



Transcript for Podcast Episode: 042

5 Autism Legal Lessons I've Learned Over the Past Decade

Hosted by: Dr. Mary Barbera

Mary Barbera: You're listening to the Turn Autism Around podcast, episode number 42. In this week's episode, I am talking all about legal disputes in the autism world and some lessons learned over the past two decades. Next week's episode is going to be an interview with Gary Mayerson, who is an autism dad and as well as an attorney who's litigated a lot of cases around autism. So he is going to have some great insights. So in order to prepare for that interview and that episode, which will be next week, I decided that I would do a little episode this week on my experiences.

Mary Barbera: So I usually give a shout out to a podcast listener, but instead of doing that, I would love it if you've listened to this podcast before or if you enjoy this episode, if you could go on Apple Podcasts or wherever you're listening and give me a great rating and review. That would really help me spread the word to other parents and professionals. So let's get to episode number 42.

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.

Mary Barbera: Hi, welcome back. I'm Dr. Mary Barbera and today's episode is all about five lessons I've learned as a autism mom and a board certified behavior analyst, as I've found myself in legal disputes along the way. So according to report from the school superintendents association published in 2016 that I'm going to link in the show notes, the school districts in the United States spend \$90 million a year in conflict resolution with parents of children with special needs, not just autism. So I know there are people all over the world that listen to this podcast, so it's not going to be completely United States specific, but I know from members of my online course and community that even from over 65 countries represented over the years that there aren't many or any laws in many places in many

countries. But in the United States there are laws and I have been through two due process cases, mediation, facilitated IEPs, fair hearing process, you know, just a variety of special education, legal system options. And so I thought it would be really good if I could jump on here and do a summary of some of those processes and some lessons I've learned along the way.

- Mary Barbera:
- So when Lucas was three years old, the day before he was three, he was diagnosed with moderate to severe autism. A couple of weeks before that, I had read a book called, Let Me Hear Your Voice by Catherine Maurice. And in that book she details the recovery of her two children who were diagnosed with autism and then received Lovaas type ABA approach. And they got all better, recovered, became indistinguishable, whatever you want to call it. And pretty much from that book that was based on the 1987 Lovaas study, the whole field of behavior analysis was created based on the need created by that book. And what also happened was a lot of due process cases started from that book as well.
- Mary Barbera:
- So Lucas was diagnosed in 1999. I found myself in due process right after his diagnosis. Maybe a month or two later we went to mediation and it was not successful. And actually the school the body that was over the three to five population in my County actually filed due process against us because we did not accept their program. So I had to get a lawyer to figure out if that was even reasonable, and anyway found myself obtaining a lawyer who was a father of an adult son with autism at the time. And he was great because he agreed to take my case pro-bono, which means he would litigate the case without charging me anything. And then he would recoup his costs from the school district when and if we won.
- Mary Barbera:
- So there's a lot of times when, you know, we consulted with another attorney back then and it was like, you know, you could risk \$30,000 or more just trying to litigate this. So the cost benefit really has to get weighed out. And anyway, so this lawyer was, was pro-bono and the due process, most people settle when they go to due process, but unfortunately we did not settle. And we went to 10 days over the course of a year and a half. And it was after my testimony for five hours at the end of the case. It's kind of like a court in some situations. I mean, it's in usually a building in the classroom in the school, but there's a court reporter there like a stenographer and there's a hearing officer and there's two lawyers. So in a lot of ways it runs like a court. And so we went 10 full days of having this lawyer come and litigate the case.

Mary Barbera: And in the end we actually lost the case the first round and then it was appealed and we partially won some. And in the end it all worked out and it was actually my first attorney who suggested that I look into becoming a behavior analyst. So I think in the end it just all worked out. But it was, it was very taxing. It was really draining. And one of the things I'm going to tell you in this short podcast is, I would avoid due process or any major litigation if you can, because you're already going through a lot having a child with autism no matter what the age is, you're already going through a lot of strain and this just really adds to the strain. But we're going to get to all that.

