22;51;20 - 00;23;22;15

Sandy Corbett

That and if we spend all of our time looking around at everything that's happening around us, we're also missing what's happening right in front of us. And all of you that are listening to this podcast right now for obvious reasons, you are wanting to raise your awareness and how to do a better job, a good job, a good enough remember, you're just doing a good enough job and perfection.

00;23;22;15 - 00;23;40;29

Sandy Corbett

It's not the goal. It's doing a good enough job that you can look back at this moment and say, Wow, we had this great moment and putting those snapshots together and then trying to we're trying to minimize the ones that are a little less desirable.

00;23;42;22 - 00;24;01;23

Melina Danko

Sheila I wanted to shift topics a little bit and talk about what are the different kinds of vacations that families can take. I know we've talked about, you know, the big ones like Disney, but what are some other ones that you recommend as a travel agent?

00;24;03;16 - 00;24;33;06

Sheila Harman

If Disney maybe too much, there's all inclusive where you just go and you explore whenever you can. You just spend the day on the beach or by the pool. And a lot of the resorts are becoming special need certified or Autism Certified Nickelodeon Resort is one of them that has recently become Autism Certified at the beaches, which is incorporated with sandals.

00;24;33;06 - 00;25;01;04

Sheila Harman

They are as well and they have clubs for the kids too. You Royal Caribbean. I've seen a lot of special needs families on our ship that, you know, took a cruise cruising. It scared me when we did it because I always had the fear of the kids leaning over the balcony or but it took us a year to just get eaten, ready for the cruise.

00;25;01;04 - 00;25;29;11

Sheila Harman

And I mean, it was the social stories, the watching YouTube videos. And if I had clients that were on cruises, they would send me pictures of them so she could see the water and and things like that. But there's cruises all inclusives and, you know, just even, you know, Nashville, like just going and sightseeing. That way you can, you know, go back to your hotel.

00;25;29;11 - 00;26;01;19

Sheila Harman

And because, you know, when your child's got a meltdown, there's a lot to choose from. And, you know, a lot of the parents are special needs. They're afraid. I mean, we were having four. So start small, go and maybe spend a night in a hotel and and learned what your child doesn't like the feeling of the sheets or the towels or and a lot of places do accommodate with, you know, dietary restrictions and things like that.

00;26;02;13 - 00;26;03;26

Melina Danko

Did you guys have fun on your cruise?

00;26;05;00 - 00;26;35;20

Sheila Harman

We did. It was very untypical. They didn't really get to enjoy the cruise. Within an hour after we sell, the wind started going and they closed the pool down. I mean, an hour after sailing. And that night, the ship was rocking and I was getting sick. My son was getting sick. And I mean, Eden was a rock star, so she was just in her chair and she was like, hey, you know?

00;26;36;10 - 00;27;12;01

Sheila Harman

And then even the next day, we couldn't port at in the Bahamas because of the wind and things like that. And even when we went to okay, they had wheelchairs there for sand, you know, the beach certified wheelchairs and that and one thing that my husband brought up to the Royal Caribbean cruise director was when you take your regular wheelchair out to get into the beach wheelchair, you have sand on your wheelchair.

00;27;12;24 - 00;27;36;00

Sheila Harman

And nobody knew how to get that sand off the wheelchair key ended up talking to several different people, going up to the pool deck and using a water hose to whittle it off. And he told the cruise director, he said, you know, I'm not the only one that's had this wheelchair. You need somewhere to at least be able to clean it off because you don't want that sand and stuff in your room.

00;27;36;00 - 00;27;59;26

Sheila Harman

And but she she was she was all in all a rock star. She did not like the weather at Cococay at all. I never dreamed I would be in the Caribbean in a sweatshirt, but we did not see sun until the day we were in the Bahamas, so it was nice to be able to take them to the Bahamas.

