



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 001

Lessons I've Learned on My Autism Journey for Parents and Professionals

Hosted by: Dr. Mary Barbera

Welcome to the Turn Autism Around podcasts for both parents and professionals in the autism world who want to turn things around for their children or clients, be less stressed and lead happier lives. And now your host, autism mom, behavior analyst and best-selling author Dr. Mary Barbera.

You're listening to the Turn Autism Around podcast, episode number one. In this episode, I'll tell you about my fall into the autism world as both a parent and as a professional and I'll cover lessons I learned over the past two decades that I'm really hoping will help you.

Hi there and welcome to the very first episode of the Turn Autism Around podcast. I'm your host, Dr. Mary Barbera and I'm thrilled that you are here. Whether you are a parent of a toddler just showing signs of autism or you're a parent of an older child, teen or even adult who has pretty significant autism. Or if you're a professional that works with a wide variety of clients, I think that this podcast is going to really be a great thing for you to listen to.

I have been in the autism world. I fell into the autism world, I say two decades ago in the late 1990's when my firstborn son, Lucas first started showing signs of autism and then was diagnosed and then I went on to become an autism professional and an author and I'm going to tell you about that journey during this episode.

This is the one episode where I am just going to tell you my journey. I'm sure that if you've been following me for a while, you might know parts of my journey, but I wanted to give you a rundown of exactly how it happened with some key lessons I learned both as a parent and as a professional. So, I'm hoping that these lessons will be will be insightful to you and might help you on your journey wherever you are in that journey. I am planning on doing a podcast every week and I'm planning to make these episodes about 30 to 45 minutes in length. Just enough

that you can, you know, exercise while listening or while you're driving or walking the dog or whatever you do routinely where you listen to podcasts.

In addition to being an autism parent and professional, I'm also an award-winning online marketer. I was named Jeff Walker's Launch Club Spokesperson of the Year in 2017 and I won a cruise. I took 15 of my family members on a cruise and I won a mastermind with Jeff Walker, who is the creator of Product Launch Formula. And he also wrote an awesome book Launch, which helped me really get started with my online courses.

I've also been inspired by a few online marketers, especially their podcasts. And those two individuals that really inspired me to do this podcast are Amy Porterfield and Pat Flynn and Pat Flynn in addition to doing weekly podcasts, which are amazing, he also has a course called Power Up podcasting, which I binged watched last week. And so I really am going to make this a big part of my online business to bring information out to you all each week so that I can spread my message and I'm on this goal to turn autism around for 2 million by 2020... and now that it is newly 2019, I have a lot of work to do, even if we consider the end of 2020 that still gives me under two years to reach 2 million and not only to reach them, but to help you turn autism around.

So, I'm sure that some of you are even questioning the title, Turn Autism Around. What does that mean? There's a lot of debate about whether children with autism can recover from autism. And turning autism around in my mind looks different for different children for the very young children. My next episode is going to be about early detection and catching autism as early as it shows up and really turning it around. And in some cases, if you catch it very early and you treat it very aggressively, autism can be completely turned around. And I've seen that, I've seen that with my own eyes.

It was actually proven in the late 1980's that with intensive behavioral treatment that kids with autism could become indistinguishable from their peers or recover from autism. This was proven three decades ago and which is amazing that a lot of people don't know that even people in the autism world, so 47 percent of the people of the kids in the original Lovaas Study recovered or became indistinguishable.

And so, I don't see 47 percent become indistinguishable, but I also don't see a lot of kids getting very intensive treatment very early on. So, I want to be part of changing that. Now turning autism around looks very different as kids get older. My son is now in his early twenties and he still has moderate to severe autism. He has mild intellectual disability. He needs a lot of supervision and care. And so, for him, turning autism around is just continuing to treat any problem behaviors that occur, to treat any medical issues very aggressively so that he can get back to baseline and continue to be happy, be safe, be independent. Turning autism around for an 11-year-old that... the mom of an 11-year-old took my course and

she reported that child was able to have his first bowel movement on the toilet at 11. Some eight-year-old learning to speak for the first time.

So, turning autism around doesn't mean turning it completely around and recovering. It means helping each child reach his or her fullest potential and to be as safe as possible, as happy as possible and as independent as possible. I'm going to cover on this podcast, not this episode, but in future episodes. I'm going to cover reasonable treatments from my perspective and reasonable topics. The autism spectrum is so wide. There're so many different camps.

I'm going to be covering autism from a behavioral perspective, since I am a board-certified behavior analyst. I'm going to be covering autism and have some guests on about the medical issues. I'm also a registered nurse. The psychological emotional issues, the financial issues that are impacting all of us and the political issues that are a part of autism as well. I have some amazing guests lined up already and I plan to do a mixture, like I said, of solo shows where I'll be speaking only like this show and then some shows on one of the episodes coming up I'll have a single mom, Kelsey, who has two young boys with autism and we'll talk about her journey and some of the ways she has made improvements in her sons.