Mary Barbera: But like I said, in addition to two due process cases, I've also been involved with other legal system options, and I'm going to talk about that as we go as well. So just a little history background. In 1975, the education for all handicapped children was passed in United States federally, and this allowed kids with a variety of disabilities to begin going to public schools. Up until that point, they were largely excluded. And then in 1990 that education for all handicapped children, it was renamed as IDEA, which is the individuals with disabilities education act. And there's been revisions to the 1990 IDEA in 1997 and 2004. Also in 2001 no child left behind was added as a law. And that does complicate things a little bit, makes the school districts have to do a lot more data, a lot more measurable outcomes. And kids with disabilities are also included in needing to show and make progress every year. So in a lot of ways the no child left behind became extra burdensome for both parents and professionals.

Mary Barbera: And I did want to loop back and say this podcast is for both parents and professionals in the autism world. And I'm, as both, I am going to be giving advice here, not of course quote unquote legal advice, but I'm going to be giving some advice from my perspective mostly as a parent, but being in the field now as a professional to a litigation conflict, negotiation is tough. And especially tough when you're talking about a child education. It's tough for both the parents as well as the teachers, administrators, paraprofessionals, speech and language pathologists. It causes a lot of strain that we're going to get to the lessons in a minute.

Mary Barbera: So we have some laws in the United States and the IDEA pretty much ensures a free, appropriate public education in the least restrictive environment. So when you think about free, it should be completely free. Appropriate is one of those words, when I was, you know, learning when I was thrown into the autism world, thrown into this big hole and I had to climb out and I read the Maurice book and I'm like, okay, we gotta get on this. Lucas needs intensive intervention. I want him to recover from

autism; very black and white thinking back in the day from me and you know, I'm like, I want him to reach his fullest potential. I want him to have the best therapy, the best outcome.

Mary Barbera: And I quickly learned from my attorney that using the word best in writing in person was not going to get me very far because IDEA says free appropriate public education. And the law is clear. It doesn't have to be the best. It doesn't have to... Have the child reached their maximum potential. And I was told to, it kind of equates to you can have a Chevy but you can't have a Cadillac. Or you can have the Cadillac if you can afford to pay for it, but it's not going to be like the car has to have wheels and has to run, but it doesn't have to be great.

Mary Barbera: So that's something to keep in mind as you advocate for your child or as you're in meetings or writing emails. Of course, my whole goal is for each child to reach his fullest potential and be as safe, independent and as happy as possible. And I, you know, fullest potential eventually, you know, that's great. But I would just use appropriate, I want, you know, him to be independent kind of label. I want him to use words, you know, trying to avoid the word best. So as I said, Let Me Hear Your Voice, the book written by Catherine Maurice was really pivotal in increasing the due cases and there is an article, a study written by Yell and Drasgow, and I am going to put this in the show notes. It was published in 2000 and it looked at litigation due process cases related to wanting Lovaas ABA therapy back between 1993 and 1998.

Mary Barbera: So to get to the show notes, you can go to Marybarbera.com/42, and that'll get you back to the show notes where I'm going to link a couple of these articles that I'm recommending. So Yell and Drasgow basically looked at 40, I think it was 45 published due process cases, and they looked at the winners and the losers. And so the parents that won due process, they mostly won on procedural issues. You know, the school districts weren't ready for this flood of due process cases. And we went into due process starting in 1999 so we weren't included in this study.

Mary Barbera: But one of the things I've learned along the way is there really is no such thing as winners and losers in due process because the side who loses like I lost on the first level can and will probably appeal. So once they appeal, then the other side is like... at some point somebody's gonna settle usually. I mean there have been some cases I think that have gone to the Supreme court, which we're going to talk to Gary Mayerson next week in episode number 43 about, but in general, once one side loses, they'll appeal and then eventually things will settle. But you can find

yourself like I was in a yearlong dispute and then a year to get any kind of financial reimbursement. It can be quite, quite a long and tedious.

