

## Ep #110: What No One Tells You (Part 2)



### Full Episode Transcript

With Your Host

Lisa Candra

## Ep #110: What No One Tells You (Part 2)

You are listening to episode 110 of *The Autism Mom Coach*, What No One Tells You (Part 2).

Welcome to *The Autism Mom Coach* podcast. I am your host, Lisa Candra. I am a lawyer, a life coach, and most importantly, I am the full-time single mother of a teenager with Autism. In this podcast, I am going to share with you the tools and strategies you need so you can fight like hell for your child without burning out. Let's get to it.

Hi everyone and welcome to the podcast. I am so glad you are here. I am recording this podcast on April 4<sup>th</sup> and it is snowing in Connecticut. Not what I expected at all and I am hoping this clears up quickly and we can get onto some sunshine.

Anyhow, in this week's episode I am doing a part two of what no one tells you. Because I got so many responses on Facebook and Instagram and in my emails from moms sharing some of their experiences. And I wanted to give voice to all of these experiences. So while I'm not going to say people's names, I am going to read you what they shared with me.

But before I get to that, I want to talk to you about some really good news I've had with some of my clients who are graduating from my three month program. And all of the amazing changes that they've been able to make and implement in their lives in a short period of time. Going from feeling completely out of control, second guessing themselves to feeling calm, confident, and capable.

Moms who now understand how to take care of themselves in ways that make sense, in very practical ways that fit into their lifestyle of working full-time, having multiple children. Having lots of responsibilities and still being able to make time to ensure that they are regulated. Because we all know when we are dysregulated, we're not helping the situation with our child. And it makes it really hard to sustain that level of energy day after day if we're always dysregulated. We tire out, we burn out, we feel helpless and diminished, all of that.

## Ep #110: What No One Tells You (Part 2)

And I'm just so proud of these moms for all the work that they have done and the changes that they've made in their lives and how that's enabled them to show up as such amazing moms to their children. They were already amazing and now they have just up-leveled because they're starting to understand the distinction between what they can and can't control. And that's helping them empower their children, whether it's putting on and taking off shoes or self-regulating after a long day at school.

All things that they didn't think were possible before, all things that they thought they needed to be on top of to make sure it happened, now they are letting it be imperfect. They're letting their children be uncomfortable. They're letting themselves be uncomfortable without making it mean that they've failed, they've not done enough, or they've done something wrong. This is all the normal process of parenting but with Autism moms, it's complicated.

We are used to being the person for our children. And while this can benefit them in many ways, there are points where it doesn't and especially when mom is taking on so much responsibility for other people's emotions, that she is unable to manage her own. That's where it's a lose/lose for everyone. So this is all to say, if you are struggling with feeling calm and confident in your parenting experience, if you are feeling burnt out, if you want a way of doing this better, I am here to help you with my Resilient Autism Mom Program.

It's my one-on-one coaching program where I will work with you to customize what I teach to your real life experiences. So you will know exactly what to do and how to get the results that you want. Alright, with that, I am so excited to share the responses that I have received this week to what no one tells you about Autism. Are you ready?

First, how all of the studies were done on males, so females don't get diagnosed until adulthood. This mom's daughter with Autism did not get diagnosed till the age of 13 and that was considered early. Now, I actually know who this respondent was. She was one of my clients. And I have a couple of clients, who, this was the exact same situation. These parents

## Ep #110: What No One Tells You (Part 2)

had suspected Autism. They had raised it with the pediatricians and with the specialists, and they were all waved off.

But then when middle school came around and the dynamic really does shift with children and there's just so much going on in the teenage brain. And the transition to middle school is when it really popped out. It's because they were no longer able to mask their Autism and their anxiety in the ways that they were before.

Next, no one talks about the effects on siblings and how there is no support for them or outlet for them to work through everything they are experiencing and being exposed to. Yes, I totally feel this one. As an Autism sibling myself, I remember feeling very torn. On the one hand I felt really sorry for my sister, especially because she had seizures. And I felt really bad for my parents because I could see how worried they were and how hard they were working to get her the supports that she needed.

But sometimes I also felt confused and resentful because you know how it is with siblings. We expect everything to be exactly the same. We expect our slice of cake to be exactly the same size, our bowl of ice-cream to have exactly the same amount of ice-cream. And when I saw my sister getting away with things that I couldn't do, that annoyed me. It did not annoy me as much as it annoyed my middle sister because I was about seven years older than my sister with Autism.