00;27;59;26 - 00;28;23;00

Sheila Harman

And it was somewhere my husband and I had been and have the kids, you know, somewhere that we loved. It was like full circle. But she she loved the sun at in the Bahamas. And they even hollered another cruise and were like, Well, let's get over this. But I couldn't have been prouder of them.

00;28;23;16 - 00;28;40;15

Courtney Ringstaff

Sheila, when families reach out to you, do they usually have an idea of what type of vacation they want and you just help them, like figure out a destination? Or are they like, we don't even know what we can do. This is the disability. Give us our options. How do you usually, like, work with families?

00;28;41;22 - 00;29;08;03

Sheila Harman

Usually they they ask about Disney and they they say, can we do this? Like, what is your experiences? How do they accommodate? And I'm able to tell them, you know, Disney is fantastic. And because you don't, they have the rods there that you can just will the wheelchairs onto so you don't have to, you know, transfer them over.

00;29;08;03 - 00;29;36;15

Sheila Harman

And they have what they call a day pass. And a lot of people didn't even know like that even existed. So they didn't have to wait in line and do all that. And, you know, the just the cast members, they're fantastic. They'll see, you know, meltdowns and things like that. And they'll they'll come and they'll see if they can help hand out a sticker like stickers are and make everybody smile.

00;29;36;15 - 00;30;02;12

Sheila Harman

It seems like occasionally I will have some families that say, you know, we we have this and this and this and we want would like to do this. But where would you suggest? And, you know, a lot of times it's you know, I'm able to help them cause SeaWorld has a lot Legoland has accommodations and but it's mostly just the car ride.

00;30;03;04 - 00;30;42;27

Sheila Harman

Help me with the car ride and, you know, we we've done, you know, presents halfway through three fourths of the way through, you know, just anything like that. But I really enjoy helping the families take their vacations because I get to play a small part in helping them make those core memories. And I'm able to help them. Mother, you know, not stress about having to worry about what happens with this meltdown or what happens if the feeding tube does fall out or get clogged up.

00;30;42;27 - 00;31;08;01

Sheila Harman

You know, there's a doctor here and a doctor there, and now I'll just ask questions, what do you need? And I'll do the research for them or cause a lot of parents. I mean, before I came, a travel agent, I spent hours just researching to find with this vacation would be suitable. You know how do they accommodate for this and this and this and even dietary needs?

00;31;08;01 - 00;31;15;12

Sheila Harman

Like I get a lot of that. My child can have gluten encased and dyes.

00;31;15;12 - 00;31;36;18

Brandy Brown

Yeah, I think the the car ride, as you said, that tends to be one of the most common things that people probably worry about, especially if they're driving long distances and sometimes even not driving long distances. I mean, it's difficult for a normal, typical developed person to sit in a vehicle for, you know, six, seven, nine, 12, 18 hours.

00;31;36;25 - 00;31;56;02

Brandy Brown

Some of the advice that I always give, whether it's parents or even adults, I've had, you know, adults when I worked in in rehabilitation that what has to drive, you know, 11 hours home from the rehab hospital. And they had had a stroke and couldn't use one half of their body. And, you know, the husband's like, well, how do how do I do it?

00;31;56;02 - 00;32;18;08

Brandy Brown

How do we get them home? How do we do this? It's basically if you MapQuest it or Google Maps it or whatever you use and it says it's going to take 7 hours to get there and you usually allow another hour for traffic. I always tell people to add another device, whatever their total time is and half, and add that to your trip to give you plenty of time to take rest breaks.

00;32;18;16 - 00;32;48;01

Brandy Brown

My son, he he has to get out and it drives my husband nuts because he doesn't understand all the time, you know, his his sensory needs. But anytime we stop to go somewhere, he's always like, I want to get out. I want to get out. I want to get out. Because he just he has to get out. He has to walk around sometimes, you know, as if a child has those sensory needs where, you know, they need more of that kind of what we call vestibular or that input of like moving around sometimes just taking like a ball with you.

