Ep #98: Parenting and Puberty with Carrie Cariello

Full Episode Transcript

With Your Host

Lisa Candera

Ep #98: Parenting and Puberty with Carrie Cariello

You are listening to episode 98 of *The Autism Mom Coach*, Parenting and Puberty with Carrie Cariello.

Welcome to *The Autism Mom Coach* podcast, I am your host, Lisa Candera. I am a lawyer, a life coach, and most importantly, I am the full-time single mother of a teenager with Autism and other comorbid diagnoses. I know what it is like to wonder if you are doing enough or the right things for your child and to live in fear of their future.

I also know that constantly fueling yourself with fear and anxiety is not sustainable for you or of any benefit to your child. That is why in this podcast I will share practical strategies and tools you can use to shift from a chronic state of fight, flight to some calm and ease. You are your child's greatest resource, let's take care of you.

Hello everyone and welcome to this week's episode of the podcast. Before I introduce my conversation with Carrie Cariello, I want to give you two big updates. First, if you would like to meet Carrie and have one of her books signed, you can do that this weekend, January 20th at Beanz Café in Avon, Connecticut. Carrie will be there from twelve to two signing books and chatting with parents. I'll leave the link to this event in the episode notes and I hope to see as many of you as possible there.

The second announcement is my upcoming webinar on January 31st , Lessons from Rock Bottom where I am going to teach you how to bounce back from any setback and obstacle you face like a boss. The webinar will take place on January 31st from 7:00pm to 9:00pm Eastern. You can register by using the link in the show notes.

Okay, onto today's conversation with Carrie Cariello. For those of you who don't know Carrie yet, she is a wife and a mother of five children. Her second eldest child, Jack, who is now 18 years old, is on the Autism spectrum. Carrie has written three books about her journey as an Autism mom. She started about 10 years ago when Jack was seven or eight years old with her book, *What Color is Monday*? followed by *Someone I'm With Has Autism*. And now her latest release, *Half My Sky*, where she talks about the messiness of building a family and keeping a marriage together alongside Autism.

In this conversation, Carrie so honestly shares some of the ups and downs and the heartache of raising a child with Autism, especially when they get to the teenage years and puberty hits and everything goes a little bit haywire. She talks about Autism being heartbreak by a 1,000 cuts. And this resonated with me so much and I think it will with you too.

She talks about what it's like to be a young mother of a child with Autism and how her view of her role has changed so much from when Jack was a little boy to now as a young adult in a college program. So without further ado, let's hear from Carrie.

Lisa: Carrie, welcome to the podcast. I am thrilled that you are here. Can you please take a minute to introduce yourself?

Carrie: Absolutely. Thank you for having me. This is so fun. My name is Carrie Cariello. I am married to a man named Joe and we have five kids together and our second son Jack, is diagnosed with Autism. And I've been writing and blogging about Jack and family and marriage for over 11 years now. We live in Southern New Hampshire. My oldest son is Joseph. He lives in Philadelphia, he goes to college.

Jack is also in a college/residential program a few hours from here. My middle son, Charlie's 18, is a senior in college. I'm sorry, senior in high school. Don't rush it. And my daughter Rose is 16 and she's a junior in high school. And then my youngest son, Henry, is a freshman. So they all grew up when we weren't looking.

Lisa: Wow, so you have a little bit of a busy life, right?

Carrie: Yes, it is busy. It's a different kind of busy now. I look back and think, wow, we had five kids in under six years. My oldest was five and a half when my youngest was born. And people ask a lot if the youngest is a girl, four boys and then a girl. And I always [crosstalk] the story that, "No, she's the fourth. And then there was supposed to be an appointment to make sure she was the youngest. And the doctor canceled the appointment." And I had a 10 pound four ounce baby boy nine months later.

Lisa: Oh, wow. Well, listen, meant to be.

Carrie: Absolutely meant to be. He is a delightful human.

Lisa: Carrie, again, I am just so excited to have you on the podcast because so much of what I coach my moms about and so much of my own experience, especially as of late with my son being 16 years old is captured so beautifully and eloquently in your latest book, *Half My sky*.

Carrie: Thank you.

Lisa: But I also just want to go back a little bit because this is your third book, I believe about Autism. Is that right?

Carrie: Yes.