But the middle sister and my sister with Autism are closer in age and that just did not go well and she simply did not understand why some rules applied to my sister and others didn't until she got older.

Next, I got a few comments about grief. One mom said that it is okay to mourn the life you thought you would live. And yes, this is so true and I know it's difficult. I really stuffed down this fear and I see it in my clients all of the time. They really look at wishing things were different or being sad that they're not different as a betrayal of their child. And really, when you're doing that, all you're doing is doubling down on your pain. You are already

## Ep #110: What No One Tells You (Part 2)

in pain, you're already sad, you're already disappointed, but then you add on that layer of judgment.

And so I completely agree with this mom. It is okay, it is expected for you to mourn the life that you thought you would have. No one tells you about the long battle with grief, how hard being a caregiver to a high needs child is and about the supports that are available. Yeah, true that, I mean, grief like I have said before in the podcast, it's not one and done for us at all. It's like grief by a 1,000 cuts. This is an ongoing process.

I remember when my son was diagnosed, Autism Speaks had the 100 day toolkit and they had in it a little bit about grief and they talked about the five stages of grief, which are completely not applicable to this. But in any event I remember reading that as I need to get to acceptance fast or else I can't help my child. And that's just not the case. Grief and acceptance are ongoing. And I think it's so important for us to know that for ourselves, so again, we're not judging ourselves.

No one tells you that you may never sleep with just your spouse in the bed all night ever again. Yes, that one made me laugh, or that you will never sleep in your bed ever again. I really did think that up till a certain point. Although when my son got into his tween years, he wanted nothing to do with me so that was a plus. No one tells you how much those well-meaning 'I could never do what you do' comments bother you. Yeah, this is one Autism moms get all the time, "I don't know how you do it, I could never."

I think from the perspective of the person who is saying it is, that it's a mark of admiration or of acknowledging how much you do. But at the same time, it doesn't feel good because no matter how much you think we are doing, we actually always feel like we're not doing enough. And also those comments just highlight the difference, the gap, the big difference between what you as a neurotypical parent experience and what I experience.

And look, I am never trying to script what people can and can't say to them. And so if you've ever said this to another Autism mom, God knows, I've said it to my friend whose child has type one diabetes, "I don't know how

## Ep #110: What No One Tells You (Part 2)

you're able to track all of this so well." She's so on top of things. And what I really mean is, you're fucking amazing and I am so in awe of you.

No one tells you that comorbidities with Autism are the killers, not the Autism itself. Oh my God, yes, yes, yes. I was joking to one of my son's therapists not that long ago, that if I ever write a book, it will be called *I Miss Autism*. That's because, and of course, this is from my experience and it's also a comparative experience, because I'm sure I considered Autism much more challenging at the time. But now compared to the impact that anxiety and profound OCD has had on my son, I would take Autism any day of the week.

Now, where does one begin and one end? Who knows? But this comment definitely does resonate with me. And I remember in my conversation a few episodes back with Carrie Cariello, I remember her saying, "I don't have a problem with Autism, but anxiety is another story." And I think that is the experience of a lot of us, especially as our children get into those tween and teen years.

No one tells you that you will have no support after high school or how hard it is to work. The next commentator said, and hallelujah to this, "We are not crazy, just tired and burnt out from doing the best that we can with what we know and the resources we have. We want the best for our children just like everyone else." Yes to that.

Next, we have to meet our children where they are and change our expectations. It's a mind shift that I never thought was part of parenting. I think that this is such a great point and one that Autism parents learn pretty early that in order to connect with our children, in order to teach them, in order to support them, we really need to, one, change our expectations. Not for their quality of life, but really how we're going to interact and what it's going to look like so that we can support our child in the best way that we can.

The next commentator said, "It's exhausting and rewarding, just like most parenting. But sometimes it's hard to keep up with the same shenanigans

## Ep #110: What No One Tells You (Part 2)

in their 21 year old body as when they were three, and you're no spring chicken anymore." Yeah, for sure, this is for sure true. It is a lot easier when they're younger and you can throw them over your shoulder and get out of dodge. But when they're older and they're bigger and they're having some issues, it can be more difficult.

