



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 019

Advocating for Children with Autism: 5 Steps for Parents and Professionals

Hosted by: Dr. Mary Barbera

You're listening to the Turn Autism Around podcast, episode number 19. In today's episode, I'm going to be talking about the five steps parents and professionals can take to advocate better for children with autism, and I'm really looking forward to presenting this information to you.

Before we do that, I'd like to give a shout out to one of the professionals that gave me a five-star ranking and review on iTunes, and that is Behavior Babe, which is Dr. Amanda Kelly. Dr. Kelly actually was featured on episode number eight, but she left a review the day after my podcast went live in January of 2019, and she said, "In addition to being knowledgeable, Mary is also easy to listen to and her information is easy to digest. I recommend this podcast for parents and providers alike".

So if you want to hear that interview with Amanda, you can go to marybarbera.com/eight to listen to what Amanda has to say about advocacy. But in today's session, session number 19, I'm going to get be giving you five steps you can take whether you're a parent or professional. So let's get to that 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 I'm thrilled that you are here listening to my advice, whether you're a parent or professional, I really think this podcast is going to cover five steps you can take to better advocate for children with autism. If you've been listening since I started my podcast, I did talk in episode number one a little bit about my journey and how I ended up in due process, which is basically educational court. I went to due process twice for Lucas, but in the end, knowing what I know now, what I learned in the past two decades is that you seldom win due process, um, you end up appealing until you finally settle. And at the time I felt like it was necessary to go to due process twice. But knowing what I know now, I probably could have avoided it, especially in due process case number two.

I'm not going to get too into what due process is, but I am going to give you five steps I think to avoid some of the formal litigation processes that I've been through. So as you probably know, if this is not your first podcast you're listening to with me, is that the goal of my podcast, the goal of my video blogs, my online courses, my book, is for parents and professionals to work together to ensure that each child reaches his or her fullest potential and becomes as safe as possible, as independent as possible, and as happy as possible. And one of my online course members, her name is Penny and she has a 12-year-old son with autism, and she lives in Pennsylvania and her son is actually in a verbal behavior classroom and she's been taking my course for several months now and she's been listening to the podcast a lot too. And she reached out to our private Facebook group that's part of the course and community and she really liked Dr. Megan Miller's interview, which is podcast number seven, and Dr. Megan Miller is a behavior analyst, doctoral-level behavior analyst and she has expertise and talked a lot about alternatives to using escape extinction, which is escape extinction is pretty big word for like keeping the demand on nagging children. Even many behavior analysts, not including me, uh, use some form of blocking to keep a child sitting, attending both my courses and um, Dr. Megan Miller's approach are uh, different than that.

We really strive to prevent problem behaviors to um, not use those procedures that lead to potentially more problem behaviors and more aggression and those sorts of things. So we are very much into a positive approach where we're not getting into big struggles with children. Anyway, Penny, our member who gave me permission to use her name here, she reached out and she said that after listening to the podcast, she asked some questions on our monthly Q and a call that's part of the course. She watched a bonus video that I did on advocating and she was able to go into her IEP meeting for her son just last week and she was able to advocate for him, advocate that they stop using escape extinction, advocate for um, a behavior analyst to go in to assess and to oversee her son's program. So she was able to use the information she learned in the podcast, the information she learned from the online course and she was able to make improvements for her 12-year-old son.

So there's an example where, you know, she learns some advocacy skills that helped her. We've also have several professionals in our closed Facebook group who talk about how they worry about their, their jobs if they advocate too hard and that, you know, you kind of have to toe the line when you work for a school district or an agency that serves school districts, and then it becomes kind of a struggle between what the parent wants, what the organization wants, what the funder wants in terms of, of looking for certain progress in certain areas. And it sometimes feels like a fight.

