



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 002

Early Detection and Treatment of Signs of Autism in Toddlers

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 two, and today's podcast is all about detecting and treating early signs of autism. 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 bestselling author Dr. Mary Barbera.

Welcome back to The Turn Autism Around podcast. I'm your host, Dr. Mary Barbera and I'm thrilled that you're listening. If you haven't listened to episode one, I would encourage you to do that as soon as possible. While you don't really have to listen to these podcasts in any particular order. Since this is only episode number two, it might really help to start with episode number one, and if you've already listened to episode number one, I would love it if you would subscribe to the podcast, share it, leave me a rating or review and help me get the word out to other parents and professionals working with kids with autism or just signs of autism.

This episode, as I said, is all about early detection and early treatment of autism. But I know there are many people who are listening who are parents of older children or professionals who don't work in the early intervention field and you may not think this episode is necessarily for you, but I would urge you to listen anyway because there are going to be points made in this podcast episode that might really be valuable, especially if you have a family member or friend or a client approach you looking for advice about their own toddler or preschooler. They might be wanting reassurance from you know that you're in the autism world and in this podcast episode you will learn strategies how to react to someone

who's asking you for advice, how to give them hope, how to get them out of denial and into action.

As you may know, especially if you listen to the podcast, episode one, I'm on a mission to turn autism around for 2 million by 2020. So, we've got a lot of work to do and I'm really thrilled that I've been able to start this podcast and that you are listening right now in addition to helping you help your children or clients reach their fullest level of potential. I also, through this podcast want to make your life less stressful and I want to give you strategies to make your life happier and by learning techniques not only to help your child or client, but also to help you.

So, in this episode, first I'm going to cover the early signs of autism, why these signs are often missed and talk a little bit about what snapped me out of denial, which was learning about autism recovery. Then I'm going to give you five action steps you can take if you're worried about a toddler, whether that's your own child or a family member's child or whether it's a neighbor, friend or client of yours.

Then we'll touch on the importance of early intensive behavioral intervention. I'll tell you what that is, how many hours per week that a child should be receiving, and also, I'll tell you how to get started with learning more about getting that in place. So, as you probably suspect, the best time to truly turn autism around is at the very first signs or even before the first signs appear. And this is where I went into almost a year and a half of autism denial, when my husband first mentioned the possibility of autism when Lucas was just 21 months old.

He's a physician and we had two beautiful baby boys. Lucas was just 21 months old and Spencer had just turned two months old. He was worried that Lucas only had about 10 or 20 words and he was watching a lot of TV and wasn't really interacting much. And I think what really concerned my husband was Lucas's lack of awareness about the baby. You know, by 18 months old you should be able to be like, Mommy's having a baby. Look at Mommy's big belly. And with Lucas there was no awareness of the pregnancy. No awareness of his baby brother.

So, on that day when Lucas was 21 months old and my husband said, so you don't think he has autism? I completely freaked. I told him I never ever wanted to hear the word autism again. Lucas didn't have it and I wanted to hear nothing about it and so he didn't bring it up. But in that following year, 15 months of my autism denial, he had planted a seed. So, I was, when I'd hear autism on the news, I was more... My ears perked up when Lucas would do something kind of odd, I would think, well maybe that's a sign, but in the process, I was getting a lot of false reassurance from the speech therapist.

Lucas was going to typical preschool without any support, so I was pretty much thinking, oh well that's just a phase. He's a boy, you know, it was my firstborn son. I didn't realize what developmental milestones he should be reaching. And so, what got me out of denial, which I touched on in episode one, was I went to a woman's house, another mom of a son with autism, who also, that child also had hyperlexia. I began to search the Internet. Lucas was interested in letters and you know, those were some of his first words and I thought, well maybe his hyperlexia not autism. So, went to this woman's house. She was great. And she told me about the fact that a decade prior, so this is, this is late 1980's. It was proven that kids with autism could recover from autism or become indistinguishable was the term they used.