We'll have Dr Megan Miller on who will be talking about some standard behavioral procedures that are usually backfiring and what to do instead. We'll also have Dr Amanda Kelly aka Behavior Babe on in an upcoming episode to talk about social media and just all the things she's involved with. So, lots to cover in the upcoming episodes and I'm hoping that if you are here and you are listening to episode one, that you will immediately download any of the episodes that are available, that you will share the podcast.... And that you'll leave me a great rating and review, and you will subscribe to this podcast, meaning that you will get access automatically to the shows that are upcoming. All these actions, you leaving a rating and review and sharing and subscribing really help generate a lot of interest and a lot of excitement and also it helps me get out there to many more people. So, if you could do those things, that would be awesome.

So, in this episode, I know I feel like we have a lot to cover. I am going to cover pretty quickly my whole journey from parent and professional journey. I'm not going to get into the online marketing fall and all those lessons I learned, but I will be doing that in an upcoming episode for sure. So today I'm going to cover parent professional and some of the lessons I learned along the way. And these lessons will be weaving their way through upcoming podcasts and I'm not going to be able to cover them in any detail so and during this episode, but each episode in the future might have a whole episode on one key lesson. Okay.

So back to 1997 when I had Lucas in 1996, so he was one year old and he was developing fine and I got pregnant with Spencer and everything was really going as planned even though Lucas was regressing and showing some signs of autism during my pregnancy. I didn't recognize them.

And after Spencer was born two days after Christmas in 19... late 1997, I thought everything was pretty much going as planned. Everything was. I was married to Charlie, still married. He's an emergency medicine physician and we had two boys. I thought they were both healthy and everything was fine until Lucas was 21 months old and Spencer was about two months old and my husband mentioned the possibility of autism. And I write about this in my book, the verbal behavior approach on the first page I write that I was shocked, angry. I told him Lucas didn't have autism. He was warm and cuddly. He had some words like, you know, he didn't know what he was talking about and I told him on that day when Lucas was 21 months old that I never ever wanted to hear the word autism again.

So, he like a good husband didn't bring it up. I say that, like a good husband because, that was a very bad thing for me to go into such denial for over a year, well over a year, and what got me out of denial was, and I'm going to talk about this a little bit more in detail next podcast, but I started looking into a thing called hyperlexia, which is the ability to read letters and read words before you can speak basically. And Lucas was really interested in letters, so I was like, well maybe he has hyperlexia and not autism. And it led me to this woman, this mom of a, of a young son with autism with hyperlexia. And she's the one that told me about the Lovaas study, which was published in the late 1980's, which showed that they took up 59 kids with autism, I think they were about three years old and they gave a 19 of them very intensive, 40-hour week ABA treatment.

Then they had a control group that got a little bit, just a little bit of their ABA therapy. And then they had another control group that got, you know, just eclectic therapy. Anyway, the main experimental group out of that 19 children, nine of them or 47 percent became indistinguishable from their peers by first grade. And then they went on to become still stay indistinguishable. So, once I found out about the Lovaas study and this woman, I didn't have Lucas with me. So, I was just like, oh, it's probably just a severe language delay. And she said basically, even if it's just a language delay, you need to find out what they're doing for kids with autism because if they can recover kids with autism, then you know, if it is just a speech delay with Lucas, you should be able to be really set.

So, I on the way home, got to books, read them. And he was eventually, as soon as I read the books, I was like, oh my God, he has autism. And Oh my God, I've been in denial for over a year thinking that nothing could be done. And so, I did an about face. Got him on a short waiting list about two to three months until we were able to go down to the Children's Hospital in Philadelphia. And he was diagnosed one day before his third birthday and we started the Lovaas type ABA therapy, which Lucas made progress with, but he didn't make the kinds of leaps and bounds progress that was a part of where he'd need to be to become part of that experimental group that was going to recover.

And, and I don't know, you know, I say that when the doctor diagnosed Lucas the day before he was three, I asked them about recovery because I had read

these two books by Catherine Maurice outlining recovery and the doctor said that in his 30 years of being a developmental pediatrician that he's seen recovery, but it was only with kids that were more mild than Lucas and he diagnosed him with moderate severe autism.