Kelsey, who's a single mom living in Canada with two young kids under the age of five at this point, Kelsey is featured in an interview in podcast, episode number three, um, marybarbera.com/three, and Kelsey revealed that when she, before she found my online course, she was driving her son Brentley an hour each way to an ABA clinic where they were working on the wrong things. They were working on colors, they were working on things like that. He was banging his head on hard surfaces to the point where the the behavioral analyst said that if she wanted to continue bringing Brentley to the clinic, that first of all, she wasn't

allowed to come in anymore to observe or to give her input because she was learning a lot through my online course. And secondly, if Brentley continued there she would have to get him a helmet because he was banging his head on hard surfaces so much. So there's, uh, so Kelsey, um, actually ended up withdrawing him from the clinic. Even though the insurance was paying, Kelsey stopped driving him to the clinic and he is now almost five years old. He's not wearing a helmet. He's not banging his head. He is talking in little phrases. He knows his colors now. She was able to build language on her own using my online courses and she actually now is our online community manager, but as you can see, parents and professionals are struggling with advocacy. What's the best practice? What are we talking about when we're talking about advocacy? And so now I want to cover five steps that I think we should all be taking to get better with our advocacy for children with autism.

The first step is that... I know I used the word already "fight". Advocacy should not be the same as fighting. It's, it shouldn't be us against them. We should be working together to ensure that each child reach their fullest potential. I tend to step way back, I always say, let's step back. Let's look at the forest, not the trees. We have to step back and look at this child, this child's assessment where they're at. Through my online courses, I encourage parents and professionals to do a one-page assessment that I can link to the show notes here marybarbera.com/19 to do a one-page assessment, to also do quick little videos. I usually like to see videos of a child alone playing, see how they play. One to two minute videos, very short. Another video, one to two minutes with you, the parent or professional trying to engage the child. And the third video is um, the child having some kind of problem behavior.

So if I have the one-page assessment and these three little videos, I can get a really good handle on where we should go from here. And so sometimes people get too far into, should we have a goal for teaching three features from four items or you know, very, uh, focused on the trees and we need to all step back and say, okay, if this child is four what are our goals, what are our goals for when he gets to be eight, when he's in school, when he's a teenager, when he's an adult and we... no one has a crystal ball, we don't know how these children are going to progress. But what we can say is we need to just step back and look as a parent or professional as where the child is currently and what supports and what goals he needs to get to the next level.

There are a couple of good resources I used way back, uh, two decades ago and one decade ago when I was advocating for Lucas. Uh, one is a book by Gary Mayerson called *How to Compromise with Your School District Without Compromising Your Child*. Gary is a parent of a son with autism and he's also an attorney. He wrote a great book and um, I know it's a little dated, but I think it

is still a great resource for both parents and professionals, probably more so parents. Another great resource which is still available is by Peter and Pam Wright, and the Wright is spelled W, R, I, G, H, T and they have wrightslaw.com and they sell books. They have online resources and they have live training way back, more than a decade ago, I attended a two day, Wrightslaw boot camp where they talked all about educational law. They talked about, it really showed me

how to take Iq tests and look at the subtests for higher language, higher functioning kids, and really see where the child was having their strengths and their deficits. I had a dentist come up to me years ago. I was getting a tooth pulled and she said, I had worked with her son years prior and she said, you know, I'm thinking, I don't know where my son, he's in ninth grade now, I have no idea... Can he go to college? You know, what should we be looking at?

And I had worked with her son years prior in a classroom. So I didn't know him well, but he was very scattered at the time. And I don't know, you know, I hadn't seen him for years, but I asked her, I said, have you ever had Iq testing, academic testing? Like we need to assess where this boy is at to see, um, if college track is a viable option if it's something that he could handle. And she looked at me and she said, and he's in ninth grade and he has autism, and she said he had never, to her knowledge, had an Iq test done.

And so that was kind of alarming, and she ended up getting an advocate and he ended up going to a private school for kids with learning disabilities for a few years. And last I saw her, I just saw her recently a couple of months ago, and this boy is in his third year of college doing well, driving, and those sorts of things.

So I think it illustrates, it's never too late. Not every child with autism needs the same thing. Not everyone needs a one to one aid. Not everyone needs a secluded, segregated intensive teaching session area. Not everyone can benefit from full inclusion. So step number one is don't equate advocacy with a fight. We just need to say we're advocating for the child for his prognosis to be as to reach his fullest potential.

