00;00;09;13 - 00;00;20;23

Heather Merritt

During those fun holidays. If it is a one ornament kind of tree, it's a one ornament kind of tree. If there's not a Christmas Eve dinner and it's getting the pizza to go, it's okay.

00;00;20;24 - 00;00;29;19

Peggy Hovatter

Family members who can laugh at themselves or find the humor in a situation. In actuality, their children seem to thrive.

00;00;29;23 - 00;00;45;16

Amy Burt

Do what works best for you, and take care of yourself.

00;00;45;16 - 00;00;57;05

Courtney Ringstaff

Welcome to Adjusting the Sales, a podcast for parents, caregivers and service Providers for Children with Disabilities. I'm your host, Courtney Ring Staff and this is my co-host, Melina Danko.

00;00;57;16 - 00;01;00;10

Melina Danko

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

00;01;00;20 - 00;01;19;13

Courtney Ringstaff

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

00;01;45;13 - 00;02;16;04

Heather Merritt

My name is Heather Merritt. I am with the Positive Behavior Support Program at the CED. I am the curriculum developer, but I also support families with resources and through the triage intake process. I also have many years experience providing parent support and parent education, particularly with young children under the age of 12, navigating a different obstacles for children that are either with global delay or on the autism spectrum.

00;02;16;23 - 00;02;45;14

Amy Burt

My name is Amy Burt. I am an occupational therapist. I'm also an associate professor in the Division of Disability Studies and Occupational Therapy. I have a couple of decades experience as an occupational therapist, specifically pediatrics in the school system, and also an early intervention in my main area of practice is outpatient focused a lot on autism, developmental disabilities and feeding the O.T. on the team at the Center for Excellence in Disabilities, or the CFD for the feeding clinic.

00;02;45;14 - 00;02;58;19

Amy Burt

So I work with a lot of kids with challenges, with feeding and just developmental delays and different things like that. I've also focused a lot on sensory processing and behavior concerns, so happy to be here.

00;02;59;15 - 00;03;23;27

Peggy Hovatter

I'm Peggy Hovatter. I'm an autism specialist with the West Virginia Autism Training Center. Our main office is at Marshall University. But I live in north central West Virginia. The Autism Training Center provides different tiers of direct service to families in West Virginia. We serve people on the spectrum of all ages. We provide services at no cost to the family.

00;03;24;03 - 00;03;46;06

Peggy Hovatter

They just simply have to register either online or by giving us a call and have a clinical diagnosis of autism. And then they would be ready to receive services from us. I'm in the middle of my 23rd year with the Autism Training Center. I also have the nephew with autism who I watch grow and I'm very close to.

00;03;46;06 - 00;03;50;13

Peggy Hovatter

And now that I think about it, he's 42. So it's been a while.

00;03;50;16 - 00;04;18;05

Courtney Ringstaff

Thank you all for joining us today for this panel discussion. We really sought out a couple different panel discussion topics that we thought would be important and meaningful for our listeners who are parents and caregivers navigating life with a child with a disability. And when it comes to holidays, that can be an extensive time of the year because we are starting our holidays at Halloween and then covering Thanksgiving and then Christmas.

00;04;18;11 - 00;04;49;18

Courtney Ringstaff

And so we thought we would get you all together to kind of discuss what families can do to prepare their child or to prepare their environment or to prepare one another. And other family members and caregivers for this time of the year, we kind of thought to separate the disabilities into two different categories, and we're thinking of disability as those that are sensory that might make travel or Halloween costumes or, you know, family centered activities difficult.

00;04;49;18 - 00;05;14;02

Courtney Ringstaff

And then we thought about the mobility piece and how people whose homes may not be accessible or who travel time may be impossible for them or difficult for them, how are these types of people with these two types of disabilities enjoying the holidays? And what can we do as the specialists and experts in the field to just make parents lives easier or to prepare parents for this time of the year?

00;05;14;14 - 00;05;34;28

Courtney Ringstaff

And so that's really why we brought you guys all here today and we handpicked you each specifically for for this subject because we knew that that you've worked with families that are facing these types of challenges. And so thank you all for being here. We really do appreciate it and thank you for introducing yourselves. The first holiday that's approaching very quickly is Halloween.

00;05;35;19 - 00;05;52;09

Courtney Ringstaff

Maybe we can start by talking about some of the concern that families have brought to you about Halloween and some of the challenges maybe that you've seen kids face for Halloween and how we can, as a community help children enjoy this time of the year.

00;05;52;18 - 00;06;17;27

Heather Merritt

I'll start. I often have heard and continue to hear sensory overload and just changes to what things look like. Typically decorations, the change in activities like the week of Halloween is different because there's all the preparation that goes into it. And so I think a big concern for parents is how can they help their children get ready for Halloween?

00;06;17;27 - 00;06;39;10

Heather Merritt

And some of the things that come to mind for those changes and how things look like there's big decorations, some are very scary can be triggering for children to talk about it in oh, you know keep the conversation going maybe even as early as when things come out in the store. The items are coming out in the stores now in August, July, even at the end of July.

00;06;39;10 - 00;07;01;26

Heather Merritt

And I think, you know, having that opportunity to say, oh, this is a pumpkin, you know, or, oh, it's a scary ghost. But look, it's just for fun. It's just for play and to really talk about the mechanics or the actual inner thing of the decoration. Right? It's just a decoration. It's not real. Maybe going on drives in the neighborhood to look at decorations together and talking about whether they like them or they don't like them.

00;07;01;29 - 00;07;22;00

Heather Merritt

The different sounds that some families might play at trick or treating or at parties talking about it, just being on the radio or just a song, you know, that's playing in the background like a movie song. And really the prep piece I think is helpful. Talking about it before actually going to do it or to see it is best instead of going at it cold.

