



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 051

Developmental Regression: Child with Autism is Making No Progress!

Hosted by: Dr. Mary Barbera

You're listening to the Turn Autism Around podcast, episode number 51, and today I'm going to talk about autism regression, lack of progress, and getting unstuck. So let's get to that crucial information.

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

Welcome back to another episode of the Turn Autism Around podcast. I'm your host, Dr. Mary Barbera, and today I'm going to cover when parents and professionals feel stuck; whether that's due to regression or just a chronic lack of progress in kids with signs of autism or with a diagnosis of autism.

I remember back in like, 2000 or 2001 I went to see Dr. Vincent Carbone speak up in North Jersey and he did a talk on programming for intermediate learners. And for those of you that are familiar with the VB-MAPP now, those would be level two, level three of VB-MAPP learners. And Lucas was always pretty much an intermediate learner. Once he was in ABA therapy for a few months, he became more vocal. We got to echoic control and he was an intermediate learner and it was hard to program for him because everything out there was just beginning to help us program for early learners.

So I went up to Dr. Carbone after his grade talk and I said to him, don't you think that kids with autism who are intermediate learners just get stuck? And that's, you know, kind of the end of the road for that. I don't think I used those terms, but he looked at me and he shook his head and he said, no, I think, you know, no one should be getting stuck, and that is just people not knowing how to program for your son. And back then I wasn't a behavior although, we had, you know, what I would consider the best ABA I could find. But over the past two decades I've felt stuck a lot, both as a parent and as a professional in the field, stuck on a variety of issues. So today in this podcast I'm going to cover five main areas where I think kids get stuck the most frequently, whether it is a regression of some sort or just a chronic lack of progress. I'm going to talk to you about what can be done and we're going to cover those five areas specifically.

But first of all, I want to say that autism regressing of any skills when you are young or older is heartbreaking. A lot of times it could be a medical issue that's causing the regression; it could be an abrupt regression. Like overnight... Your child starts seizing or overnight he starts not talking and the later it is, you know, the more vocal-like I've heard stories... apparently according to the research, 20 to 30% of parents report that their child did regress into autism, that they were developing on track or mostly on track. And then either had a sudden or slow regression. And I noticed a regression mostly in hindsight with Lucas shortly after his first birthday and I was pregnant with Spencer. So I wasn't really noticing, but you know, he regressed, he stopped saying hi; he stopped weaving. He used to really have a nice wave and you, you think like, oh, he's just becoming a picky eater or he has a cold or he has an ear infection and he's just a little off and it was spiraling. And he was actually regressing and the little cute baby songs and fill-ins that he used to do were gone.

But I was pregnant then I had the baby, then it was wintertime. So it is, it's heartbreaking. It's confusing. And we're going to talk about that a little bit with getting you unstuck. So if your child has a regression or just lack of progress, older kids can regress, too. But you know, that situation is very alarming when suddenly a 10-year old regresses; even a 10 year old with severe autism, if they suddenly lose skills that they once had, or again, more slowly, how do you turn things around? How do you help the child get on unstuck?

The step number one for any of these areas, and I'm going to go over the five areas in a little bit, but step number one for any kind of autism regression or lack of progress is an assessment. And that doesn't have to be, you know, waiting in line for a doctor to assess or having a behavior analyst assess. It can be a one page assessment like I created that you can get at no cost at marybarbera.com/join. You can get a guide with that one page assessment and you can get started. So my thought is you really need to step back and look at the whole picture. So when you assess we need to know, you know, the age of the child and what their medical status is. Do they have a diagnosis, do they have other medical complications? And that sort of thing.

And speaking of regression, it's really, really important that especially if it's a sudden or even a slow regression, that you rule out medical problems, high lead levels, you know, brain tumors, any kind of metabolic issues, hearing loss; that can all mimic signs of autism. There are autoimmune problems, there are bacterial infections like PANDAS or PANDAS, which I've done video blogs about, that can all cause a regression or cause things, symptoms of autism. So you do want to go to a pediatrician or a family doctor. You might even need to go to a specialist who specializes in autism treatment and really look closely to see what's going on.

So whether it's a regression or just a lack of progress in the areas of anything, whether we're talking about a child who is not talking and you don't know how to get them talking. If they are 10 years old and not taking a shower themselves, or if they are having reading problems, or if they are having sudden or chronic problem behaviors that you can't control, you need to assess where they're at and where they should be at.