Lisa: Yeah. And so I just want you guys to imagine. This was almost 10 years ago. I was in a Barnes & Noble because that's the one thing that my kiddo really liked to do. He liked the Thomas trains at Barnes & Noble. And so he would just play and whatever made him happy, we do. And so we were there and I just remember browsing these special needs parenting books. And there was probably two, and yours was one of them. And as soon as I saw the title, *What Color Was Monday*? I just knew instantly that I'm getting this book and I loved the book so much.

But when I read it, my son was about your son's age. And so I feel like I've tracked with you through the years. And so before we talk about any specific book or your blogging and everything else you do in this community, I just want to ask you. Why do you share your story?

Carrie: Well, I'm a person who, and this will show up again later, I'm a person who lives out loud. I always have been, it's just consistent with my temperament and my personality. But I had a real kind of light bulb moment of where I really wanted to be more intentional about sharing our story. And it was before I started writing *What Color is Monday*? It was before I started blogging. We were in a hotel and I write about it in the book. We had just taken the kids to a water park. It's something we had done a couple of years in a row.

And we got to this one hotel where we always stay and Joe kind of dropped me and all five kids and they were really little at the time and went back to get the suitcases. And I walk into the lobby with the kids and there's a man standing there with his dog. And at that time, Jack was absolutely terrified of dogs to the point of complete panic, really almost a panic attack. The times that I worried he would run into the street if it meant getting out of the proximity of a dog. So immediately all the kids and myself are kind of on high alert.

And the other kids say to me, "Mom, a dog, it's a dog." And I said, "I know. Okay, let's just wait and see what happens." Because Jack was at least staying within the lobby, which was progress in and of itself. And I went up to the hotel desk and said, "There's a dog in here." And they said, "Yeah, in the last year we became dog friendly." So still Jack was in the room and I thought, alright, let's just see how this might play out. Joe, in the meantime had come into this space and I sort of gestured to him, let's just give this a moment, let's just all breathe.

And I said to the man, I said, this makes me emotional, I said, "This is my son, Jack, and he has Autism." And the man started to call out really quietly, really gently, "Jack, this is Gracie. This is my dog, Gracie, and we're waiting for you. We're here and we're waiting for you." And Jack at that time, his anxiety manifested. He would pace and circle the room, and he was circling and circling. And the man sat down on the floor and he said, "We're waiting." He just said it many times.

And Jack just sort of, over the course of 10 to 12 minutes, circled closer and closer. And he reached out and he touched the man's hair first. And then he pet the dog. And I thought, this is the side of humanity I want to show people if I can. This beautiful, gentle breaking down of barriers between boy, dog and man. And I remember riding up in the elevator to our room, thinking, I want to write. I'd never been a writer, ever, never really written anything. I said, "I want to start writing." And that was sort of the birth of the idea of, *What Color is Monday*?

Lisa: Oh wow, that's beautiful. There's a lot of fear out there, I think, in the Autism community for sure about what other people will think of our kids and us in public. And I'm not going to say that it's not warranted. But I have also had experiences that have taken my breath away. I was on a train from Connecticut to Philadelphia with my son and his OCD was the beer. And you talk about this in your book about how you just sort of can't explain it until you've experienced that constant need for reassurance.

And I paid extra so we'd be in the business area where it would just be the two of us. And I was hoping that no one would be next to us. But there was a young man sitting next to us with his laptop doing work. And I was just like, "Oh, this poor kid." At some point my son got up to go to the bathroom and the young man turns to me and he's like, "I don't know what's going on here. But you're doing an amazing job." And I lost it. We don't know what other people are thinking. We don't know what their experiences are. And sometimes we are really pleasantly surprised.

Carrie: I agree. I've never really had a moment where I felt outraged. And I know people have. I've had moments where I had to stop and think, how far do I want to take this conversation? Just a couple of weeks ago I was at a cocktail party and one woman said to me, "Well, you know, it's a spectrum, right." And I thought, okay, I do know.

Lisa: Tell me more. It's my first day.

Carrie: Yeah, it's not really my style to sort of combat people. I don't think that's where true advocacy lies. I had a conversation with a woman about a year and a half ago, just as my son was about to leave for this program he's in. He's in a residential program that has a lot of scaffolding and support. And it took quite a process to find it, get him applied, get him in, all of it.