Then number two-step, and I kind of alluded to that in step one is we need to start with an assessment. This dentist's son is way different than what my son would need and they're basically around the same age. We need to step way back, look at the whole situation and based on that assessment we can decide as a team where we think the goal should be, where the placement should be. So a lot of people right away are like, I want my son in typical preschool or I want my son in this school for high functioning kids. Do you think that's a good idea? Well, it depends. It depends on their assessment. If they have our VB-MAPP level two or three learner, then going to an all-inclusive setting without one to one support, without one-to-one teaching is not going to be a good fit. Um, if they are above the VB-MAPP level, then we're talking about a different type of learner potentially, they... And I know I bring up the VB-MAPP a lot.

For those of you that are new to listening to me, the VB-MAPP is, um, stands for the Verbal Behavior Milestones Assessment Program Placement, something like that. I might be messing up the last two P's. Anyway it was, it's a curriculum, it's an assessment tool and it was written by Dr. Mark Sundberg and published in 2008. I have been using it since 2006 because I helped to field test the VB-MAPP back when I was with the Pennsylvania Verbal Behavior Project grant. And so my courses, my early learner course, and my intermediate learner course, are basically around how to program from the VB-MAPP. Sometimes I see, um, institutions, organizations, school districts use the VB-MAPP, assess the VB-MAPP every six months or every year, but

they're not programming based on the VB-MAPP. So if you do a VB-MAPP, then the goals for reducing barriers for getting language in my opinion, should be based on the VB-MAPP and I don't see that happening much.

So number two-step is to start with an assessment and make sure that everything that you're doing, what goals you're selecting, what targets you're selecting and what placement the child is at is, um, meshes up with their assessment. Some people think full inclusion and mainstreaming is the way to go, but many kids within the VB-MAPP have these needs... intensive teaching. They need data collection on a bunch of skills. They need data collection on teaching. Even things like hand washing and potty training. They may need data collection on teaching pronouns and prepositions and how to answer yes and no, and the building blocks conversational skills. Just putting kids in inclusive settings to be near typically developing peers rarely works and most children that are placed in settings that are too high for them where they don't understand just end up wasting a lot of time.

And I think I talk about that in some of the other podcasts, namely the podcast a few weeks ago on social skills and when and how to teach them. So you may want to look back for that episode. We also have to base the assessment and base our advocacy on um, the age of the child. But just because a child is school age for instance, just because they're eight years old or just because they're 12 years old doesn't mean we have to or we should be focusing on reading, math, writing, and spelling. I've seen advocates where they're all about that, yet the language comprehension is just not there. The self-care skills are just not where they need to be and it may not be appropriate to teach a child even number identification or how to spell words if they can't comprehend basic language skills. They can't ask for what they need if they are not potty-trained, if they have major problem behaviors, if they can't speak, um, there are children that can learn to read and spell and do math and write that can't speak, but we have to constantly be assessing their understanding of language, not just their expressive language and we need to be building the base very solidly. So it's kind of like a pyramid where on the bottom you have, you know, the base skills and a lot of times people get too in a rush to get the higher language skills or the academic skills, meanwhile, everything's falling apart.

So most kids, in my experience over the past 17 years working as a behavior analyst, I think most kids with moderate-severe autism who are school age have VB-MAPP skills that still have some deficits and a lot of those kids need systematic programming. They also, many of the kids need one-to-one support and board-certified behavior analysts. Not every child but based on the assessment, but if you are a 12-year-old like Penny's son, still within the VB-MAPP level of learning and language which is under a four year old chronologic age, then there's a big disconnect and then we're going to have really been looking at what supports need to be in place. Also, one more point before we go to the third step is that just throwing a one-to-one shadow or one-to-one aid at a child is not going to be the answer in most cases because the one to one is going to need not just initial training, not just a four hour training session, they are going to need ongoing training, ongoing supervision, we're going to need to know what the one-to-one should be saying, doing, how much are they should be promoting, what data they should be collecting. And we're still going to want the child to be making nice progress, and so

there sometimes is a jump to push a child into full inclusion with a one to one who has no supervision, no guidance, no data collection. And that's going to be an issue as well.

