

# ep19 post

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## SPEAKERS

Michelle Rogers

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Welcome to the autism mommy's potty talk Podcast. I'm Shelby Rogers, autism mom and life coach. I help parents of children with autism who are pre verbal to start communicating potty train guarantee. You are listening to the autism moms potty talk Podcast, episode 19 Hello autism families. I am excited to come to you today because we're going to talk about something completely different. We're not going to talk about the tactical steps for potty training, communication or problem behaviors. I've already done a bunch of podcasts on that already. Today, I want to talk about the theme for this month coming up. And my daughter Juliana is going to be 11. And it's a monumental month for us because so excited to celebrate another year of milestones for her every year. I can't think of it getting better. And every year, she surpasses that expectation. And I remember, she's nine years ago, when she was diagnosed on the spectrum a little over the age of two, thinking her whole future went black. And I didn't know what was going to be possible for her, or what her what you know, I just didn't know you know, I how I knew about autism at that time was a movie in the 80s with Tom Cruise and Dustin Hoffman co Rayman. And it was about a brothers reconnecting and one of the brothers had autism, and he was living in a group home. And I felt that that was her future. And that's what was in store for us. And I think a lot of us still kind of we get the autism diagnosis, have these visions of what we thought we were gonna have, and then it's lost. And I do talk a lot on grieving the neurotypical experience. But I think all of us have when our children are diagnosed, and it's a real thing, and I went through it and all the families I've worked with, have definitely gone through it. But what I really want to hit home today is the message I want to bring this November. So every year, in November for Julian's birthday, since I started champions for our children. We run a amazing live events. And it's an online live event. It's free everybody who's listening to the podcast, as long as you're on my email list, you'll get an invitation to join us for this live event. And every year I do it, I want to celebrate Juliana in a very big way. And the last couple of years when I've done it. I've always talked about our story and kind of really gone through like from the witness she was born she was developing your typically how she said maps she loved Dora the Explorer said map at nine months. When she lost it. I started noticing changes in her around 13 months, it seemed like she went from a happy baby to a not so happy baby crying all the time. tantruming she had like OCD ish behaviors, drooling, excessively hand flapping twisting toys in her hands. And every year, I usually talk on our experience no like, this is what happened to us. This is what we went

through. And here are all the steps I took her to having language completely losing it, teaching her sign language getting her to make sounds, again, word approximations potty training with a sign to speaking. And Juliana went from the most restrictive Special Education pre as special education classroom. A 614 was an autism classroom to where she is today. She's thriving, this is her second year, and a gen ed class with minimal supports. And I just didn't know if that would ever be possible for us when that diagnosis came. And every year I do this presentation and I talk about our story and it's really a celebration of her life and I absolutely love it. This year, I'm gonna do it again. But we're gonna do a little different. And that's what this podcast is gonna be about today. I want to start breaking the mold of what people think an autism diagnosis is. And I've really been thinking hard on this because if you go on social media, there's tons of Instagram accounts, YouTube channels, a family's car analyzing or journaling, video journaling, their experience raising children with autism. And most of them talk about the struggles they're very honest in what they go through. They should show a lot of the real things they show wins. But a lot of them talk about this alternate life that they never thought that they were going to be experiencing. And I don't have any issue with that, uh, you know, I love it. I love the rawness of them of the trueness of it but there's something about it that's always sat very uncomfortable for me. And this is probably going to be a very unpopular opinion. And I may lose some of you but I'm okay with that because I really had to come full circle Thinking about how we were going to celebrate this year, Juliana being 11, how I believe every child on the spectrum deserves to have a chance to the life that Julianne has lived and will continue to live, because she will live an independent life. And I think I've seen this trend in social media where most of the stories are about living this neuro diverse lifestyle. And just recently, I saw a video of a father, who was talking about how the normal experience of raising a child is basically, you know, you're gonna raise them until 18. And then when they turn 18, they're going to kind of go off on their own, and then maybe they're going to help you out in your later years. And that that's not the experience of an autism parent, that an autism parent will actually have a much different experience, they will raise this child to their dead, pretty much, I don't know how to say it. Other than that, basically, he was explaining that his child will need forever care, the child will never be able to take care of him when he's older, he will always worry about what's going to happen to the child until his dying day. And he's going to work the rest of his life to enjoy the journey. And not so much focus on the destination that he didn't intend before autism came. And the one that he's pretty much resigned to now. Here's the thing. I'm not saying that those existence don't happen. I'm not saying that those outcomes don't happen. What I want to do this year, when I do my training in November, is I want to break the mold, I want to think about autism in a very different way. And how I want to do that is I want to stop thinking about a life of limits, and start living this journey of a life of possibilities. And I think messages like that seem like they're real, raw, inspiring. I think they're dead ends. And I say this with love. Because here's the thing, you have a choice as a parent, when you have a child, right, we all had expectations of how we were going to show up as parents, all of us intended to I'm assuming go balls to the wall with the job, right? We're gonna go and we're gonna do whatever it takes to make this baby, the best version of themselves. I always describe my babies as my masterpiece, my masterpiece, my creation and progress. And however I leave this earth, that's my calling card. That's my gift to the world when I'm gone. And something happens when an autism diagnosis comes in society today, where we kind of shelve that expectation. And we just embrace the child and their autism. And it feels to me that progress is never discussed, it feels to me that these parents shut out the idea of continuing to show up, whether they believe it or not. And I honestly haven't thought about that too, because I don't think you can show up. You can't fake it till you make it with this. Not showing up in a way that's continuing to move their child forward. So I can I, you know, I don't even remember the name of the reel I saw that kind of really inspired this blog today. But it's not even about that blog, this podcast, but saving about that real it's this general conception, about 95% of

