Ep56 - Profound Autism

Thu, Oct 09, 2025 11:38PM 16:41

SUMMARY KEYWORDS

Autism, communication, potty training, independent living, social media, profound autism, emotional expression, AAC device, parental responsibility, teaching methods, child development, emotional intelligence, parental support, educational tools, child potential.

SPEAKERS

Michelle Rogers

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You. Welcome to the autism mommy's potty talk Podcast. I'm Michelle B Rogers autism mom and wife coach. I help parents of children with autism who are pre verbal to start communicating a potty train. Guarantee you're listening to the autism moms potty talk podcast episode 56 Hey, parents, I want to talk to you today about something that's probably going to make lots of people uncomfortable, potentially make me up more unpopular than I already am. But I need to say it, because I'm seeing this more and more, and it's not just bothering me. It's making me feel like as a society of autism parents, we are headed in the wrong direction. And I personally feel my gut is telling me that there is some sort of social media revolution about to happen where we may either there's going to be a big split and there's going to be people who like social media the way it is now, and then there's going to be people who want it to change for the better, and that's what I'm hoping for. And maybe that splits already happened, or maybe it's about to happen. I don't know. I just feel like there's just a tide is about to turn with us, because I see stuff like this constantly, and it's just so frustrating.

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And I just feel like I need somebody needs to stand up for the other side. And that's kind of how I want this podcast to feel. For parents, parents who are listening to the me aren't parents who aren't going to want to help their babies, parents who are listening to this podcast, or parents who really want their children to live independent lives. They're not resigned to the fact that they believe that Autism means that their child will never be independent. They want to fight for their survival. They want to fight for their their chance to live an independent life. So I'm going to assume that most who are going to listen to this are going to understand where I'm coming from, or at least have a new perspective to ponder on. So a couple days ago, I'm on these I'm into this new thing now it's called Step bet, and I'm trying to walk more and show I've got a situation here where I'm walking more. And it's basically you bet money for this six week challenge. It estimates you're walking based on your like Apple Watch health, and it tells you, it tells you, okay, this is how much you have to walk for the next four weeks. And if you do it, you not only will you not only will you get your $40 back that you threw in the pot, but anyone who quit the challenge, you get to split that pot with everybody. So I'm a degenerate gambler, so I'm like, All right, I'm going to do that. So I've been consuming a lot more social media than I normally do, and I've been seeing a lot of reels pop up. And of course, because I'm an autism coach, I see a lot of parents of children with autism who post reels. And I saw this reel, and it was a boy with autism, and he was maybe around 11 or 12, and he was crying tears down, rolling down his face in the reel, and he was using his AA VI, AAC device to say over and over again, I'm sad. And he kept hitting the button. I'm sad. I'm sad. I'm sitting. It was very touching, like it was very sad to see that. But here's what got me wasn't that he was tapping the AEC device and saying that he was sad. That really kind of hit me in a not so great way. The caption from the mom said something like this, this is profound autism. He's sad, but we'll never know why, and that's what hurts the most. And I checked 1000s of hearts, likes, views, comments, encouragements, love and compassion. And let me be clear here, I do have compassion for a crying child. I love children. Somebody had given me a quote that from the Bible that I thought was so beautiful I'm gonna, I think I'm gonna get it and print it on my frame it and put it on my wall in my office. And it was like when Jesus said, Let the little children come to Me, that's how much I love children. When she said that to me, almost cried, because I feel like the work I do. I just love children I have believed so much in their potential, so I have full compassion for a crying child. No one wants to see a child in plane, especially me, and no one wants a child to be sad or hurting or overwhelmed. But that post really bothered me, and it's not because I don't care, it's not because I lack empathy. It's because, for me, the message behind it is this idea that his sadness was somehow mysterious, that there's nothing we can do, and that this is just what profound autism is. And I'll tell you, this is a brand new fucking way to describe autism. It makes me so crazy. We were we were mild, moderate to severe, back to when my daughter was diagnosed. Then we transitioned to level autism, level one, two and three. And I just I hate the way we find creative ways to describe autism, which the latest and greatest way is calling it profound autism, like we're getting more and more creative with the labels. And, you know, I think it's so makes me so frustrated with this. If we put half the energy into solving the problems of helping this child be able to tell us why he's sad, then we do romanticizing new adjectives to describe autism in a way. Way that leaves us helpless. A lot of us would be further along. So it's just that that's a whole other conversation in itself, all of the all of the creative, romanticized labels to describe debilitating autism that make us feel like shit and make us feel like we can't do anything for our kids. But the more intense the label, the more we subconsciously accept the progress is out of our reach, and I hate that, and we're putting more energy into labeling our children's limits than we are into unlocking their capability. Now let me go back to that video, because here's what I saw. I saw a child who is pre verbal using a tablet not to say wants and needs