Mary Barbera:

Okay. Let's get to the lessons I've learned. There's five of them, five main lessons. Of course I have tons of other lessons. So five lessons that I learned during legal disputes over the past two decades. Number one, whenever we're looking at any kind of problem, problem behavior of the child, conflict, anything, we have to start with an assessment.

Mary Barbera:

So when people start saying, Oh, I'm in big fights with the school, this parent's being out of control, whatever the situation is. Okay, let's start with the facts. Okay. What's the assessment? What's the assess? When was the last assessment done? What does it show? Language wise, behavior, academic levels. Just as much assessment data as you have to get a clear picture. The age of the child, whether they have siblings in the district, how far they live from the school, whether they're transitioning in as a new kindergarten student or if they're transitioning between the elementary school and the middle school. Those are all factors; what the child was getting last year, what they're getting this year, if there's been any regression. Just all those things come into play.

Mary Barbera:

Also looking at, besides the assessment, looking at the current plan, whether that's an IEP in the United States or whether that's if you're young in the United States, if your birth to three you'll get an IFSP. If you're older and an adult you'll get a different type of plan. But you know, maybe you're in another country, maybe there are no plans, but if insurance or someone is paying education system, someone's paying for ABA or for some educational program or behavioral program, there is probably an assessment. There's probably a plan and there's probably a few goals in place. That's just in my experience, the way things work. So you'd want to start with an assessment and really look at where we're at.

Mary Barbera:

And then we need to also look at the placement. What I find a lot is that people are like, well my son needs a one to one; or my daughter would do better at a private ABA school. She's floundering in public schools. Or when my son goes to kindergarten, I want him to be in fully included without an aid. That's jumping to the placement before we look at the assessment, the plan, the goals and things like that. So if that's your goal that your child is going to be included in kindergarten without support, but he's only three, then that's not really... you shouldn't be thinking that far out because you're just going to have, everyone's going to have to see how he does what his assessment is, what his plan is, what his goals are.

- Mary Barbera: And when I talked about free appropriate public education in the least restrictive environment, that's another thing that gets a little hairy is this least restrictive environment. That doesn't mean that Lucas should be fully included when he was in kindergarten or in third grade or in ninth grade. Because of Lucas's needs and his moderate severe autism, his very significant language disability and the fact that he would not be able to understand pretty much any of the language, then the least restrictive environment for him was actually a mostly... most of the time he was in a special education autism classroom, and then he would get included for some parts of it; but it wouldn't maybe be for the whole music session of special, it might just be for the hands on part because he wouldn't understand the language part of Mozart and the C note goes here and the D note goes there.
- Mary Barbera: So when you are thinking about the placements, we have to always say it's gotta be based on the child and what they can handle and what they'll understand. You know, I was at a conference once and they were selling shirts that said on the front 'I have autism', and on the back they said 'don't waste my time'. And I thought this was really good. I am very pro-inclusion but only if it's maximally beneficial to the child.
- Mary Barbera: So while my number one lesson, my number one thing that I would recommend is you always start with the assessment and plan and goals and placement, before we go onto the next thing, if you find that your child is not in a safe situation, you know, then my next couple of steps are kind of out the window. If you find that, you know, you hear this on the news and it's horrendous, you know, kids are being, you know, locked in a bathroom or abused in any way then of course you'd want to act and call child line and get an attorney or whatever you have to do. But in the vast, vast majority of cases, even if you don't agree that the placement is appropriate, it's not like the child's well-being isn't being, you know, managed and well-meaning people are trying to educate your child.
- Mary Barbera: So unless there is a significant, you know, definite something is not good, then I would move on to my second tip, which is picking a collaboration style over a competitive style. So before we get into the second lesson, I just want to couch this by saying I received my PhD in 2011 and so from 2006 to 2011, I, in addition to being behavior analyst and writing my book, I also was taking PhD level courses in leadership. And I chose to do my one paper, which was on negotiation and conflict resolution on due process and how, and I began to analyze all of my negotiations and due process revolving around mostly Lucas's first due process case.