And so, it's kind of really, well, he didn't say that my year of denial caused Lucas not to be able to recover that's the way I felt. And I don't have a crystal ball and nobody knows. Like if we would have gotten on the whole autism track, if Lucas was 21 months old, if we could have gotten a diagnosis and treated. I mean, you know, no one knows. I mean, you do the best you can with the information you have. And it's not like I'm waking up every day. Oh my God, if I wouldn't have been in denial, Lucas would be fine. I don't know if I even believe that. I mean, who knows, and he had neurologic damage and it's pretty significant and he didn't recover.

I also, in the next couple of years after he started ABA therapy, transitioned to the verbal behavior approach and began, I also began educating physicians, namely pediatricians on the early warning signs of autism through a grant, through First Signs. And I was the founding president of the Autism Society in my county. So, I really like once I, once I met with this woman who told me about recovery, I was all in was a huge advocate. I was a leader. I was just like, oh, let's get, get to this.

So, Lucas did not recover obviously, but over time he has made lots and lots of progress with ABA therapy, which looks a lot different than the ABA therapy when he was a small child, but he still receives services from a behavior analyst. He has a one to one who's highly trained in the verbal behavior approach, applied behavior analysis. So, some of the parenting lessons I've learned before I get into my fall, into the professional field of autism. Number one, it's important to not stick your head in the sand about anything, not just about early detection, but any issue. If your child is having new headaches or your child is suddenly falling behind with reading, if they're at that level or your child, any, any issue.

If your child is having problems, we should not be going into denial hoping that it's going to get better on its own. My year of denial and waiting was very bad. Lesson number two, hope is essential and shifts over time. I remember when I was getting my PHD, I did a paper on hope and I showed that through looking at studies that there really is no such thing as false hope, that hope we need to let parents hope. We need to encourage them to hope.

If they're very young and the children are very mild and we can turn things around, then we should encourage parents to hope for full recovery or hope for to get them to their fullest potential and that there's no such thing as Joe normal or a perfect child with no issues. Every child, every adult is going to have their strengths and needs and this hope will shift over time, but I still have hope for Lucas that he's going to continue to stay stable.

He's going to continue to be happy, he's going to be cared for, he's going to stay safe. Lesson number three, hope is not enough. We need, we need treatment. We need behavioral treatment. Even if kids don't recover like Lucas, they can learn through behavioral treatment every day. Lucas has learned to, you know, make his breakfast, sweep the floor, get a shower, tie his shoes, ride a bike. He's also learned to answer questions and to sing songs and to play the autoharp and just a bunch of skills that are so important for him to be happy.

Okay, so those are the, some of the lessons I learned as a parent. Now I want to tell you a little bit about my fall into the professional field, how I became a behavior analyst and an author. And then I'll give you some more lessons. So right away when Lucas was diagnosed, he was transitioning because it was the day before his third birthday, so he was transitioning...

In the United States, in my state, he was transitioning from the birth to three provider funding source to the three to five funding source. And what, what happened was, because he was diagnosed right at that transition, he kind of fell into this, you know, it wasn't great planning and that wasn't anybody's fault. It just, you know, because he was diagnosed right at the transition.

So, what happened next was that I ended up in due process, which is an educational court litigation system because I wanted ABA therapy and they wanted to transport him to a school for kids with autism. He was already going to typical preschool. I wanted to start an intensive ABA therapy program in my home. And so, we got into this legal battle which lasted over a year. Thank goodness that that year we managed to continue to send them to preschool. We managed to start the ABA program ourselves.

And so, during the fight, Lucas was getting what he needed, but it was my first lawyer who was a father of an older son with autism who told me that I should become a behavior analyst. And I looked at him and I was like, what, what's that? And this was 2001 and the behavior analyst certification board and everything just started a year or two earlier. So, I was able to take a distance learning program through Penn State and become a behavior analyst in 2003. And right as I was transitioning to that role, I was offered a job as the lead behavior analyst for the Pennsylvania Verbal Behavior Project, which was a statewide grant in Pennsylvania, which served hundreds of kids. And I stayed in that role for seven years working with hundreds of kids all across the spectrum. The project is, it used to be called the Verbal Behavior Project now is the Pattan p, a t, t a n the Pattan Autism ABA Supports Initiative, I think it's called.

And they're still remain doing really great work across the state of Pennsylvania in public school, mostly autism classrooms, working with teachers and speech pathologist and paraprofessionals and occupational therapists to give kids in public schools ABA therapy and to train everyone so that every child is

reaching their fullest potentials. While I was in the project and working on, on spreading the word to pediatricians about the early diagnosis process.

I also came into writing my book which was, is called The Verbal Behavior Approach, How to Teach Children with Autism and Related Disabilities. And it was published in 2007 and is now sold over 50,000 copies and is available in several languages. So, the book was, was just an attempt to get everything out of my head onto paper to help more people. I had no idea was going to be so, so well received.

