

Ep #123: More Is Not Always Better



Full Episode Transcript

With Your Host

Lisa Candra

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You are listening to Episode 123 of *The Autism Mom Coach: More Is Not Always Better*.

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 and I hope you're doing well. Before we get to today's topic, I wanted to announce that I will be offering the Keeping Your Cool during a Meltdown training this July 22nd at 7pm Eastern. During this training, I will teach you my three-step process for keeping your cool during a meltdown, and I will answer your questions. To attend this webinar, you can register now using the link in the show notes.

Okay, on to today's topic, which is going to be a little bit of a rant, because this topic has me fired up, and it actually bolted me out of bed last Sunday morning. To begin with, every Sunday, I receive an email from Google listing all of the articles for the week that mentioned the word "Autism". I set up this search about 12 years ago, so that I would stop compulsively googling "Autism" every day. I would just get one email a week with all of the headlines and I would leave it at that.

Over the years, the topics have been fairly consistent; the causes of Autism, the treatments of Autism, the feel-good stories about Autism, and the sad stories about Autism. Some weeks I read the articles, but most weeks, I just skim the titles and delete.

But not last week. Last week, as I was in bed and I was scrolling through my emails, I saw this one headline and I sat straight up. Here's what it said: "New studies suggest higher amounts of intervention may not be more helpful for children with Autism."

Ep #123: More Is Not Always Better

Well, this caught my attention fast. Because in addition to being one of the many mothers that was told that I needed to get my son 40 hours of intervention a week when he was diagnosed, I am now coaching a lot of moms who have received the same recommendation and are struggling to get even 10 hours a week, and are beating themselves up because they don't think it's enough.

I will have to say, intuitively I never believed that 20-40 hours a week was actually beneficial. I mean, the idea of giving a child a part-time or a full-time job of therapy seemed really unrealistic to me. That you would hit the point of diminishing returns quite quickly, and risk having the child burnout and not wanting to engage in any kind of therapy or interaction at all.

So, I'm going to read parts of this article and I'm also going to link the article in the show notes. Here's what it said.

“When a child is diagnosed with Autism, healthcare professionals often recommend intensive interventions, which can amount to 20-40 hours per week to support their development. However, a study led by Micheal Sandbank, PhD, Assistant Professor in the Department of Health and Sciences of the UNC School of Medicine, and other researchers across the United States has found that more does not necessarily mean better. Using data from 144 early childhood intervention studies, which involved 9,038 children between the ages of 0 to 8, researchers conducted a meta-analysis to determine whether higher intensity interventions provided increased benefits for young autistic children compared to less intensive interventions. They found that intervention outcomes did not improve as intervention intensity increased. These results were published in JAMA Pediatrics.”

And then there's a quote from the article, “ ‘We concluded that there was not rigorous evidence supporting the notion that increasing the amount of intervention produces better intervention outcomes,’ said Sandbank, who was first author on the study.” Okay, so this lit me up. But next part had me boiling over.

Ep #123: More Is Not Always Better

The article goes on to say, “The most commonly recommended approach for autistic children in the United States is called ‘Early Intensive Behavioral Intervention, or EIBI. The current clinical guidelines regarding intensive intervention arose from a 1987 study which found that autistic children who received 40 hours of behavioral intervention per week had more cognitive improvement than those who received only 10 hours per week.”

At this point, I went a little off-road and I had to Google this 1987 study. So, I did. I looked it up, and this study, it's called the “Loveless Study”... I will also link it in the show notes... it involves 59 kids, between the ages of 0-4, split into three groups. So, between 18 and 20 kids per group. One group got 40 hours of intervention per week. How the fuck do you get 0-4 year olds to do anything for 40 hours per week other than sleep?

Anyhow, of this group of 18 or 20 kids, 47% of the kids... Which, what is this, 8 or 9?... were found to have attained “normal cognitive or educational functioning.” Now, to me, this sounds like complete bullshit. But it went on to be the gospel, this janky study from 1987. And despite a shit-ton of criticism that it received over methodology and the classification of what “normal” is, is the reason we were told that 20-40 hours was the gold standard.

It's the reason we were led to believe that more is better. It's the reason we were led to believe that if we do more, our kids will be “okay”. And as a result, so many of us have stretched ourselves thin trying to meet these demands. Believing that our ability to provide more therapy could be the difference between our children struggling or growing out of Autism. This belief has led to endless hours of guilt and stress and unrealistic expectations.