00;32;48;01 - 00;33;06;00

Brandy Brown

If you bring a soccer ball or kickball or any type of little ball that you can get out and play toss or kick the ball around at a rest area that sometimes can help. Sometimes just we if there's a nature trail at a rest area, we'll walk on the nature trail just to get him out and kind of in the nature because that's something that calms him.

00;33;06;09 - 00;33;28;01

Brandy Brown

But yeah, we basically planning ahead, planning to allow a lot of extra time for for breaks and not just like 15 minutes. I'm going to run into the rest area and run back but breaks that you know, like I know I'm going to have to be with him for 30 to 45 minutes at one of those stops to let him just decompress and then gear back up for getting back in the vehicle and then starting.

00;33;28;01 - 00;33;47;11

Brandy Brown

And, you know, you're going to have to go on like if I know next year I'm going to go to Legoland and it's going to take me 12 hours to get there, then I would probably start planning some smaller trips that are a little bit further away from home so that I can figure out what my son is going to need.

00;33;47;22 - 00;34;07;28

Brandy Brown

That way I'll know you know what he's great for two and a half hours, so I know I'm going to have to stop every two and a half hours because on that four hour trip, assuming a half hours, when we tried to push past that, it was a disaster. A lot of it is planning. And Sheila, I know that's what you do as a travel agent is you help families to plan these vacations.

00;34;07;28 - 00;34;37;14

Brandy Brown

And even with, you know, accommodations at hotels and that type of thing, oftentimes that stuff isn't always readily available on the website or wherever it is you may be going. So you have to call or another good place to look for. Things like that would be travel blogs. You have travel blogs of other families that have traveled. They usually have really good insight and information on those as well for, you know, things that work for riding in a car or these are great vacation places to head out.

00;34;37;14 - 00;35;02;21

Brandy Brown

If you have a child that has special health care needs or sensory needs or dietary needs or or whatever it is. And then I think the other thing that I wanted to comment on was, I guess just growing up the way that I grew up and, you know, we could never afford to go to Disney. The only way we ever went to Disney was because my mom had to go there for work and they basically paid for it.

00;35;02;25 - 00;35;25;26

Brandy Brown

So I know for a lot of families, doing things like that isn't isn't feasible. A child with a disability is expensive in and of itself. So I think it's important to note that your vacation is what is what you make. It is it is yours and yours alone to plan. It doesn't have to be a cruise or a Disney or something all inclusive.

00;35;25;26 - 00;35;48;28

Brandy Brown

It can be as simple as taking a day trip to a park or a day trip to the zoo or, you know, going to the zoo and staying overnight in the hotel, and then the next day going to the jelly bean factory or whatever it is. But I think I think it's important to know that vacations don't always have to be weeks or days, you know, 3 to 5 days long or a week.

00;35;48;28 - 00;36;13;10

Brandy Brown

So they don't have to be at some formalized resort or on a boat or whatever it is. It's really just time for you to spend with your family. What's the focus being on with your family, doing something that's enjoyable for most of the people in your family? I think that's that's kind of the key or the core to you, at least for us, for vacations, for us.

00;36;13;15 - 00;36;32;24

Brandy Brown

We, my son loves to go camping. My youngest, that has other issues and we have a camper. And so I consider when we go camping for two nights in our camper like Bassa vacation, for me there's no wi fi. We just hang out, we relax. He gets to go to the pool. There's never anybody at the pool. So he loves it and that that's vacation for us.

00;36;32;24 - 00;36;50;19

Brandy Brown

So I think it's important to note that vacation looks different for everyone and to not fall into the comparison trap with vacations. Because, you know, Sandy, I believe you said that your friend's son has cerebral palsy as well. And if I said, hey, we went to Disney and you went to Disney, let's compare our Disney notes on how our vacation went.