So, with only with intensive behavioral intervention. And I didn't have Lucas along on this visit to this mom of the, of the child with hyperlexia and autism. So, I was just at that point, still thinking it was a major language delay. And she basically told me, she said, you just need to find out about ABA. You need to find out if they can treat kids with severe autism, then you should be able to put the same procedures in place to help your own son, even if it's just a mild speech delay. So, the Lovaas study, I'll just talk a little bit more about that because I think it is really important and even parents of kids now who have a diagnosis of autism are not learning about the power of applied behavior analysis treatment. People are saying that there's no chance of recovery, those sorts of things.

So back in the 1980's, Dr. Ivar Lovaas, I think I'm saying that right, he was psychologist at UCLA and he did a big study funded by lots of funding and he took 59 children with autism. I believe they were three years old at the time and he separated them out into an intensive experimental group which received for each child received 40 hours of one to one ABA treatment for two years. So there were 19 in that group and then there was a control group, one which had 20 children who were all diagnosed and they received 10 hours of one to one ABA treatment per week for two years, and then the third group, 20 children, they received whatever was available at the time in California, little bit of speech, little bit of occupational therapists therapy, little bit of teacher time, and out of the experimental group.

The 19 children, nine of them became indistinguishable from their peers by first grade and went onto become, remain indistinguishable at the age of 13. They didn't need any IEP, or any kind of specialized treatment, no aides in the classroom, those sorts of things. So, when she told me about the study, I was like, oh my gosh, I can't believe I never heard of that because I thought at the time in the late 1990's that getting a diagnosis of autism was a lifelong, for sure, very bad diagnosis. I didn't realize that there was any hope for recovery. Even if the odds were two percent, five percent, not 47 percent, I would have been like, let's just try it. I mean, you know, we just have to get on that and on the way home from

this woman's house, I stopped at the bookstore and I got two books that she recommended.

One is called, Let Me Hear Your Voice published in 1993 by Catherine Maurice when the mom of two kids who did recover from autism and then Catherine, Maurice and some other authors, professionals in the field. They authored a book called Behavioral Intervention for Young Children with Autism and that was published in 1996. So, I got these two books. I read them as soon as I read them and there were examples of this child did this and said this, and as soon as I got the books and read them, I knew that Lucas did have autism and that I needed to get him a diagnosis as quickly as possible. But I think why it's so confusing and why denial is so real is because kids with autism do have a range of signs. You know, a lot of kids have speech delays as one of their first signs.

Lucas had a speech delay, but he always talked. He actually talked a little bit early, he said hi to people at like seven or eight months. And but with, with Lucas, as for many children, they actually regress with some skills. So, while he could say hi and he could wave hi and do those sorts of things, then that slowly went away and I was pregnant with Spencer, you know, and I'm not an expert in development at the time. And so, I was just kind of hoping for the best. Oh, well it's just a phase. Oh, he just got sick. Oh, he didn't sleep well, making excuses. So, I think with some of the higher functioning kids, some of the kids with very mild symptoms of autism, there's even less urgency it's like, oh, don't worry about ABA that's just for kids with severe autism.

Meanwhile, those kids with mild autism could do so great if we just got them some good therapy. So, there's a lot of false reassurance. A lot of it's just a phase. Maybe he'll grow out of it. Lucas, I didn't realize that lack of pointing with the index finger was such a big sign of autism, but Lucas rarely or never pointed. Maybe he used to and maybe that was a regressive sign as well I'm not really sure. But what he would do instead of pointing was he would do this thing called hand leading, which you would take my hand and put it on things and when he wanted something and that is a bad sign, which I didn't know. He had this little routine at the mall where we would go to the mall and he would want to go up to the department store and look at the mannequins in a certain way and then he would want to go to the video store and look at the back of the...

