



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 066

*The History of Autism & Autism Moms
Becoming Experts in the Field*

Hosted by: Dr. Mary Barbera

You're listening to the Turn Autism Around podcast, episode number 66. I'm your host, Dr. Mary Barbara, and I'm thrilled that you're here. Today, we are talking all about autism, mothers who become leaders and experts, and some of the advice that we autism mother BCBA's are giving to the professionals in the world.

So before I get to the show, which is just gonna be me for a change, it feels like it's been doing a ton of interviews, I wanted to wish you all a happy autism awareness month; that is April every year. And next April in 2021 will be the publication of my second book through Hay House, and I'm super excited about that. So I've been working diligently.

So happy autism awareness month. We've got some great shows coming up this month to highlight some of the work of autism moms and professionals in the world.

So let's give a shout out to one of the listeners whose name is Katherine. She left a five-star rating and review on Apple podcast. She said, "I'm a behavior analyst and listen to your podcast every week. I appreciate your up to date information and learned so much that I use in my weekly therapy appointment. I send parents to your podcasts for extra parent training. You are amazing. I also have your book and lend it out to parents when they ask for more information. You're making a difference. Please keep up the hard work." Thank you so much, Katherine, for taking the time to recognize the hard work. It is hard work to keep this podcast going and to pay my team members for editing and all that stuff. So if you have two minutes to leave a five-star rating and review where ever you're listening, I would greatly appreciate it. It helps me spread the word.

And now the Turn Autism Around podcast is available many places, including my website, Apple podcast, Spotify, Pandora, I Heart Radio, you name it, we're there, so search Turn Autism Around and recommend it to other parents and professionals. I would love that. So today's show is all about autism mothers and their role in the autism world becoming experts and leaders. So let's get to that great content.

Welcome to the Turner 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.

Okay, well, welcome back. This episode is going to just be me talking. I feel like I've been mostly doing interviews lately, so it's nice to get back on and just share my thoughts on a specific topic. And one of the topics near and dear to my heart is the role of autism mothers. And we're gonna take a look back at the history of the role of autism mothers a little bit today, too. And some of you this might be new information that autism mothers weren't always thought to be the greatest thing in the world. So a few weeks ago, I had Dr. Bridget Taylor on episode number 64, and we talked about the characteristics of moms and dads who go on a mission to try to change the lives of many children, not just their own child with autism. And we also talked briefly about my article, *The Experiences of Autism Mothers Who Become Behavior Analysts*, a qualitative study. But I thought I'd do a whole episode on autism mothers. And I'll talk more about this qualitative study as well.

Also, as you probably know, if unless you're here for the very first time, is I fell into the autism world in 1999 when my firstborn son Lucas was diagnosed with autism. So that journey has totally transformed my life. And in episode number one of the podcast, [MaryBarbara.com/1](https://www.marybarbara.com/1), I talk about my journey and then 15 lessons for both parents and professionals in the autism world.

I also interviewed Kelsey in episode number three, and she is a single mom living in Canada and she is working as behavior therapist. She's got two kids with autism. She is on a mission to change things. She's also our community manager within our online courses because she took my courses early on, and it really changed her life. And so she's really helping me in many ways to answer questions and be supportive of other parents and professionals in my online communities.

I also interviewed Laurie Unum, who is an autism mom, and she's an attorney who was instrumental in the autism insurance reform movement. That is episode number 31 of the podcast. And Deidra Darst is a speech and language pathologist, autism mom, and her episode is number 39.

So I have interviewed other autism moms who've become leaders and experts in the field of autism who are using both her professional credentials as well as their on the job experience, if you will, with their own child to really make a difference to help others. So let's talk about the history of autism and the history of autism mothers.

In 1943, a pediatric psychiatrist by the name of Leo Kanner with a K, he started describing autism around the same time a man Hans Asperger just started describing a milder form of autism, and that was actually called Asperger's Syndrome. And so it was around the mid-40s when autism was first coined. Back in the forties, the field of psychology was dominated by, say, psychoanalysis. So autism was quickly deemed a psychoanalytic disorder. And Bruno

Bettelheim presumed that autism was actually caused by cold and uncaring mothers. And he labeled moms of kids with autism as refrigerator mothers. Those cold, uncaring moms were actually causing the disorder. And so when a child was diagnosed with autism, they recommended institutionalization partly to get the child away from the mother who they thought was causing the situation. This was around 1950 when refrigerator mothers was used... the term was used. This went on for more than a decade.

