



**TURN AUTISM AROUND**  
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 060

## *Mother with Autism Shares Her & Her Son's Autism Diagnosis Story*

Hosted by: Dr. Mary Barbera

Mary Barbera: You're listening to another episode of the Turn Autism Around podcast. I'm your host, Dr. Mary Barbera, and today I'm doing something I haven't done before: I'm interviewing someone who is on the spectrum. And I'm going to tell you about that interview in just a second.

Mary Barbera: Before we do that, I do want to say that this episode and all my episodes are sponsored by my free online course webinars that you can attend for free, at [marybarbera.com/workshops](http://marybarbera.com/workshops). During these free webinars, you'll find out more about my approach and more about joining my online courses and community to find out the latest information directly from me.

Mary Barbera: So now into the introduction of Eileen, who is a writer and a photographer. She wrote the book called *All Across The Spectrum*, which was published in 2019, and she is the founder of the Autism Cafe blog and Facebook group where she shares the ups and downs of raising a severely autistic child while being on the autism spectrum herself. Eileen was born in France and now lives in Austin, Texas with her husband and two sons, Charlie, who is six years old, soon to be seven, and he is on the autism spectrum; and her younger son Jude. So it's a great interview. She shares her perspective, so can't wait to share it with you now.

*Welcome to the Turn Autism Around podcast for both parents and professionals in the autism world who want to turn things around, be less stressed, and lead happier lives. And now your host, autism mom, behavior analyst, and bestselling author, Dr. Mary Barbera.*

Mary Barbera: Okay. So, welcome Eileen. Thanks so much for your time in joining us today.

Eileen: Yay. Thanks for having me.

Mary Barbera: Sure. So you are my first person who actually has autism that I've interviewed for the podcast. So this is going to be a special treat. But first I want to talk about your fall into the autism world. Not for yourself, but actually when your son started showing signs. So can you tell us about your initial fall into the autism world?

Eileen: So it all started with my son's diagnosis, which was when he was almost two years old. And we didn't know at first that the signs he was showing were actually signs of autism because it was our first child, and we didn't know a lot about autism. But he's always been in his own world like, you know, bubble almost, you know, he wouldn't approach other kids. He was crying a lot. He wasn't talking much. And then he had a regression; he lost all the words he had. He only had 10 words. So, but still like he stopped talking altogether. He would not make eye contact with us. He would not approach us in a way he used to, he wouldn't play with us. And he would spend his time lining cars up. Like he could do that for 10 hours a day. That's all he wanted to do. And if you move the car out of the line, he would like freak out. And so we called a ECI, which is Early Childhood Intervention to know, you know, to get help. And...

Mary Barbera: Were you thinking autism at this point?

Eileen: No, I was thinking something is odd, but not necessarily autism. Maybe he's just delayed, and of course they came and evaluated him and he qualified for everything they offer; speech, OT. And after two months of doing ECI, so he was like 18 months at that time, they were like, this is out of our league. You need to get him evaluated for autism. And we did the MCHAT. Have you heard of it?

Mary Barbera: Yes. Yes. I actually, I have a video blog on the MCHAT and we can link that in the show notes. So yes, thanks for bringing that up. Okay. So you did the MCHAT when he was about 20 months old.

Eileen: Yep. And he scored 18 out of 20 after the follow up question. And I seen the risk for autism is like after three, or something like that. So he was like off the charts and yes. So we met on an appointment with a developmental pediatrician, which she's who diagnosed him when he was 22 months I think.

Mary Barbera: Wow. You got in quickly, is this in Texas?

Eileen: We got so lucky. So what happen is that we had an appointment six months away... but you know, we were struggling so much, it kept getting worse; Charlie's symptoms. And we called a few times and were

like, if there's a cancellation, please call us. And one day they said, actually we just got a cancellation, can you come in next Monday at eight? And we did.

Mary Barbera: Wow. So being persistent on the wait list really helped.

Eileen: Yeah.