00;07;22;13 - 00;07;23;04

Heather Merritt

And I think another Thing to add to that is don't feel like you have to do it all right? Don't feel like you have to go head to toe costume, face paint, you know, the prettiest glitter costume or the biggest superhero costume. Do what works for your kid. If they want to be Spiderman, think about the size of the costume. Maybe they usually wear five, but maybe it's better to go up a few sizes so it's not as tight and snug on them and there are a lot they can move.

00;07;47;07 - 00;08;15;29

Amy Burt

They can also practice wearing their costumes at home, kind of going off what Heather said, practice does a lot and even if they're siblings, they can practice wearing their costumes around. So they get used to people looking different and kind of out of character. The other thing is to just be sure you have that conversation about the purpose of Halloween and if if they don't want to dress up in that costume, then they can wear Halloween colors or then they can just be who they are and walk around and you can let the people know.

00;08;15;29 - 00;08;30;07

Amy Burt

We call it advocacy. Let them know why your child might choose or you don't have to write. You don't have to have that conversation and keep it private. My kids just going out and having fun and kind of don't be afraid to be different, I think is a really good thing and just comfortable with it.

00;08;30;22 - 00;08;53;12

Melina Danko

Amy One thing from an OT perspective, I heard Heather mention we hear a lot about sensory overload and that is something that we hear often. That is a real thing. However, some people really don't know what sensory overload is and then also trying to explain what that is to grandma or aunts and uncles who may not have a clue.

00;08;53;12 - 00;09;03;16

Melina Danko

Can you explain to us what what is sensory overload? And then how can you kind of teach your family or friends or community what that is?

00;09;03;25 - 00;09;38;00

Amy Burt

Yeah, I always think about sensory as like a thermometer or a gauge. So when you're processing your environment that it is not overloading you or under stimulating you, you're kind of at this we call it a just right level. And then people who are prone to sensory overload can be very sensitive to sounds, smells, touch movement, and it just requires the littlest bit of that sensory input to put them over that just right threshold and then their systems are out of sorts and they've got to figure out how to regulate themselves.

00;09;38;10 - 00;09;58;28

Amy Burt

You also see it on the opposite end, where people who have sensory concerns will be under stimulated. They're always seeking sensory input, so they actually require lots and lots more input to get to that just right level. So say a kiddo loves to run back and forth. They're doing that for a reason. They they need more movement to help them feel at that just right level.

00;09;59;05 - 00;10;20;11

Amy Burt

They're not doing it to be distracted or to run away or to be oppositional. Sometimes they are. But maybe the reason is sensory and they're just getting that input that they're looking for to be satisfied. So understanding the other, I think confusing part about sensory is you can be a mix of both, you can crave input or you can avoid input all in the same person.

00;10;20;11 - 00;10;47;25

Amy Burt

So maybe someone is aversive or overloaded with visual, but they're seeker or they're wanting that input for movement and it could be in different situations as well. So understanding how sensory is impacting a person in the holidays are definitely going to really be extremely more sensitive for those kids who can be overloaded because they're so much lights and sounds and movement and different smells and you know, just that intensity is there and just kind of a tip to go off that is just figure out a plan.

00;10;47;25 - 00;11;08;02

Amy Burt

What's the escape route is? A lot of times we say like, again, don't feel like you have to be a part of it. Kind of figure out a plan like if I notice my kiddos getting overloaded, let's just step away. Let's have a room that we can go into. Let's have an exit plan, a back street to walk down for trick or treating, or just take 10 seconds and figure out how to regroup.

00;11;08;02 - 00;11;17;24

Amy Burt

Maybe you have some really good strategies that work for your family and implement those strategies right in the moment and then get right back on the path and continue with whatever activity you're doing.

00;11;17;24 - 00;11;47;17

Melina Danko

So thanks for sharing that. And it made me think when you were talking that Halloween could be a really fun time to explore some of those sensory things you think about like slimy pumpkin seeds or soft squishy toys that you can give out that are pumpkins or spooky ghosts and things like that. So that could actually be a fun way to explore some Halloween things and help meet those sensory needs, right?

00;11;48;07 - 00;12;16;22

Amy Burt

Yeah, absolutely. Take advantage of all that ooey gooey and the messy and then all that glitter and whatever it comes with all these different holidays. And then also kind of on the flip side, if if you are an overload or there are a lot of sensory friendly options out there, like I know we're talking currently about Halloween, but there's like sensory friendly Santa events where the Santa is trained to work with kids who demonstrate sensory overload or they prefer to run around instead of sitting.

00;12;16;22 - 00;12;32;24

Amy Burt

There's all sorts of different trick or treat like trunk or treat situations that are focused on sensory friendly environments. And usually those are on social media or on websites that were advertised. I know a good bit of churches really focus on sensory friendly environments too for all these different holidays. So take advantage.

00;12;33;19 - 00;12;55;29

Peggy Hovatter

When it comes to autism and Halloween, it's going to be one of two things. The child or the person with autism is either not going to be interested in anything that has to do with the costume or it's going to be one of their enthusiasms where if they're a Spider-Man and Suzy is, they're going to really love to wear that Spider-Man costume.

00;12;56;08 - 00;13;18;09

Peggy Hovatter

And you may be looking at where they want to continue to wear the costume long after Halloween is over. And that's okay, because the if it's something that they connect with, then they feel comfortable when they're wearing it, they then they may feel more confident. I know masks are normally a really tough thing for kids with autism to tolerate.

00;13;18;09 - 00;13;30;01

Peggy Hovatter

And in face paint, things like that. But the actual costume part of it, maybe we can use it as something that boosts their self-esteem. And like I said, just let let them let them wear it as long as they want.

00;13;30;17 - 00;13;50;20

Amy Burt

And to kind of jump off the costume theme if people didn't know. But Target does have adapted costumes. They have a really big support for all adaptive clothing, but they really focus a lot on adapted costumes for wheelchair users, for kids who have sensory issues and different things like that. So it's really cool that a lot of products are being developed to help kids be a kid.