And I was talking to this woman at a cocktail party about her daughter who was going away to college also. And she said, “Well, if it doesn’t work out, you’ll just find another program.” I wanted so badly to chomp at that bit and be like, “There is no other program, you don’t get this, the magnitude of this.” And I have to check myself in those moments and think, I’m not teaching anyone. If I’m reactive, no one is teaching or learning. So it just really all begins with storytelling. And I always say, “If compassion is a house we build. Storytelling is the key to the front door. I don’t think you can get in anyone’s hearts and minds otherwise.”

Lisa: I definitely agree with that and I have had to fight that bitterness in myself because I’ve gone through something very similar with Ben. Did a lot of work to get him to a place and then the place didn’t work out and the finding of another place. And well-meaning people saying, “There has to be something.” And I would love for that to be true, I really, truly would. And I don’t want to jump down your throat. But once you’ve gone scorched Earth across the country looking for places and getting rejected and you hear something like that, it hurts.

Carrie: Yeah. It’s perspective for sure. And I just think I’m so glad you don’t have to worry about this. That’s what I say in my mind.

Lisa: That’s a lovely way of putting it. Alright, so I would love to talk to you about *Half My Sky* and this is your most recent book. But I first just want to say, wherever you are in this Autism journey, be there. So if you have a seven year old, be at seven. If you have a 12 year old, be at 12. If you have a 16 year old then come with us as we talk about this. And I just say that because part of my hesitance sometimes in sharing our story in my podcast, or even in my social media is, I don’t want to scare the crap out of people.

I mean, quite truly this might not be your experience at all. We know all of our kids are so different in so many ways. And there are people who have the experiences that Carrie and I are going to talk about. And so if and when you have them, you know that you’re not alone. So I just say that with the caveat for everything that we talk about is, don’t use this against yourself. Don't use it to terrorize yourself. Just take it in as information from two Autism moms who have done a thing or two and are here to support. So with that, Carrie, can you just please tell us about why you wrote *Half My Sky*?

Carrie: Well, the number one question I get is about puberty and the close second is about how we found Jack's program. I think both are really unexplored topics. And like you said, we have traveled this road. And I think when Jack was young all I wanted was an older Autism mom, somebody who was 10/12/15 years ahead of me. And now I, as that person, feels a somewhat of a responsibility to share what I know and share what did work and didn't work.

And I think *Half My Sky* really captures all of that in a storytelling way. I had first expected to write it as a traditional book and I went to my editor. So the backstory is, I had a publisher, the same publisher as *What Color is Monday?* And I started to flesh it out. And I said to my editor, "Just the chapters are not working for me. I can't do chapter style."

Lisa: Too rigid, too rigid for your lifestyle.

Carrie: And we agreed I could move to letters. And I wrote the whole thing and she said, "I love this book. I absolutely love this book but it is not what you promised us. You promised us a guidebook." And she's right, I did. I went back on my contract because then I was starting to be like, "Well, now what, they don't like it for what it is." And I did promise a guidebook, even Joe. So I'm not great at reading contracts. So I'm like, "Did I say that?" And he's like, "Yes, it's right here, you signed at the bottom for a guidebook."

We tried to wiggle around in it and she'd say, "Well, at the end of each letter maybe you could say, dear reader, what would you have done with your mother-in-law in this situation?" And it felt like tearing my own skin off. I said, "Absolutely, I can't alter it, but what I can do is write your guidebook." Which I'm doing right now, which is kind of fun and it's stretching me differently as a writer. But I said, "How about I just keep this and I'll just see where it lands." And that began the road of self-publishing. And that's what *Half My Sky* is, self-published.

And it was fascinating because it went on pre-order November 1st and I found out three weeks later. Now, I have a nice following. I have a wonderfully loyal audience. I'm by no means as big as many of our peers. And I logged into IngramSpark which is what you use to self-publish three weeks in. And I said, "What is this number? What does this mean, 8,000 units?" And I called Joe over and I'm like, "I really don't know what this means." It can't mean what, you know, I figured a couple 100. If I had a couple 100 in pre-sale, I'd be thrilled and it was 8,000 copies sold.

And at this point, we're close to 10,000, which when I share this information it is not a humble brag. I am as blown away…

Lisa: Wow. I'm blown away that you're blown away.

Carrie: I'm blown away and deeply honored that people see a piece of themselves inside of our story. I always say, "Good storytelling helps a person see a piece of themselves inside of it. Great storytelling helps them, even infinitesimally change the way they live their own story." And I don't have any idea about where I would fall in that. But it is so meaningful to me that people see reflections not only of their Autism journey, but just motherhood and parenting and marriage.

