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S8 E1: Summer of Fun

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Transcript

Lisa Dieker

Welcome to Practical Access. I'm Lisa Dieker.

Rebecca Hines

And I'm Rebecca Hines. And Lisa, are you ready to have fun this summer?

Lisa Dieker

I am ready for fun, except, darn kids. No, I'm just kidding. I'm just saying. So yeah, our theme is how to have fun. We thought we'd kick it off by sharing some things, maybe to put in place for fun, which sounds kind of weird, would you agree, Becky?

Rebecca Hines

Well, I think a lot of things you say sound weird, Lisa. So yes, I think our goal is to brainstorm some things that kids of all types and all abilities could enjoy over the summer and maybe some ideas for thinking about how to support them.

Lisa Dieker

Yeah, you know, and I often think about fun. We happen to live in Orlando, so we'll, we won't do a commercial here, but I think you can imagine there's fun to be had coast to coast, from top to bottom, and yeah, one of the things that I think I learned early on is my own son, as you know, has Tourette's, really likes fun, but likes structure with fun. So those sound counterintuitive, but I learned, really early on, like if we were gonna go to Disney, not to tell him too soon. Because then it was, well, what day are we going? What day are we going. I want to go to Universal. What? There we go. I can't. Can I ride this ride? But I would often say, you know, about a week in advance. But I would also give parameters like we're gonna go really, really early because it's gonna be hot that day. We're gonna... So I think when you start thinking about structure and fun, they really do go together. For all kids, but I think for kids with disabilities, especially thinking, you know, do I want to be there during the middle of day when it's 93 degrees and a 90% chance of a rainstorm? Or would I go early? Maybe we leave for a little bit, go somewhere else and come back from where we're going and we're going to the beach. You know, maybe your kid doesn't really like the texture of sand and you're gonna take sandals. You know, again, predicting those things that are hard for kids with disabilities, I think, is both structure and managing those expectations early. So those are just one of my quick thoughts. That fun is fun if we all have fun. Fun, not just for the kids.

Rebecca Hines

Yeah. And you know Lisa, using some of those supports that a lot of parents use all the time. Kids, kids with autism spectrum disorders or other disabilities that really look for that kind of order. Maybe your son wasn't someone who you use things like social stories regularly with, but it sounds like that's the type of thing you're recommending for summer. And I know in my case my nephew, he really does well if there's a calendar cuz he's so excited to come and see me. So they have a calendar of, on the wall, and every day they put a big X so he knows exactly when he's coming. Otherwise, he's gonna do exactly what

you said. You know, every day. Am I going to Aunt Becky's? Am I going Aunt Becky's? And I think that if we can structure in really intuitive ways, I think that's a great start. Another thing, Lisa that I'm gonna also just speak from experience. You know, my nephew is significantly physically disabled, and finding opportunities for him can be challenging for a lot of reasons, but I'm learning that there are supports in different areas that I didn't even know about. So, in Daytona, for example. They have beach wheelchairs, which are really expensive to purchase, but they have them at their lifeguard station, and you can schedule in advance to use one of the wheelchairs. But it's first come, first served. Now listeners aren't in Daytona, but it's the idea of reaching out to the places surrounding you because there may be unexpected supports available.

Lisa Dieker

Yeah, it's funny that you say that. So I took my mother-in-law, who was older and didn't have a disability, and I called SeaWorld, and I said, hey, what are you doing? They're like, oh, we have a green parking zone. And I'm like what? No, like, well, it's not a handicap, but if you park there, there's wheelchairs available and it's near the front of the park. And I was like, what a great thing. And if I hadn't have called, I wouldn't have known. So again, I think, you know, not just disability, but in general we do a lot of prepping to go somewhere whether it be the beach, or a park, or what have you, but calling ahead or checking the websites for those accessibility pieces can be really powerful. I have another one I think about and it sounds so the opposite of fun again. So I don't mean to be this negative person, but is this word meltdown. I don't know, Becky, you're the behavior guru, I'll talk a little bit about what I did. But I'm curious if you have any advice for those parents who happen to have a child, with or without a disability, who you're on vacation or you're out for the day of fun and it just goes wrong.

Rebecca Hines

Well, you're really putting me on the spot, Lisa. I will say I'm gonna say that first and foremost, you have your mantra and it's not a, it's not that this is a problem, or you're bad, or you're having a meltdown, but it's the one thing you always say to cue your child to stop. And you know, so something that I used to say is, let's sit down, and say it very firmly while taking my child and placing him or her on my lap. But at least this is, you know, socially appropriate behavior. And what I know, and you know, is that the general public doesn't always understand. For some of the parents who have kids with behaviors that are very challenging, it's misinterpreted when you try to work with your child in public. People judge, they think you're being mean, et cetera. So first and foremost, I would, I would come up with something that is your common phrase, so this child learns to understand exactly what you mean, and it gives you a way to address something in public. That's my first, simplest thought.