00;13;51;01 - 00;14;04;12

Melina Danko

Yeah, and there's so many DIY boards on Pinterest with different kinds of Halloween costumes and things like that too, that you can make yourself, which are always fun or overwhelming depending on your level of craftiness.

00;14;04;27 - 00;14;19;28

Courtney Ringstaff

And that makes me think too. Like from a community standpoint, like if someone was listening to this and they may not have a child with a disability necessarily, but what can they do to their homes? Like, I know that there used to be like a tail pumpkin thing, but I don't know if that's outdated now or is there like a light?

00;14;19;28 - 00;14;27;29

Courtney Ringstaff

Like what can we do as a community to try to make Halloween as accessible of a holiday as possible for the kids in our neighborhoods?

00;14;27;29 - 00;14;51;02

Amy Burt

There was a big push a couple of years ago to recognize children who were on the autism spectrum, to have a blue pumpkin, either to carry around and get their candy or someone to have a blue pumpkin painted on their porch to say that they were an autism friendly house. There has been some controversy about it, but I still think people do it because there's two different sides of the coin when you think about autism advocacy.

00;14;51;08 - 00;15;11;23

Amy Burt

So you still might see that out and about. But there are some people who do believe in it is not the best option. The teal pumpkin concept is for food allergies. So there are different efforts out there that focus on supporting people who have differences and also letting people know that, hey, come on over, we got you. So different colors of pumpkins mean different things.

00;15;11;23 - 00;15;33;11

Amy Burt

Another thing I was reading about since the Blue Pumpkin thing is not for everybody is just to let people know or practice with your child who might be minimally verbal or nonverbal, that it's okay to say you're autistic or just not and just be like everybody else and you don't have to pointed out. So it's essentially your choice on how you want to engage with your community and how you want to advocate or just go through it.

00;15;33;11 - 00;15;41;03

Amy Burt

But there are things out there that people do promote, but again, not everybody's buying into it. So, you know, I think you'll see a variety of different supports out there.

00;15;42;22 - 00;16;02;04

Heather Merritt

Also, I have found that I don't hand out the candy like personally, like I stay outside because, you know, I have children of my own and I like to be a part of the community and see all the costumes and have fun. But I make it so that the kids can grab whatever treats I have without having to come all the way up to me.

00;16;02;04 - 00;16;25;04

Heather Merritt

Because I am a stranger to the kids. I mean, my neighbors, nobody. But if there's kids visiting from other neighborhoods or family members with those neighbors, you know, it's not as intimidating to walk up. And I don't expect anything from the children. And I think that might play into how do we prepare grandmas and grandpas or other family members like it's okay if they forget to say thank you or they don't say thank you.

00;16;25;08 - 00;16;50;27

Heather Merritt

It's okay if they don't say Happy Halloween. Like Amy said, it's okay to walk up and just get what they want and not have anything to say. And I think just making it very low expectation and very friendly, friendly porch, you know, I know at my house and some other houses, there's some steps. I take everything out to where it's easy for the kids to come right up instead of having to go through the sidewalk and to the step at the front door.

00;16;50;27 - 00;17;36;11

Heather Merritt

So simple things like that go a long way. Yeah. And also something I think that is easier to have something for everyone is to not always have a particular kind of candy or something like that. Not all kids like candy or some kids are getting so much other candy that they're really excited to come to your house and see a glow stick or some kind of cool slinky or, you know, there's all those different kinds of things that you can buy that aren't necessary silly candy related or food that would then make it open to anyone, whether they had a food restriction, has food sensitivity or just a preference.

00;17;37;10 - 00;18;08;16

Courtney Ringstaff

The pinata stuffers are a really good, cheap way to do that. But now around Halloween time, they actually have a lot of like novelty toys that are packaged in like packs of ten that are like little, you know, glow in the dark skeletons or pencil erasers and things like that. I don't think they had that kind of thing at the store just readily available for you to buy when I was a kid, but now as an adult and I tried to purchase some sensory friendly things for some events, I went to and now I'm like, Wow, they have all these little novelty things so that you don't you're not just cornered into purchasing a big

00;18;08;16 - 00;18;34;29

Courtney Ringstaff

bag of candy or spending a fortune on little toys from somewhere else in the store. Let's move to Thanksgiving because we're talking about food and dietary restrictions. And when I think about Thanksgiving, I just think about this meal that you spend 8 hours preparing for your family. And what kind of challenges are we seeing for those families that are taking their child and going to grandmas?

00;18;34;29 - 00;18;45;09

Courtney Ringstaff

And, you know, they have this big spread of food and their child's not going to eat any of it. And how are we preparing families for that or how are we helping families to navigate that and have conversations with our families?

00;18;46;24 - 00;19;20;24

Heather Merritt

One of the things that I start out with when discussing Thanksgiving with families is preparing the family that you're going to visit. If, say, grandma is hosting or an aunt or uncle is hosting Thanksgiving dinner, prepare them well ahead of time about what your child's preferences are, what your child's needs are. I think that's an important piece to keeping the parents dressed down that knowing that the other family members or friends are aware of what the needs of the child may be on that day, may not be able to stay for a full day of food and football and pie.

00;19;20;24 - 00;19;41;07

Heather Merritt

You know, it may be we're going to be there for at 2 hours and then we're going to have to leave and just setting that precedence early so that everyone's aware, nobody's disappointed or feelings aren't hurt. I hear often from parents all but I'm going to hurt my mom's feelings and it's explaining to them what your child needs is what's most important on that day.

00;19;41;07 - 00;19;47;25

Heather Merritt

So thinking about preparing, always talk ahead of time. That would be my first go to, I think for Thanksgiving.