So if it's a young child, I did a video blog on the M-CHAT. These are tools you can check yourself to see 'is my child falling really far behind'? I did a toddler guide, Is It Autism, ADHD or Typical Toddler Tantrums. You can get that at marybarbera.com/toddler. So just assess and when you assess don't count language and skill the child had more than a month ago. Especially if you're seeing a regression because it's not really helping the situation if you say, you know, yeah, my child touches body parts, but he can only touch his body parts if you sing a song. Or you haven't heard the word ball for three months, but you're still counting that as a word and I get it. I totally did that. I totally counted all kinds of utterances that I heard from Lucas before he regressed. But, so step number one is an assessment. Medical assessment, language assessment, self-care assessment, problem, behavior assessment. You want to know where your child or client is at and where they should be at.

I use the VB-MAPP as a base. I also use the self-care checklist, which I find really helpful by Dr. Mark Sundberg. And I also really, whether you have a young child or an old child who's stuck, we also need to look back and look at safety, look at independence and self-care and look at happiness, too. I think the field of ABA gets really caught up in diving in and trying to teach kids, but we really need to step back and make sure they're safe and make sure they're happy, make sure they're comfortable and stop really keep pushing if there's a problem and if they're stuck then just keep pushing with the same programs, the same targets, the same procedures is not going to get them unstuck. And this is why I'm really excited that you're listening to this podcast and open to a new approach. And I have a new approach that is getting kids on track every day, which I am credibly excited about.

So for Lucas, my son, who's 23 years old now, despite two decades of the best ABA therapy I could find, he remains non-conversational. And you know, that doesn't mean I don't continue to teach him language. We teach him new language for new job title, like job work. When he goes to work, he has different jobs. So we teach them the names of the jobs and the materials that are part of the jobs because he needs to be able to request the parts of the jobs. I'm also teaching him names of new people that are in his environment, people at work mostly. And then teaching him, I'm just started to teach him to answer why questions like, why is the pool closed? Or why is so-and-so not here today? Or why didn't you go to church with daddy? And just trying to teach him because, and the answer, and it's working. We're, we're having some success.

But just to remind you that, you know, not all kids are going to be conversational. And it's not because of lack of trying. And you know, I'm not here to tell you that there's no chance. There's always hope. There's always a chance. And working on conversational skills with Lucas, answering why questions, he can answer a variety of questions but answering why questions teaching him yes and no responses that are reliable, those kinds of things will really improve his quality of life. So for Lucas, I believe he has reached his full potential, but like that's not a once and done thing that's continuing to have him reach his fullest potential, be as happy, be safe, be as independent as possible.

He has major problem behaviors at a near zero and a lot of that actually was due to medical intervention. I did a podcast with Dr. Murray, Lucas's psychiatrist. That's episode number 28, so you can find that at marybarbera.com/28. Anything I'm giving out in terms of links you can find at the podcast show notes. So if I know I'm giving out a ton of links, they will be listed in the show notes at marybarbera.com/51, which this is episode 51 so we're almost at the end of the year. I'm very proud that we've managed to put together this podcast and we've come out every Tuesday since then. So it's super exciting.

Okay, so after you do an assessment, then step number two, whether it, no matter where you're stuck, what area, and I'm going to go through the five areas briefly in a second, but step two after assessment is you want to make sure that if you're stuck, your plan, your goals, your targets, your programs are not correct. It's never the child's fault, it's always the people who are very, very much trying your best, trying to help the child. You need to... I use the analogy like peel the onion back. You need to find the layer where your child is going to be successful.

So step number two after assessment is to revise the plan, the goals, the targets, the programs. If there's no progress in a program for weeks or months or years, you've got the wrong programs, goals and targets. The child is missing prerequisite skills. I remember my first consultant who came in, she, you know we had a Lovaas style ABA program in the beginning and I talk about that in episode number one, how we switched over to a verbal behavior approach. It's all throughout my podcast, but I remember her saying, you want to get into a program and get out of a program. If you get stuck for weeks or months or years with no progress or limited progress, it's not the right program and you might have to put the program on hold and go and fine tune what the prerequisites are that are missing.

Okay, so let's talk about the five areas where I see people, parents, and professionals getting stuck. And I know for me I've gotten stuck with all of these areas and I'm going to tell you where they get stuck and where you might be getting stuck and how to get unstuck. Obviously this is a short podcast. I'm not going to be able to cover everything intensively here. I'm just giving you some ideas. Okay. So the first place where people get stuck is going from not talking, non-vocal, nonverbal, whatever you want to call it, not talking to talking.

I've seen kids that are, you know, obviously one and two years of age who are not talking three and four. But I've also seen, you know, 16-year-olds who are not talking. So talking and communication are two different things, but we're not going to talk about communication and augmentative communication devices or sign language or anything like that, which obviously, you know, we want our child to be able to communicate. But let's just talk about getting a child vocal. And going from non-vocal to vocal is a big area where people get stuck. So there is a ton of information about how the procedures I use to get kids talking in my, in my free online workshops, in my paid online courses, you can go and see the free workshop which tells you about some of the mistakes people are making and also gives you some idea about whether the online courses that I offer are a good fit for you. So you can find out that marybarbera.com/workshop I cover how to get kids talking both in my toddler course for

parents and early intervention professionals of young children, as well as within my early learner course, which is for professionals and parents of kids over five.