00;36;51;00 - 00;37;07;00

Brandy Brown

Even if they have the same diagnosis, it's not going to look the same because we're not the same and they're not the same. So that's one thing I really want families to know is your vacation, is is your vacation, and it is what makes you happy and the things that that you enjoy.

00;37;08;09 - 00;37;33;01

Sheila Harman

That's what my husband we have a camper, too. And we had spent just a lot of hotel nights sleepless because, you know, she even didn't feel comfortable there. And, you know, you could tell with the meltdowns and the tearing up of stuff. So we did get a camper and that way that was her space. She was familiar with it.

00;37;33;01 - 00;38;01;23

Sheila Harman

And my husband, he would rather go Myrtle Beach in camp, go to Pigeon Forge and camp. And I you know, I have a lot of clients that go to next month. I have some going to Memphis, just staying in the hotel there and driving back home. So I'll I'll help anybody take any type of vacation but the the camper I will have to say, did help out with just things because it was the familiar.

00;38;02;18 - 00;38;28;17

Sheila Harman

Everything was familiar. That was her space, you know, we had to bring every type of food. It was us cooking and it did make things a lot easier. I am very high maintenance so they camper is not my cup of tea and the kids always kid my husband come summer. Well Mommy's going to be uncomfortable so let's just see how many camping trips we can get in there for.

00;38;28;23 - 00;38;37;20

Sheila Harman

Yeah, it's exactly. Vacations are exactly what you make it, you know, whether it's camping in your backyard or, you know, going to the all inclusives.

00;38;39;14 - 00;39;00;03

Melina Danko

I think that's a good point when we talk about campers, because I know we have one as well and my kids pack all their stuff, so then they can take their own bed stuff, they take their own blanket, their own pillow, their own stuff. And I'm like, Go ahead, load it up, put whatever you want in there. I don't have to worry about fitting it in a suitcase and then lugging it through an airport.

00;39;00;12 - 00;39;23;15

Melina Danko

But I've also heard that a lot of families really enjoy just renting a house somewhere because of that same thing that you mentioned. Sheila, they can take their food, they can take all of their equipment and they can, you know, go with the flow. They don't have to be on anybody else's set schedule to go and eat at a certain time or, you know, go on a tour at a certain time.

00;39;23;15 - 00;39;50;24

Melina Danko

And I think that's a nice one. But I have a question to any of you guys. I'm very much of a Packer, a planner and organizer. Have any of you guys ever seen like a checklist or had recommendations on how to create those things? Because going on trips is a lot when you have to pack for a family, let alone when you have to worry about all of the medical supplies, medical equipment, food, things like that.

00;39;50;25 - 00;39;54;08

Melina Danko

Has anyone seen those types of checklists.

00;39;54;08 - 00;40;15;07

Sheila Harman

Or chichi I actually do packing lists for my clients and I'll send it to them. Their child has special needs and I'll just put medical supplies and I even do like checklist if they're going to Disney or Universal so they can try to see everything. And if they're going back, you know, that's okay. They know where they left off.

00;40;15;21 - 00;40;34;04

Sheila Harman

So I try and incorporate that with my families because I'm very I'm a packer, I'm a planner. I'm Monica Geller, like in, you know, in everyday life. So I, I do that just to make things easier for people.

00;40;34;04 - 00;40;55;02

Courtney Ringstaff

And speaking of lists, it just has me thinking with it here has the accessible parks and trails list. It's like a booklet and I know it's accessible online. We'll link it for families who maybe want to do a staycation and want to stay in West Virginia, but carve out family time at places that are known to be accessible.

00;40;55;14 - 00;41;19;09

Courtney Ringstaff

And so I think with it has a really good list. I know I've looked through it before and linked it in some other materials that I've shared. I'd like to list in this episode as well. Is there a list like that or just popular vacation spots that you know of Sheila or anyone that aren't specific to West Virginia, but that just include what might be considered an accessible vacation?