cookies, tickle, go outside, but to say I'm sad, that's next level communication. That's not a deficit, that's not hopelessness, that's a fucking start, my friends, a second level start. That means that child can already use that device to express wants and needs, and now he's expressing feelings on it. If a child can identify they're having a feeling that is flipping huge. Yes, of course. We don't want to hear him crying. We want to solve that. We want to wipe his tears and kiss his head. Of course, we want all of that. But I don't feel bad for him. I'm excited for him, because if you could say he said, I can figure out how I can teach him to tell me why he said, and that, you know, to be able to be able to for a child on the spectrum, to have that self awareness, that emotional communication, that's connection. It's huge. It's on, you're on the way to developing conversation skills with your child, and you're telling me that because he can't say why he said, we're just going to assume we'll never figure it out. And that's profound, that it's it's out of our control, because it's profound autism. This is where I get all stirred, and that's the part that gets me, because when you tell the world this is profound autism, he said, we'll never know why you've already given up. You've already closed the door to continuing to to Teach Your Child continue that communication pathway. You've made a decision in that moment by describing your child this way, that you've decided that this is the best it's going to get, that this is our story, and it's already written cover to cover, but it's not it might not be today, it might not be next month, but if your child can say I'm sad, then we can build from there. We can teach him to identify the why. We can teach them to ask for help. We can teach them to point, to choose, to show us we can problem solve. But that takes belief past my child has profound autism, and we'll never know why he'll say he's sad, and that belief is what's missing from parents who post things like this. And I'm not angry at the child. I'm not even angry at the mom. I always tell my parents who talk to me for the first time, sometimes I like blow shocking. I blow a lot of shutters off of their homes when I speak to them, and they say, awareness is a gift, because if I didn't know I was showing up in this way, I can't change it. I know that pain. I've lived that pain, and I know what it's like to live on the other side of that, going from disbelief to full belief. But I never, ever, I'll tell you in all of this experience with Julianne, I mean, I was scared, I was worried that we weren't, you know, I didn't know what was going to happen to her, but I never believed that it was completely unchangeable. And there was, I mean, all I knew about autism at when Julianna was diagnosed as rain man. I know I've said that so many times, but it is such a profound There you go. That profound word, a profound definition of what I thought autism could mean. But I was never resigned to really believing that's the best I could do for her. I never believed that that that that identity was permanent. I always was looking for somebody who had a result that I wanted to create for her, and when I couldn't find it, because back then, it just wasn't either I couldn't find it or nobody was kind of saying, Hey, I'm here, or whatever. At that time, I really couldn't find what it was I was looking for. But I believed, because I know the world that there are a lot of exceptions to the rules, and there are a lot of people that have to go first to create that identity that maybe I was looking for. It's very possible that I, of course, have a beautiful baby, and I have made amazing results in my life that people said you could never do that, of course, by extension, because she is my cub, that we would be able to do the same. As crazy as that may sound, I guess I'm a nut, but this is what I truly believe about myself and my capability, and this is what I believe about my daughter. And I remember a point where she was at, where this boy was at, she was vocal, she was verbal. That's the only difference between the two of them, is that he's not for and I'm curious about that, because he's very intelligent with that device. Why he's not verbal. But I digress. It's a whole other podcast, but here we here's Hear me out here, when my daughter was little, and this is still to this day, our work in progress, she all of a sudden, would get up and throw up. Now she had a feeling in her stomach that she wasn't feeling. Well, but she never said it. She was actually, if you think about it, he's least able to say sad. There was a time where she would just throw up, and I was playing, you know, catch up to figure out what happened. Why wasn't she able to communicate that before she threw up and she could, she couldn't tell me she was sad. Either she couldn't say that her head hurt. She couldn't even say, I'm scared or my stomach doesn't feel right. But I never sat back down and said, Okay, well, that's autism, you know, we'll never know. I decided we're going to figure this out. I did realize that there's not a lot of help for the next level communication skills out there, and I had to kind of create my own protocol. So when she would get sick like that, obviously we already cleaning up the mess of the throw up. That's fine. So then what I did was I came up with a one to 10. I said, Okay, on a scale from one to 10, how much do you feel like you're gonna throw up again? A three, a, five, a, seven. And then eventually she'd start to connect, because we would do these exercises, not just when she'd throw up when she was sick, but when she had a headache, when she when she was feeling other things, when she was emotional, when she was sad. It helped to create these systems to put in place so that she could eventually not be dependent on me giving her prompt questions, but start to like. What we do is we make it very we prompt support them all through the process of teaching sad. All right, what are all the possible reasons my son could be sad if I'm looking at that podcast that reel and I see this son, and he's crying, I'm sad, I'm sad, I'm sad. She's like, Oh, poor baby, poor baby. Listen, I get it.