Half My Sky was named really for marriage because I would love to hear what you think as a reader of it, but to me the book began to represent this central love story, this jagged, complicated love story at the center of our family. So I'm thrilled by all of it.

Lisa: That really did come through to me, for sure, and transparent. I am divorced. I was married when my son was diagnosed and for a few years later. And I know some of the paths that people take in that mom going all in on everything and dad's grieving in a different way and those paths not crossing. And that's a lot of complication there. And just the way that you and your husband have been able to navigate and manage that over the years, I think is really beautiful.

Carrie: Thank you. It has not always been easy. I really am determined to share the raw parts and the jagged pieces as well as the good times.

Lisa: Well, I think that's why people connect to you and connect to following your story is because, I mean, I've been following you too. And you are pretty clear about some of the things that you don't love at times or aren't going great. And I think people need that because otherwise there's just this idea that other people are doing it better than me, they've figured it out. And I think that really is intimidating to people. They just use that against themselves. So to be able to see the other side of that or just to know that it exists, can be a comfort.

So, Carrie, there is so much in this book that I highlighted that it became a little bit ridiculous after a while. But I just want to read one of the things that I highlighted and talk to you about this. This is something that I've been talking to my audience about a bit and that is the grief that we experience as Autism parents. And there is no describing our grief because it's not your typical grief. I talk about it as more of chronic grief, it's continuous. And so you say, "Autism is heartbreak by 1,000 paper cuts." Can you tell me, what do you mean by that?

Carrie: Yeah, I first thought of that because I often sort of observe the world around me and it often includes seeing a kiddo Jack's age doing something that Jack would find difficult or would have no interest in. And for example, I could see a kid, Jack's 19 now, a 19 year old sort of flirting at the mall with a girl or bouncing a basketball in the corner. Or I could go to one of my other kid's sports and see a boy running up and down the court. Jack is nearly 6'6, he's very, very tall.

And I can't help but wonder sometimes if Autism hadn't sort of stolen his coordination, his muscle tone, his interest in anything to participate in with a group, he really could have perhaps been an athlete, quite an athlete. And I feel that staying inside and I have to acknowledge and think okay, well, it's fair and it's there and move forward with it, but they're not to be overlooked.

Lisa: Yeah. So say a little bit more about the acknowledging because were you ever at a point where things like that created resentment and anger in you, and have you evolved over time or were you always this gracious?

Carrie: I don't know that I ever had resentment or anger. I was always able to celebrate the accomplishments of other kids in my universe and seeing my nieces and nephews move forward when Jack was a little bit stuck. If I had anger, it always manifested as anxiety. So anxiety, I say it's comorbid to Autism. I wish I had known that when it descended upon Jack at age six. We were absolutely shocked at what was going on.

And people ask all the time, "Would you take Autism away?" And I say, "I don't have an answer for that." Because I can't think of a time when Jack only had Autism. So I don't know what that looks like. Only really, I mean he was six, but it complicated so much that I remember very little before anxiety descended. So I feel angry at anxiety because it's very difficult behavior to continually try to solve.

Lisa: Yeah, I feel the same way about OCD. I joke to my friends, "If I ever write a book, it's going to be called *I Miss Autism*. Because I was like, "I've got this." He was thriving. He was doing well. I think I've figured this out. I figured out how to live alongside this and for him to thrive. And then when OCD came, it just pulled the rug out from under us and it really just made life so almost impossible.

Carrie: How does his OCD look? Jack's OCD's fairly managed with medication.

Lisa: Yeah. Ben's is what they, we were at Bradley Hospital in Rhode Island for four months in an intensive program. And what they said is, "Ben's OCD is ever present in his brain." And so it could be, I don't know if three years ago when I passed my principal in the hallway if I thought that I didn't like him, it's stuff like that. And so there is no way for you to close that loop.

And depending on how much his anxiety is up and how he's doing in other ways, that can result in self-injurious behavior towards himself because he's feeling frustrated, destroying things, aggression toward parents, that kind of a thing. It really depends. But for at least three years it feels as if we've been held captive by it, so yeah.