00;19;49;06 - 00;20;10;19

Amy Burt

And even let them prepare since they're they're in it to win it for those holy hours like cooking a turkey and stuffing and all that stuff. It's okay to let them know that you're going to you might bring different food like I my kiddo needs a special diet or they have certain preferences or this is the only thing that they eat 365 days of the year, whatever it might be, just let the host know that you will bring different food.

00;20;10;19 - 00;20;33;11

Amy Burt

It's not intended to be insulting to them, but it is to support your kid best so they can participate as much as they want or they can during that family event. So it kind of goes along with the the preparing ahead, but just being really open and honest about that and I think like other specific things is if you do have a kid who has sensory needs, just explain to people like, I know we all love to hug.

00;20;33;11 - 00;20;53;04

Amy Burt

We haven't seen each other in months, but hugs are my kids favorite thing. So how about a fist bump or or just say, hey, let's let's chat about three favorite things and just talking about personal space. Or maybe a kid is a hugger and they're going to hug people frequently and just let them know they're doing this because they're kind of craving that input or, you know, they really just love hugs so much.

00;20;53;04 - 00;21;08;19

Amy Burt

So if you're okay, any time they're looking for a hug, if you could give them one, it helps them. Stay with us at the Thanksgiving table a little bit longer. So, again, just preparing people and letting them know maybe why something's happening and so they can kind of figure it out and support the child.

00;21;08;19 - 00;21;34;01

Peggy Hovatter

Best you could use examples because for some kids with autism, being close to food can be a very unpleasant physical experience for them. It's not just that they're being picky. It is. It is very difficult for them. And you can use an example such as you're sitting down to the table and it's the middle of summer and you've got five day old roadkill on your plate.

00;21;34;01 - 00;21;56;02

Peggy Hovatter

But we expect you to say, Oh, it's okay, you can handle it, but when in reality it is extremely unpleasant. So to use references like that may help family members understand a little bit better as far as ways to involve your child, have them help prepare now. Not necessarily they're going to get their hands sticky or be around something that they don't like.

00;21;56;02 - 00;22;14;15

Peggy Hovatter

The smell of, but in some way have them help in the preparation, even carrying it into the home. If you arrive in a family member's home, spotlight them saying, well, he helped with the biscuits or he helped me carry in the cake. It's just tiny little ways to get your get your child more involved.

00;22;14;27 - 00;22;58;11

Melina DAnko

One thing, too, that I think about is that sometimes families can so hyper focus on the meal and the eating part. But really it's about being together as a family for that whole day. And so if there's something that your child likes to do, maybe take that and invite your family to participate with them on that activity before dinner or after dinner, whether it's blowing bubbles outside or taking a walk after you eat or coloring a picture or watching a particular show, thinking about that might be easier to say, Hey, this is something that we're going to go and do.

00;22;58;11 - 00;23;06;04

Melina Danko

Do you guys want to come and join us for a few minutes? And I'll bet there would be a lot of people that would say, like, Oh, sure, I'd love to go for a walk.

00;23;06;13 - 00;23;30;25

Amy Burt

Absolutely. And that goes off like using a strength based approach. So thinking about what every person has the strength, no matter who you are, you have a strength. So what is that strength of the child? Maybe they love to draw or write letters, so maybe they can make the place settings with everybody's name on them. And that was their contribution to dinner or you know, they could be good at origami and everybody gets a specialized placing or, you know, maybe they they're really strong in church.

00;23;30;26 - 00;23;51;07

Amy Burt

Maybe they're the person who does say grace. So even giving them a job based on their strength and it could be as magnificent or whatever level it needs to be. But I think including is always a really important thing in the kind of the way you decide that is what their strength is, kind of what Melina said, you know, if they're jama's bubbles, everybody has a bubble party after and we're all celebrating it together.

00;23;51;07 - 00;23;53;13

Amy Burt

So yeah, great idea.

00;23;53;13 - 00;24;16;18

Peggy Hovatter

When it comes to strengths, kids with autism often have what we call enthusiasm. The whole terminology was obsessions, but we prefer enthusiasms where they know a whole lot about a particular topic. So you could arrange for them to be able to share this, and we'd have you would have to have guidelines that you can talk about this topic for for 5 minutes.

00;24;16;18 - 00;24;42;14

Peggy Hovatter

And and everyone will will really look forward to hearing about that. What it does is it it opens up so that other family members really see the intelligence of the person with autism. And it showcases them and gives them an opportunity to do what they love, which is talk about their enthusiasm. So that might be an event you can fit in to the to the holiday for either Thanksgiving or any holiday.

00;24;42;14 - 00;25;04;06

Heather Merritt

I love that. To always having the child be involved with anything and planning ahead and speaking up, planning ahead. I think one of the ways parents can help their child prepare for those events coming up, especially if you're traveling and you're not going to be staying at home. Social stories are such a wonderful tool to use, especially with young children.

00;25;04;12 - 00;25;27;29

Heather Merritt

You can create your own. There's lots of great websites that have free templates and there's also videos on YouTube now that are social story videos or pulling from their favorite characters. Most of the books have holiday specific stories, and so starting that early and reading those stories, I have worked with families to have the relatives that they're visiting take pictures of, like the bedroom.

00;25;27;29 - 00;25;44;20

Heather Merritt

They're going to stay in the kitchen where or the dining room where they're going to have their special dinner, maybe the backyard. If there's something fun to play with the backyard and have those pictures on hand ahead of time, maybe even making a copy and put them in like a little notebook so the child can carry that around and prepare.

00;25;44;20 - 00;25;52;23

Heather Merritt

And they're thinking about it and they know what they're going to be seeing when they get there. That piece of preparation is really key to making it a successful trip to.

00;25;53;15 - 00;26;10;17

Amy Burt

Yep. And those I think those real pictures are really what makes the difference instead of using animated pictures or pictures anywhere from the Internet, but actually showing them actually what is going to happen so they can plan and have that routine with it all. And another fun fact I learned yesterday is some people are calling social stories, teaching stories now.