Lisa Dieker

So when I was at an unnamed park and my son was in the clothing rack, and I'm pulling him by his feet, people might have been judging me, and I get that. And yet, you know, your child is sometimes stronger than you, both in will and in physical. And I learned very quickly to never take on the physical. I think for us, what tended to work with distractions.

Rebecca Hines

Well, I was just about to say that as well. Distraction is definitely, going in advance and planning for that distraction is critical in in our case. You know? Yeah, we do a quick Zoom call, let's you know, let's not zoom, FaceTime, you know, let's FaceTime Aunt Cheryl, you know, it's an immediate distraction. So having that in your hip pocket literally. I also agree.

Lisa Dieker

Yeah. And I wouldn't. And for us, it was often a distraction that was counterintuitive to whatever tick or whatever issue, you know. So if you're really wanting to look at the clothing, I'm like, yeah, well, we're done with that. However, you know, it's really exciting, look, over there, there's, there's blank, and so often that change of venue would be like, and I wouldn't say we're done with that, but in my head, I was like, I am done with the clothing rack, and you playing inside and swirling around, but trying to figure out what the next stage was to get there. But I also think what's really important is planning for meltdowns. And I found that if we took a little break, and we took food, and what I learned to do anywhere we went again, water was, you know, and I bet you heard this from your own twins. I'm dying of thirst. It's like alright. It's not that bad but it becomes that bad very quickly. And I think that becomes a mantra in a child's mind. But I also learned to pack things for myself because I found if my blood sugar went down, and my caffeine intake was down, or whatever it might be, I became the problem more than he became the problem. So again, think about not only what does your child need, but what's your go to. You know, I'm a big licorice fan. Because sometimes when I'm like done with, you know, a little chewing on licorice can make a difference, but whatever it is for you, I think we have to take care of ourselves and the child.

Rebecca Hines

Well, and that kind of brings me to my closing thoughts on this, Lisa, think even more broadly about taking care of yourself. So, for parents, caregivers, we have to remember to plan for respite in any way we can. I know for myself because I, you know, have grown-ish children now, I schedule them to stay with their cousin, to do things with their cousin, for certain hours of the day, when I have my nephew with me. Because it is physically demanding, he has a lot of physical needs that are very demanding, and if I don't schedule in time for me to rest, and literally physically rest and also get my energy back, then he's gonna have a kind of a much crankier Aunt Becky to deal with. But I do take advantage of the free respite around me, but I schedule it so that I also just like we said about the kids, so I know even if I've had a tough morning, you know, changing clothes multiple times, doing different toileting things, trying to shower up 18 year old, I know that at noon somebody is going to come and help me, or at least give me a little break. So we have to think about ourselves in scheduling rest. But some people have reached out and they have services in their state to plan for formal respite and that's great. Be sure and find out what you're eligible for.

Lisa Dieker

So yeah, my last one is, you know, set some expectations for your child to be a grown up. And I don't mean, you know, they're two and they've got to be 22. But honestly, anytime we went anywhere, our constant mantra was, you know, what? You're to watch us. We're always going to want to watch you, but your job is to watch us when we're having fun. Because otherwise none of us have fun. If constantly I'm looking around. And so I love it. We took our friend to the theme park, who also had a child with exceptionalities and kept kind of the kid kept running off. And my son says my mom's not kidding you, she will leave you. And I was like, well, I hope I didn't stress him out. But at the same time, I love the fact

he's like, it is your job to watch the adults because you're in a different place. And again, that's not just a bad practice for having fun. That's just a good practice in general to say, look, this is a reciprocal fun relationship. And so, what's our expectation? The other expectation we always set is that we would get out of whatever we were doing, the heat, the sun, whatever, for about an hour, and just have fun sitting and doing nothing. And I think managing that and saying, ohh but we're here for 12 hours so we have to have 12 hours, and I'm the person who's always going. But knowing there's some shady spot, some regular place you go to, create that routine of just sit and talk and listening. That was probably one of the best things we did in my whole life. And so sometimes fun doesn't have to cost money. Sometimes it can just be spending that quality time and doing it in a way that feels good for both of you. So this summer, have some fun. But I loved your tip, Becky: take care of yourself in the process. Well, we thank you for joining us. You can send us a tweet at @accesspractical or post us your ideas for fun or questions you'd like to ask on our Facebook page. Thanks.