

Ep #109: What No One Tells You



Full Episode Transcript

With Your Host

Lisa Candra

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You are listening to Episode 109 of *The Autism Mom Coach: What No One Tells You*.

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.

Hello, everyone, and welcome to the podcast. I am so glad you're here. I hope you're doing well. I wanted to start this podcast out by saying thank you to all the moms who reached out to me after Episode 107 "Reality Check".

I got a lot of messages from moms thanking me for that episode and saying how true it was for them. And how it felt good to hear somebody else talking about the fact that we're all working our asses off for our kids. And it doesn't mean that doing all of the things gets you the results that you want for your child.

It is so easy to internalize that and for it to feel like you did something wrong, you didn't do enough, when you know how hard you're working, how hard you've worked. And sometimes the result of all of that work, you're not seeing it or you're not seeing it right away. Or maybe you never see it. And that is really frustrating, and it's heartbreaking.

So, I want to thank all of the moms who reached out to me. One thing I want to note about the moms who reached out to me, every one of them had a child over the age of 15. I thought that was really interesting, because it kind of went along with what I was saying in the episode.

That in those early years after the diagnosis, so many of us are running on that idea, that belief, that hope that if we do enough, if we do the right things, that our child will somehow not be autistic anymore, or they won't be impacted by the Autism in any real significant way. And by the time you get to 15 you're like, "Huh, maybe not."

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I mean, I know for me, my son was cruising there for a couple of years. I had gotten used to the idea that everything was just a lot more. That on a scale of 1-10, if for somebody it was a two, it was always a 10 for us, right? We were just always working extra hard. But that was just part of how we did things.

I had gotten so used to it that it didn't even faze me. And in fact, it really seemed, around fifth or sixth grade, my son was hitting his groove. He was gaining more confidence. He was very pro-social. He was having successes in school. He was having successes in extracurricular activities.

And then came puberty, and everything changed. My fantasy, "Oh, as he gets older this is going to get easier," well, that flew right out the window. So, it makes sense to me that I got contacted by parents of older children. Because when you've been at this long enough, you've been through so many ups and downs. I think you understand more deeply that this doesn't get easier, it just gets different.

So, I do want to invite all the moms who reached out to me after that episode, where that episode resonated with you. I want to hear more about what you want in this podcast. I want to hear more about how I can support you.

As you know, I'm going through this along with you. As much as we can do this together, and work together, and I can support you in any way I can, I really want to do that. Because I do realize, as all of you do, that 99%, it seems, of the focus on Autism is on their early years.

Which is really frustrating, right? Because our kids are only young once, and they are adults for the rest of their lives. And so, there's not much for that. And of course, that falls on us, the parent, to figure things out while we're trying to take care of ourselves, caretaking for older parents, having jobs, paying bills, all of that.

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And so, I invite you to send me an email, Lisa@theautismmomcoach.com. Tell me what you want to hear about. Tell me where you want support, and I'm going to figure out how to get it to you.

Okay, moving on. This episode is airing the day after World Autism Awareness Day. Which for all of us, I mean, we're plenty aware, I know. But I also know, in the first couple of years of my son's diagnosis I was that mom fundraising for Autism Speaks, I was an ambassador for the state of New Jersey. I was doing all the things.

I don't really do that stuff anymore. I attend a lot of events as a vendor, so that I can reach out to families, I can get to know people, I can tell them about my business. But I'm not so much really doing those things anymore as a parent.

But I wanted to share with you, a couple of years ago after my son was in the hospital for special care... He had been in their inpatient and in their partial hospitalization step-down program. My son, in my opinion, he's very well-spoken. He's a very thoughtful kid.

Dr. Minhas, who was his outpatient doctor at the Hospital for Special Care, had his APRN reach out to me to see if Ben and I would be interested in being on a news piece about the Hospital for Special Care, their inpatient unit, and how they were expanding their beds.

Ben thought this was amazing. He's like, "I'm going to be on TV. That means I'm going to be famous. Sign me up." And so, we were both interviewed by a reporter. Ben just did a beautiful job of talking about the Hospital for Special Care and the inpatient experience. He was so excited to see this on TV, so the news anchor told us when it was going to air.

So, we're watching TV, we're eagerly awaiting for our interviews to come up about the Hospital for Special Care and their expansion. And as we're watching, it shifts to one of the news anchors, and he says, "April is Autism Awareness Month."

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And then he goes on to give you the information about Autism that you could probably find on Wikipedia; it impacts one out of 36 children, it's a neurodevelopmental disability, some kids flap, some kids have poor eye contact, some kids have sensory issues.