Carrie: I feel that. I understand that deeply. That sensation of being stuck is so real when you're right alongside them. Jack, I was bringing him to the bus to return to his program over Thanksgiving, and he started to rock, he stims even at his size and his age. And he was rocking in his seat and he kept saying, "I can't get this thought out of my mind." And I said, "What thought?" He said, "I know I put my bag in the car, I know I did." And I knew he did too. Jack would never forget anything.

And he said, "I'm just not sure." And I said, "Okay, that's easy to fix, let's pull over." We're right at the end of the road. "Take a look and see that you did it." But I thought, same thing, it's always there.

Lisa: Yes. That would be us every week on the way to skiing. I would have him put his stuff in the back seat, but before we turned into the parking lot, he would just be like, "I don't know." That loop would just return. With OCD it's really hard, at least for me, to not be annoyed.

Carrie: Of course.

Lisa: [Crosstalk]. Yeah, I packed it. It's not my first day. Come on. And then realizing this is just, it's manifestation.

Carrie: It's easy to take personally. And that kind of makes me think of something I talk about with puberty is that in sixth grade, Jack had terrible, terrible behaviors. I was going to pick him up, walking past the carpool line, deep in shame. And it took me a while to understand the idea, the inclination we have as parents to tie our own moral compass to our kids' behaviors. We're not a family that hits people. What are you talking about? We don't swear in church, we don't.

When it comes to Autism and puberty, it's really important to untether yourself from that idea. It is not a reflection of who you are or who your family is. It's just a perfect storm of hormones, anxiety and Autism, all wrapped up into one.

Lisa: I completely agree because when this happened with my son, there were the people before and the people after. And the people after, who were meeting him was like, "You have a violent child." The people before were like, "Who are you talking about? This is the kid that I would sit next to the new kid in class or I would send to the principal's office to pick something up." And they had no idea. They were just flabbergasted. And so I am trying to impress upon these new people and I'm sure they thought that I was in deep denial.

I was like, "You don't understand. A couple of months ago he was in a contest in front of his entire school, competing on the stage. He was learning how to ski for the first time in his life and he was going to parties." And I think really it's like I was mourning. That was the trajectory I just hoped would keep going. And it's been interrupted right now. I don't know where we're going to get back, but it's definitely been interrupted and that was just really hard to wrap my brain around.

Carrie: But I like the way you phrase that, an interruption. That's a really beautiful way to look at it.

Lisa: Yeah, I'm going to have to remember to keep telling myself that. This book really hit on so many of the things that I coach about and that I'm dealing with. And it's really the intersection of puberty and Autism and then the untethering of the mom child relationship. And I think this is so tricky because of our children's diagnosis. We are really called upon to be their eyes, their ears, very early in life, interpreting the little things, understanding, all of that. And so it becomes part of who we are with these children.

And then you have a child who doesn't really take comfort from many people or you're the person who can do the comfort, you want to do it. And then you get to this place where you're like, "Okay, well, now I have to unwind this because they have to fly on their own, or them being dependent on me to self-soothe is not useful for them and it's not useful for me." And so please just talk about that, all of that.

Carrie: Yeah. I mean it is a fascinating concept to me. I'm still continuing to explore it as he moves further and further into a somewhat independent life. And once we figured out where he was going to go and he was excited, we had to take steps to make sure he was physically ready. And could he manage his medication and get refills? Could he manage money to some degree? Keep his wallet safe, all of those prosaic practical measures. And then I had to say, "Is he emotionally separate from me enough to stay away from me?"

I think the inclination is to create, for lack of a better word, a somewhat codependent relationship. It's no one's fault. It's just the nature of life alongside a diagnosed child. And I certainly was guilty of it to some degree. One example is that I name in the book is that whenever I was out of the house for any period of time without him, he was always standing in the doorway waiting for me, always. And it was bittersweet and sometimes it was maddening because you just want to sit in your car and scroll through your phone for two minutes.

And seeing him standing there one day, I thought I don't want him always waiting for me. I want him to grow and blossom in different ways. And so just practically started to talk about how, notice all your brothers and sisters don't come to the door for me. They wait till I come inside the house. Ways that he could envision himself separate from me. So I took these steps to make sure he could emotionally sort of be away from me. Once he got to the program though it wasn't a 100% success story.