Mary Barbera: Okay. So he was diagnosed at 22 months of age. Okay. And he was given a score of up severe autism at that point?

Eileen: Not then, but yeah, the next appointment, six months later he was diagnosed a level three.

Mary Barbera: Okay. So now when you get a diagnosis initially, at least in your case, they don't give you a score or a severity level until six months later, or you think maybe that was just your position?

Eileen: I don't know why didn't give it right away, but yeah, the next time it was on the paper 'level three autism'. What they did the first time when he got diagnosed they recommended ABA therapy to start with 25 hours a week. So that was like so overwhelming. You know, we had just learned Charlie was autistic. Like we didn't really know what that meant at that time. And yeah, that's it. So then we started looking for an ABA center.

Mary Barbera: So how long did that take to find and to secure an ABA center?

Eileen: About two months.

Mary Barbera: You're good luck on quick speed here. So what year was this? He's almost seven now?

Eileen: So 2014, 2015? Yeah, 2015.

Mary Barbera: Okay. So you know, cause most people that I talk to in my online courses and community are like, it takes them nine months to two years to get a diagnosis and then it takes them another six months to 12 months to get ABA started or any a spot and ABA center. So it sounds like you were, you were pretty fast tracked, mostly from you pushing, I'm sure. I'm sure it wasn't like everything was handed to you. I'm sure you had to make a lot of calls and all that. Right.

Eileen: We were very persistent and I've seen that really helped, you know. One call that you're sure there's no room and you know, we're ready for it. It's like whenever you can get us in. And that helped.

Mary Barbera: So up until that point, when he was diagnosed at 22 months of age, you never knew or thought that you had any autism yourself? At what point did, did you start to think, well maybe I'm on the spectrum myself?

Eileen: First of all, I grew up in France and their autism... of course it's a thing, but people don't know about it. Only like the most severe kids are diagnosed. And even then like the mother is blamed; kids are putting institution. I mean you think of France as this country that's like so advanced when it comes to mental health and all these things. But really it's not like that. So I grew up in France and I've always felt different. I always knew something was different about me, but it wasn't until Charlie was diagnosed with autism and that I learned about the severity levels, I started thinking, well yeah, maybe I'm on the spectrum, too.

Eileen: Because my mom, I told my mom that Charlie was diagnosed obviously, and I told her the signs and she was like, you were the same as a kid so Charlie can't be autistic. Except that I had language and that was the difference to her. And I decided to go through a therapeutic assessment. Which is like, you know, hours and hours of testing. And yeah, I was diagnosed with high functioning autism, which would have been Asperger's, you know, they changed the term. So I'm considered a level one, is my diagnosis.

Mary Barbera: Okay. And what year were you diagnosed?

Eileen: That was the year after Charlie. So 2016.

Mary Barbera: Okay. And you said you had hours of evaluations?

Eileen: Yeah, yeah, it takes a long time. The therapeutic assessment process is like very long. They do a lot of tests. You know, when you check boxes; a lot of talking with the doctor; and also they talk to your family and people who are close to you because autism starts in childhood, right? Like you don't just become autistic. So then it's, you know, about me growing up and all of that. So it's a very long process and it's, you know, it's thorough.

Mary Barbera: Yeah. Did you have problems in school and during play dates and that sort of thing?

Eileen: Yeah. And I never understood why... Like people would always laugh when they were around me, the way I was talking. And I had very different interests from, you know, my peers. Like I listened to music from the 19th century, and I didn't really care about music that was, you know, new at that time. I liked reading. I didn't like going to the grocery store, I couldn't do social things if there was more than one one kid and I just fell apart. Yeah. Different.

Mary Barbera: Yeah. And what about the grocery store, you know, was hard for you, or maybe is it still hard for you?

