



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 004

Is it High Functioning or Low Functioning Autism?

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.

Welcome back to the Turn Autism Around podcast. I'm your host, Dr Mary Barbera and I am thrilled that you're here. If this is your first podcast that you're listening to... The first episode, I want to thank you for joining us. You may want to go back to the first three episodes to get a feel for the podcast itself and some of my background and lessons. I know I did a great interview last episode, episode number three, with single mom Kelsey, and we have a lot more in store. You definitely don't need to go in order, but it might help you for some context to go back and listen to the first couple. If you have listened to all of them so far, I'm really excited about that and I would love it if you would subscribe to the podcast, share it with others who might benefit, and leave me a rating and review if you love the podcast. And this will really help me spread the word to both parents and professionals.

For those of you that do know me pretty well, uh, you know that most of my work, including my book, the verbal behavior approach, my video blogs, which I've done consistently on a weekly basis for the past two years, my three online courses and this podcasts are for professionals and parents living and working with toddlers through teens and even with some young adults with autism spectrum disorder. Most of my work does revolve around autism plus language impairments, but today we're gonna talk about the whole spectrum and what it means, what I think it means to be high functioning or low functioning and why I don't really like to use those terms. In my first few podcast I did talk about denial and early detection and recovery and as you know, if you listened to those that I was quote unquote gunning for Lucas to recover from autism.

I, in chapter 12 of my book, I talk about how I envisioned a recovery party for Lucas when he was when he was a young child and I felt like he was really pretty high functioning when he was young because, mostly because when he was two, he went to typical preschool without a shadow, without any diagnosis. He didn't throw a fuss. He was not aggressive. He didn't have

any stereotypical behaviors that I could see. He just looked like a quiet kid who was very language impaired and kind of in his own world. So, I thought if he does get a diagnosis with autism it would be very mild. And even though I told my husband that I didn't want to talk about autism when he first mentioned the possibility when Lucas was just 21 months old, I, the seed was planted and pretty much every time I would turn around if somebody would say autism, you know, autism would be mentioned on tv or I...

I did know one girl with autism who was a couple of years older than Lucas. When I'd see her or her mom, I would, you know, get nervous like, and every time Lucas would do something weird, like he used to do this weird thing where he would kind of hoard things and carry items from one basket and put it on the couch and create a little pile. And I would get worried like, well maybe that's a sign of autism if you'd play with a string on the couch or something for more than a couple of seconds, I would worry, you know, so autism would swirl around my brain quite often. But I kept thinking, well if it is autism, it's very mild and he's very high functioning and maybe he'll just get better.

But because of the denial and me over a yearlong denial period, he was... Lucas was diagnosed with moderate severe autism one day before he was three. And that was at Children's Hospital of Philadelphia with Dr Copeland, who I mentioned in my book, and he... I think he's still practicing, but he's no longer at Children's Hospital of Philadelphia. What I rarely talk about is that the month, about one month before our scheduled appointment with Dr. Copeland, Lucas went to see a psychologist through the birth to three programs. They paid for it. They were worried about his transition to the three to five-year-old program and they came out to do an evaluation and then they said if I wanted to go somewhere sooner than Children's Hospital, I could get into the psychologist locally who would evaluate Lucas. He saw us for one hour exactly. He did an IQ test on Lucas, and this is before he was three years old and he had significant language impairment. I remember Lucas sitting on my lap for all the testing, and my husband was there, and when he was done, he pretty much, very flippantly said he has PDD NOS, which stands for Pervasive Developmental Disorder Not Otherwise Specified, which is pretty much mild autism.

I started to cry and he said, well, I could diagnose him with, you know, autism. And he just really was not very supportive. I remember asking him, well, you know, do you think I should go down to Philadelphia to get him diagnosed by a developmental pediatrician? Get him evaluated, you know, the three to five-year-old programming they're offering like two mornings a week; is that enough treatment? I think I had already read the book, the Catherine Murray's book, and so I knew about recovery. I knew that intensive ABA was needed, and he was just very, um, well, I'm going to say rude. He was, he said, you know, why would you go to Philly? I just told you what you need to know. He has PDD NOS and when I asked him about the two days a week or three mornings a week, which was being offered, um, he's like, yeah, that should, that should be fine. Just very, uh, not giving me any hope. And then what happened next was even worse.