00;41;19;09 - 00;41;53;25

Sheila Harman

Um, I, I don't actually know of that. I can definitely research that and find out because I know, like when we go to, like the tavern's, the one in Lewisburg isn't handicapped accessible versus the one in Luray is handicapped accessible too. And like we had to call and find that I think that that would be so beneficial to have that just to know what is handicap accessible.

00;41;54;05 - 00;42;16;27

Brandy Brown

And a quick search of the famous Google. There are lots of lists out there for accessible if you just research accessible vacation spots. I just did a general search. I didn't specify it to a state, but it will come up and there's a lot of list of of different places that you can go that are accessible. And I'm sure you could narrow it down by state or by region or whatever it was.

00;42;16;27 - 00;42;37;16

Brandy Brown

But I mean, it has there's one for most accessible spots around the world for vacation, in the United States for vacation. So I think you could probably find it online somewhere. But having it easy to navigate as I am like one place where you can go and all 50 states are listed and you just click and there's a list within that state.

00;42;38;04 - 00;42;44;22

Brandy Brown

Didn't see that right off the bat, but there is information out there.

00;42;44;22 - 00;42;45;12

Sheila Harman

Thanks, Brandi.

00;42;46;12 - 00;43;06;16

Sandy Corbett

Circle and back to something that one of you said when you're talking about staycations and you're doing these day trips, and I'm thinking of this these lists, you know, as a family, then you can see we're only an hour away from home. Now we know this is what we need to add to the list for the next time we go it.

00;43;06;19 - 00;43;22;06

Sandy Corbett

I'm thinking as far as personalizing the list, which I'm sure, Sheila, you do a lot, but as a family who is going on day trips as you're practicing maybe spending to the weekend, you can adapt your list accordingly.

00;43;22;24 - 00;43;41;15

Brandy Brown

Sometimes we'll do like a scavenger hunt in the car. So if I know I'm traveling from, you know, where I'm located in Charleston, West Virginia, and I'm going to to Morgantown, and we sometimes will go and like print out pictures or have pictures on our phone. We'll get my son like a list and we'll say, okay, this is your list.

00;43;41;15 - 00;44;10;17

Brandy Brown

Whenever you see this thing, that means that we are not there yet. When you see this things, that means we're getting closer. When you see the big concrete dinosaur like my mom perhaps is just up the hill and that helps them having those visual landmarks. We've done it so much that now he knows them and he will point out, like as soon as we get off the exit and he sees the dinosaur, he's like, I can take my coat off in a little bit, but but even on those longer trips, it it kind of helps give him something to look for.

00;44;10;17 - 00;44;26;21

Brandy Brown

And it's it's there's no words. It's just pictures sometimes, you know, you can put it on a board with Velcro if you like, get real fancy and be like, okay, here, take this one off because we've made it this far. Take that one off. And when you have no more or less, then guess what? We've arrived at our destination.

00;44;26;21 - 00;44;38;17

Brandy Brown

So it's just something that keeps him kind of looking around at his environment. But also it keeps him from. Are we there yet? I mean, there are we there? Are we there yet? Are there yet? Hey, mom, are we there yet?

00;44;40;06 - 00;44;49;19

Melina Danko

Are there any places or types of vacations that you guys would just say, just avoid that? Like it's not good, you know, with.

00;44;50;12 - 00;44;50;18

Sandy Corbett

No.

00;44;50;18 - 00;45;02;02

Melina Danko

Matter what, you know, is there any bad experiences that that you guys can imagine sharing with listeners that maybe they should just steer clear of?

00;45;02;02 - 00;45;40;23

Brandy Brown

I feel like that's very dependent on who's who's going and what their their needs are. I know for for us, that list is going to be different than it would be for Sheila and her family based on their needs. And and you also have to ask yourself, what are you willing to handle as a parent? I can take my son to Disney, but I know if I do that, I'm going to have to be willing to handle increased tantrums, increased meltdowns, pulling him out, not being at the park for very long.