Eileen: So hard, and I do grocery pickup whenever I can. I'm really trying to like, you know, push myself out of my comfort zone. But sometimes I go to the store and I fell and I have to leave still. And you know, it's, yeah, I'm still working on it, but it's the noise and the people. I think that people is, the hardest thing for me because, I don't know where to put myself. I don't want to look at the people, and it's like so loud and there's just so much going on at once and it's overwhelming, I would describe it.

Mary Barbera: Yeah. Yeah, I can imagine. Okay. So you are married and you have two kids, and you had both your kids before you knew you were autistic. And how was introducing the, well... Not just Charlie's autism, which we're going to of course talk more about, but also your autism. I mean, how... Let's talk about your autism. How has that affected, has that affected your marriage or your relationships?

Eileen: It effects my marriage. You know, I don't always see the other person's perspective. Like it's something I try to work on a lot, but I often say, this is how I feel so this is how everyone must feel. And so it's hard for me to understand that people might feel differently, but I'm aware of it. So I'm like, you know, making an extra effort to see my husband's perspective, or people in general, but it's really affected my friendships for the same reason, I would say. And I don't always pick up on verbal and nonverbal hints, and all of that. And it's hard. And you know, the fact that I don't want to do certain things and people don't necessarily understand like, why do I not want to go to a concert? And I have to, you know, say no. Cause obviously it's like so crazy for me to do that. Yeah. It's affecting my relationships for sure.

Mary Barbera: Yeah. So let's talk about Charlie a little bit. Once you got him into an ABA center, did he start making progress? Is he still at the ABA center? Or how is he now from ages two to six?

Eileen: I mean, he made progress. Now he can communicate basic needs with an iPad. So that's something. So he can say, 'I want' plus items. So I want water, I want cookie. So it's progress, but you know, we want him to be able to communicate more than that because he can't tell us how he's feeling. He can't tell us if he's hurting or anything other than 'I want' plus item. We're working on self-care skills still and yeah, he's making a little progress there. Like he can address himself if you help him and things like that. But yeah, he's still struggling a lot and we're still at the same ABA center, actually, that we started at.

Mary Barbera: And what happens now that he's getting older? Can he stay at the ABA center or does he have to go to school, or is the ABA center a school as well?

Eileen: Well, he could go to school, but they don't have the means to help him. You know, he gets so much more out of one on one therapy at the ABA center that for now we don't feel like it would be beneficial for him to go to school where he wouldn't get the same attention he's getting at this school. So we're just trying to keep him in ABA one more year hoping that maybe I'll make enough progress that school would be a good solution for him. They do circle time and try social interaction there. You know, it's not a school setting, but they do work on group stuff to prepare the kids for school. So yeah, we're just taking it one year at a time, I guess.

Mary Barbera: Yeah. So I did a podcast at the end of 2019 in terms of the five areas where kids get stuck, and it sounds like he's kind stuck or making slow progress in pretty much most of the areas. One of the areas is nonvocal to vocal, like getting him talking now. Is he is talking a little bit or just with the iPad?

Eileen: He mostly uses the iPad. He started repeating words a couple of years ago. Like he tries to repeat sounds and he has a couple words that are very clear like 'cookies'. But he has apraxia too. And so basically no one can understand him and he doesn't understand they're talking, you know, he can only repeat.

Mary Barbera: Yeah. So, I mean, some of my podcasts would be good for him. Like [Marybarbera.com/51](https://marybarbera.com/51) is the areas where kids get stuck. One of those areas is also self-care. The nonvocal, the vocal receptive language. So like the ability to touch body parts, ability to touch items, and then expanding it into more complex skills. Another one within terms of the apraxia, which is common, I have done like four or five interviews with speech pathologists. Some of them are also behavior analysts. One who is Mags Kirk, who is a behavior analyst and an SLP. And she's also talk tool

certified, which we've used for some of my past clients who've had a apraxia. So you may... we're going to link these different podcasts in the show notes to help anybody when they're struggling with kids with autism and a apraxia, which is definitely a lot trickier.

Mary Barbera: So now let's kind of weave back into, I know you are a writer; you write blogs and that's how I found you. Is that, is that what your career was and is?