But starting in the 1960s, another psychologist by the name of Bernard Rimland, whose son started showing signs of autism, was diagnosed. He knew, because he was a psychologist, he knew what the theory was about refrigerator mothers. He knew that his wife and his son's mom was not cold and uncaring. And so he really challenged this belief. And in 1964, he published his classic book, *Infantile Autism*, which then changed the way people viewed it to a neurologically based developmental disorder.

A year later, in 1965, Bernard Rimland led and created, founded the Autism Society of America and started really rallying parents to change; change the law; change the way kids were treated; change the way moms of kids with autism more perceived. And that was such a great thing. I don't know if I mentioned it many times, but I founded the Autism Society of Berks County, where I lived in the year 2000. And it is a chapter of the Autism Society of America still going strong. But, you know, parents have since the 60s banded together and that banding together has changed local laws, has changed local education. What's available has, you know, Laurie Unum, as I mentioned, in episode number 31, I mean, she changed each state. She went around the United States and she changed the law so that autism ABA coverage was mandated to be covered by insurance.

So 65 was the founding of the Autism Society of America. And basically, by that point, refrigerator mothers was not the presumed cause of autism, but it took until the 1980s, until autism was recognized truly as a separate condition, separate from childhood schizophrenia or mental retardation. In episode one of my podcast, I talk about my journey, my journey with denial when my husband first mentioned the possibility of autism. And I say this all the time is like back then and that in the late 90s I felt like I had fallen into a dark, deep hole and needed to climb my way out. Even back then, the internet was just getting started and there was just not the level of support.

The other thing is that that's why when I interview people, I always start with, describe your fall into the autism world. And whether you're a parent or professional, you got here somehow. And most of the time it's by like Bridget Taylor said, she answered an ad and she started working with the Maurice kids and she started working with other kids as well in their homes to do behavioral treatment. Another big difference is back in the late 90s, when Lucas was diagnosed, the rate of autism was thought to be one in 500. But now it's about 1 in 50. And this has made it quite cumbersome for evaluations. There's waitlists for evaluations, for diagnoses, for treatment.

The whole ABA movement was pretty much started by... It was pretty much started because of the demand for behavioral intervention based on the Maurice book and the Lovaas study. So that was, you know, why we're here, why we're even talking about ABA, why I'm doing this podcast for parents and professionals, the fact that we are board-certified behavior analysts, the ones of us that are certified... It all comes down to the work of a mom who refused to just institutionalize her daughter, had the knowledge to do research in the library, to find the Lovaas study, to get Bridgette Taylor in there, to help her to get other professionals besides Bridgette in there to help her, and then her younger son was subsequently diagnosed.

And so this whole what we're talking about was all created from moms and dads. Bernard Rimland was, you know, an amazing autism dad. So not to exclude dads. I just wanted to talk more about the moms and my article, which is just for moms. But there are dads who are similarly really leading the way. And I think autism parents in general are leading the way.

So 1993, the book *Let Me Hear Your Voice* was published. Again, that's kind of started the whole need for the board-certified behavior analyst. Maurice and some colleagues wrote another book called *Behavioral Intervention for Young Children With Autism* in '96. And these books really outlined how to start ABA if you couldn't find professionals. And this also gave parents, empowered parents to know that they could actually start doing something and start trying to help. In the past three decades, there's been hundreds of studies proving the efficacy of ABA treatment. In 2003, I became a board-certified behavior analyst after my first attorney told me about it in like 2001. He said, you know, you should become a board-certified behavior analyst. And I'm like, what? What's that? And he said, well, you need a master's degree. You already have a master's degree. You seem to know what you're doing. And so it was a natural transition for me to become a behavior analyst.

In 2007, I went on to write my book, *The Verbal Behavior Approach*, which is in over a dozen languages. And this really helped, too, because the reason I wrote my book is because that *Let Me Hear Your Voice* book, which had been such a Bible to me, I was doing things a lot different. And I do recommend everyone learn and become expert at incorporating Skinner's analysis of verbal behavior. And I just don't see that within a lot of traditional ABA programs. So I needed to write a book because everything was in my head and I needed to write a book and now I'm writing another book to be published next year.