00;45;41;02 - 00;45;59;20

Brandy Brown

So just knowing upfront the reality of of doing that, I don't think any vacation is off limits, but I think you just have to know your limits as a parent and you can tolerate and what your your child or the adult that you're taking with you on vacation can tolerate.

00;45;59;20 - 00;46;28;02

Courtney Ringstaff

I think we should talk about some tips and tricks or hacks for hotels and also car rentals. When we think about what we have to bring for just any child, the amount of things that you have to pack, but especially when there's like particularly specific medical equipment or communication device that like all these types of things. And so what are what are some tips and tricks or hacks that you all have encountered or that you recommend to your to your families and clients to help with hotels and rentals.

00;46;29;10 - 00;47;05;08

Sheila Harman

Bringing familiar items, things that they that they like, you know, they're there blankets there. There's stuffed animals that helps even aluminum foil, putting that on the windows to make it darker. If your child likes the dark, we've hung garbage bags over the windows as as well just to if she does fall asleep to keep her asleep just a little bit longer, things that was, you know, just they're familiar things.

00;47;06;10 - 00;47;09;04

Sheila Harman

So they start to feel comfortable.

00;47;10;01 - 00;47;39;21

Brandy Brown

I would say familiarize yourself with whatever airline you're flying with, whatever hotel you're staying in, you know, go on the website, familiarize yourself with their their policies regarding carry ons and luggage and also how most airlines have I don't want to say, is like an accessibility department. I don't know what they say call it, but they have someone that's on there that is kind of their go to person for accommodations and accessibility for their airline and same thing at hotels.

00;47;39;21 - 00;48;18;03

Brandy Brown

So my advice appearance is to always call and physically talk to someone. That way you're not standing at baggage claim and thinking you're going to be able to track a wheelchair and a, you know, a car seat and. The other 800,000 things that you have to bring with you whenever you you travel. And because sometimes there are exceptions and calling ahead and knowing that you can avoid a lot of chaos and confusion whenever you're actually trying to check your items, whether that's at baggage claim or whether that's getting, you know, on the actual airplane.

00;48;18;20 - 00;48;49;00

Brandy Brown

The other thing with flying in particular, some tips for that. Most airplanes are airport usually allow for priority boarding that, you know, for women and children, individuals that utilize wheelchairs to get on board first. It could be that maybe your child or the adult you're with is in a wheelchair, but also has sensory issues. So maybe they don't want to get on first because then they're going to have to watch every single other person go and stand in line and be in front of you as they as they're going and trying to board the plane.

00;48;49;08 - 00;49;07;07

Brandy Brown

So oftentimes, if you know, that's going to be an issue, just asking like, hey, I know we have priority boarding, but is it okay if we board last because that's going to work better, better for us as far as that goes. Or if you're traveling with somebody, having them get the seat, then that person board the plane last.

00;49;07;07 - 00;49;30;13

Brandy Brown

And that's something that works well for a lot of families with kiddos or adults that are more sensitive to whether it's sensory issues or even just that feeling of like being claustrophobic. Right. If you've ever been on an airplane, they're small. They're they're not. You know, most of the ones that are as normal people fly on, unless you can afford the big fancy first class seat and all the luxury, they're they're relatively small.

00;49;30;13 - 00;49;49;23

Brandy Brown

So if you imagine sitting up front and being up front in a wheelchair and being crowded into almost a four by four foot space with people looming over you in luggage, and it's not a very comforting picture. So that's another thing. One of the things, too, with with airports in particular, my kid has to run. He likes to run.

00;49;49;23 - 00;50;10;07

Brandy Brown

He likes to move. He is he's energetic. He's not going to sit still. So we always they make these really awesome carry ons now for for kiddos that are more movable, that has wheels on them. And so you can literally just sit on it and ride it like a scooter. So we got that for him and he loved that.