00;26;10;17 - 00;26;17;19

Amy Burt

So just in case you're searching it up, you might find it called teaching stories instead of social stories. So I'm not sure of the change, but it's there.

00;26;18;22 - 00;26;42;14

Melina Danko

The one thing, Heather, when you mentioned about traveling, it made me think back to when we did the podcast on taking vacations and we actually had an O.T. and a positive behavior support person on their and they talked about recognizing the importance of like where you're going to stay and the sleeping arrangements. And if your child is used to having white noise, take that.

00;26;42;14 - 00;27;01;27

Melina Danko

If your child is used to having particular sheets or blankets that they sleep with, you know, thinking about that ahead of time could make a big difference because if you go somewhere and the sheets are scratchy in the hotel or, you know, you can hear people walking or you don't have their, you know, particular stuffy or a favorite pillow.

00;27;02;05 - 00;27;23;04

Melina Danko

And I thought that that that could totally apply for traveling for holidays, too. Absolutely. But anything even snacks, drinks, water bottles, sippy cups, whatever is that child's go to, all of that should be packed, which I know can create a little bit of parental stress on making sure you have room for all of the goodies, especially if you're flying.

00;27;23;04 - 00;27;43;26

Heather Merritt

That can be tricky, but I have had families work with their families and friends that they've had to fly to, to have things on the other end, like sending things ahead of time, enlisting other family members and friends. Hey, do you have an extra copy of this video or, you know, that my child likes or this kind of pillow that we use, we can't necessarily travel with it.

00;27;44;01 - 00;27;48;17

Heather Merritt

Things like that. Just that preparation is really key to make everybody comfortable.

00;27;50;06 - 00;28;18;20

Courtney Ringstaff

One thing I was thinking about that I think might be important for parents to just keep in mind, especially when we're talking about having conversations ahead of time or in the moment with other family members is how we are explaining our child and their needs to that family. Because I think especially if the child is younger or maybe the child doesn't talk, there's like this thought that they don't understand or that they don't care what's being said.

00;28;18;20 - 00;28;40;13

Courtney Ringstaff

I think it's important that families kind of be conscientious of how they're talking about their child. No matter that no matter that child's age, when they are explaining some of these differences to their family and why, you know, they can't eat that meal or why we had a pack, the certain thing, does anyone have experience with that or can validate that?

00;28;40;13 - 00;28;52;13

Courtney Ringstaff

Because I see that sometimes here in the clinic, especially with parents kind of talking in front of their child and we've had to kind of take children into another play area because we want to be mindful and we want to be respectful.

00;28;53;28 - 00;29;19;26

Amy Burt

And I think a really big area to consider. We always delineate it like receptive language and expressive language. So receptivity, what do I understand? How do I follow directions? Can I hear you know and comprehend and put together what people are telling me? Right. That's reception. And then expression is how can I say what I want? And it's not only spoken language, it's gestures, it's proximity, it's using pictures, it's using assistive tech.

00;29;20;01 - 00;29;38;22

Amy Burt

There's lots of different ways to do all those things, and they don't go hand in hand. So just because you don't speak verbally doesn't mean you don't comprehend verbal directions towards you. So just kind of recognizing that there's a difference between, hey, when I hear is what I hear and I completely understand you, even though I can't communicate verbally that that's what I heard, right?

00;29;38;22 - 00;29;56;21

Amy Burt

So really putting those pieces together and kind of finding the right words to explain it is tricky, but I think always giving examples is the way to go for people who don't have health care experience. Like, Here's an example of what you did in school. I'm going to show you that he knows how to follow a fire drill schedule, you know, with all of his peers.

00;29;56;21 - 00;30;11;29

Amy Burt

And he did a really great job and he was the leader, but maybe he can't tell us about it, you know? So just using real life examples to show people that, yeah, they're, they're doing really well just because they have a disability doesn't mean they can't do stuff. It's just who they are. And that's what makes them different from everybody else.

00;30;11;29 - 00;30;36;06

Courtney Ringstaff

So and I'm glad you said that because it actually reminded me of something else. Why you want to be respectful of the way you're talking to other people about your child and telling them what their child's needs are. You're also modeling how to advocate for your child's needs. I'm not saying that it's best for the child to never hear you talk to others about what they need or, you know, what their differences are, or, you know, why things need to be a certain way for them to be comfortable in that space.

00;30;36;06 - 00;30;47;12

Courtney Ringstaff

Because I think it's also important to model how they can tell another person what their needs are. And so it's kind of like a line to walk because you want to remain respectful, but you also don't want to completely not do it in front of them at all.

00;30;48;14 - 00;31;03;15

Amy Burt

I guess jumping on that train of like we call it, self advocacy, right? Teaching a kid how to how to talk about themselves and let people know. So I think that's a really great thing to even I don't really know what the right age is to start it. I would just say match it with the ability level and the learning of the kiddo.

00;31;03;15 - 00;31;19;06

Amy Burt

But if like we use the example of not liking hugs from Aunt May and if they're not a hugger, teach the kid to politely say, I don't like hugs. How about a fist pump? Or when someone's coming up to them with open arms, teach them to put their hand out and that that's a different way to self advocate, right?

00;31;19;06 - 00;31;32;18

Amy Burt

So their they might not have to use the words to explain it, but their body language is expressing like, I do want to greet you, but I'm going to greet you in a different way. And this is my way to do it, to make me feel safe. So I think there's a bunch of different ways to just think about it.

00;31;32;21 - 00;31;50;11

Heather Merritt

Courtney Yeah, and along that same line, I think there's a difference in, you know, we always say it's not what you say but how you say it. So if you're saying it like that, let's say Aunt May is coming up to hug your child instead of saying he doesn't like hugs, you could just say like, oh, well, you know, we don't hug.