The next commentator said, "It can be a very lonely and isolating journey." Yeah, it can. And I know that that's why, in my opinion, it is so important for us Autism moms to have community. I always say to the moms that I coach, "Find people who understand your life, that you can talk to. Because when you have that, you can let your friends be your friends, you can let your co-workers be your co-workers because you already have an outlet."

So when they're talking about the lives that they're living with their neurotypical kids and you feel like you're an alien on another planet, that becomes less of an intense experience when you know that you have your people and you have your outlets.

The next commentator said, "We have to advocate every single day for help and services that we need, they are not just handed to us and some of them are non-existent." This mom said, "Also don't use cliché quotes about us like, we are super moms. That one is very tiresome." She says, "We aren't super human, we just love our kids fiercely."

The next commentator said, "It is a whole different world of, gee, I hope I'm doing the right thing. Sometimes I don't even know what the options are. I don't understand what my kid needs and this can be frustrating as hell. My child is also the light of my life and I love him fiercely." Yeah, I can't agree with this more. The uncertainty that comes with Autism parenting, it really is part of the package. We're always weighing imperfect information, imperfect resources in order to make our decisions, and it can lead to a lot of second guessing.

Alright, the next mom says, "How no one believes you because your child is so good at masking in public but at home they have meltdowns about things like schedules and routines." Yes, this is a big, big one. And then one

## Ep #110: What No One Tells You (Part 2)

that I've seen, even with the highest functioning kids who are really good at masking, by the time these kids get to middle school and high school, they're just not able to maintain it, even in the school. And that's why you'll see a lot of these diagnoses at this time, especially in girls where it's most often missed.

I know with my son, he was a star student. He was the teacher's pet. He was a people pleaser. He did everything perfectly. When he got to school, he was all please and thank you and excuse me, making sure he was always doing the right thing. The teachers loved him because he followed all their instructions, everything. So when I would email them after school about things that were going on at home, they were just completely puzzled. They had no frame of reference for any of this behavior until they did, and that's when things really changed.

And I've seen that with a lot of my clients too, their kids do such a good job of masking. And what happens is, and we've all experienced this, the Coke bottle effect, they do all of that masking during the school day and when they get home they explode. That is their safe place. They are tired of keeping it in. They can't keep it in anymore and so we see that side of them while the school might not, or at least, not yet.

The next mom commented on my post where I said, "No one tells you that the Autistic diagnosis is a bunch of hurry up to get in line." And this mom agreed with me. She said that her family got accepted for ABA after three years and now the insurance company is telling her that her child is too old. So frustrating. That's another thing that you can't even comprehend if you're not a special needs parent is the amount of paperwork that you have to fill out. It is daunting. It is unrelenting. So I really feel for this mom who jumped through all of the hoops to get the ABA in place, only to be told, "Sorry, too old."

And finally a comment from the mom says, "No one tells you how much time you will spend crying in your car unexpectedly." Oh my God, yes. For me it was my car and sometimes the train on the way to work. I remember driving my son to school and some days he would get out of the car, no

## Ep #110: What No One Tells You (Part 2)

problem and some days he wouldn't. And depending on how the morning went and the level of stress and how I'd reacted to him, I would spend the train ride to work, beating myself up about how I had reacted or overreacted or just sad for my kid because I saw how much he was struggling. And so I feel you there, on, crying in the car.

Alright, that is it for this week. I just wanted to share more voices with you. I wanted you to have your voice heard if you shared with me and tell you how much I appreciate that and more, please, tell me what you want. Tell me what you need. Tell me where you need support. The best way for you to do this. You can either email me or you can join The Resilient Autism Mom Group on Facebook, I will leave the link in the comments. Alright, I will talk to you next week. Thanks so much.

Thanks for listening to *The Autism Mom Coach*. If you are ready to apply the principles you are learning in these episodes to your life, it is time to schedule a consultation call with me. Podcasts are great but the ahas are fleeting. Real change comes from application and implementation and this is exactly what we do in my one-on-one coaching program. To schedule your consultation, go to my website, [theAutismmomcoach.com](http://theAutismmomcoach.com), Work With Me and take the first step to taking better care of yourself so that you can show up as the parent you want to be for your child with Autism.