So one of the things you want to do if you have a child that's nonverbal, not vocal, not talking, is really assess whether that is indeed true. Most of the time when I go into independent evaluations, which I don't do anymore, but when I used to do first time assessments on kids, a lot of times kids were labeled nonverbal when actually they were saying some things; they were saying some sounds, they were saying some word approximations and they had pop out words, which are just words that they say here and there.

One of the really biggest things that I've done in my courses and my work over the past decade since I published my book is I really have focused on multiple control activities. So my shoe box program for instance has multiple control. So it is part manded or requests because I'm holding up a picture of something that's preferred and we have established putting things in a shoe box as a reinforcer. So I might be saying Apple, Apple, and say the child does say Apple or some approximation for Apple. They are getting the picture to put in the box. And that response of them saying Apple or close to it is part mand because they want the picture to put in the box. It's part tact because they can see the picture. It's part echo because I'm saying it first; and it's part a receptive listener responding where they're putting the the picture in the box if they don't do that on their own. So we establish lots of manded, tact, echo combinations very quickly with the shoe box program, with potato head, with puzzles, with lots of activities. And that has really made the difference. And one of our course participants in the toddler course, just last week posted a video of her grandson saying Apple. And she literally wrote two weeks prior when she purchased the toddler course, her grandson was completely nonverbal and now he has words.

So it's exciting when I see something like that and when I see and hear about kids getting vocal or a lot more vocal with these procedures and I know it's possible. And it's possible even if you have an older child, we have a participant named Anna who joined my online course when her son was eight years old and he was labeled nonverbal using a communication device and she got him vocal; hundreds of words now over the past few years. And so it's always possible and especially it's possible if your child has any sounds, pop out words, or word approximations.

Okay. So the number two area where people get stuck is receptive ID or receptive commands that is following directions, like touch your head or come here or touch the banana as you have pictures down on the table. That is all receptive without a visual prompt.

So if I say touch your head and I give a prompt that is actually part imitation and part receptive. And that's actually a good way to teach it. But if you don't feed your prompts systematically you will get a child who does not understand language. And I have seen young kids and older kids with little to no receptive language. And this is a big problem for cognitive awareness, for everything. I mean if you don't understand the language that people are using, it can lead to a lot of issues. And people say, well, you know, he's not making progress and, you know, what should I do? But the biggest things I teach is for receptive body parts for instance is you want to

make sure you have the imitation really strong. So we would start with imitation with objects and then we would go to imitation with body parts. And then we combine that with touch your head and the child touches head. And then we would use transfer procedures to say, touch your head without a prompt.

But obviously this is very complicated and it doesn't always go that easily. But I do think in addition to boosting up your imitation skills to get those receptive body parts and receptive commands going, we also have to increase the matching and the scanning before we really go to receptive ID or receptive identification, touch the banana for instance. We want to get that as a match. So giving them a picture of a banana, and instead of saying match, I actually usually say banana, because I want everything to be as multiplied controlled as possible to get as much as I can for free.

So number one area that people get stuck is non-vocal to vocal. Number two area is receptive identification and commands. The number three area where I see parents and professionals getting stuck is with getting kids who are talking to be conversational. And that is a big jump. And Lucas is still not conversational, and I don't see him being fully conversational unless some miracle happens. You know, which there could be a medication or there could be something that happens that makes him fully conversational, but he can communicate his wants and needs. His major problem behaviors are at or near zero, and he is pretty independent with his self-care and those sorts of things. So getting kids talking who are already talking to be more conversational is an area where people get stuck a lot. Kids that are talking but not conversational, that have autism, usually moderate to severe autism, they have weird language. They are scripting and stimming and a lot of people just like, oh, fingers crossed he'll be conversational.

But it involves a lot of systematic teaching of language, and the quicker you can get on that, the better the odds are that your child or client can be conversational. And just because Lucas isn't conversational doesn't mean he's not making progress with language. There are the really abstract language concepts that are so important. Like yes, no, answering yes, no within a mannered, within a tact. So do you want ketchup on your hot dog, or within a tact is this a cup or is this blue or is this green? And then answering questions with yes, no. Did you go to the store today? Did you was a coworker there? Yes, no, is huge. I've done a video blog on that as well. Yes, no. Intro-verbal categories, intraverbal webbing, teaching colors, teaching, reading, math, writing, it's all complicated. And these kids that are talking but not conversational are almost always those intermediate learners who script and stim and have problem behaviors.