social media, social media channels, talking about autism journeys, is about just embracing the neurodiversity. And I love that I don't have an issue with that. But listen, the world needs different people. The world needs all kinds of mines. And that was from Temple Grandin. His TED talk, you don't know Temple Grandin is She's a scientist. She's a professor. And she is a adult with heights who had severe autism symptoms, and now lives an independent life. She speaks all over the world for autism rights advocacy. And she talks about how the world needs all types of minds. I couldn't agree with that more. Where it gets a little hairy for me, is kind of embracing this destination before it's been fulfilled. How do you know that your child is going to be forever care? How do you know that they're



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never going to be able to be independent. And here's the thing, if I start showing up in an energy, that that's the expectations of their life, then the actions I'm taking during this journey are going to reflect that. So instead of maybe doubling down on getting communication out of my child, I might become complacent with an AAC device. Instead of really pushing for this child to pee on the potty. I look at their agency, you know what I just don't think it's ever gonna happen. And here's the thing. I understand the mission of these social media accounts is to help families cope with their situation. And I'm okay with that. Where I have a problem with this is when we're not forward thinking still for our children. When before the autism diagnosis came, we said we were going to be a certain type of parent, we were going to show up in a certain kind of way. And that all goes out the window, because autism is here. So why is that acceptable? Why is it acceptable to be a different type of parent? Because autism is here? Why is it acceptable to not still shoot for the fences for your baby with autism, I don't care where they are on the spectrum. And here's the thing, I have a child that is moderate to severe on the spectrum, just like my daughter was, by the way, my other students spec spectrum, I spent the first couple of years of her diagnosis, thinking I could cure her of it. Now, I know that Juliana now will live with autism for the rest of her life. At that time, that thought, even though it was incorrect, and I acknowledged is incorrect, now, it fueled my fire, to try so many things, to withstand doors getting slammed in my face, to do everything I could to help them survive. And that's what I want you guys to walk away with today. What do you want your life to mean? Here? What do you want the journey with your child to be? Do you want it to be a bunch of reels on Instagram talking about all the struggles? And what it's like? And hey, be my friend? Because I haven't, you should be grateful for what you have because of what I have. And or do I want to look at my life and say, Listen, if life is about the journey, just as much as it's about the destination? Do I want my reel of life? Because I'm a God fearing woman? Right? I don't know why I think this, I thought this a lot. When Juliana was little that, you know, for a while there when she got diagnosed, I was in denial. And then I was depressed. And I was angry. And I felt like God had wrecked this beautiful child with this diagnosis. And then I had this epiphany one night when I put the kids to bed. So I'm gonna die one day, who's gonna care for her, like her mom. And something about that. Something about that thought snapped me out of my depression, set me into action. So what if every one is wrong? What if I can cure her of autism? And here's the thing, you know, I know that that was wrong now. But the fuel, the energy that went behind the actions I took, were unmatched. By anything I could have thought if I was just complacent and accepting that this was going to be our future. And she was going to have a limited life. And that's what I want everybody to take home today. So here's the thing, right? Do you have the option of embracing autism wearing my puzzle piece wearing shirt, having my little puzzle magnet in the back of my minivan, right? Being a proud member of the community. Or I can do all those things, and still strive for what I wanted before the diagnosis scheme for my kid. Now, I'm not going to tell you that that journey isn't going to be different. It is going to