From his first day there he started texting us 20/30 times a day. Again, bittersweet, but also maddening. It was incredibly disruptive. And it was little things. What he had for lunch, what the weather was, if a celebrity, God forbid, passed away, that was the whole news announcement in and of itself. We had the opportunity to work with a phenomenal parent coach that was given to us as part of the program, her services. She never met with Jack, she only talked to us.

And she said, “You have got to disentangle his frontal lobe from yours. For so long your frontal lobes were connected.” That was really fascinating. So in my head, I sort of came up with this model, it’s time to move him. And I actually made the W with my hands, move him from a we to two I’s. And that again was just very practical work. It was, “Jack, I will answer texts from two o’clock to three o’clock today.” That was the only time. “We’re going to talk on the phone once a day.” And it was gradual.

Our success with this was gradual and I’ll give you an example. He just started his second year there. I said to my husband two days ago, “I haven’t heard from Jack today.” And he said, “Neither have I.” And that is success in our world. That is success. I think as I move into this next season of life, where I no longer really live with my son, it’s very eye opening to me in the ways, not only did I participate a little bit in that codependency, but the steady narrative of mothers around me. I’m the only one that can do this. I’m the only one who can keep him safe. He’s got to live here forever.

I understand those are fear driven and it very much depends on the profile of your kiddo’s diagnosis for sure. But I’m here to say that that’s not always the case. And now when Jack comes home, he’s coming home in two days for the holidays. Watching him around this house, it’s like watching him put on a sweater that he’s outgrown. He’s outgrown us. It doesn’t fit anymore. It’s itchy for him. He doesn’t want to be parented. He wants his life. He wants his life.

Lisa: That’s so interesting. So, Carrie, there are so many rich topics in this book. And in my opinion, I think that this book is really good for anyone, no matter where you are in the journey. Because even if you’re not here to get the perspective of someone who’s been through as much as you, I think could be really helpful for parents who are trying to do everything. They’re always second guessing whether they’re doing enough and the right things.

And I was just really struck by you saying, “Do I think it was that extra speech that I pushed for that gave us the outcome that we have now?” No.

And I think that a lot of parents struggle with this, if I don’t get the IEP right this year, then he’s going to be homeless. At the end of it, he’s going to be homeless. And so just from somebody who has perspective, who’s probably been through ups and downs in the services that you’ve gotten, how would you respond to that?

Carrie: Yeah, I get that question a lot, always from a young, earnest mom, “What should I ask for at the IEP table?” And I always say, “That is not what, like you said, got Jack from A to B.” You’re trying to raise a whole child and a whole child doesn’t spring off of a conference table. Take inventory of what you’d like your family to look like. This is an opportunity. And a diagnosis is an opportunity to reinvent the life that you want. We decided we want our family to eat dinner together at night. We want one activity per kid per year, something that’s really meaningful to them.

My husband really wanted religion to be a part of our life, family, interactions to be a part of our life. So we took all of that and sort of folded our family around those pillars. And it had nothing to do with the IEP table. Jack learned from his father everything Joe could think to teach him, how to change a tire, how to hang Christmas lights, how to pray in church. He set the table with me every night. We always had sort of this list for lack of a better word, of soft values we wanted to extend to Jack.

How do you cheer someone up after a bad day? What does forgiveness look like? What do you buy your cousin when she has a baby? That is a huge part of living and thriving in our world. And you can build speech and OT around those activities. I always say, “Beware of the distractions. When you’re chasing hippotherapy and gluten free, and maybe that’s important for your child’s profile, but just be aware if you’re also utilizing that as a distraction.”

Lisa: I, 100% agree with that, because what I see is a lot of parents sort of buffering and avoiding their own fear by just doing more and more and more and more and more. They think the answer is in the more and truly it's not. This is going to be difficult. This is going to be challenging. There is no when this gets easier per se. You can get better at how you handle it by growing your resilience, growing your resourcefulness. And I always like to talk to people about these ups and downs are the rule and not the exception.

Because I see a lot of moms coming to me, they're like, "If it's not one thing, it's another." And I'm always like, "Yeah, such is life." While I understand the sentiment, I also know that living in that frame of mind is really discouraging and defeating. And so instead, trying to focus on how are you navigating this? How are you problem solving in this? What skills are you utilizing? And so I like to think of myself at this point as I'm a master problem solver and I can get my brain on board quickly.

So we had the situation where my son was in Utah, all of this effort to get him to Utah to this school. Within one week he was discharged from the school, a number of things happened. And so all of our hopes and dreams were on Utah for months. And within a 24 hour period, it's not Utah anymore.