And you know, a lot of people don't realize, but stemming and scripting, especially if it's very excessive, can be a major problem behavior for inclusion, for working in the future. So all these things to think about. So getting kids more vocal is one, getting kids to receptively understand language is two, and the third area is the kids who are talking, getting them more and more conversational. And really the best way I know how to do that is by considering joining my intermediate learner course, which is part of the verbal behavior bundle. Of course you can go to the workshop, the free workshop, which we'll link again in the show notes to help you learn

more. But I wouldn't accept a kid who's 10, you know, just accept the fact that he can't be conversational because if you put these building blocks in place and really teach language systematically, no matter what the age, there's always hope.

The fourth area is where people get stuck is self-care. I remember when Lucas was young, he was diagnosed with moderate severe autism. I also brought him to a psychologist at children's hospital around the same time. And that psychologist diagnosed him back to back with the, with the developmental pediatrician, the psychologist diagnosed Lucas with PDDNOS, which is not even a thing anymore, but I was like, how could you know, a month apart she be doing? And she was doing more testing, IQ testing, which Lucas has always been below 70. So, you know, we've done a subsequent IQ tests and they've always been below 70, which means that he has a diagnosis of intellectual disability, too. And I remember back when he was three and four and worried about his IQ and, and worried about his programming at the table and those sorts of things.

And I remember the psychologist really giving me good advice. She said, you know, don't just focus on table time activities because a lot of his ability in life and a lot of his IQ scores in an assessment on mostly self-care and, or a lot of self-care. And it basically gives you an IQ score. So the higher your self-care is if you are four and potty trained for instance, or you're five and not potty trained, that will have a significant effect on your IQ. It will also have a significant effect on your placement, and on your ability to be included. So not focusing on self-care is another area where people get stuck.

And this again needs systematic instruction, which I provide in my online course. I actually show videos of kids teaching them to dress. I have a very, you know, a discrete video of my son with within his showering routine within my paid online course. So I understand. I'm a registered nurse and a behavior analyst and a mom and I understand how to teach these self-care activities which are just so, so important no matter what the age of your child is.

And the final area where people get stuck, parents and professionals is they get stuck with not knowing how to reduce problem behaviors; whether that's major or minor problem behaviors. They just feel stuck with months or years of the same issues. And if it's aggression, self-injurious behavior, property destruction, it can obviously lead to very limited choice in terms of who is going to care for the child, who's going to provide respite, where the child can be in school. It's just so, so hard.

So obviously it's a complex, tight topic of how to reduce problem behavior. I'm not even going to really get into it. I've had tons of podcasts and video blogs, if you just Google 'Mary Barbera problem behavior', you'll find an assortment. Again, this is a big focus of my online courses, is not just to improve good behaviors we want like language and learning and self-care and getting more conversational, but also at the same time reducing those problem behaviors. And it is two sides of the same coin. We need to constantly be increasing good behaviors and decreasing problem behaviors.

So in general, no matter if you're stuck in any of these five areas, you always want to start with an assessment and a revision of the goals, the plan, the targets; peel back that onion, figure out what is going on and put one foot in front of the other. It's not going to be a day where all of a sudden you're turning things around, but turning autism around, whether that is for an older child who is not toilet trained or not talking; or turning things around for a young child just showing signs of autism, it's always possible to make progress. Kids should be making progress. They should at least be safe, independent as possible, happy as possible. They should have the big three of being able to request their wants and needs, whether that's vocally or with a device; they should have major problem behaviors at or near zero; and they should be, especially if they're over five have the ability to use the toilet as independently as possible.

These things are going to affect their quality of life; it is going to affect the family's quality of life because they're going to be able to get babysitters and respite workers and the child is going to be more and more able to be included and have a happier life. The more progress we can make. Of course, we as parents and professionals only have one life, too. So try to remain as less stressed as possible. I know when I interview guests, I'm always asking them about ways to reduce stress and putting one foot in front of the other is the way I reduce stress. Like whatever the problem is. Okay, let's assess the situation. Assess the gap. Like is it a huge gap? Is it a little gap? Make a list, make a plan to work towards fixing it or making it better. That's all what life is, is just making things as good as possible.

So again, I hope this podcast was helpful in terms of the five areas where people get stuck. Hopefully you can get yourself on stock. I really urge you to attend a free workshop at marybarbera.com/workshop and I hope that you'll hear from me again next week. If you have listened to this podcast and have yet to leave me a five star review and a rating to help me spread the word even farther with this podcast, I would love it if you would go on Apple podcasts or wherever you're listening and let me know your thoughts. Let me know ideas for future episodes, and I will talk to you next week.

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