

Transcript for Podcast Episode: 024

Jenna P. (Autism Mom): Autism + Other Diagnoses and Risk of Autism in Siblings

Hosted by: Dr. Mary Barbera

Mary:

Welcome to another episode of the Turn Autism Around podcast. Today I have a very special guest. A former client's mom, Jenna, came to my video room and we recorded her podcast here and I'm so excited to bring it to you because Jenna has so many insights. She's a mom to Cody, Ava, and Mabel. And we're going to talk about Cody's diagnosis of autism, and his additional diagnoses that came along the way. We're going to talk about the sibling rate of autism and her decision to go on and have a third child and what her life's like now. And she gives a lot of insights. So I'm really excited to share this special interview with Jenna.

Mary:

Before we get there, I'd like to give out a shout out to a listener who left me a five star review. The name is just a bunch of initials so I'm not sure who this is, but that person said, "Mary Barbera continues to bring hope and help to parents of children with autism. Her new podcast is wonderful and very informative, and I can't wait to hear more. Always inspired so by Mary's willingness to share her own personal stories and lessons with other parents, she has truly changed my life."

Mary:

That is so nice to hear because one of my goals is to give parents hope because there's always hope; no matter what the ages of your child or clients... No matter what the ability level or the severity of autism, there's always hope that things can get better and that you can turn things around for every child so that they, that child can reach their fullest potential. So I'm so excited to read that review and I think Jenna, our guest this week is going to have some great insights to help both parents and professionals. So let's get to that interview now.

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.

Okay, so today I have a really special guest, a former client's mom, Jenna, is here and she is local so she's actually came to my video room and we're recording it live. So this is really exciting. I haven't had a lot of parents on the podcast yet, so you are only our, I think, third parent that I'm interviewing? And so before we get started on, you know, strategies and those sorts of things, can you tell us about your fall into the autism world?

Jenna:

Sure. My oldest is now eight, but when he was born back in 2011, we noticed by the age of three months that he was having developmental delays in multiple areas. One of the first things we noticed was that he wasn't reaching for toys around three months of age. He wasn't grabbing for them, wasn't really making good eye contact with us. And from there it just progressed to where he wasn't meeting gross motor skills. So he wasn't crawling when he should; he wasn't sitting up when he needed to; he wasn't walking. And from there we were able to get some intervention through EI services and eventually that led to going down to children's Hospital of Philadelphia and getting a diagnoses of autism.

Mary: And what age was he when this happened?

Jenna: He was 21 months when he was diagnosed.

Mary: Okay. Were you surprised?

Yes, I think I was more in denial. I knew a general idea of what autism was...

You were not thinking when you went in there, this is how the autism. What were you thinking it was going to be?

I thought he had cerebral palsy. Which he, I mean we can get into that later, but he was later diagnosed recently with a minor form of cerebral palsy. So I thought for sure we'd go in there and they tell me there was... It was kind of a rough childbirth so I thought they wold tell us that there was damage and he was going to receive a diagnoses of cerebral palsy, and I remember looking at the paperwork that they handed us and it was all... The doctor had written that his referral was because my son was showing signs of autism and I'm sitting in the office going, he doesn't have autism, and just being surprised then when the diagnosis came through that he did in fact have autism.

And who referred him... is this a developmental pediatrician you went to Jenna: At CHOP It was.

Mary: So the regular pediatrician thought it was autism but didn't tell you?

Jenna:

Mary:

Jenna:

Mary:

He did, but he didn't tell us. And I love him, but yeah, he didn't, he didn't tell us that he thought it might be autism. And so in our minds, in my Google searches, I had, you know, diagnosed him myself with cerebral palsy and then we found out that it wasn't that, or it was more than that.

Mary:

Right, right. Yeah. Okay. So at the time, I think I remember there was something else going on. In fact you were pregnant.

Jenna:

I was pregnant, so my son was diagnosed on January 9th of 2013. That date sticks with you. So I was about three months pregnant at that point with our daughter.