Carrie: Wow, that's a lot.

Lisa: But I could stay here with all the reasons it shouldn't be this way, all the things that I think should have been done. It's not Utah anymore, we're moving on.

Carrie: I understand that completely. You can't linger. You can't linger. You try things and you hope for the best and then if not, you try something else.

Lisa: Yeah. And I think another thing that happens is when we're always so hyper focused on these different achievements. And I especially see this with my parents where their child is say in third grade, but they're at a first grade reading level or whatever it is. Whenever we're focused on those types of achievements, we're always missing out on the amazingness. And I think about telling the story about Jack and the cowardly lion. There's just so much intelligence and understanding another point of view and empathy. There's so much in that. It's like, where did you get that from? That wasn't the IEP table.

Carrie: Right. We were sitting around watching them. It was [inaudible] and when it was over, he sat up straight, I think he was eight or so and he said, "The lion has Autism." And I said, "Why would you think that?" And he said, "He's afraid all the time." And it was such a glimpse into his heart and into the fear. Like we talked about earlier with OCD, we really cannot understand what that feels like for them. And it's hard for me to fully process what Jack's ever present anxiety feels like for him.

And in terms of easily focusing on the lack of progress or all that's going wrong. This parent coach, last year, Jack hit a few speed bumps and we didn't know if he was in the right space. And there was a lot of pressure to make this work, given how expensive it was and how few places there are, just like your Utah. So I was doing a term called catastrophizing. I'm good at it. I like it. It's very comfortable for me, where I imagine all the worst case scenarios. He's going to get kicked out. He's going to live here forever.

His heart will be shattered when we have to go pick him up because he loves it even though he was making very impulsive choices that said otherwise. So this parent coach said, "You know what? Get a whiteboard. Get a whiteboard and list all the things that are going wrong and then list all the things that are going right. And then you have them all just spelled out for you in one spot." It was beautiful because I often call it the Autism balance sheet. And I've had it in my brain since the day he was diagnosed.

He's not talking, but he ate a banana. He slept two hours last night but he took a nap. Constantly checks and balances, to this boy.

Lisa: I totally relate to that and I have to say that I was probably deluded for longer than maybe I should have been by the fact that my son was talkative and so pro social because I really viewed that as unlike Autism. So I just had so much hope for where that would go. And now those assets are almost liabilities in some way for him. And so the fact that he is so socially engaged or wants to be, then it’s seeing the pain of him realizing that he doesn’t connect with his friends like he used to.

He doesn’t understand what you call the fluidity of friendships. And then there’s times where I’m like, “I wish he was impacted in a way where that didn’t hurt him”, because it’s painful to see that.

Carrie: Yeah, I understand that. There’s a certain sort of vulnerability and rawness when your child is self-actualized as Jack and Ben are. Jack knows who he is in this world to some degree. He knows what he has and that causes him a little distress.

Lisa: I was so surprised last year, my ex-husband, I forget what he got him for Christmas. He [inaudible], “Ben, you’re never going to believe, guess what happened.” I think maybe it was a new movie came out or a new game. And Ben says, “They’ve found a cure to Autism.” And I was really blown away by that. I was like, “Oh, my gosh. I didn’t realize that that was in there for him.”

Carrie: I know when we visited Jack for a parents weekend, he said, “Do you think I’ll ever get married?” And yeah, they want things for themselves.

Lisa: Ben very clearly wants a girlfriend. He’s been very clear about that.

Carrie: I talk a lot about the duality that exists within kids like ours. They have their physical age and then they have their emotional age. And for so long we only parented the younger version. And now as Jack is sort of transitioning into young adulthood, it’s really important that we honor both versions because they both exist fully in him. I don’t think one takes up bigger room than the other. And so I see a lot on social media. Now that I’m here I’m more attuned to it, sort of not to infantile him.

I stopped calling him, big guy. He’s very tall, but I was calling him that a lot. I’m determined to sort of make sure he understands that I respect him as a young man.

Lisa: Yeah. I think that's so important. I mean, that's interesting, in our household that's been something that I think we have done well in that, having very separate space and him having very certain responsibilities. And us not going into one another's space. I don't just walk into his bedroom, that kind of thing. And so that's definitely evolved over the years because before he was attached to me. And so as they get older, they're less wanting sometimes, hopefully to be that attached.