It's all of this really basic information. And then it shifted into our interview, and I was thinking myself, "How does that make sense?" They basically said to people, "Hey, Autism is a disability where people have a difficult time with communication. And here is an in-patient hospitalization for kids with Autism." There's a bit of a disconnect there.

The reason that there's the disconnect is because there's so much that they don't tell you about Autism. That's why the general public knows squat, unless they're personally impacted by Autism, because of stories like that. "It's a spectrum." It's not even 101.

So, as I was thinking about that, I was just getting fired up. I was thinking about all of the things that they don't tell you about Autism. Not just that they don't tell the general public, of course. Things that they don't even tell the parents. I'm not talking about things the general public doesn't know. I'm even talking about things the parent doesn't know. The things that I was never told as a mother of a newly diagnosed child. The things I learned along the way.

I just wanted to share this. And if there's any news anchors that are listening, and they want to do a *real* piece on Autism, please call me up. Alright, here's the quick list that I came up with of the things I wish that I knew and no one tells you.

Number one: There is no magic bullet. Which was news to me. Because my understanding from the beginning was, if I worked hard enough, if I got my son ABA therapy, if I got him in school, if I socialized him with other kids, if I did all of those things, then his Autism wouldn't impact him as much as it actually does. And, that's not true.

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I did all of the therapies. My son has been in therapy, with an actual therapist, since he was four years old. He was doing art therapy; we've done tons of different things. And guess what? My son still struggles mightily with his Autism.

In some ways, not in the ways that you might think. It's interesting, because one of my friends is a coach for moms with Autism. She's doing a program for parents, so parents can help children who are already potty trained, can communicate, and have little to no problem behaviors, with certain skills for autistic kids to learn.

And as she was ticking down the skills, I was thinking, "You know what? We actually didn't have any problems with those. Those weren't our challenges." It was not a challenge for me to take my son to the doctor, to get him to eat some fruits and vegetables, to get him to go out into public, to have playdates, to have sleepovers. Those things weren't our big challenges.

ADLs? I mean, no. He was on his ADLs; he woke himself up for school, he dressed himself, he brushed his teeth, he flossed. I mean, he had OCD, so he overdid all of those things, actually. And so, those things weren't issues for us. I mean, as I think about it, they probably were, compared to a neurotypical kid, but overall they weren't significant.

So, from that point of view, I should be in the clear, right? And, I'm not. My kid's not in the clear at all. Because what they don't tell you is, yeah, you can help the Autism traits a lot with these different therapies and things like that. But here comes anxiety when they hit puberty. And the interaction of that, and hormones, and all of those kinds of things, there's no magic bullet for any of that.

When my son got slapped with puberty, and our house got turned upside down, it was like, holy shit, you would never know that I have binder upon binder of all of the different therapies we've done over the years, because it felt like it all flew out the window. Okay, so that's number one: No magic bullet.

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Number two: Doctors don't know. Now, I am not anti-doctor, I am not anti-science; I am just the opposite. I actually say this with all due respect. Doctors know what is available to them right now. And I believe that what we understand, truly, about the brain, about the autistic brain, is a drop in the ocean.

I've had so many experiences, for instance, with medications. Where the doctors will say, "This is what this medicine does in neurotypical kids. We'll see what it does in your child." I know that sounds terrible and experimental, but that's the reality. Our children react differently to medications.

This is an art, not science. And by 'art, not science,' that means a bit of trial and error. Which, again, feels terrible as a parent, but the fact is that we are relying on them for their expertise. And yes, they have expertise, but so do we. We live with this child. "You're telling me this SSRI is supposed to calm down my kid. So, why is he punching his walls?" "Oh, SSRIs in kids with Autism sometimes backfire." Wish you had told me that.

But apparently, this particular doctor did not know that. So, doctors don't know everything. Which is really disappointing to me, I wish that they did. I wish that Autism was straightforward and they could just say, "Take this medicine and this medicine, and you're all good." But that's just not the case.

Number three: Regression does not just happen in the early days. I really did think we were out of the clear once my son started to speak and grow and develop socially and emotionally, and mature. But when he hit puberty, the onslaught of that anxiety, and the regression that that caused, was so significant.

My child, who was so capable, so willing, and brave and confident, became another person. He regressed in a lot of ways. It's so heartbreaking to see, because I just had this glimmer of this kid and where he's headed. And I'm not saying that he can't get there now, but there's been a significant

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interruption that I never saw coming. I just thought we were on an upward trajectory and that's how it was going.