00;50;10;07 - 00;50;27;19

Brandy Brown

That was one of our go to things for the airport and he was able to sit on it and kind of ride it around in his own little corner over by himself and has lights on it. And so he was able to entertain himself with that pretty much the whole time we were during waiting for the plane and during our early overflights as well.

00;50;27;19 - 00;50;46;08

Brandy Brown

So that was something that worked for us. More and more airports are also getting sensory friendly rooms. I think there's one in the Pittsburgh airport, if I'm not mistaken, so that those are also an option. Some of them have playgrounds. So really a lot of it is just it's planning. And I know we said that over and over and over again, but it's planning.

00;50;46;08 - 00;50;57;22

Brandy Brown

It's looking in advance, calling, asking the questions, getting it all laid out in advance so that when you do get there, the issues that arise should be should be minimal.

00;50;58;14 - 00;51;18;15

Melina Danko

Also, not being afraid to ask for things because what's the worst thing they're going to do is say no. But I know a lot of hotels will give you a smaller like mini fridge for your room. If you need to refrigerate medication or if you're traveling, you know, with food that needs to be kept at a certain temperature.

00;51;18;28 - 00;51;38;07

Melina Danko

So I think that's important is just to to think about kinds of things that you could use that would be helpful and that you don't want to have to lug in a big cooler from the car everywhere you're going and just asking more. So I'm going to say is, no, we don't do that. But the best I could say is guess what?

00;51;38;07 - 00;51;44;28

Melina Danko

You don't have to bring all your own because we can do that special and then you don't have to worry about it. One more thing, you can check off the list.

00;51;45;24 - 00;52;15;05

Courtney Ringstaff

I was thinking too, when we talk about planning ahead, a lot of times people don't even know what they need to plan for. And so a good starting point for that is, like you said, like Google. But we're looking for like those blogs or those lists or just those parents writing articles. It me to me, it needs to come from parents who actually have lived and have done it and have tried it and like learning from their failures and their successes.

00;52;15;09 - 00;52;48;23

Courtney Ringstaff

And so when I started researching for this, like my research started in those parent blogs because you can't just call a hotel and and try to hash out what your child might need there because the person on the other side of the phone doesn't know about your child or doesn't know about your particular family's needs. But if you start with the blogs of you know how to travel with the child with this sensitivity or how to travel with the child with this complexity or how to travel here to this particular place, with this type of child, I feel like there are more than likely there's parents who have already tried it or already done it.

00;52;48;23 - 00;52;52;00

Courtney Ringstaff

And so we can kind of learn how they navigated that well.

00;52;52;04 - 00;53;11;22

Brandy Brown

And also in doing that, Courtney, too, I think in learning that could make our planning process more efficient. I wouldn't waste my time calling 15 hotels to be told no. If I know that the Marriott or the Holiday Inn or whatever is super accommodating and they're accommodating as a chain and kind of narrows down who I have to call or where I has to look, too.

00;53;13;03 - 00;53;22;21

Melina Danko

If there was one thing that you would want a family to know as they are planning a vacation, what would it be?

00;53;22;21 - 00;53;44;21

Sheila Harman

It will be afraid. They'll be afraid to go. You never know what's going to happen until you go. And then you learn from that. This meltdown happens. Just learn from it and just. Just go. You can't be afraid to not do something with your child is though.

00;53;44;21 - 00;54;12;17

Sandy Corbett

Remember that I think I would say challenge by choice in knowing your child, knowing knowing the setting and challenging yourself just enough. Challenging the child just enough. I keep coming back to the when you were talking about the airplane travel and knowing what you're going to need to plan for and what you carry on and what you put.

00;54;12;28 - 00;54;23;02

Sandy Corbett

If you think about that in terms of, oh, there might be a layover. So yes, there are going to be those challenges and you can do this.