be different. I'm not going to tell you that journey ain't gonna be hard. It is going to be hard. I'm not going to tell you that if you do this, at the end of the rainbow, you're going to have a child that lives an independent life because I can't say that. But what do you want your calling card while you're on this earth to represent as you as their parent I would rather fight to give her everything every opportunity she could have to live an independent life then just just white flag it is which I call it this kind of what I call this when a parent just kind of gives up and just as well this is what we got. Let's just make the best of what we got. Is that how I want to live my life? Is that the calling card I want to leave. So I said when that night when I had that epiphany I'm gonna die one day, who's gonna care for when I was gone? What I really imagined in my head was me standing in front of the gates of heaven because I'm a God fearing woman and God's playing back the real the life that I've lived before he lets me in and we're gonna now you're gonna analyze it I don't know where I got this whole scene. He's gonna put put the tape in. He's gonna hit play and then the diagnosis is going to come and where am I am I puzzle piece wearing shirt? What right you know doing the autism walks I don't even have a problem with any of this. As long as I'm forward thinking at the same time am I just like happy to slap on the diaper and just say this is it and I my kids just never going to potty train. Am I just happy to just continue to be hand led to the pantry because my kids never going to talk? Am I willing to fight with the parents on the chunky cheese ride line because my kid just drops the floor and cries and they don't understand about waiting their turn. And I'm trying to fight with the neurotypical parent explaining how they need to give my kid a pass. Or do I want that reel of life? Even if it was a life full of things tried that didn't work, showing me swinging for the fences every fucking step of the way. Even if it meant that what I tried, didn't work. Even if it meant most of the things I tried, didn't work, which real do I want to play back and be proud to watch with my maker. And that's what I want to leave you guys here with today. And that's what November is gonna be all about not just celebrating that she's 11. She's having this amazing party. I'm going to share all the details on our social media, we're going to an indoor waterpark, we brought two of her closest friends, were renting a hotel room, in a separate hotel room for the kids connected to ours. And they're going to play, you're gonna have a whole day's waterpark. They're going to celebrate her birthday in such a big way. And experience I never thought we'd even have with your typical friends. And had I ever had any other thought than being a mother that just fought for what I did for her. I don't know if that birthday party would even be real, if it ever would have happened. And I'm okay and I want like guys to understand something like, here's the thing, you've got to be okay with shooting for the fences and missing 95% of the time. Because if I miss 95% of the time with Juliana, and 5% of what I did do worked, it was worth it all of the pain. It was worth it. And you get a choice and how do you live your life as a parent to this child? Do you want to just embrace all of the things that are the struggles of it? Or do you want to strive for a better life for your child and be okay with uncomfortable? Be okay with disappointment? Guess what? Disappointment never killed anybody. It's not about that. It's almost like the anticipation of disappointments more dangerous than the actual disappointment. I'm afraid to put myself out there Michelle, I'm afraid to believe that my child with severe autism Michelle could live an independent life because what if it doesn't happen? I'm gonna be so upset. I won't be able to survive that I'd rather survive that and survive a life meet with my head and the couch cushion and never knowing anything else. So I'm on a walk today and I'm sure you could this audio sounds hopefully it's good enough. And my kids just follow me. I hope this is helpful. Let's celebrate November and a big fucking way Mom Did you know your back and keep checking back? Join me for this special event. I'm gonna really blow the lid off of what everybody thinks about this. I'm gonna everyone's gonna hate me. I don't even care. I'd rather you hate me and fight the become complacent and die live in a life wishing that you had shown up different for your kids. talkies? Hey, autism parents. November

is a special month around here because my daughter Juliana, the girl who inspires me inspires all of us is turning 11 And I want to celebrate this milestone with you in a big way. So keep your ears open for more information coming soon. On a special live training you won't want to miss