Number four: Puberty changes everything. Now, this is true for any child, but I think it's 10 times more for a child with Autism. I mean, what happens between hormones and the autistic brain, it is not pretty; or it hasn't been my experience. A lot of my clients say that things change dramatically. Everything was just turned up to a 10.

It so impacted his personality; the anxiety, the depression that came with it. And then, with all these brain changes, a developing brain and hormones and medications and the autistic brain, it goes a little berserk in there.

Again, I remember with my sister, my parents had gotten her to a really good place with her ADHD meds and her seizure medication. And then she hit puberty and they all went out of whack. They had to recalibrate all of them. But that was only after she had had a couple of seizures that were kind of serious.

Number five: Relationship strain. Now I know that there is the pretty well-known statistics about the parents of special needs kid having higher rates of divorce. I guess that is true. And if it's true, I'm one of those parents. Ben's father and I divorced shortly after Ben's diagnosis. But that's not the only relationship strain that I'm talking about.

I'm talking about the relationship strain with your friends, your coworkers, your other family members, your neighbors. Those relationships are impacted by the Autism, and by you having a child with Autism.

For example, your best friend wants you to come to her kid's spectacular birthday party, that's going to be filled with cousins and neighbors and farm animals, for some reason, and a bouncy house. So you say, "We'll drop off the present before everybody else gets there, say hello, and then we're leaving." And she takes offense, she's doesn't understand why. Those kinds of things, right?

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Or maybe it's something like your best friend, or your sister-in-law, who's posting all of the amazing pictures of her kid doing all of the things that you wish your child could do. And although they haven't done anything to you, that could impact you, right? Your feelings about that could have an impact on how you interact with them, or how much you want to talk to them, or how you feel about them.

Now, granted, I'm not saying any of this is their fault. But these are the ways that having an Autism diagnosis, and carrying this tremendous responsibility, can seep out. One of the more long-term impacts for me has definitely been in my relationships. And more specifically, in the amount of time it takes me to set myself right about my relationships.

To be in a conversation with friends when they're talking about something that I only wish my child could do, and remind myself, "They're allowed to be who they are. They are not saying this at you or against you. This has nothing to do with you. You can still be sad." That actually takes a lot of mind management, and it's well worth it. I want to have friends. I want my friends to be who they are. But I do feel the strain at the same time.

Next: What no one tells you when you get the Autism diagnosis, is that this diagnosis is going to impact every facet of your life; every decision you make, where you live, what you do, what you don't do, what you eat, where you eat, if you eat outside of the house, where you go. All of it is impacted.

Every decision I've made since my son was diagnosed has been in light of that diagnosis. Where I work... After he was diagnosed, it was for sure time for me to get out of law firm life; where there was a billable hour requirement, where your time really wasn't your own. It was time for me to step back and have a different career with different expectations.

For every decision, I've just had to put a lot more thought into it, and being very aware of the impact on my son, how he might react to certain things. And that is just an ongoing thing that I do so much that I don't even think I realize it anymore.

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For instance, when we were moving to Connecticut we decided to move into an apartment complex. I was very clear with the realtor, “I’m only looking for an apartment that is on the ground floor, that is an end unit, and has its own door in and out.” Because we can’t be on a top floor. Oh, hell no, we would have gotten kicked out immediately. I thought being on an end unit, with our own door in and out that wasn’t a common community area, would be our best bet.

Now, as soon as a townhouse opened up, where we could have our own space, and again, I had to have an end unit, that was a better position for us to be in. It gets hell-a loud in our house. I didn’t want to get kicked out. I didn’t want to burden the neighbors. I just didn’t want any of that.

But it was also a really real possibility. And so, I was very clear about, “You have all of these different places open. And I’m not taking a one of them until you have these very specific places open.” That’s just what I knew I needed to do.

Another thing no one ever tells you, and God I wish they would say this on one of those news casts about Autism, is that Autism is very expensive. I mean, it’s so expensive. I joke and I call it “the Autism tax”. But everything for our kids is just more expensive. Their medical care, ABA, speech, O/T P/T, all of that.

Now, some of that might get funded through the school, but maybe not all of it. Developmental pediatricians; maybe your insurance picks up the tab, maybe they don’t, or they only pick up a portion. And then there’s all of the things that you might just pay extra for so that your child can actually do it.

Ben was obsessed with the Empire State Building, that’s what he wanted to do for vacation. He wanted to go to New York, and he wanted to be on top of the Empire State Building. That’s what he wanted. I looked into it ahead of time, and I got this understanding about how the elevators work, and depending on how many people, and the lines... Lines, for us, are no, up to a point, right? I knew that in New York City, in the summer time, that these lines were going to be insane.