00;31;50;11 - 00;32;17;25

Heather Merritt

We get fist bumps. Hey, can you give him a fist bump, you know, or something like that? So still addressing it, but but not having it be something that's perceived as a negative thing. One thing I wanted to ask about is, you know, we talk about all these holidays that have to do with meals. Everything centers around food and food is such a big thing in our culture and in our our family's lives.

00;32;17;25 - 00;32;47;28

Melina Danko

What what people do eat, what they don't eat, what they can eat, what they can't. And one thing that that I have found throughout life is if there's something that I'm worried about, then I'm going to offer to bring something that I do like. And that's something that families can do for themselves, too, is to say, you know, I know that my child is not going to eat turkey and mashed potatoes and gravy, but they really do like corn or rolls or something like that, you know.

00;32;47;28 - 00;33;06;14

Melina Danko

And so that's what I'm going to bring. So that way I can guarantee that there's something on that table that my carer will eat. So that's just a really easy way to, to kind of contribute, but also make sure that you're making having something available.

00;33;07;16 - 00;33;26;26

Courtney Ringstaff

Let's move on to Christmas specific challenges as and I don't want to just pigeonhole us into Christmas because there are Hanukkah and other holiday celebrations around the same time of the year. And so what are some of those specific challenges that families are brought to your attention that they were concerned about? And how did you help them prepare for that?

00;33;28;08 - 00;33;57;07

Heather Merritt

We talk a lot about sensory and and all of the things we've already discussed definitely apply for Christmas. But I do want to touch on how the holidays, especially for children in kinship care or foster care or adoptive care, the holidays can be a very triggering event depending on their life experiences. Children that may have been through multiple placements may have been transitioning during holiday celebrations or times of holiday celebrations.

00;33;57;07 - 00;34;25;25

Heather Merritt

When things are supposed to be happening are usually happening. You know, the holiday itself can be triggering. And the and the moment momentum building up to the holiday can be very triggering. Some of that, I think, comes from a place of that actual life experience. But I do think some of it is just that change in routine, because routine and structure is so critical for children who have experienced change often or experienced traumatic events prior to being with the family, they may be with kids.

00;34;25;25 - 00;34;46;15

Heather Merritt

So that change alone in the routines and the structure and the way things look can be triggering. So I think keeping in perspective for those caregivers to make time to talk to those children about what the holidays may look like in their home and asking, well, what did you do last Christmas? Or How do you celebrate New Year?

00;34;46;15 - 00;35;04;24

Heather Merritt

You know, and what did you like about it? What did you not like about it? And really listening to what works for that child and and their memories and their preferences and creating maybe even new traditions and new activities that that child comes up with to make them feel even more trusting and secure in that home.

00;35;05;20 - 00;35;27;24

Amy Burt

I think that idea of developing your own tradition is really important because, especially in West Virginia and in even parts of Pennsylvania, right? Families, generations and generations in many homes do have multiple generations in it. So you feel like you have to carry on what people have been doing forever. And if you don't do that with your kids, then you're not doing what your parenting is expected to to have succeeded around the holidays.

00;35;27;24 - 00;35;50;09

Amy Burt

Right. But it's okay to change and you want to adapt or think of how everybody can be their best around those times and to minimize stress. The holidays are stressful enough without having specific needs and you throw these other things in there and it's going to add that. So how can you make it worthwhile for what you have to do and what your families bring to the plate and how can everybody engage?

00;35;50;09 - 00;36;08;22

Amy Burt

So don't be afraid to do it differently. And it might be different the following year and it might be what you hoped for or the year that you tried. The different is exactly what you've been wishing for forever, and that's what you're going to carry on and change with your family tradition from there out. So yeah, just jumping off of what Heather was, was telling you.

00;36;08;22 - 00;36;33;29

Peggy Hovatter

There's several little things that that you can do. You can have your child help pick out the decorations. You can also practice opening gifts, teach how to take turns. A visual would be really helpful here with my turn your turn card or or just a big card that says my turn and it's passed to each family member when it's their turn to open gifts.

00;36;33;29 - 00;37;04;26

Peggy Hovatter

A visual, visual supports and autism are critical. Sometimes we don't realize just how critical they are, where if we can just provide some type of a picture or some type of a written word, it really helps calm them and help them understand. For some kids, what we can do as far as visual preparation as well is have a calendar that kind of lets them know what are the school days, how many days am I going to be home, when are we going to grandma's house and have either pictures or words?

00;37;04;26 - 00;37;26;29

Peggy Hovatter

Now with some kids you can do an entire month to show all 30, 31 days. For others, it has to be possibly a week just to show that particular week like Monday, we're going to be home. Tuesday, we're going to grandma's now. Wednesday will be back home then for other kids, it could be just a couple of days or even a first.

00;37;26;29 - 00;37;49;22

Peggy Hovatter

Then situation to where you have first we're going to Walmart and then we're going to go on to to grandma's house. So and picture showing that to that will really, really help them make sure that a quiet place has been established to talk to the family members ahead of time about we need a spot where we can go and regroup and kind of self-regulate.

00;37;50;06 - 00;38;18;20

Peggy Hovatter

And teaching self-regulation skills is is so important. There's there's so many deep breathing exercises, resources out there that you can Google with different, you know, different ways to teach deep breathing. I like the one called Mountain Breathing because the child or the person uses their hands where they hold up one hand, five fingers, and with the other hand they take a finger and they go up the side of, say, your thumb and that's where you inhale up the mountain.

00;38;18;20 - 00;38;40;00

Peggy Hovatter

When you get to the top of the mountain, you hold it and then you go down the finger and you exhale. By the time you get through all five fingers, you're pretty relaxed because those are five really good deep breaths. It also is good because it has a definite beginning and end. You start with the thumb and you know when I get to my pinky that I'm finish with my deep breathing exercise.