Eileen: Well I mean, yeah, it's always been a lot easier for me to express myself writing then talking. And so after Charlie was diagnosed, you know, I felt very alone and I started writing on a Facebook page and the response from people was so amazing. I felt like I connected with people and I just started a blog and from there, yeah, it's become what I do as my job. And then I wrote a book, too.

Mary Barbera: Oh, you did? I don't think I know about your book. Oh, what's the name of the book?

Eileen: All Across The Spectrum.

Mary Barbera: Okay. Yes, I did. I did read that in the intro. Okay, so you have a book called All Across The Spectrum. So when was that published? Is that self-published, and tell us about that book?

Eileen: Yeah, it was published by Third Catalog last year in August. So it's still pretty new. It's been six months. And it's about our journey all across the spectrum because I speak about my own diagnosis being high-functioning and raising a severely autistic child. And it has all my photography too, cause I do a kind of a photographer. So yeah, it's a picture book.

Mary Barbera: Oh cool. So the book is about you and your son's journey.

Eileen: It's really for people who feel like they're alone. You know, I speak a lot about feelings that parents may go through that people don't really like to talk about because it's uncomfortable. Things like grieving and you know, negative things that are also totally normal when you have a child who's been diagnosed with autism or any other things. So, yeah, I wanted to be comforting to us as parents, you know?

Mary Barbera: Yeah, yeah. That's great. I was thinking when you said that you have high functioning autism and your son has severe autism... I was thinking of another podcast interview I did with Lori Unum, who is a lawyer, and she is responsible for helping to get insurance coverage for all 50 States for

ABA. And she has a son with pretty severe autism. And in the process found out that her other son, her younger son, who was like eight at the time, has high functioning autism. And so we talk about that in that podcast as well. But it, you know, I've worked with several families with kids, multiple kids, on the spectrum. Not in your, like in your case is unique because I've never worked with anybody who was an adult with autism who had a child with autism as well. Is that a very unique thing or have you met other people like you?

Eileen: Well, I've met a few people like me, but not a lot. And all the other people are high functioning with high functioning children. And I feel like it's a different perspective. So our views on autism are not exactly the same.

Mary Barbera: Yeah. Right, right. And that is what I find, especially with some high functioning adults are, are anti-ABA and... They don't really have the understanding that severe autism. Actually, the blog that led me to you, was you wrote a blog or an article recently called autism is not a gift, or not a gift for everyone, or something like that. And because my son Lucas is 23 and he has severe autism and it's like when you read, you know, if you are high functioning or your child is high functioning and not struggling and you consider autism a great gift, that's awesome for you. You know what I mean? But when you and I work as a behavior analyst for many years and it's like when you have a child who's, you know, self-injurious or aggressive or smearing feces or whatever... completely unsafe needs, total supervision day and night, it's not a gift. It's a struggle for many families. And so, you know, and I don't know how to resolve that.

Mary Barbera: One of our guests on an episode, I'm blanking on her last name, Amy. And she has a son with severe autism and she was pivotal in starting the National Autism Association for severe autism or something, a severe autism group that are lobbying because the higher functioning adults are also very vocal. I'm not sure how many percent of them feel strongly against ABA, but they feel strongly against, you know restrictive environments like ABA schools or centers or, you know... And it's like we need to have options, especially for our kids with severe autism or kids that turn into adults with severe autism because they can't be included in many situations or they can't be meaningfully employed.

Mary Barbera: So let's talk about your article about autism is not a gift. Can you tell me why you wrote that and just some of the things that are in there?

Eileen: Yeah, it's for the reasons you mentioned. The section on the internet is really focused around autism as being just a differentially wired brain. And a lot of people, autistic adults speak about how it's a gift for them. But I feel like it gives the public a false perception of autism because autism can be, is different for everyone. It's different for me, for my son, for you know, everyone on the spectrum is different, and some people will see their autism as a gift and like you said, that it's great for them, but they can't claim that autism is a gift for everyone, and that it's not a disability and just a difference. It's not...