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So, lucky me, there was a more expensive option that I could choose. Where we would get faster access to get up and out. And so, we weren't in a long line, we weren't in a crowded elevator, and we were able to get to the top relatively quickly. That wasn't inexpensive, but it was the price of him having the experience. And so, I paid it.

Just like for skiing. There were regular ski lessons, or there were specialized ski lessons. Well, that was a no-brainer, because we tried the regular ski lessons one afternoon and it was an absolute disaster. But again, those adaptive ski lessons, they weren't cheap at all. But that was the price to pay for him to have the experience.

There are so many examples of this, for families, of things that they pay more for. These are just two small examples. There are lots more examples about how expensive it is to have a special needs child. The accommodations, the medical issues, mental health issues, all of the different therapies. And that's not even to mention incentives.

So many of us parents with children with Autism, we use incentives to motivate our children to do certain things. And I sure know that incentives, when Ben was younger, were really manageable, they were fake gold tokens.

But as he got older, it was Lego sets and Nerf guns, that's what he wanted. And I sure wanted him to have a good week in school because I worked full time. I didn't want calls picking him up in the middle of the day, or anything like that. I wanted him to do well in school. And so, it was a price I was willing to pay for peace; and it was pricey.

Finally, what no one tells you is that your standard for what is normal is dramatically lopsided. It looks very different from parents of neurotypical peers. Now, for parents who have children who are autistic and who are not, you might see this very clearly all of the time, so maybe it's not that much of a surprise to you. But I know it has been for me.

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And when you're living at an 8 or a 10 all of the time, that just becomes your new normal and you don't even realize it. In some ways that's benefited me. It has raised my level of resilience. It has raised my level of resourcefulness. It has raised my level of competence.

I remember, specifically, a couple of my friends, when their children turned around seven or eight, they were noticing ADHD and they wanted to address it with the teachers and the school. But they weren't really sure how.

And I was like, "Oh, I'm a pro with this all day, every day. Here's what you do, here's what you write, here's who you copy, here's the language you use, here's who else you get involved." All of it came very natural to me because that was my norm. That was a day-to-day thing for me, so it was no sweat.

But for most parents, their only interaction with the teachers are parent-teacher conferences, maybe a couple emails back and forth, and that's it. And that's not a slight on them, their reality doesn't call for it like so many of ours do. This just really just goes to everything; all of our day-to-day activities as Autism parents.

Everything I've been talking about, the relationship strains, having to work really hard in your head to get yourself straight about your friends and about other people and letting them be who they are, getting on something like Facebook or Instagram, and keeping yourself together about it. Right? Just managing that grief, and some of that jealousy or the resentment, that becomes a normal part of our lives that a lot of people aren't experiencing in this way.

Think about all of the work you do around transitions; previewing things to your child, getting them ready, getting them prepared, giving them a heads up. All of that effort to simply walk out the door, it just becomes your normal. And so, your norm is always going to be working 10 times harder. That is the norm.

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Taking your kid to the dentist, right? That's, for so many of us, not a straightforward proposition like, "Let's get in the car and let's go." Luckily, for Ben, for whatever reason it was. But I know so many parents who had to get the last appointment of the day, had to alert the staff ahead of time, there was a [inaudible] involved sometimes, there was lots of crying, lots of screaming; lots of effort just to get the kid in the front door. But that became the norm of going to the dentist.

Same thing with doctor's appointments and getting needles. Going on a play date, all of the prep for that. I remember, with my son we would often do social stories around playdates, about sharing, about taking turns, about not touching other people's stuff.

One of his best friends had an amazing collection of Legos on a shelf, and my son was just fascinated by this. All he wanted to do was get up on that shelf and touch the Legos and play with them. Really having to work with him, like, "No, you can't do that." And I'm going to be honest here. I just told the parents, "Please, lock that door. I don't want him to knock over all of those Legos."

But at any event, a lot of work to just have that simple experience of a playdate. And sometimes I just see kids, and they're just walking around with other kids. They're kind of doing their own thing. I'm like, that's amazing. That's so fantastic. I was like that helicopter, "What's going on? Is everybody getting along? Is Ben understanding what's happening?" I was always a bit in the background because I was monitoring.

I've always been sort of monitoring the temperature, is it time for a break? Does he need to take a break? Does he need to walk away? When do I tell the other kids to leave? I've always, always had my ear out for that stuff, and it's just been my normal.