I mean, I'm really dating myself now. The VHS boxes. He'd like to look at the back of them. I didn't realize that this was like insistence on a routine. He likes certain things. He would watch movies. I mean he didn't. He didn't have a lot of what we call self-stimulatory behavior, but he would like to watch the same movies over and over again. And that was kind of the way he stemmed. So, as you may or may not know, Lucas, my firstborn son was diagnosed with autism one day before his third birthday at Children's Hospital in Philadelphia by a developmental pediatrician. Luckily, we only had to wait a few months to get into that appointment, but when we got in, we got him diagnosed. I right away asked the

doctor about recovery because I had read Catherine Maurice's books and the doctor said that Lucas had moderate severe autism at that point.

And he had in his long career of 25, 30 years that he had seen recovery and he had seen autism get all better. But that was more for kids with more mild symptoms. And I was just like sitting there kind of in a you know, the fog and, and then, uh, the days. And I was thinking, you know, if I would have listened to my husband at 21 months old and got him in evaluation right away, you know, he would have been milder as we let time go by as I let time go by, he fell further and further behind his peers. And so, while the doctor didn't say that my denial hurt anything, I just felt that it, it definitely did. And this was back in the 1990's, late 1990's when Lucas was diagnosed, when the rate of autism was thought to be one in 500.

Now the rate of autism is much higher. It's one in 59. Some studies they one in 29, I just saw on a website one in 40. So, it is happening a lot more. So, there's a lot more kids and the waiting list to get those evaluations instead of just waiting like two months like we did the waiting list for an evaluation to see if it's truly autism is taking several months to even years. I have heard nine months, many, many times. It's taken nine months to get into an appointment. It's taken a year, I've heard that so many times, and then I've also heard from a handful of people that it's taken them two years to get an evaluation and those that year or two or six months or nine months are critical windows of time where those early signs of autism are not being treated. And that's really where I want to get the word out to empower parents and empower professionals who are going to help parents learn strategies to start acting even before the diagnosis.

I want to get the word out that recovery is possible. It's not going to happen for everyone. Lucas has not recovered from autism. There is, you know, he's in his early twenties. He is not going to recover from autism but ABA, Applied Behavioral Analysis, treatment over the years. First very intensively, 40 hours a week of treatment for two or three years. Now we use ABA for, you know, pretty much to teach him everything the principles of ABA. I can't even imagine what he would be like without that base of ABA, both to increase language and learning skills as well as to reduce problem behaviors. So now that I told you, just you know, and I know I'm glossing over this and we're going to get more into this in future episodes, but I do want to give you five steps you can take if you're in denial.

If your partners in denial, if your daughter in laws in denial, your clients think they might have a child with autism, I want to give you five steps that you can take to ease yourself or others out of denial and into action. Just like that hyperlexia mom helped me get me out of denial. I am really on a mission to help parents get out of denial and into action.

So, one thing you can do is you can send people to this podcast to learn more, but my podcast might be a little bit too much for, for parents. You know,

they may be so in denial that whatever relationship you have is just going to, you know, they're just going to shut you down. And not listen, there is another thing you can do in that I do have a three step, a guide called Is It Autism, ADHD or Typical Toddler Tantrums, Three Steps You Can Take Today Instead of Worrying.

So I also do weekly video blogs and some of them are on topics such as denial and Is Recovery Possible and you know, is it ADHD or autism, is it sensory processing issues and just different avenues that you could find a short video bog potentially and send the parent to it or go yourself, but so one is get some information and share some information maybe in little bite size chunks and maybe sending them directly to this podcast which is MaryBarbera.com/two.

The second step is to download this tool, this free screening tool called The M Chat, which stands for the Modified Checklist and Autism in Toddlers and it is valid for 16 months old to 30-month old and it's basically just a parent's screening. The parent circles, yes or no and it' things like the pointing. Does your child point with their index finger to show you things? Yes or no.

Does your child enjoy bouncing on your knees, singing songs, those sorts of things? Yes or no? Is your child or was your child delayed with walking? Studies have now shown that kids with autism can have a physical delay, but not always, so you don't have to get all yeses or all no's in order for you to be concerned. You can download this, this M Chat for free and we are going to link all these short video blogs and the toddler guide that I was talking about and this M Chat within the show notes right under this podcast at MaryBarbera.com/two.