So, I leave there. I'm still going to keep my appointment in Philadelphia, you know, going to try not to get too freaked out by the psychologist who was very flip. Then I get the report from the psychologist which outlines that he did this IQ testing and that Lucas was barely, you know, able to do anything. And in addition to giving him a diagnosis on what they call it, like an access diagnosis. He also gave him a diagnosis of mild mental retardation, which completely wiggled me out. I was just horrified and I was just like, he can't even talk. And then you're judging him. He can't... he has very little attention. I didn't know how to teach him words. I didn't know how to teach him to follow directions. I didn't know anything.

And now he's pinning not only the PDD NOS label on him, but he's also pinning mild mental retardation on him. Now, now this is 1999. We don't call mental retardation that anymore, we call it intellectual disability. But this was before the change over to the new term.

In episode number one I talked a little bit about my fight for ABA treatment for Lucas and how I ended up in one year long due process case. And that I had, I had a lawyer who told me to become a behavior analyst. That same lawyer who had an adult son with severe autism as we were preparing for the due process case, he was looking at these records. I was kind of, didn't even really want to give him that psychologist evaluation because it had this mental retardation label on it. I was kind of freaked out by that whole thing, but you know, I gave it to him anyway.

And he was actually pretty excited about the, uh, MR Diagnosis. And I was looking at him like, why in the world would you be excited about an MR diagnosis? And he basically said that having a mental retardation diagnosis was better for services, and that in the long run I would be better off if Lucas was low functioning. I remember staring at him wanting to like, claw his eyes out. I'm like, I am killing myself to help Lucas; giving him ABA treatment, going to due process, bringing in a low VOS consultant. Like all this stuff we were doing to help Lucas recover, get as close to recovery as possible. And here was my lawyer telling me that I'd be better off if Lucas was low functioning. What he meant was that kids who do have an additional diagnosis of mental retardation do tend to get more services.

Lucas has gone on to get many more IQ testings and every time his IQ has not changed. That doesn't mean that I don't have clients whose IQ has significantly changed. And when I got to CHOP to the developmental pediatrician evaluation, one month after this psychologist diagnosed him, he was diagnosed with moderate severe autism. And I asked about the mental retardation diagnosis and if that was really legit, if, if I should be concerned or if that made any difference. And Dr Copeland said that at research institutions it was, it was not ever recommended that a child like Lucas with a speech and language delay with autism, with regression would be diagnosed with MR mental retardation before the age of five or even eight years of age because a lot of kids in the original Lovaas study and in his practice made major gains in IQ once they were taught language and following directions and imitation and those sorts of things, to the point where the study, I think the IQ, the IQ of the kids in the experimental group went up by 20 or 30 points.

So, another thing I don't talk about a lot is Lucas actually was evaluated again two months after his July visit. So, he was, he was evaluated in June by a psychologist who diagnosed him with PDD NOS and mild mental retardation. He was diagnosed in early July by a developmental pediatrician diagnosed with moderate severe autism. And then in September I took him back down to CHOP, to Children's Hospital of Philadelphia, and he was evaluated by a psychologist there to do baseline testing. This was recommended by the, um, the ABA providers to get a baseline to show his IQ gains and his gains once he was treated with intensive ABA therapy. And that second psychologist in September evaluated Lucas and she ended up diagnosing him again with PDD NOS.

Now this is years ago using the DSM-3, I believe, or DSM-4. So now we are using the DSM-5, which no longer is PDD NOS a thing. It's not diagnosed. It shouldn't be diagnosed ever. Um, even Asperger Syndrome, which I'm sure you've probably heard about, which is very high functioning autism, that is no longer diagnosed as a diagnosis. So, under the DSM-5, it is Autism Spectrum Disorder. And so, all of these terms I'm throwing out, I know it's a lot, but what I want to get across is in September of 99, he was diagnosed with PDD NOS. And to get the results, we had a meeting, my husband and myself, we brought Lucas and we had a meeting with the psychologist who diagnosed Lucas with PDD NOS in September. And the developmental pediatrician who diagnosed with moderate severe autism, we had them both in the same room.

And I'm like, okay, which is it? Is it, is it autism, is it moderate severe autism or is it PDD NOS? Because in my mind they were completely different things. And the PDD NOS was much more what I would want him to be diagnosed with because, in my mind, that meant more hope for recovery. Remember at the time he was still three. So, the developmental pediatrician, Dr Copeland was very wise, and he said it depends on the day, how much sleep Lucas got, it depends on what kind of testing was done. Real testing versus just by report. It depends on, on just a bunch of things where any evaluator would place Lucas. And I remember going back to the day where the psychologist evaluated him, um, we had bought a soft pretzel on the way in and when she got the doll and the plate and spoon out, Lucas for some reason came over, took a hunk of the Pretzel and put it on the plate and that, for instance, scored him as having pretend play.