Eileen: I see my son who is severe like yours and I don't even know if he'll be able to live independently. Like, this is not a gift. It's not. He can't communicate. I see the distress it causes him when he's in pain... Or if he's even in pain cause I don't know, he's just screaming because he can communicate. Then he gets so frustrated that he starts self-injuring. Yeah. I really want people to understand that autism is a broad spectrum and this is why I wrote that post just to shed some light on this side of the spectrum that we don't really hear about. You know, in the media, it's all about the inspirational story of the kid who started doing this and...

Mary Barbera: And then becomes a doctor and is just a little quirky, and it's like, that's my dream for a child to get to that point. Like that would be, you know... but it's not that it's not a great percentage like people on the spectrum, especially kids that are diagnosed with severe autism in early childhood, the chances of them becoming a doctor are very, very slim. It's great if it happens, but let's not pretend that that's half the cases or even 10% of the cases, or 1% of the cases. It's a very, very slim minority. And so I just, you know, I want to respect people on the spectrum like yourself. I want to work with people to understand like... I am genuinely curious, you know, what are your reactions at grocery stores? And concerts, like what is it? Because Lucas can't tell me what bothers him.

Mary Barbera: And so, you know, I think we need to come together as an autism community to really understand the situation. But I think it's so different being at one end of the spectrum versus the other end. And then all the ages, and then all the cultural differences. And then all the different therapies, all the different professionals who also have different views. It's become... It's almost like a whole form of politics. It's very political. It's almost like religion or politics. It's so, it's just everybody's fighting. And my mom said, you know, early on when I was, you know, in due process, I'm fighting, I'm trying to get Lucas the best therapy. I'm fighting with, you know, insurance companies and the schools and you know, all these people. And then I founded the autism society, my local county.

Mary Barbera: And she's just like, all these moms that come, they're so angry and they're fighting, they're fighting so hard that they start fighting each other because they can't, they're just in bite mode, you know? And they just don't know how to make it productive and work together to get people to live to their fullest potential.

Eileen: Yup.

Mary Barbera: So, I mean, one of my goals for, all the people I know, for adults and children, is that each person become as safe as possible, as independent as possible, and as happy as possible, reaching their fullest potential. You know, my son Spencer just turned 22 he's going to med school next year, you know that doesn't mean that... And he's obviously at his full potential now, but he still has to remain safe and independent and happy and he could, you know, get injured, get a disorder... You know, that we would have to then work to get him back to reaching his fullest potential.

Mary Barbera: Lucas is as safe as possible, but it requires a lot more support to be safe, you know? And so any adult or child, whether you have autism or not, I think we all should be looking at the same goals. Now whether use ABA or another type of therapy, we're all striving to be as safe and happy as possible. And if someone, like one of my clients for instance, a couple of years after I worked with him, he actually wandered away from his home and he drown in the neighbor's pool. Like how... Autism in that case is obviously not a gift. And you know, the level of supervision that our kids need is so high that it just becomes this real issue of how to keep them safe and then how to get them to reach their fullest potential, whatever that is.

Eileen: Yeah, yeah. No, just thinking about ABA therapy.... the criticism is that it's to make kids normal when we just want them to be, like you said, safe, happy, independent. I mean we want them to learn skills that everyone has, like communication or a kid should have self-care and yeah. And keep themselves safe and be happy. I mean, that's what therapies for.

Mary Barbera: Yeah. And some adults didn't go through testing and are diagnosing themselves as having autism or, you know, and it's a wide spectrum. Like do you ever think about like, was it really necessary that you got diagnosed with autism? I mean, are people critical? Like why did you get yourself diagnosed or...