So, you want to get and share information. You want to download The M Chat or encourage the parent to. And then the three steps that are in this guide are you want to know what the milestones are for each age, so you should know when, when should a baby sit up, when should toddler point, when should a child put two words together, when should they pretend play? When should they interact and answer questions?

And so, I think the CDC Act Early website has pretty good milestones to look at for two-month, four months, I think it's maybe starts at four months, four months, and then six months, 12 months, 18 months, 24 months. It goes all the way up to the age of five. So, know your milestones. And the second step in this three-step guide is if you see a discrepancy between the milestones and where your child is at, I would urge you to contact your pediatrician and schedule a sick visit. Don't wait for the next well visit, which could be months away, schedule a sick visit to discuss your developmental concerns. And the third thing that's in this toddler guide is to learn about ABA treatment because ABA is stands for the applied behavior analysis and it's the science of changing socially significant behaviors.

While it's proven and used a lot for kids with autism, these techniques, especially the techniques that I teach in my book and my online courses in my free workshops, all can be used for kids with and without autism. Even if you just have a speech delay or some tantrums that are troublesome, you can learn these ABA techniques and start to turn things around for you and your child.

So now that we went over the five steps, if you or someone you know is in denial or concerned, you can help them get out of that concern and into action. Now I want to switch gears a little bit and talk about the importance of early ABA treatment. Some people call that early intensive behavioral intervention and very few children with or without autism receive early intensive behavioral treatment. Early intensive behavioral treatment is, we use the acronym EIBI, and a lot of people get that confused with early intervention, which I would recommend calling early intervention and getting a free or low-cost screening and low cost or free therapy.

We did that for Lucas in my home when he was under the age of three. We had a speech therapist come to the home. We also did private speech therapy. Early intervention is not going to hurt the situation. The problem is that most counties, states wherever you live and there's people listening from multiple countries, I'm sure it all varies in terms of what you can qualify for, how much it costs, if anything, if it's free.

But typically kids with delays like my son before he was three, all he qualified for was one hour of speech therapy per week. That is not intensive. It is not behavioral and that kind of treatment which a lot of kids are receiving is not going to result in the kind of results of the Lovaas Study, so it's very common for kids to receive one hour of speech therapy a week, one hour of occupational therapy a week, one hour of teacher time a week, even if they have a diagnosis of autism.

It is very common for kids because both parents work, go to daycare to then also be bused to maybe to a special needs school or classroom where they received no one to one time or very little one to one time and that again is not early intensive behavioral intervention. The Lovaas Study, and even currently the Lovaas Institute is still operating and still going strong as well as the behavior analyst certification board, which behavior analysts are the ones that would organize and supervise and intensive behavioral treatment program.

So according to the Lovaas Institute as well as the BACB, behavior analyst certification board, 40 hours per week of ABA therapy is still what is recommended as the best therapy. And some... there have been some studies to show that 40 hours isn't really necessary, that we could do 25 hours, so 25 to 40 hours of ABA therapy a week for an 18-month-old or two-year-old for two or three years is as you can imagine, like very life changing to the family.

Very costly to someone. Now in my situation where I was living in my state, Lucas could qualify for medical assistance regardless of family income in order to qualify for that 40 hours of ABA treatment. And so there wasn't a lot of out of pocket costs. But I know many families from different states over the years have done second mortgages on their home, have gone into extreme debt over getting ABA treatment. The good news is that ABA treatment is now mandated by many state legislatures. So, ABA is usually covered in the United States as therapy, whether that's 20, 25 hours or whether it's 40 hours per week. And some families have said like, I can't deal with, you know, eight hours of therapy Monday through Friday for my two-year-old or three-year-old. I have four other kids. I have to, you know, I just want to have a normal life... I don't want all these therapists in my home.