And it's still selling great more than a decade later. I've traveled the world speaking about autism and I also left The Verbal Behavior Project in 2010 to finish up my PHD and started working with the early intervention kids in my county through the, through a contract from the birth to three agency and I finished up my PHD with a dissertation on training individuals on the verbal operands. So that's when I fell into the online marketing space because I had my PHD. I didn't think it was efficient to be going door to door through the early intervention program. I didn't think it was efficient to go traveling around the world speaking to smaller, large groups of people. I really wanted to affect the masses.

So, some of the professional lessons I learned was lesson number four. There are so many different camps in the autism world and there's a lot of infighting even among ABA providers, among the parents in certain groups, professionals in certain groups.

There's just a lot of people that are not, you know, just not open to finding out how to really turn things around. I mean, I've known for two decades and it was proven three decades ago that recovery is possible, so this is just not known. Like I spoke at an entrepreneur conference just a couple months ago and there were 900 people in the audience. I said, how many of you know someone with autism and 95 percent of the room raised their hands. And I said, how many of you, before you heard me speak, knew that recovery was even a possibility if treated very early and very aggressively and like five hands went up out of the whole crowd. I know there are a lot of behavior analysts who do very good work, who some people say even behavior analysts, they don't oh recoveries not a thing. Yes, it is a thing.

And it was proven, you know, way back in the 1980's that it's possible. A lot of people say when I post medical things, like I posted one time a folic acid study, it was, it was placebo. They use a placebo. It was double blind. And I posted that. I thought, well, this, it's small, but that's a really interesting thing. And I had behavior analysts post in the comments like, how dare you post pseudoscience, like everything in the biomedical field is pseudoscience. It's like, no, it's not. And you don't really. If you're a behavior analyst and not in the medical field, you really can't speak to that. There's a lot of things that over the past two decades are need, just need more, more attention and need more studies and it's just not getting there. Lesson number five, I believe wholeheartedly that applied behavior

analysis plus bf skinner's analysis of verbal behavior or the verbal behavior approach leads to better outcomes than not using the verbal behavior approach.

Lots of debate on that. We'll get into that in future episodes. Lesson number six. I think there are three main things that are important no matter what the age or ability level of children are. And that is problem behaviors at or near zero. The ability to request your wants and needs and independent toileting. Without these three things or focus on these three things I see relatively quote unquote high functioning kids who are doing double digit math, but having major problem behaviors doing it and people are just focused on the wrong things. Lesson number seven, if you see problem behaviors, the demands are too high and or reinforcement is too low. That will we be weaved throughout. Lesson number eight, we all need a positive to every negative. I learned this through Glen Latham. Again, we're going to be talking about this in future episodes.

Less than number nine, choices lead to happiness. This whole podcast is not just going to be about helping kids get better. It's also going to be about increasing happiness for both parents and professionals in the autism world and some general lessons for everyone. No matter what your role is.

Lesson number 10, there is too much struggle in the autism world and little has changed in the past two decades that I've been here except for the rate of autism is rising. The waiting lists are getting worse and longer and there's just a lot of confusion and a lot of people finding themselves in autism mazes without a lot of help. Lesson number 11, advocating by both parents and professionals for better treatment and funding takes a lot of time and energy and I've been at this for two decades and I continue to be my son's best advocate.

Lesson number 12, don't think in black and white life is mostly gray. I wrote in my book in Chapter Twelve that when Lucas was diagnosed, I was so set on recovery that I was envisioning a recovery party that never happened, but even for the kids who have gotten all better or have gotten significantly better and are now going to college and learning to drive it, sometimes it's very gray. You know, they still have learning disabilities. They still have anxiety, different problems that aren't related to diagnosis of autism, but they have other issues.

Lesson number 13, we only have one life to lead so being in a chronic state of stress is not good for our wellbeing. And I'm going to have some episodes to really focus on mindset and our wellbeing and lowering stress and increasing happiness. Lesson number 14, we will need to make lemonade out of lemons and choose happiness. And choose to be positive every chance we get. And my final lesson to wrap up this podcast episode is we've got to make big shifts of the autism world and I'm hoping that my podcast is going to be a part of making those shifts.

So, I hope that you enjoyed this episode number one. If you would like to see the show notes or get the transcription for this podcast, you can go to MaryBarbera.com/one and I would love it if you would leave me a rating or review, share this podcast and subscribe. We have more episodes coming up that are going to help you and not every episode is probably going to help you in the same respect that others will, but I hope in general that we can go on this journey and start really turning autism around for you, your clients and your children. Take care and I hope that you tune in next time.

Thanks for listening to the Turn Autism around podcast with Dr. Mary Barbera. To join Mary's mission to turn autism around for 2 million by 2020, go to MaryBarbera.com/join.