And so, I say all of this because I talk to parents every day who say to me things like, "I don't think I'm doing enough. I think I should be doing more." The fact is, you have no idea how hard you're working, and how much harder you're working than most people. And not to make it a comparative

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thing, but just in terms of being able to gauge yourself. You don't even realize that working 10 times harder is just become part of who you are and what you do. And so, you just do it.

One of my friends said to me, "Watching you made me tired. Watching everything that went into getting Ben in and out of the house, or going out in public and doing an activity." She said, "You have no idea how tiring it was to just watch you." And for me, it was just normal.

Get up in the morning and we go to the farmer's market. The farmer's market is over and we go on a hike. After the hike, take a nap. Then we're out again, maybe at the bookstore; he loves to go to Barnes & Noble and play with the trains. And then, one thing after another to keep him engaged. But also, while I was keeping him engaged, monitoring, right?

So, he's at Barnes & Noble, he's at the table, and he thinks that these are *his* Thomas trains, and they're not, there are other kids there. So then in that, teaching taking turns, teaching stepping away; all of that, instead of just sitting there chillin' with the other parents with my cup of coffee. I was like on the ground with the kids. And that became the norm. All of it is to enable our children to participate in life.

So, that basically wraps it up. These are just some of the things that no one told us about Autism. And goodness knows, they didn't tell us. We have kids with Autism, and nobody else knows this. Nobody else really understands that, because how the hell would they? But we do.

The fact is, you do, you do understand it. You do know how hard you're working. You do know how much more effort it takes you to do something with your autistic child than it does with a neurotypical child. And for those of you who only have one child, look at your friends. Look at your sisters and your brothers, and those kids who are neurotypical, it's a big difference.

It's not because you're not doing enough, there's a big difference about what it takes to enable our kids to participate than it does a neurotypical

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kid. And to make that happen, it's a lot of work for us. And even then, it can be really difficult. It can be really challenging.

No one tells you that, they just tell you, "Get a lot of therapy, do it fast, do it soon." But no one tells you that. Because parents are being told, "Do as much as you can, as fast as you can. And if you do all those things, then your child's going to live this wonderful independent life. End of story." As we know, that is not always the reality for our children, and it's not the reality for us.

Our lives are significantly impacted by having a child with special needs. They're impacted in every single way. We all become different people in this experience. And this is why I think it's so important for Autism moms to have community. Because all of us know this; we get it, we understand it. It's the unspoken rule of all of our interactions.

It's such a beautiful thing to be understood and to be gotten and to not feel alone, and so that's why I wanted to give some voice to the things that no one tells you and no one knows. Because they are real, they are happening, and they have a real impact on all of us.

When we are carrying around this weight, this invisible weight, it can feel really lonely. We start to second guess ourselves, and invalidate our own experience. And when we're doing that, we're just making things harder on ourselves. We're adding suffering to our own pain. That is something we can control.

We can control how we treat ourselves when we are shouldering all this responsibility. We also get to decide, "Who is the person I want to become from this experience?" Because this experience changes all of us. And we get to decide to step up and step into the next level of ourselves. To do our best with our reality.

That is my mission every day in my own personal life, to do my best with what is happening right now, the cards I've been dealt, and also to help as

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many moms raising kids with Autism who are having these experiences, as I can.

So, if you are one of those moms who is struggling, you aren't and you don't have to do this alone. You can go right now and join my online group, the Resilient Autism Mom group, on Facebook and introduce yourself to the group. This is my online community of Autism moms only, and the conversation there is about whatever you want it to be. So, if you're struggling, raise your hand and say so. You can always message me separately.

And of course, for everyone who's ready to take the next step, and work with me one on one as your coach so I can teach you the tools and strategies you need, customized to your exact experience so that you can show up energized and confident as the mom you want to be without burning out, that is exactly what I can help you with in my coaching program.

If you are interested in that, you go to the show notes or my website, TheAutismMomCoach.com under "work with me", and you schedule your consultation. If you are coaching curious, now is the time. I've had a lot of clients who have waited to work with me three and six months, who are working with me now, and they are feeling so much better after just two sessions. They're getting results right away.

I want that for you, too. So, if you want to do tomorrow better, if you want to feel better in your experience as an Autism parent, I can help you now. Again, the show notes, or my website TheAutismMomCoach.com/work-with-me, and schedule your consultation.

Alright, that's it for this week. I'll talk to you next.

Thanks for listening to *The Autism Mom Coach*. If you're 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 a-ha's are

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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/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.