And you know, unfortunately your child needs intensive behavioral treatment. Now that may look not like 40 hours or maybe not even like 20 hours. But the more you learn about ABA therapy, the more you yourself can provide ABA treatment during most of the child's waking hours. So, you could provide the kind of behavioral intervention at the grocery store and in the bathtub. And you could be working with your child from morning until night and supplementing it with more intensive therapy with professionals who would come into your house. But as you can see, this is going to be like a whole other maze.

There could be potentially waiting lists to get quote unquote good providers. There are different philosophies of ABA, so just because you can get ABA treatment and just because you have a board-certified behavior analyst, if your child is not making progress, if there's not enough parent training and parent collaboration, if it's too much of a distance from your house, if the copays are too high, it becomes not a very realistic thing for you to do.

So, there's just all these variables and this is one of the reasons that I developed my online courses and community because there are so many different variables no matter where you live. I started developing my online courses back in 2015 and we don't provide obviously 40 hours a week of ABA. We don't provide anything. We just really provide professional and parent training and the source of support a community support to help you become if you're a parent, your child's best teacher and advocate and if you're a professional to help you make a paradigm shift towards a very family, child friendly way of approaching ABA, using bf skinner's analysis of verbal behavior or the verbal behavior approach to help each child reach their fullest potential. Working very collaboratively with the parents.

So, I have three courses. I have my original course, which is the early learner course, and then I have the intermediate learner course which comes directly after the early learner course and then a couple of years ago I started my toddler course, which is mostly for parents of toddlers with delays on waiting lists with a

new diagnosis of autism, waiting for treatment, getting treatment, but just wanting to learn more about it.

And this toddler group has been a really successful experiment to help parents really become the captain of the ship. Besides my push to help parents see that they really can do a lot of this themselves and learn about ABA using simple techniques and simple things that you probably have in your house already, like a shoe box and Mr. Potato head, an inset puzzles and those are the kind of materials we use to help parents learn how to teach their kids and learn how to pair up the environment and get problem behaviors low and language coming in.

So besides that, action step that you can take and you can learn more about any of my courses through my free workshops MaryBarbera.com/workshops. Remember we're going to link all this in the show notes, which is MaryBarbera.com/two, but one piece of advice besides becoming the captain of the ship is if you want to try to find ABA therapy that may be covered with your insurance or find out how to go about getting help professional help to come into your home or for your child to go to a clinic situation.

I find the best way to do that is to Google ABA, verbal behavior, and then your city and state or your country. If you're from a different country, your city and country. So, if you lived in San Diego, California, you would type in the search bar, ABA, verbal behavior, San Diego, California, and see what comes up. I obviously as the author of *The Verbal Behavior Approach*, I would only ABA therapy using a verbal behavior approach. Hopefully you can find that, but in addition to learning all you can about ABA, that is the way I recommend even my online members.

I tell them to do that search to try to find reasonable behavior analysts and ABA providers who are going to work with you to help your child reach their fullest potential and if you're a professional in the field and you want to work somewhere that has the verbal behavior approach or you do work somewhere that uses a verbal behavior approach, but you've never taken my courses, then that is another way you can get more information to really collaborate so that every child can...

We can build on their strengths and decrease their weaknesses and work collaboratively with parents and professionals. So, in summary, there's a lot of denial. There's a lot of waiting for an evaluation and there is a lot of hope for recovery or major improvement with ABA treatment, no matter what age the child is, but the earlier the better.

There are several steps you can take to help parents get out of denial. Those are to share information, maybe in little bits like a video blog, maybe in my free three step guide, maybe by downloading *The M Chat* and helping the parent fill that out, helping the parents see that there is hope, that they do need to take action and even if they learn ABA and everything gets better, they're just really

learning techniques to help them be a better parent and their child's own best teacher and advocate for life.

So, I hope you enjoyed this episode of The Turn Autism Around podcast. If you did, I would love it if you would subscribe and leave me a rating and review. Share this podcast with others who may benefit and I will see you here next time with a special interview. Have a great week.

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.