Eileen: I didn't know for sure. Like I knew I had, I recognize myself in some of their behaviors, but I'm not a doctor. I can't self-diagnose myself with something as important as autism. So I wanted to know, you know... I

didn't go into the therapeutic thinking I need to get an autism diagnosis. No, I wanted to know why I was troubling was all of these things. And then it turned out that I ended on the spectrum. Because there are so many conditions that can have some of the autism symptoms and not be autism. And the only way to know for sure if someone is autistic is to go through an assessment.

Eileen: Now, the downside of that is that, you know, it cost a lot of money in the US, so I understand it's not available to everyone. But yeah, I have issues with people just trying to control the autism conversation when they themselves are not even diagnosed with autism. Those people would tell parents that they shouldn't speak about their child's autism if they're not autistic themselves. And there's a lot of , harassment that goes on social media and that's why I try to, you know, be honest in what I share on my blog so parents know they're not alone.

Mary Barbera: Right. So your blog is housed at the Autism Cafe. So what, how'd you come up with the name Autism Cafe, and is that a website and a Facebook page, or is everything just on Facebook?

Eileen: It's all everywhere on social media. And then my blog is the AutismCafe.com. I just, since I'm French and I like, you know, going to cafe and bar, so I said Autism Cafe was fun, you know, it's a place to have a conversations, so I liked it.

Mary Barbera: Good. So it's TheAutismCafe.com with 'the' in front of it. Right. And that's your website. And are you also speaking at all or just writing? How much do you produce blogs or is it just when you feel the urge?

Eileen: Yeah, I post on Facebook a couple times a week and on Instagram pretty much every day. I don't do speaking much because it's really hard for me. But I have my first speech in April in Arizona, so I'm excited about it.

Mary Barbera: Where are you speaking?

Eileen: It's a photographer retreat and since it's in April, they're doing a, you know, autism awareness there and I'm going to be the keynote speaker, so.

Mary Barbera: Wow, that's awesome.

Eileen: Thanks.

Mary Barbera: You look a little nervous, right? But I'm sure you'll do great. So on social media, is it THE Autism Cafe or is it just Autism Cafe on social media?

Eileen: Yeah, THE Autism Cafe.

Mary Barbera: All right. Just so we can put it in the show notes for this episode and we can also, you know, make sure everybody knows where to find you. So are you in touch with other families that have kids with severe autism?

Eileen: Yes. Finding Cooper's Voice, but it's basically only on social media. I don't know anyone in real life who has a kid like Charlie, which also sometimes makes things isolating, you know? And that's why I like my little internet world where I can connect with people who, you know, who goes through the same struggles we're going through. And again, like it helps us feel like we're not alone.

Mary Barbera: Yeah. So part of my podcasts goals are for parents and professionals to be less stressed and lead happier lives. So do you have any advice for our parents and professionals who are listening?

Eileen: Again, like the only thing that helps me is to know that I'm not alone. There are a lot of people who do it and it's going to be okay, but to be honest, all of the time I am stressed. So it would be hard to get give advice here.

Mary Barbera: You're still in the thick of things. I personally think that from the ages of like, diagnosis or first signs until about eight, I think is probably the most stressful time for me looking back. I mean you might have obstacles along the way and everything, but it sounds like you are, you're finding your way. Plus you then had the diagnosis of yourself on top of it. So all the grief and navigation for you.

Mary Barbera: And then I think you're a great voice though to try to be a voice for, Hey, let's look at the whole spectrum. You know, it's not a black and white issue. Each family, each child is different. We're all after the same goal to help each child or adult reach their fullest potential. And, you know, your writing is beautiful and I think you have a great perspective. So I wish you the best. I can send people to your website and your social media column and we'll link that again, but [TheAutisCafe.com](http://TheAutisCafe.com) and all over social media.

Mary Barbera: So I wish you the best of luck and yeah, I'll definitely be tuning into watch as you're writing progresses over the years and as you continue your journey. So thanks so much for your time and joining us today.

Eileen:

Thank you for having me.

*Thanks for listening to the Turn Autism Around podcast with Dr. Mary Barbera. For more information, visit [Marybarbera.com](http://Marybarbera.com).*