Mary:

Okay. And at that point at 21 months, he was already getting some early intervention services for his motor delays and you were seeing gains, but he still, he wasn't even walking in 21 months, so he was really delayed. So I know some of the story because Cody was a client of mine. So he had early intervention services in place and by the time I got there, I think my date that I was going to start was actually the day you went into labor or something. So I got delayed a little bit more, and by the time I got there, I think your second, Ava, was a month old.

Mary:

But at that point Cody was two and a quarter or something like that, and at that point, the early intervention providers were doing a great job with walking and those sorts of things. But he was starting to have some really concerning behaviors. What kind of behaviors was he having?

Jenna:

He would bang his head on the floor, so he'd get frustrated. He just hit his head constantly. He would throw toys and a big issue we had was just biting his hands until the point where they were bleeding. And lots of sensory issues. So anything, you know, I was just talking to my husband before I came here about how he couldn't handle a bath; He couldn't handle a haircut. And I remember one of our first visits with you, he hadn't had a haircut in like eight months or something. And you were like, eventually he's going to need a haircut, like we need to work on this.

Mary:

Well, I think you even told me that he even had problems with tolerating the wind blowing.

Jenna:

Still, still. I mean, he definitely, he can go outside in the wind now, but wind has always been major behavioral trigger. He doesn't run anymore. We've come far, but yeah.

Mary:

Yeah. So he had a lot going on there behaviorally... because I'm a behavior analyst, so my role in going in there just so happened that Jen and I have a

mutual Facebook friends. So when Jenna received the diagnosis of autism, she reached out to a friend and their friend recommended me. I just so happened to have a contract at the time with the birth to three agency, so it all was just, it just worked out. And I just showed up and... the other early intervention providers still came too. We had speech and OTPT, he had a bunch of services and they all remained in place.

Mary:

And I think probably because you were... you know, well Cody had all these needs, but you did also a good job of coordinating everybody and becoming, you know, the captain of the ship so that one person wasn't coming in giving contradictory advice, you know. And your biggest concern in terms of my help was getting these problem behaviors down.

Jenna:

And I think even when we started with you, I didn't really know what ABA was. You know, I was a former teacher teaching at that point and so in courses we had been taught kids on with autism, the best treatment is ABA therapy, but I didn't know what it was or what it did. And we had gone down to CHOP and they said get ABA, and my husband and I went home and were like, oh, we're supposed to get ABA. And we went to the next appointment and the doctor was like, no, you really, you really need to find ABA.

Jenna:

But this was down in Philadelphia, not up here where we live. And so we didn't have anyone that could connect us to ABA. And my Facebook post was actually just, does anyone know how you get ABA? And a friend happened to know you, who then got us in touch, and it went from there.

Mary:

It is a problem, or at least it was back in 2013, in our county, it's a problem to try to get ABA for a two year old. It's a problem to get ABA for any child, but a lot of the agencies won't even start at two and you know, insurance, copays and all that. It requires like a lot of time and effort and coordination just to get ABA. But fortunately I had this contract with birth to three, which didn't require all that stuff. And then I was helpful in terms of trying to get you into an agency that would provide a therapist who could implement a lot of the techniques that I was showing you.

Mary:

But when we first got started, we got started with just some of the simple programs that I now teach in my online courses, like the Mr. Mr. Potato Head, shoe box program, matching, inset puzzles, and just the really basic things that you could do. And even though you're general education teacher, it didn't require that. I mean it was very simple. And we got a table, I remember him like running to the table, helping us, like he was excited about it and that's the way we want kids to be.

And yeah, so we implemented a lot of those things, but you know, my program, and 15 minutes a day, which you can definitely start with is great, but at some point you need intensive ABA; not just a little one hour a week or three hours a week or whatever I was doing, we needed 20 hours a week, plus me; plus the speech; plus the OTPT.

Jenna:

And I had a newborn baby.