I don't know why he did that. He didn't try to feed the doll, but I think his action of putting that little piece of soft Pretzel on gave him some bonus points, and what Dr Copeland said was that it's like saying something is light red or dark pink. A lot of times it's in the eyes of the examiner and that what I really wanted to know was what Lucas was going to be like at age eight, or age 15, or age 25, and that neither of them knew what, how Lucas was going to turn out, and that these diagnoses... parents just grabbing onto, well I liked that diagnosis better than that diagnosis. It doesn't really matter what the exact diagnosis is or where children fall exactly on the spectrum. The important thing is that you look at the child, you look at the strengths and needs, and you put intensive ABA in place.

Another professional who gave me very similar information, and different slant on this was Dr Glenn Dunlap. I believe he was from Florida and he was up in my local area. I think after I went

to that first psychologist, but I hadn't gotten the report yet about the mental retardation, so I went to this presentation, this one day, ABA presentation by the psychologist Dr Dunlap and he was talking about ABA, Intensive ABA, and so I went up to him at break afterwards, and I basically said my son just got a diagnosis like a week ago, of PDD NOS, and that he was, I thought very mildly affected, very high functioning. He was in typical preschool by himself and that, you know, I didn't know if I needed intensive ABA, those sorts of things I was saying. And I remember Dr Dunlap looked at me and he said, you know, I have seen 30 years of kids with autism and he's like, you know, I see kids like you're describing with Lucas who pretty mild mannered, no big aggression or self-injurious or self-stim behaviors, and they're doing pretty well at age three and I think, oh by age eight they should be, they should be in good shape and he sees them at age eight and some of them are in good shape and some of them are a mess.

And then he said, and then I see other two or three-year-olds who are severely impacted with autism. And I think, Gosh, there's, there's not as much hope. There's, you know, kids gonna have a tough life. And he's like, and some of those kids at age eight looked pretty good, and some of them are still a mess. And he's like, the most important thing you can do is treat Lucas's autism, like is the most severe case of autism you ever saw. Turn up the burners as far as possible. Get the most intensive ABA program you can find and then you won't look back and say, I didn't do as much as I could. I rested on my laurels. Meanwhile, kids with severe autism are bypassing my son because he just didn't get what he needed.

So, I did. I treated it like the most severe case of autism. It was really good advice. And having these different diagnosis just in that four to six month period initially helped me realize, you know, um, for my clients long term, I mean I wasn't a behavior analyst back then, but you know, I've seen a long for the past two decades where parents, especially moms are holding onto, it's just Asperger's or it's just mild autism, and these kids are not being treated nearly enough. I've a couple other examples where, you know, other clients of mine have some experience with the high functioning, low functioning trap. So, I have a mom of three kids that I think I talked about last episode, one of the previous episodes, and all three of her kids were affected. Her middle child was... I was treating the middle child and then come to find out that the kindergarten child was also showing signs of autism. But if you get to kindergarten and you get a diagnosis of autism, then you are probably pretty mild.

I mean it takes a lot to just, you know, I guess it does happen and I've seen it happen a handful of times where kids get to kindergarten and it's like, oh my gosh, they can barely talk or they're not able to sit and they haven't gone to preschool or daycare and um, haven't ever been evaluated. So that does happen once in a while. Her older son did get diagnosed with autism and then her younger one did as well. But this boy, the older son is now learning to drive, applying to college. That mom recently to get ready for her final evaluation at school, she looked at his original diagnosis and stuff and she said she had like five different diagnoses, ranging from PDD NOS, to somebody diagnosed him with moderate autism. Somebody told her that it would be unlikely that he would ever be able to write or even to be conversational.

Her middle child's IQ was really low when I first started working with him and it went up 30 points in one year while I was coordinating the ABA Program. So, I do know many examples of clients and friends of mine whose kids IQ dramatically improved in a year or two following ABA treatment. I also have another mom, she has two boys with autism and they were both diagnosed with severe autism, and diagnosed at Children's Hospital in Philadelphia too. And they have both, one of them has come completely off the spectrum and the other child is functioning in early elementary school without any support and just an IEP for some minor services. So, it definitely can change.