On top of being wrong or incorrect or not the entire story, this study, in my view, was dangerous. Not only was the study faulty, it was creating a standard that by any standard was unrealistic for most families. First, financially. Only up until recently have insurance companies even been willing to cover Autism services.

Ep #123: More Is Not Always Better

And then, you've got to find the services. That means you have to get on the waitlist. You have to hope the services are in your area, that they'll provide for your child, that they have the capacity, that you get off the waitlist in time that your child can actually avail themselves of the services, you have to make sure that the times meet up with your time, that you have the ability to get your child to and from, or you have the ability to have an adult at home to supervise them while ABA services are in the house.

And on top of all of this, the willingness of the child. I know for me, when we received a recommendation of having, I don't know, 20 hours a week of in-house therapy, they might as well have said 2,000 per week, because it was just as unrealistic. My son believes in a strong separation of home and work. And anything that involves somebody else coming into our home to do anything, he is not about it.

We tried it and tried it over and over. And I really saw so little benefit to it. Because even when my son wasn't resisting their presence, he was really just counting the minutes until they left, and doing everything he could to avoid any minute that he could with them, because he just simply was against it to begin with.

So, gold standard or not, it wasn't for us. And because of that, no matter how much I've done over the years, and I have done a lot, I've always felt like I was falling short. Because I was never approaching that 20-40 hours per week. I see this with so many of my clients. It's why they never relax. It's why they tell me they feel like they should always be researching, or always looking for something new, or always doing something with their child.

Because the underlying belief is "more is better". And, "If I do more, then they will be 'okay'. They won't struggle as much. They won't be autistic?" All based on faulty information; not just faulty, dangerous. Dangerous in the way that it's impacted us.

Because the impact on us, the guilt, the sadness, the regret, the burnout, all that impacts our children much more than any therapy. We are more

Ep #123: More Is Not Always Better

important to them than any therapy. Our wellbeing on any given day is more important to them than a couple more hours of speech or behavioral intervention, just to say that you did it.

Okay, so if 20-40 hours isn't backed by the studies, then what are we supposed to do? Here is what Sandbank suggested, and I could not agree more. She says, "...We recommend that practitioners consider what amount of intervention would be developmentally appropriate for the child and supportive to the family."

I thought this was so beautifully said, for a couple of reasons. "Developmentally appropriate to the child," so important. Developmentally doesn't mean by age, it means by where they are in their development. That is something that we need to assess. And we are the best people to assess that, because we are the experts on our child.

And "supportive to the family," yeah, our kids aren't robots that we can stick into therapy for 20 or 40 hours a week. They are part of families that have needs, that have schedules, and that have real practical things that we have to deal with every single day.

So, for instance, if Ben is freaking out about having ABA in the home, that impacts the whole family. Now, Ben doesn't have siblings. But if he did have a sibling, that would impact the sibling. This is so important and so overlooked. It has to work for the child; it has to work for the family. Because if it doesn't, how helpful could it possibly be?

In my opinion, this comes back to what I have said on this podcast time and time again, and what I tell my clients all of the time. You are the expert on your child. You are the best person to be making the decisions about what kind of therapy and how much they need.

And now, I'm hoping that you can make these decisions without the unrealistic pressure or belief that 20-40 hours is realistic or helpful. Instead, trust your instincts. Trust your expertise. Focus on quality and appropriateness of intervention; not just for your kid, but for your family.

Ep #123: More Is Not Always Better

Keep an eye out for signs of burnout, for both your child and yourself. And prioritize rest, play and family time wherever possible.

If you struggle with your fear of not doing enough, or not doing the right things, or trusting yourself as the expert, I can help you with this. In my one-on-one coaching program, I help my clients step into their role as the expert on their child, and teach them how to be the CEO of the extended care team that will be supporting your child throughout the years.

They come and go; you are the thread through all of it. That is why it is so important for you to take care of yourself and to feel confident in your own decisions. And you want the support of someone who's been there and is doing it. That is me, and I am here to help you.

To get started, schedule your consultation by going to the show notes. Now, when you schedule a consultation with me, you're scheduling a conversation. We're going to talk about what you're struggling with, what you want help with, and whether coaching with me is the next right step for you and your family. Again, to schedule your consultation, go to the link in the show notes.

Alright, everyone, that is it for this week. I will 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 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.