Mary:

Right, right. So what was it like, you know, a month or two months or when you got the therapist in there, you know. It provides new challenges because then you have a stranger in your home and all that, and you're kind of... my dad, who used to come and watch Spencer sometimes while I'd take [inaudible] be there for Lucas and the therapist, while I did something outside the home with Spencer. My dad said, it's like you're on house arrest. Like this is ridiculous. And I said I know, I can't go anywhere because you have to be home... at least in the state we live, you have to be home to be the guardian. And so you're really kind of trapped.

Jenna:

It's a time commitment. I mean, I was fortunate, we had already, before Cody was diagnosed, decided that I was taking a year off of teaching... the year that turned into six years, but I was taking a year off of teaching. And so once we got started with you, I was home. I had planned to be home for that year with the newborn. And I mean it worked out well that I didn't have a job to go to, which benefited me in that situation.

Mary:

Right. Because before Cody... before Ava was born you were working, and Cody was going to daycare and they were having trouble because now all of a sudden he was biting his hand and throwing fits and he wasn't walking. So I imagine he wasn't able to progress to the next room, you know? And that's where like I did a video blog on this a while back on like, when your kid gets kicked out or doesn't progress in daycare or preschool, because, you know, the ratios of staff to students gets worse and they have to be drinking out of an open cup. They have to be potty trained. They have to be, you know... And to progress up a lot of kids, even with delays and not autism, they can't be, you know, biting other kids and that sort of thing because, you know, it's just like a safety issue.

Jenna:

Right. For us, I think that Cody being so little, a lot of times it was passed off as, oh, he's one, you know, this is a one year old's behavior. He's 18 months, this is normal. But I think definitely within the daycare as he got older we would have seen more and more of an issue.

Mary:

Yeah. Yeah. Okay. So when Ava was developing she had some speech delays too...

She did. She had speech and gross motor delays that we noticed about six months where she wasn't rolling over and she wasn't babbling as much. And we had the benefit of having Cody's speech teacher working with us every day. And so I would kind of ask her, what do you think, what do you think? And you know, just to get an opinion, a professional opinion on what needed to happen. And so that combined with her gross motor delays, we decided to get her evaluated by the early intervention program. They did find that she had torticollis and so we started physical therapy with her and she also did have a speech delay. And I think by the time she was one she had graduated out of both. So she had met, you know, this or made the skills that she needed to make.

Mary:

Right. And you also, the sibling rate of autism is, it's really scary. I mean it... There haven't a ton of studies but the most recent study that I know of, maybe there's something since then, but it was 19%. That if you have one child with autism, the chances are 19%. So one in five that a second child will be affected. And then even greater percentage chance that the second child would just have a speech delay or some kind of other delay. So did, were you aware of the high percentage?

Jenna:

I was. I was scared actually. We actually ended up putting Ava in a sibling study down at Children's Hospital of Philadelphia. And so they were monitoring her progress as well. They weren't willing to give a diagnoses if they noticed that, but they would have suggested that we get an appointment with a developmental pediatrician. And so that kind of put my mind at ease that every three months we were going down and they were checking where she was at and following her and we did that until she was about two, and then it just got to be too much, and we ended up dropping out of the study at that point.

Mary:

Right. Because those kids have to go under like MRI. So I mean... I guess you don't have to, but like to participate fully, you know, and if you live in the United States and you're listening to this, like there are siblings studies, I don't know if there's five or 10 centers around the United States, but like Children's Hospital of Philadelphia is our closest, but I know there's one at Kennedy Krieger and there's... You know, so if you're worried about a sibling or even if you're pregnant, they actually like to enroll newborns. Really, very much newborns as quick as possible.

Mary:

So yeah, so I would suggest that you Google sibling studies and the local, the most, you know, the hospital that's closest to you because it does provide... I have another mom that is going to be on the podcast in the next month or two hopefully, whose daughter was part of the sibling study and she ended up getting a diagnosis, but she's doing great now, like conversational great.