And I think comparing what level of autism you're at or where you are on the spectrum is like comparing cancers. You know, someone might have thyroid cancer and have a better prognosis than somebody with pancreatic cancer, but cancer is horrible no matter what stage you're at, what kind of cancer it is; it's life changing diagnosis and comparing cancers and trying to be like, well, my son just has Asperger's is really not helpful to anyone. I think parents have higher functioning kids often get quote unquote snowed by school systems and everybody that's trying to be like, don't tell anybody, you know, don't ask for any services and you know, because you don't want any stigma. Meanwhile those kids could do great with some intensive therapy and so I think older kids are- no not older kids. Kids that are higher functioning as they get older, if they are higher functioning, they are more aware of their differences. They are more aware of if people tease them or they have more emotions in terms of jealousy and those sorts of things that they do have a higher co-morbid rate of anxiety and depression and there's a lot of overlap between OCD and other kinds of issues.

So I think that's one of the reasons that my first lawyer told me that I'd be better off if Lucas was lower functioning because I think it's tough no matter where you are on the spectrum, but I advocate that each child should reach their fullest potential and be as independent, as safe as possible, and as happy as possible and so no matter where your child or clients fall on the spectrum, I'm always promoting that we can get them to a better place to a safer, happier, more independent place. When Lucas was three or even four, I thought, as I said he was high functioning, since he went to the typical preschool and he didn't have many problem behaviors. As he started to get a little bit older, six and seven and entered kindergarten at our local public school, I started to realize that he wasn't going to be in the best outcome group and the chances of recovery for him were getting slimmer and slimmer by the day.

At that point, I started looking at an approved private school for him versus the public school. Because he was pretty impaired. He was probably the most impaired kid in our local elementary school and the only person that knew what she was doing was pregnant and going out on maternity leave soon, and so I looked at an approved private autism ABA school that was about an hour from my house and this is where I got another big Aha lesson about high functioning versus low functioning. I was used to Lucas being in typical environments including regular kindergarten, and he would have pull out with the special ed education teacher who was one on one with him. But at this autism school I was observing circle time and there was a little boy who's probably the same age as Lucas, maybe eight years old, seven or eight.

And in the middle of circle time this boy threw a fit. Flung himself to the ground. I think I may have started my ABA coursework, but I certainly wasn't a behavior analyst at that point and I was kind of alarmed by this tantrum that this eight-year-old was throwing. And I was also concerned about the drive and concerned about a lot of things. And when the director and I met after my observation, she asked me if I thought this would be a good school for Lucas, and I said that actually I was concerned that Lucas was too high functioning for this school and brought up the fact that that boy flopped on the ground and threw a tantrum and I didn't think that that was good for him.

So, she told me at that point that that boy Nathan, even though he had some problem behaviors, he could read chapter books, he had a lot more language than Lucas. He had a lot more skills in a lot of areas. And so, calling Lucas higher functioning really wasn't accurate. And at that moment just kind of a light bulb went off and I thought, wow, you know, like you really can't line these kids up in terms of who's higher and who's lower functioning because it, it depends on what skill we're lining them up about. Are we lining them up in terms of their reading ability, language ability, problem behaviors, self-care, toileting, self-stimulatory behavior? Like if you would line people up in terms of who you could bring on a plane into a pool to a restaurant, Lucas would have been very high functioning because at the time and still today, he's pretty easy going and loves to go out and is good in the community.

So, it's really not fair to line kids up. What's fair is that we look at each child's strengths and needs and we program for their weaknesses, use their strengths, and we try to get them as high functioning as possible, as independent, safe and happy. And those are the things I want for Lucas and the same things I want for Spencer, my college age son who, you know, I want him, I want Spencer to be safe. I want him to be as independent as possible and I want him to be as happy as possible too. So, I think my whole paradigm shifted that day when Nathan threw himself on the ground and I learned a lot about high functioning versus low functioning. So, I really hope that you enjoyed this episode of the podcast on high functioning versus low functioning.

If you would like to see the show notes with any, um, any highlights, you can go to Marybarbera.com/4 and I would be thrilled if you would subscribe, share the podcast, um, give me a rating or review and help me spread the word to more parents and professionals. I also hope that you plan on tuning in for next week's episode of the Turn Autism Around podcast. Thank you very much.

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.