00;38;40;00 - 00;39;07;15

Peggy Hovatter

So it's very visual and concrete. But like I said, there's there's so many deep breathing techniques out there. Take along a bag of sensory items, make sure they take their favorite toys, because with autism, it's so difficult for them to predict. They they're kind of live in the moment kind of people. And when they're in a moment, that is that is upsetting for them, it's hard for them to understand that this too shall pass kind of thing.

00;39;08;04 - 00;39;16;07

Peggy Hovatter

So anything that might be comforting to them and familiar is very important, especially if you're in a new situation.

00;39;17;12 - 00;39;34;09

Amy Burt

Peggy I love that idea that you brought up of the use of the calendar because the holiday season, I'd say, I mean really starting in October, but really hitting it hard right after Thanksgiving, kids schedules are off, so letting them know a whole bunch ahead of time that things are going to be different in the value of routine.

00;39;34;09 - 00;39;53;20

Amy Burt

So also kind of thinking about what did they do in school, what was their best time in school, and maybe trying to keep that routine as close as possible at home. Like when is lunch time in school? And that's when you would schedule lunch time at home. So just to keep as much as you can or if they really love going to the library, make sure you're incorporating that in on the holiday breaks.

00;39;53;20 - 00;40;08;22

Amy Burt

So however, you can, as best you can, try to try to keep some of those patterns in there. So it helps that kiddo transition between all these these ofttimes that we all have to deal with and then going back into the swing of things, when we come to January.

00;40;08;22 - 00;40;31;15

Melina Danko

Yeah, I really like that too. We all get so out of sorts when we get off of our schedules. No wonder everybody freaks out when you know you're you have to get up early and go back to to regular school and work, right? It makes everything harder. Amy One thing that I've really liked that you mentioned is about deciding that this year's the year that we're going to do something different.

00;40;32;00 - 00;40;54;14

Melina Danko

And it made me think back that, you know, so many people are worried about, oh, we can't change our tradition or we're anxious about it. And I just can remember my husband is very like, this is how his family has done it for years. And the year that we sit I suggested that for Christmas Eve we have lasagna or pasta and things like that.

00;40;54;14 - 00;41;12;21

Melina Danko

He's like, Oh, no, no, no, we can't do that. And then the next year, his cousin's wife did it and they were everybody loved it and they were like, Oh my God, I'm so glad we don't have to eat turkey again. And I'm like, See, I told you, like, you were so rigid in the structure of the tradition that you didn't even think for a minute that people might actually enjoy it.

00;41;12;21 - 00;41;42;06

Melina DAnko

Instead, you were thinking about the judgment that people were going to have because you were doing something different. And that's not normal when really that judgment is so much in our head sometimes that we get anxious about it, that finding a new thing can be really exciting and fun and some people might actually enjoy to eat well, Azania instead of Turkey, you know, or might enjoy going to the beach for a trip instead of everybody getting together in the freezing cold.

00;41;42;06 - 00;41;45;00

Melina Danko

You know, that might be a fun thing to explore.

00;41;45;20 - 00;42;05;14

Amy Burt

Yeah, absolutely. As humans, change is scary at work, at school, in our in our personal lives, anytime you have change. But be the change maker and who wants to pitch a new idea? I think more people will be on board than really expect it. And if it changes, it decreases your stress level. Hey, that's a game changer for a parent or a caregiver or a grandparent, whoever is involved.

00;42;05;22 - 00;42;28;11

Melina Danko

Yeah. And get out of your own head like not everything is going to be perfect. It never is. And there's probably 15 other things that have gone on that day that have made the day not perfect, that have nothing to do with you and your family and your kiddo. Somebody probably overslept. The turkey wasn't defrosted. The smoke detector went off because you know this.

00;42;28;13 - 00;42;47;11

Heather Merritt

They forgot to put the buttons in and you know, they're not ready. So there's there's no such thing as perfect. And it doesn't all have to be that way. And it isn't so for me. As soon as I realized that, like, okay, you know, I'm just going to take it with a grain of salt and I'm going to laugh about it a little bit.

00;42;47;29 - 00;42;53;25

Heather Merritt

Then everybody can enjoy and my kids feel that to me.

00;42;53;26 - 00;43;12;25

Amy Burt

I think that goes a long way with the idea of not having that Martha Stewart Hallmark picturesque holiday season. And just something else for everybody to think about is take care of yourself. Right. We've talked a lot about the kids. We've talked a lot about their needs and and how to prepare other people. But you as the caregiver also need taken care of.

00;43;12;25 - 00;43;29;13

Amy Burt

So if you are feeling stress on this time that you're away from work, that's probably not the best thing. If you're feeling stressed when you're supposed to be with your family and enjoying these moments, something's going wrong, right? So just kind of reflect on it and think about it. Make a list, look at those pictures and think about what those little changes are.

00;43;29;13 - 00;43;39;09

Amy Burt

Right? Maybe it is the lasagna that makes the world a difference. And that's what's going to help you to enjoy those moments together because they're going to go away. So you do you do want to take care of yourself, too.

00;43;39;22 - 00;43;46;16

Melina Danko

I'm just saying. And nobody's going to be mad if you have ice cream cake instead of apple pie. You can have both.

00;43;46;16 - 00;44;10;15

Courtney Ringstaff

So we talked a lot about prevention and preparation. Let's focus for a few minutes and talk about how to handle the crisis or the meltdown when it occurs, how we can coach our kids through self-regulation and how we kind of can recover the situation so that everyone can still enjoy, you know, as much as possible if something does trigger our child.

00;44;11;29 - 00;44;39;26

Heather Merritt

Yeah, I think Peggy briefly mentioned this before, but having a calming space wherever you're going is ideal ahead of time. Talk with whoever you're going to visit and have a space to kind of exit that dining room or accident, that living room. If it's, you know, opening present time and things become a little overwhelming, having that calm, safe space to let that child move through whatever they're moving forward through and get regulated again.