So we'll talk more about that, but I know it's a concern. And then you did end up having a third baby! So was that like a discussion, because with Ava you were three months pregnant already by the time you found out about Cody. But like, having the decision like, should we get off the fence and have a third is, I'm sure, a tough one.

Jenna:

You know, I think my husband was more concerned than I was at that point. For me I figured, you know, whatever card we're dealt, we'll take and we'll figure it out. And thankfully my daughter is almost two now and isn't showing any signs of being on the spectrum. But I mean for my husband, it was definitely a concern. Less so for me because I really wanted to have a third child.

Mary:

You put your mind to it and you did it. And she's almost two now, right?

Jenna:

Right. She'll be two in June.

Mary:

So how old are Cody and Ava now?

Jenna:

Cody's, yeah, eight. He just turned eight on April 1st. Um, Eva will be six at the end of June and then they will be two at the end of June. Okay.

Mary:

Okay. So let's talk more about Cody. So I worked with him from the time he was two till about five, five and a half, when he started kindergarten. So I was able to provide the continuity of having ABA and to have... I mean Cody was one of my early intervention clients who, you know, you've been very generous with allowing videotaping and sharing your story and sharing videos and like there's videos of Cody throughout all three of my courses and that has been a great thing to help me get the word out.

Mary:

And some of it was we would videotape to train another therapist, or to show the speech therapist something or whatever. And so we use the videotapes, also, for look back and like, oh, we should have intervened right at that moment and missed it. And then we got a bigger tantrum or whatever. So we would also use the videos for that kind of analysis. So how was the transition from the home services that you received from birth or three months old to five, and then how was the transition to school?

Jenna:

Okay. Well when we started early intervention services, he was evaluated the day after he turned one. And so they recommended he get physical therapy, occupational therapy, and speech therapy, and almost immediately within a few weeks, we had therapists coming into the home and into his current daycare to work with him.

And we saw progress. He learned to stand. He was pushing a walker to get along. You know, words were growing. This, I think we only had five by the time we started with you, but he was starting to speak a little bit more with the speech therapy. But what wasn't being addressed was the behavioral issues that we were seeing and they were increasing. And so once we started with you, when we brought in Mary, and we had an FBA done to find out what behaviors were happening and figuring out why these behaviors were happening, and one of the biggest issues being just a lack of communication.

Jenna:

So we started teaching him signs to get a cracker when he's hungry or you know, to get a drink so that he wasn't just screaming and banging his head on the floor, is when we really started to notice just a huge difference in our family and in our home. And just really a sense of peace when we had felt like we were in turmoil for two years almost at this point. And I think for us that that two to age five time was just, I think our biggest period of growth, and just all the services made a huge difference within that time as well. Before we started with Mary, he had been at daycare and there was a vision therapist there working with another child, and she looked over at my son and she said, oh, he needs to get his eyes checked, tell the mom to get his eyes checked.

Jenna:

And we did that and found out he was significantly farsighted. So we got, you know, glasses started and that made a huge difference. Just being able to see what was in front of him, you know, that in home, that age two to age five for us was just the largest period of growth. And the biggest change for our lives, it forever changed their lives to a point where we feel like we can go do things in public and our son will be okay.

Mary:

Yeah. Yeah. And I remember he had glasses when I got there and when we started working on things like matching and receptive where he'd have to touch, you know, touch the dog or whatever, there were some concerns. Like we don't know how he's seeing and, but you know, just with some behavioral therapy we could tell that he was seeing and... but now, you know, when he got to school, he was evaluated and he has what level of vision or...

Jenna:

So when we did evaluations for him to go to kindergarten, I requested... he had a lot of hesitations with stairs still, and that type of thing that were causing issues. I requested that he get a vision evaluation as well. When they did the vision evaluation, they discovered that he had no measurable death perception. And so at that point they actually recommended bringing in an orientation and mobility instructor, and he began using a long cane. So his vision corrected with glasses is about 2040, so it's not great, but he can see where he's going. He just, he can't tell where a step is.