00;54;23;02 - 00;54;54;28

Brandy Brown

Yeah, I think I mean, you walk out and I say, you stole my thunder. But it is true that not being afraid to to go on on the vacation and not, you know, and finding that, you know, Sandy, as you said, that challenge, that just great challenge on both ends for for the child and the parent, the thing that's going to cost you a little bit out of your comfort zone, but it's not going to push you so far past it that it's the worst thing ever because, you know, there's the fear of it not being there's no perfect vacation.

00;54;54;28 - 00;55;21;03

Brandy Brown

There's no perfect people. You know, you're still going to get the Instagram worthy photos no matter what. And to be honest with you, I think as parents, we worry more about what the vacation is going to be like and everybody being happy and having this this great, wonderful time. And I can tell you and every vacation I ever went on with my children, they didn't remember any negative, bad thing that I perceived as negative or bad about the vacation whatsoever.

00;55;21;03 - 00;55;40;03

Brandy Brown

In my mind, it could have been the worst vacation, the most stressful vacation that we've ever been on, like our first trip to the beach with with my son, with a helmet. And it was 90 plus degrees and we were in a camper and there wasn't any conditioning. And it was really rough, you know, for me. But both of my boys were like, that was the best trip ever.

00;55;40;03 - 00;56;04;27

Brandy Brown

We went camping with my mom, Barb, and we went to the beach and we got to see a shark in the aquarium. And so I guess just try to see the vacation through your child's eyes. That would be my best advice, is to take off your adult hat and your your adult glasses and, you know, try to see it see it through a child's eyes and how they they would see see that and live that experience.

00;56;04;27 - 00;56;29;29

Courtney Ringstaff

Thank you all for coming. We so much appreciate you being here to share your personal experiences and your professional experiences. I feel like we have a lot of good things to link for families who are considering vacations in the show notes, and I just appreciate you guys doing this. Melina No, since we just started the podcast, I'm like, there are certain panel discussions I want to have, and one of them is on vacations because it's, it's, it seems to always be a concern.

00;56;29;29 - 00;56;45;14

Courtney Ringstaff

And also for me as a selfish reason, I have a child with autism and he's only three. And so we are learning what things we can do and what things we can't do. And he is a runner. So we have to take his safety harness everywhere because he will just rip his hand out of my hand and just be gone and he will not turn around.

00;56;45;14 - 00;56;47;11

Courtney Ringstaff

He will just be gone as opposed to.

00;56;47;21 - 00;56;50;24

Melina Danko

This great idea and. Airtag Is that what you're describing?

00;56;50;24 - 00;56;55;03

Sheila Harman

Sheila Yes. Idea makes it like even in the bottom of his shoe.

00;56;55;16 - 00;57;07;07

Courtney Ringstaff

So he and his clothing. Yeah, that's a good idea. I can be the parents who just walk to the grocery store with their kid beside them. So. And be that because my kid will not will not stand beside me.

00;57;08;04 - 00;57;27;16

Brandy Brown

But with you. So, yeah, it's hard. You are not alone. We had we had a leash harness. It does need you because mine was the same exact way. And he's still that way today. The only way I let him go to the grocery store is if he's in the actual, not the child like he has to be like in the actual cart or he is just he's gone.

00;57;27;19 - 00;57;28;05

Brandy Brown

He doesn't care.

00;57;28;12 - 00;57;43;06

Courtney Ringstaff

Anyway for selfish reasons. I also wanted to have this discussion because I feel like I learned so much through all these podcast episodes because I'm navigating that as a new mom to a child with autism as well. So I just want you guys. All right, ladies, thanks again.

00;57;43;15 - 00;57;44;21

Sheila Harman

Really. Thank you. All right.

00;57;45;04 - 00;58;08;15

Melina Danko

Bye, everyone. I this podcast is sponsored by the West Virginia Department of Health and Human Resources Office of Maternal Child and Family Health, Children with Special Health Care Needs Program, and the West Virginia Family two Family Health Information Center and produced by the West Virginia University Center for Excellence in Disabilities.