Yes, poor baby. But are you sad because your show is over? Are you sad because dad left? Are you sad because our cat went across the Rainbow Bridge? I would start prompting why you are sad? Would you want to just sit in the mystery? It is frustrating. Yes, what she's describing is very frustrating. But why stay there if you don't have to? This is a prime example of a teachable moment for a child who has next level skill of being able to express a feeling with his tablet. And I love that, and I want to be able to build on that. But if I describe this situation as profound autism, the latest and greatest adjective to describe, you know, I guess severe autism, that I'm helpless, I'm feeling like this is just, there's nothing I can do but just wipe his tears and feel bad for him. And I'm tired of this culture where helpness helplessness is rewarded, Michelle Rogers 12:25

where posts that say we're lost get more love than posts that say we're learning where the white flag is waved before the fight has even started. And you want to talk about profound you know what's profound to me, the fact that a child who can't speak with his mouth is using a screen to tell his parents how he feels, that's not profound autism to me. That's not failure. That's a foundation to build from, and it's our jobs as parents to build on that, not bury it under the label of profound autism. And listen, I know every journey is not going to be the same. I know some kids will struggle more than others. Listen, I've worked with 1000s of families at this point, hundreds of families in the master class. These kids are all over the spectrum, and it's exactly true. When you meet one child with autism, you meet one child with autism. But as as much as they can be different, sometimes they can be the same too. It's so confusing, but so amazing at the same time, because you know what's uniform about all of them? They all have potential to learn, and I will never expect, except the idea that a label, any label, defines what's possible, not for my kids, not for your kids, not for that kid in that real and not for any child. When we say profound autism with a tone of defeat, we're telling the world that there's nothing we can do, that the story has been written and we're just along for the ride. But I don't buy that. That's not how I roll. You've been here for a while now. If you've been listening my podcast, this is not how I roll, you know that, and it's not how I teach. And I know this is gonna ruffle some feathers, and that's okay. I think I'm getting to an age where I just don't give a shit anymore. I'm like, You know what? I'm just gonna do me, because I know that as authentically as I show up, the better I'm gonna reach you. And I'm not here to make people feel good. I'm here to remind you that your child is not their diagnosis. Your child is not a moment on a bad day, your child is not broken, and neither are you. You are not hopeless, you are not powerless, and you are never done. As a parent, when you sign up, when you sign the parent contract, you acknowledge that I am this baby's number one educator to the day I die. You're not done, and neither is your child. So if you're listening to this and you've been feeling like that, that white flag is getting closer to your hand, do not pick it up. Pick up belief. Instead. Pick up curiosity. Pick up consistency. The number one thing that's keeping you stuck from getting any goal you want for your child, pick up your tool. Tools, pick up your kid, listen to more of these podcasts, because sadness does not mean stuck. And struggle does not mean surrender. You can cry. I've had plenty of ugly cries on things that I've tried with Juliana that didn't work, or that many times that she threw up and we had no idea that how frustrating I felt when I didn't know she was sick. I could have helped her. I could have I could have seen it coming. I could have not had her in a room by herself when I knew she wasn't feeling well. And you can cry, you can have all of the feels, but you are never, ever allowed to quit. This is not where your story ends. This is where it begins. So I hope this was helpful, little passionate, little fiery. I do have compassion for that child. I fucking hate compassion for the words of profound autism, and there's nothing we'll ever be able to do about it. I will never believe that. So I hope this is helpful. I hope this hit home. Let me know what you think. I always like to hear from you guys, and I'll see you next week. Bye, everyone. If you're ready to help your baby now with potty training communication or stopping their problem behaviors, I want to invite you to watch my free 10 minute video training that shows you how I took my daughter with autism from pre verbal to sign language, potty training with a sign to making sounds and then speaking head over to Michelle B rogers.com, forward slash training, that's Michelle M, I, C, H, E, L, L, E, B, as in boy Rogers, R, O, G, E, R, s.com, forward slash training. See you. There. You.