And so what we found was he would be falling and tripping often, where his knees were always a mess. And with the cane that's significantly decreased. He's able to navigate his environment in a much safer way. And the nice thing about school too, is we live in a great district. I couldn't say enough good things. But he was put in a verbal behavior classroom. And so the program we had had with Mary, I was able to coordinate with his current teacher. So I actually gave her all of the things that we were working on with Mary and when he started school in the fall, that program just continued and is continuing to this day with that same teacher.

Mary:

Oh, that's nice. And how much of inclusion ,regular education does he get?

Jenna:

He is in a primarily autism classroom. I think when you started in kindergarten he was something like 80/20 I think. And it has increased significantly. We're up to 75/25 now.

Mary:

25% of the time he's in general ed, and that mostly specials, and homeroom, and circle time, and recess and lunch.

Jenna:

But he is getting to the point like, next year they just wrote it into his IEP that he'll be starting a reading program. So we're starting to get into some real academic programs beyond, you know what he's been working on.

Mary:

Yeah. That's great. And how's his language now?

Jenna:

He speaks in full sentences.

Mary:

Wow.

Jenna:

He's quiet. He's hard to understand. And if he doesn't know you he's reluctant to speak. But when he knows you, I mean I remember praying that he would just say five words, and some days my husband and I are like, okay, we can stop now.

Mary:

Be careful what you wish for. Well that sounds like he's made a lot of gains. And how are his problem behaviors now?

Jenna:

Problem behaviors are still good. He still has an FBA in class, mainly for noncompliance. And so he does this thing where when he doesn't want to work, and I don't know if you remember, he would just do nothing. He won't respond to you. He might just lay on the floor. But when you started in kindergarten, we were still having some problem behaviors as far as swiping materials off the table and knocking chairs over. And I, I mean I think for the past year and a half, they haven't had any incidents like that.

Mary: Wow. That's great.

Jenna: Way, way down.

Mary: That's always my goal for every child. Major problem behaviors at or near zero,

the ability to request your wants and needs, and independent toileting. And I

know we worked on potty training and is that going well still?

Jenna: Daytime mostly we found when he's sick he tends to have a little bit of a

regression in that area and we have to spend a couple of days, you know, timing

potty times again. Nighttime is still a struggle, you know, but he's eight so.

Mary: Also he just recently got a diagnosis of cerebral palsy.

Jenna: He did. Correct.

Mary: And cause he's always had motor delays and that sort of thing. So, then that

might have something to do with the nighttime wedding and that sort of thing. So, one of the reasons that I really wanted to have you on the show is because, you know, I mean that's a lot to deal with. Like a child who's, you know, has autism, has problem behaviors, is visually impaired, and then you find out he has no depth perception so he uses a blind cane for walking pretty much in novel

environments.

Jenna: Not around the house. Yeah.

Mary: Yeah. I mean that's like a lot. Then you have cerebral palsy and it's like... And

Jenna is like, you know, a really great mom and she's not like sitting in a corner like people would. And with all that, you know, it's like it's, it is what it is... I

mean, Cody is great and he's come so far, and...

Jenna: But you know, as a mom, when you're faced with something you step up and

you do it. You know, my sister also has a son who has cerebral palsy and she used to be like, oh, I don't know how you do it. And, and now she gets it. Like when you're put in that situation, you step up and you find the energy and you

do what you need for your kid.

Mary: Yeah. Do you think you're a different parents to your girls now?

Jenna: I do. Well I find I like incorporate a lot of like ABA techniques into, like, what's

the function of that behavior? Trying to, you know, problem solve what's going on. Especially with Mabel now because Mable's two, so when two year olds want something, they'll throw a fit. And so figuring out like how to ignore the fit, not

ignore but ignore the behavior and get her to request what she wants.