But let's transition now to talk a little bit more about this article, *The Experiences Of Autism Mothers Who Become Behavior Analysts*, and a lot of the literature that has been done on studying autism parents in general. So in this study, it was a qualitative study, there were six women in it that answered questions via email. And then I combined those questions and or those answers, if you will, and created a qualitative study.

And I did present the qualitative research at an ABA conference in the... It was probably 2008 or 2009. I submitted and I presented my qualitative research and ABAI conference. And I remember one professional coming up to me and saying, you know, I've been coming to ABA

for like two decades and I have never seen a qualitative study being presented here. So. And he wasn't even like saying it was great. He was just like he was perplexed.

So one of the things I want to say to you, behavior analysts, researchers, out there is that there is a lot of validity with qualitative research, especially when you're talking about the experiences of moms and dads and families dealing with autism. And I think we go right too far when we're talking about quantitative research and even single-subject design, because I think for information like this about the experiences, I think we need a whole lot more qualitative research to begin to formulate theories and better models to help parents with coping. Okay.

So most research in general when we were talking about autism in families focuses on three issues: diagnosis period; services; and coping, including stress. In my study, I wanted to focus on a subset of these issues, including the general experiences of parenting a child with autism, coping with stress and ABA service delivery, including how can we better deliver ABA services to families with a newly diagnosed child.

In general when we're talking about literature on parenting a child with autism, most parents report that they feel frustrated and stressed. There is a constant need to plan ahead, thus decreasing your spontaneity. Families tend to have less social contact with others, less time to pursue their individual interests, less time for fun and relaxation. And while many report negative experiences resulting in the lost dreams, they do report adaptation over time and changing their world views sometimes in very, very powerful ways.

There is positive changes, including parents of kids with autism are much more patient, they have acceptance, they're compassionate and they really understand unconditional love. When we're talking about literature reviews and studies on parent stress and coping, the studies that I've looked at show that parents of children with autism are significantly more stressed and parents of typically developing kids. But they are also significantly more stressed than parents of other children with other disabilities, which is concerning and interesting at the same time.

And not really sure that the articles that I've read, I don't remember specifically say why? Maybe because, you know, kids with autism, they have scattered skills. They there's, you know, this push for recovery or getting better. There's such a range. You know, many kids with autism regress. So then you think everything's fine. And then all of a sudden you know, in my case, I'm thinking Lucas is a genius. And then all of a sudden, he's got a lifelong disability, really tends to, you know, tends to mess with your head, if you will.

I did do a video blog on the stress levels of autism mothers are similar to combat soldiers. And you can find that... you could actually find anything by just searching Mary, autism, combat soldiers; Mary, autism, potty, sleep, tantrums, anywhere you go, if you're talking to a parent, you posting online, just start saying just search Mary, autism, plus the topic and you will find what I'm talking about. We will link it in the show notes, episode number 66. But just in case you are somewhere and you're thinking, I want to look at that video blog on combat soldiers, just search Mary, autism, combat soldiers.

Mothers specifically in the studies of stress reported consistent problems with their careers. They either had to quit their jobs, decrease their jobs, go part-time because of the demands of caring for a child, coordinating the care. But most studies over time did report that stress levels were reduced. In one study, two-thirds of the parents said they were less stressed than they were a decade ago. So that's that adaptation over time. Stress levels in general were highest in the studies. If they were highest if a child had problem behaviors, especially aggression. If your child is aggressive, you are almost always stressed. And I know I can tell you that from experience. That's absolutely true.

And in Lucas's situation, he was aggressive, actually, and self-injurious because of a medical condition, which I talked to his psychiatrist in episode number 28 with Dr. Michael Murray. I do a podcast interview with him.

So I really believe that one of the biggest reasons for my podcast, my video blogs, my online courses, is we have to get kids problem behaviors decreased. We have to teach parents and professionals how to best do that because problem behaviors, especially aggression and self-injurious behavior, will always lead to more stress in parents and professionals. They will always lead to less quality of life and more even taxpayer money, less inclusion. And so that's really super important. And it is very clear from the research that stress levels and coping is so much harder if a child has significant problem behaviors.

So I just want to talk a little bit more about this study. But I don't want to read you, you know, quotes from the study or anything like this. Basically, I asked six women who were behavior analysts after they had a child with autism they became behavior analysts. I have their age ranges and their children's characteristics and all that. I asked them three questions about their transition: why, how when they became behavior analysts? I asked them to describe their experiences working as a parent BCBA. And I also asked them what type of training do you think parents of children with autism need in order to become proficient in the use of ABA techniques? And so really reading this article will be helpful for many of you, but I just want to skim over some of the major findings.