Mary Barbera: And what I found was that parents just automatically might find themselves in a big battle. And school districts on the same side might find themselves in a big battle, and it's exhausting. And I read somewhere, I tried to find the reference for this which I couldn't, but I found that I've heard in the past that if teachers are brought into due process cases and forced to testify and all that, that they have a very high percentage chance of leaving that teaching position and actually leaving the field.

Mary Barbera: You know, there's a lot of turnover and such. So, you know, having major conflict and having due process cases go on is not really good for the parents or for the school district either or the school district staff specifically. So in my PhD paper I learned all about negotiation and conflict resolution and that... when you're buying a car for instance, you don't have a relationship with the person you're buying the car from. The outcome is of high importance. You want to get the best car and the best deal and you don't, you know, you don't want a lemon and that sort of thing. So you can go in and you can be much more aggressive in your negotiation because you're never going to see these people again. So when you pick a style for negotiation, you have to think about the relationship, if there's any relationship, or if there's going to be relationship down the line. and then also the outcome.

Mary Barbera: Of course it's always when you're a parent, your child's, you know, education is always a high outcome. But it was really high when Lucas was first diagnosed after reading the Maurice book, because that was the first time I heard about recovery and I heard about the intensive ABA that was needed. And I felt like I had failed my son because I had been in denial for so long. It took me, you know, over probably like 18 months to go from hearing the word autism and being in denial to, you know, 18 months later to finally getting therapy in place. So I felt like I was way behind. I wanted him to have the best outcome. And like I said, they educational system actually filed due process against me. So it was very competitive right from the start.

Mary Barbera: But what I found out when I was researching this paper is that that is a win lose situation. Somebody wants to win, somebody's going to lose. Whereas if we can go forward and do a more collaborative style of negotiation and conflict resolution, it's the only style that's gonna be a win-win situation. However, it's really complicated because special ed law is not just me negotiating with one person. It is me negotiating with a whole system. You know, you have the teacher and you have the aids and you have the administrators, the principal, the special ed director, the speech therapist, the occupational therapist. Everybody, the regular

education teacher, everybody gets drug into it. And then it becomes where it's David versus Goliath, because Goliath is the one with more money, more power, more people. And the weaker party is almost always the parent, and they are the Davids. So if you go in as a parent trying to use a real Goliath kind of competitive stance, it's going to make it extra tough for you because there is a lot going on and it can quickly turn into this major power struggle.

Mary Barbera:

So besides the importance of the relationship with the school district or the teacher in the classroom, there's also the outcome that's important. The power differential between the school district and the parent is another factor. And then there's another factor that I learned when I was writing this paper years ago, over a decade ago, was it's called the, the BATNA: B A T N A. Which is stands for the best alternative to a negotiated agreement. So basically what you can do if you get no agreement. And this is really important because when people say they're fighting or they're advocating or they're in due process or whatever, I am always now thinking about the BATNA; basically your plan B, your options. If you lose, if your lawyer says you don't have a case, whatever the situation is, do you have a plan B?

Mary Barbera:

So when children are young, like when Lucas was three, he was already enrolled in regular preschool. I was luckily in a state that had medical assistance regardless of parent income for the child with disability, which would pay for the therapists to come in, and I could basically hire a consultant to tell us all what to do and I didn't have to deal with the three to five agency at all. I basically chose plan B. So while I fought all year in a competitive stance, I didn't have to send Lucas there every day, and that was an extremely good BATNA. However, when Lucas was nine years old and I found myself in due process again, he was in a school district. I didn't want him in a private placement. They would have taken him and put him in a private school. But I didn't want him in a private school. I just wanted him to be where he was, but not to have the bar lowered.

Mary Barbera:

And so Lucas went there every day even though we were in due process. And that makes it a little tough. Unless you're independently wealthy and I'm talking mega millionaire, you're not going to be able to just say, you know, I'll just do it everything myself. Now that there's insurance reform and you could probably piece together homeschooling and insurance and those sorts of things. However, in the end, I think working with the educational system and using a collaborative style and focusing on the child is really gonna be in the long run your best ability to help your child in the long run. So number one is focus on the assessment, the plan and

what placement they're in. Number two is choosing negotiation style and conflict resolution whenever possible collaborate.