00;44;39;26 - 00;44;58;10

Heather Merritt

But also having an exit plan, like preparing like if you know your child really not going to do well after 2 hours of a visit or dinner happens to be like right during nap time. Let that be known ahead of time. Hey, we're going to stay. But we can't stay for dessert. We're going to have to head home for nap or whatever it may be.

00;44;58;10 - 00;45;19;16

Heather Merritt

And establishing that ahead of time, I think would help decrease the chance of having that crisis moment. But knowing that you have that back, you know, backup plan or that plan already ready to go, you know, with your family and friends can help defuze a crisis that might start to escalate.

00;45;20;05 - 00;45;44;21

Amy Burt

Also talking with the kid and let them know like they're ready, know who their person is, who they can go to, but let them know that they're not going to upset you if something happens and they need to have that exit plan or they need to go to the to their room to calm down or something like that, that it's okay because there's a lot of pressure, all those extra people being in your house or you're going to some special place with all these new sites, smells, sounds, and you kind of feel like you have to be there.

00;45;44;21 - 00;45;54;23

Amy Burt

But just knowing that letting your kid I know that it's okay, that if it does change, we're there to support them.

00;45;54;23 - 00;46;25;12

Melina Danko

If any of you guys seen any fun ways or things to do about the holidays, I mean, I think we've talked a lot about like how to keep things from going bad, but have you guys seen any things that can kind of help make it be fun? I think like we talked about earlier, including the child with all of the preparation and the planning, like having special time set aside where it's a child led activity, whether it's, you know, the the cookies are already big.

00;46;25;12 - 00;46;44;26

Heather Merritt

So all they have to do is decorate them. So there's not this long waiting for the cookies in the oven. Right. Or, you know, the activities you need is together and the child gets to lead that activity with their cousins or with grandma and grandpa, you know, having them pick out the books, you know, if there's like a tradition of reading the night before Christmas.

00;46;44;26 - 00;47;03;11

Heather Merritt

Yeah. Then twas the night before Christmas. Maybe they don't like that story. And it's a tradition for the family. Well, maybe there's another holiday story that they like. Include that in that time. So really having the kids get involved can make the holidays fun and not as stressful because they get to do the activity they decorate the tree.

00;47;03;11 - 00;47;29;11

Heather Merritt

Things like that takes a lot of pressure off of us as parents. It makes it fun, you know, sit back, let the kids decorate it. It might be all ornaments on one side of the tree, but they got to participate and enjoy the moments. And there's a lot of fun in that. Yeah, I've seen the Velcro or trees or the Velcro menorah that you can have and and the kids can put them on and take them off as much as they want.

00;47;29;23 - 00;47;54;04

Melina Danko

I've seen different things where like fake snow that you can play with or you know, if it's Halloween, you know, slime and ooze and goo, you know, coming out and different things like that. So, you know, sometimes it's just thinking about like, oh, okay, here is this tradition. But what, what is a way that we can adjust it to make it, you know, a fun activity for everybody?

00;47;54;28 - 00;48;18;23

Heather Merritt

We've been talking about the fall and winter holidays, but egg hunts are really popular. Easter in springtime and don't have to be just free for that time of the year. Like, if your child loves to find the eggs, you could do orange eggs at Halloween or you could have Christmas eggs or a Christmas, I don't know, elves to find or whatever, something themed that goes with that holiday.

00;48;18;23 - 00;48;35;20

Heather Merritt

But you know, that activity and playing it over and over again. If they love it, why not? You don't always have to have candy or the little treats or prizes in the eggs, but just the act of doing it together, knowing that your child enjoys that activity for a long holiday, do it the whole holiday season, you know, like why not switch it up.

00;48;36;20 - 00;49;00;10

Peggy Hovatter

When it comes to focus interest too, for a person with autism who is really liking a particular thing. For example, Disney or there's Disney princess ornaments. No, just just trying to to take something that, you know, makes them happy and make it a part of the tradition, can help connect them to the family and to the activities that are going on, too.

00;49;00;10 - 00;49;09;23

Peggy Hovatter

Just take that take the focused interest and embedded somehow into the activity. And they will connect very nicely.

00;49;09;23 - 00;49;23;21

Courtney Ringstaff

What is your one piece of advice to a parent or caregiver that you would like them to know just to make their lives easier and help them to make their child's lives easier through this, you know, a long season of holidays.

00;49;24;16 - 00;49;51;23

Peggy Hovatter

My best advice would be get your laughing card ready, because humor will get you through the trickiest situations. What I've found in my years is that family members who can laugh at themselves or find the humor in a situation, in actuality, their children seem to thrive. I don't have any data or any research, but that's just kind of been my own personal observation.

00;49;51;23 - 00;49;57;06

Peggy Hovatter

So just be ready to laugh and be ready to relax and enjoy your child.

00;49;58;12 - 00;50;17;29

Amy Burt

I think it's to not have to fit into a bucket. We talked a lot about making your own traditions do what works best for you and I do have to nuggets. The other one is take care of yourself. Are there caregivers are there to provide for their kid and make them grow and make them be safe. But if we're not taking care of ourselves, then we're not helping them at our very best.

00;50;17;29 - 00;50;31;11

Amy Burt

So also make sure that you are paying attention to what your needs are. You're probably 1,000% invested in making sure that your child has the best time at the holidays. But how are you feeling? So make sure that it's nicely balanced with that. Maybe that's where the change needs to come.

00;50;32;03 - 00;51;01;21

Heather Merritt

And I would just add, having realistic expectations don't put too much on yourself. Like if it is a one ornament kind of tree, it's a one ornament kind of tree. If there's not a Christmas Eve dinner and it's getting the pizza to go, it's okay. It's all about just being together as a family during those fun holidays. Not expecting too much out of yourself or your child.

00;51;01;21 - 00;51;17;09

Melina Danko

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