So the first step is to not equate advocacy with fighting. Step number two starts with an assessment and make sure that whatever you're doing is based on that individual needs. Step number three is making sure the plan is based on the assessment. So whether that's a treatment plan, whether that's an IEP or where ever you're listening from. We have, in my online courses, we have people from 60 different countries, so not everybody has an IEP, but usually if some agency is funding ABA therapy, there's usually going to be goals somewhere and there's usually going to be a need to collect data to prove that what you're doing is working.

So in the United States, this is called an IEP, an individualized education plan, and we want to make sure that the goals match the VB-MAPP assessment or whatever assessment you are doing. So a lot of times I see a disconnect there too, where they might do a VB-MAPP and then the goals are like pretend play, greetings, sitting at a table for 10 minutes without reinforcement. You know, just kind of strange, outdated goals as far as I'm concerned that doesn't match the child's VB-MAPP profile.

There are also a couple of things on the IEP if you are in the United States that I look for, um, that I want to pay close attention to. One of them is... Early in the IEP page four, page seven, you know, something early in the IEP there is, does the child have English as a second language, is a child visually impaired or blind? Yes or no? Yes or no. And the last question is, does the child have behaviors that impede his or her learning and the learning of others?

So along the years, I've learned that if the child indeed has any kind of problem behaviors, that does not mean that they have to be flopping on the ground screaming, aggression, self-injurious behavior. But even if they have whining, even if they have difficulty sitting when told to sit, if they have difficulty paying attention, um, if they have difficulty waiting in line and might grab a child in front of them or push a child, that is behavior that impedes their learning and the learning of others. So almost in most of the cases that I have seen, and I've worked with thousands of kids over the years and trained thousands of people around the world, but in most of the cases I've worked with, that box does need to be checked, yes. And if that box is checked, yes, then that results in a functional behavioral assessment being done and a behavior intervention plan.

That doesn't mean that it's always done by a board certified behavior analyst though. And also a lot of times people are treating problem behaviors, what I call willy nilly. They're just kind of making things up and oftentimes it backfires. But that box is important if you are using an IEP. The other important section of an IEP is the parent concern section. And as a parent of a son with autism, we want to make sure that if the school asks us for concerns, this is going to be part of their document. Uh, this is going to be part of the assessment that leads to goals that leads to eventual placement. So we want to make sure that the parent concerns aren't just jotted down nonchalantly, that we really think about what we want for our child and that we

are put it in writing and we make it lead to the goals that we think are important and the placement that we think would be the best for the child.

Speaking of best though, and something I learned very early on in my first due process case is that in the United States, children are not automatically given the best therapy, the best treatment. They are... if you know a Ferrari car is the best, they are only entitled to a Chevy. They're not entitled to the best. So in my first due process case, I had to totally not use best. Even though I as a parent and as a professional, I want what's best for every child. So what I say now is I want each child, I want my son to reach his or her both fullest potential and I want that bar to be kept high. I want it's not a once and done reach your fullest potential and you're done. You constantly have to strive so that your child is in a situation and their life leads to their fullest potential and they are safe, independent and happy.

But if... Getting back to that little box being checked and the FBA and the behavior intervention plan and I go over all this, um, to a greater extent within my bonus video on advocacy within my online courses, that will lead or should lead to goals related to behavior reduction. It might lead to one to one support if the child needs it. It might lead to inclusion for some situations or all day. It may lead to a board certified behavior analyst supervising the child's program, not just the problem behaviors part, but also the language acquisition and the VB-MAPP goals as well. So what do you do if you have a professional that you're working with that is not, um, receptive to a verbal behavior approach or maybe they're not receptive to ABA in general? Maybe you're working with a parent who wants a different approach. They've heard bad things about ABA and they just don't buy into anything that you want to do. You have to get on the same page with the parents and professional because you're all part of the team that decides on the goals, the placement, the data collection, what you're going to be working on.

And so step number four is to educate yourself, whether you're a parent or professional, educate yourself and then begin to share information that you think would help others learn how to better help your own child or sharing with parents to help them help their own child. I do believe that my online courses are the best step by step approach to help you learn how to teach early and intermediate learners that are within the VB-MAPP level of learning, which is talking in short phrases, not conversational, not talking at all, going from not talking at all to not conversational yet.