Carrie: Right. It's a natural progression for sure.

Lisa: Yeah, definitely. So, Carrie, why don't you tell us, for this season in your life, what has been the most challenging and the most rewarding?

Carrie: The season being of Jack and all my children leaving the house. They're kind of deeply intertwined, honestly. I've been writing about Autism for 11 years. And I thought, well, when my subject walks right out the door, what will become of the work that I dearly love? And I really thought all of that would kind of come to a close. I had some anxiety about it, to be honest, in the months leading up to him leaving. It was kind of coupled with his physical leaving. And now I'm busier than ever with writing and working and collaborative projects, which is really, really exciting.

It took Jack not living here for a period of time for me to really realize something I say a lot, that our nervous systems are closely intertwined. So when he lived here, I was often on sort of high alert. And now I have breathing space where I don't have to worry about anybody else's nervous system but my own. And I'm grateful. I know that that's not popular to say, but I am grateful that he has a space to call his own, somewhere that he loves because in the long run it wasn't really meant to be for him to be with me forever that way, it wasn't natural.

Lisa: Yeah. No, I agree with that. Interesting, I have been telling my friends how pleased I am about my son. My son right now is at a mental health hospitalization. And he's doing well and he's happy and he's safe. And no mother wants to be like, "Guess where my kid is for Christmas." It's not what I ever imagined, but I know what the Christmases before this looked like. OCD had sucked the joy out of everything and in some ways it made it dangerous.

And so I am at that point now where I have been able to untether from him for quite a bit of time to stand on my own because before I was so concerned about how to manage things around him and for him.

Carrie: And I often say, Jack still has Autism. He still has severe anxiety. He didn't shed those like a snake skin. He just picked them up and moved them, three hours. But he has outstanding support. It was time for somebody to take the baton from us and see if they could get him to run a little further and that's what's happening.

Lisa: Yeah. And I did say, kind of harkening back to something you had said before about the mom being the only one. I've always encouraged my parents, whenever a teacher leaves or an aide switches and I know that those can be disruptive. But I always looked at those as just more opportunities for my son to have to adapt to other people, because, again, such as life. Because you don't want to be that single person dependency. I understand it has its benefits in some places. I understand that sometimes that's just where we are, but as a long term plan, it's problematic.

Carrie: It's not sustainable. I remember being in a school meeting, they were announcing some changes to the special ed program. And one of the changes was you weren't going to have a pairer for more than one year. And I didn't think much of it, but a lot of the parents were upset. But the explanation, which I think is really valid, is if your kiddo can only do a skill for one person, is it really a skill? It needs to transfer. I kind of modeled my own untethering with that in mind. If he can only behave in a store if I'm with him, can he really behave? If he can only take medication if I give it to him, is that medication compliant? Not really.

Lisa: No, that's such a great point. Well, Carrie, it has been such a pleasure having you on for this conversation, I really enjoyed it. And I just want to end with, is there anything that you would like to share before we wrap up?

Carrie: No, I think we've covered a lot. I am grateful for the opportunity to be here and thank you for reading the book ahead of time. That was amazing.

Lisa: Of course, yes, I was happy to do it. And I highlighted a lot of it. So I will be noting some of this in likely upcoming blogs. I actually, I did a podcast episode, you might not know this. I did it about medication shaming and it was actually inspired by you because you had posted something on your blog about medication and about how you need to do it because it softens the edges and all that kind of thing. And it just sparked in me, why is she doing this? Why are you sharing?

And I thought that maybe some of the reason could be is because we're always so questioned by it. I would never put my kid on medication. I can't believe you're doing that. And please know this was the last resort after the last resort.

Carrie: That was probably 100% why I've shared it. I try to share things in a way that people can be open to receiving. I shame myself about it. I have enough second guessing of myself and yeah, don't put me on the defensive about it. I often tell parents to come up with a toolbox of responses, particularly during the holidays for when things come up like medication. Things you can easily retrieve and they're not reactive. I know we're working on it is a great one. Something that doesn't invite other questions or any kind of debate, because that's not where you want it to happen.

Lisa: Yeah. No, for sure. Alright, well, we are going to wrap up this episode with Carrie. And for part two, I am going to be talking to Carrie about her latest venture. So stay tuned for next week as well.

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, 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.