Mary Barbera: Number three lesson is to get training. This is a whole other language. I've felt like, especially for my first due process case where my attorney was pro-bono, he had me doing a lot of the coming up with questions. Like I had to do a lot of the leg work in some respects, but it was almost like taking a graduate level course in litigation and legal disputes in the autism world. So I got pretty good at it. I attended a boot camp, a two day boot camp with Wrights Law, so it's wrightslaw.com. We'll put that in the show notes. Remember the show notes are at marybarbera.com/42. And I learned a ton at this boot camp.

Mary Barbera: One of the things I learned about the boot camp was actually more helpful for clients with higher language skills and even for my own typically developing son, because one of the things in the rights law boot camp was we looked at like IQ scores and not just the, you know, the IQ is 120 or 115 or whatever it is, or 75. We looked at the sub-tests, the sub-scores of the IQ test and talked about learning disabilities and how to see if a child is potentially gifted and learning disabled and just a whole bunch of things that I never ever thought of that were particularly helpful. So the more you learn about, you know, what would a child need to overcome some of their issues and learning disabilities and stuff. It was super helpful.

Mary Barbera: Also, Gary Mayerson wrote a book, I'm not sure what the year was, but it was How to Compromise with Your School District Without Compromising Your Child. He's going to be on the show next week and he's also getting ready to publish a second book, which I'm going to talk to him about.

Mary Barbera: The fourth lesson I've learned is, if there is disagreement among the parties, the school and the parent, the teacher and the parent, go back to the assessment and the plan, see if there's a goal. You can't just, well you can, but if you say, I think my son needs a one-to-one, is there a goal? Is there a behavior plan that supports that? Does the assessment support that? Like it all has to lead into the placement and the program which includes the fact that this child may need a one-to-one. And if there's such disagreement that you can't work it out, then at that point may be getting an independent evaluation, a facilitated IEP in the United States, somebody independent. And it doesn't have to be like an independent evaluation. It could be that you take your son to a speech therapist for an evaluation at a hospital and then use that data to show if your son is grade levels behind, for instance. So independent doesn't mean like an

official independent, although I've been a part of independent evaluations both on the parents' side as well as the professional side. Sometimes having an independent person come in who doesn't have any ties to the child or to what the outcome should be, can make a professional a recommendation as to how to solve the conflict.

Mary Barbera:

And number five, my last lesson is, don't forget about positive reinforcement. We all need at least five positives to every negative. That includes our kids, the teachers, the parents, the school administrators, the principal. If you're in fight mode all the time, you're not going to get very far. So I think in my book I talk about bringing donuts to an IEP meeting. Maybe you don't have to go that far, but do remember that when people, especially when people are really, you know, doing their all to make it better, don't forget about praise and about giving them some reinforcement.

Mary Barbera:

So just to sum it up, we have the five lessons which I hope that were helpful to you. There is no simple solution for such a complex topic of special education law, but I do look forward to having Gary Mayerson on next week's episode, number 43. That will be with Gary Mayerson who's going to answer some of our legal questions as both an autism dad as well as a very important, famous attorney who has litigated some of these due process cases. So I think it's going to be a fascinating interview.

Mary Barbera:

In the meantime, if you would like more information about how you can, whether you're a parent, a professional, a behavior analyst who wants to learn more about how you can help toddlers, older children, teens, even young adults do better, and if you're a professional you can also earn some contact hours and some type two BACBUs I would love it if you would attend a free online workshop where you can find out more. You can find those at Marybarbera.com/workshop. Hope you enjoyed this episode. If you did, I'd love it if you would go on Apple podcasts, leave me a five star rating and review and share it with others. Spread the word and help me get the word out. I do want each child to reach his or her fullest potential, be as happy, independent, and safe as possible. I am very excited to be able to give you this information each week, so I hope you'll tune in next week for a very special interview with Gary Mayerson. Have a good one until then.

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