That's a big range and it doesn't really matter the actual chronologic age of the child is it matters what the language, ability and cognitive ability of the child is. So, um, we can work with different kids of different ages. Now of course if we have a VB-MAPP from a two-year-old versus a 12-year-old and they're very similar VB-MAPPs, our programming is going to look different because a two year old needs different things than a 12-year-old. And so we always take not just the skills but the age, family values, their past history and within each child are their strengths and needs. And we always have to put that front and center. So I do think that the best way to pair yourself and to educate yourself is through my resources. I do have a lot of free resources on my Youtube channel which is [marybarbera.com/youtube](https://www.youtube.com/marybarbera).

I often tell people even within my online courses if they are thinking, wow, I wonder what Mary has to say about stemming or I wonder what Mary has to say about carrier phrases. Just Google Mary Barbera carrier phrases, Mary Barbera stemming, Mary Barbera problem behavior, and chances are good that since I've been doing video blogs for over two years now, that something will pop up either a video blog or podcast that will give you a quick snippet of what I would tell you about that particular topic.

However, if you really, you know that can only get you so far, I do produce a lot of free content but piecing all this free content together is not enough and if you really want to get to the level where you're able to program for any early and or intermediate learner program for them, language-wise, self-care, leisure, reduce problem behaviors, have parent and professional collaboration to the fullest extent, then the only way I really know how to help you is through my online courses and community.

You can find out more about joining me on that at marybarbera.com/workshop where I give you a free workshop and talk to you about some of the aspects of the course which you might be interested in. In the meantime though, looking at my free resources, listening to this podcast are excellent ways where you can think about things a little bit differently perhaps, and make some strides.

Okay, so we are on step number five. If we have team members, parents and professionals disagreeing on goals, on placement, on targets, the best thing to do, what I would advise is we need to all step back and focus on the child and the parent values. We... It shouldn't be about opinions, it should be about the child, what level they're at and um, how we can get them to the next level. And it may involve some compromise like Gary Mayerson's book and it may involve some steps just to try out different things to try out different approaches. But I do believe that when there is disagreement, we need to step back and focus on the child, the child's assessment. Maybe they need a reassessment. Maybe they need an independent person to come in and take a look at the situation. Maybe everybody's a little bit too close to the situation and we need some of the more independent to help us figure out what we think is best for the child.

So the five steps that I believe parents and pros need for better advocacy are to, number one advocate, but don't fight against each other or the goal of advocacy once again is for each child to reach his fullest potential.

Number two-step always starts with an assessment. I do have a free one-page assessment, which is part of my three-step guide, which I'm going to link to in the show notes at marybarbera.com/19. We want to make sure the plan, whether that's the treatment plan, the IEP plan, the ISP, anything you want to call it, we want to make sure that the plan is based on the assessment that goes hand in hand with the assessment. That is not just a bank of goals from somebody else that has nothing to do with the child's assessment.

The number four step is to pair yourself with reinforcement so that you can be a team player with other parents and professionals and we all need a positive to every negative. So if we want to keep pairing ourselves with the professionals if we are a parent, we need to be delivering some positives and not just demand, demand. We need to educate ourselves. Whether you're a parent or professional, whether you're an expert, you know, giving your own talks on verbal behavior. There still is a lot more we can learn. I know I learn every single day. People like Rose Marie Griffin who is featured in an interview in podcast number 10; she's an SLP for over 15 years. She's a behavior analyst for over five years. She took my online courses. She's in our online community. We're working together to get to new levels to figure out how to make it easier and easier for other and professionals to help kids.

And the fifth step is if you disagree with other team members, you need to take a step back, look at the forest, look at the assessment, make sure the assessment and the plan go hand in hand and try to compromise to really focus on what the child's needs are.

My goal is for each child to reach their fullest potential. The only way I know how to do that is really through my online courses, so I hope that you at least take a look at my pre-workshop. Consider joining us. Maybe right now is not the time, but I hope you'll continue to follow my podcast and my video blogs and sign up for our free workshop at marybarbera.com/workshop I would love to have you in our community to help you and your children, our clients, get to the next level.

Hope you enjoyed this advocacy podcast and I hope that you tune in next time for another episode of turn autism around.

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