The pilot study with these six women showed several positive themes, including all six of them had various backgrounds and they had a natural progression to becoming a behavior analyst from a variety of backgrounds. One was a teacher. One was a doctor. One was a business person with an MBA. I know I wasn't in the study, but I'm a registered nurse with a master's degree in nursing and I transitioned. So it didn't really matter about their backgrounds. They also had kids, some severe, some mild, one with many comorbid conditions.

The other positive themes were that the behavior analyst moms also had a passion for work in behavior analysis. They loved learning new concepts to help not only their own child, but others. They enjoyed advocating for all children to experience the best practices in treatment. And they were easily able to gain the trust of other parents. So that was definitely a positive. And they in some cases served as a bridge between parents and professionals, which I think is

totally the case in my experience, even though sometimes in schools some professionals might not appreciate my parent hat and my advocacy hat. We really can, I think, explain some of the things. And, you know, if a child was doing some behavior at school and they'd be like, oh, this behavior, and I mean, like, what does this child do on the weekends? What did they do at nighttime? Like, what are their leisure activities or what are they doing? And I think that constant, let's consider the whole 24 hour day like what is happening? I think that parent background is certainly helpful.

Out of the six moms who answered these questions, they did report some negative experiences when dealing with professionals and also experienced guilt, conflict and time constraints in attempting to serve both as parents and professionals. There was some discussion by some of the behavior analyst moms that they felt guilty because they were giving so much time to other kids and then kind of, you know, not as being on top of it with their own children.

I remember one time, I don't know, Spencer was probably 8 or 9 years of age. And he said... Spencer's my typically developing son. And he said something like, oh, what are you doing, you know, tomorrow? And I said, oh, well, I'll see you after school, but then I have to go and I'm helping this boy with autism. You know, I have to go for, like, I don't know, 4 to 8 or 4 to 6 p.m. and then and Spencer's like, well, why do you go there?

And I'm like, well, I go and, you know, they pay me and I go and I help them. And he's like, so he says something like, so you mean you're going there and people are paying you and then you're neglecting us. Like... Kind of like, okay.

But there's always that balance between helping other kids and then helping your own your own child with autism and your typically developing kids. If you work in general, you have those kind of problems. But when your whole life seems to be autism, sometimes it can present very challenging situations. And then the six moms who gave the e-mail responses also gave their views on training. And most participants stated that the best way to train novice parents was to provide them with guided practice, video modeling, videos to show them what to do and to empower them. So that was the basic findings from the study. But like I said, there's lots of gold in some of their responses and I would love it if you would take a closer look if you have time and interest. We will be linking that article in the show notes.

So after more than 70 years since Bettelheim's theory about refrigerator mothers were causing autism, now mothers and fathers of children with autism are actually making significant efforts. And they have led the way in terms of advocacy and becoming educators, behavior analysts, leaders in the field. So I am proud to be an autism mother slash behavior analyst.

I think we do provide a very unique background and we should continue to study the roles, not just autism mothers who become behavior analysts, but autism moms in general. I think there needs to be a ton more... you know, there's a wide range of kids with autism levels. I know a few autism moms who have kids in college now, kids that are driving, those sorts of things. And it's like we need to study those people, those families, those kids, those moms. What was it?

You know, I talked to Bridget Taylor a couple weeks ago and she was saying, you know, she sees this where an autism parent really changes their whole life and becomes a leader in the field then. And we need to study people who do that, because I think whatever we can do to increase good behaviors like language learning and academics and decrease problem behaviors in the most efficient and effective way. And we can, you know, get everyone trained on these really efficient, child-friendly approaches, the better we will do.

So I hope you enjoyed that brief overview of the role of autism mothers who become behavior analysts, who become experts and leaders in the field. I think, you know, I got a lot of the history and stuff from this article that I've done so many years ago. But I think it's always good for us to look back at the history and see how far we've come from refrigerator mothers to autism leaders and experts.

To find out more about my unique approach, whether you're a parent or a professional; toddler through teens, I would love it if you would attend a free online workshop at MaryBarbara.com/workshop. And I hope that you tune in next week for another episode of the Turn Autism Around podcast. Have a great one.

Thanks for listening to the Turn Autism Around podcast with Dr. Mary Barbera. For more information, visit MaryBarbera.com.