Right, right. Yeah. Yeah. I think it makes everybody a different parent. And as you know, I mean ABA obviously works for everybody. Not just for kids with autism. So that's great. So, so you're a certified general education teacher, um, and you've now been off of work, minus...

Jenna:

The six years.

Mary:

Yeah, minus a little trail. So is your plan to eventually go back to teaching?

Jenna:

No idea. I don't know. I mean teachings a lot. Teachers spend, I mean you give up family time, you give up summers, you know, all of those things devoted to the students that you're working with. And I have three children and my husband works long hours and just,

Mary:

Cody has a lot of needs.

Jenna:

Right, I can't just throw Cody in a typical daycare. Even if they'd accept him, it's not necessarily inappropriate environment for him. And so, I mean I do plan to work in some capacity, maybe substitute teaching or something like that. Maybe eventually. I love teaching. Yeah.

Mary:

So what would you do different or what would you recommend? Cause there are teachers, plenty of teachers and people in school settings that was sent to the show. So what would you recommend that they, you know, what strategies, like if you went back, okay, you're back, you've got 25 kids in your class, what are three things that you think, like, or two, it doesn't have to be three, but you know, anything come to mind that like right away you would do something different?

Jenna:

Absolutely. I mean, I can think of kids that I had that were what would be considered higher functioning autism. I'm trying not to put a label on where my son lies, but who really had struggle socially. And I didn't do much about it. You know, I look back and I had their IEP and that, you know, I would read it, but I had no training on how to incorporate helping these kids develop friendships or to develop social skills and knowing what I know, oh my goodness. Like, I would've made sure that I was facilitating opportunities for these kids who are really struggling, you know, but academically they were okay independently in the classroom to work with other students and to get other students to realize that they might be communicating a little bit differently, but that's okay.

Mary:

Yeah. I think, you know, teachers just really have a tough job, like you said.

Jenna:

And there's not a lot of training. I mean, I was teaching third grade and I had students with autism, but even going back to when I was taking courses in

education, there wasn't much information given to you beyond, you know, this is what autism is. I knew the definition, but even with Cody when I was like, oh no, he doesn't have autism. I definitely in my head had more of that stereotypical movie persona...

Jenna:

I mean, everyone talks about comparing it to Rain Man. But having that vision in my head of what autism was... And I had worked with one other student prior to teaching when I was working at an afterschool program, who was similar in the lack of eye contact and you know, had had a big regression whereas Cody never had a big regression and my education level just wasn't there. I didn't really understand the many levels of autism and what's included.

Mary:

Right. And how it looks in a baby. Or how it looks in one year old, how it looks in a two year old, especially given his motor delays and is it must have been really confusing. Yeah, it often is.

Mary:

Okay. So, um, one of my goals for the podcast is to provide strategies to both parents and professionals to be less stressed and live happier lives. And so I'm wondering, you know, I follow your Facebook posts and I mean, you look like you're not stress free. But you know, there's all this going on, you actually do look like you're staying pretty sane. You go out with some friends, go out with your husband and... Any strategies to make all that happen?

Jenna:

I think one of the biggest things I learned, mainly from you and other moms I knew of kids on the spectrum, was to find a community. So early on I found a group of moms and we all had toddlers that were recently diagnosed with autism, and we'd go out once a month. And we're still all in touch and I still call them up and say, hey, this is happening, because they get it. They're in the same shoes as you.

Jenna:

We also had a big church community, we're active in our church. So we had a huge group of friends that just came around us and loved us and really were there for us even though they didn't understand what we were going through. They were still there for us and they'd go out to dinner with us and they'd watch my son. And you know, that's a lot to ask of somebody. So definitely finding that community.

Jenna:

Also making time for yourself. My husband's great. He is gone a lot, but when he's home, he will watch the kids for me anytime I need a break. And just sometimes I'll just take the dog for a walk around the neighborhood and just clear my head while he's putting the kids to bed. Or I'll go to target and go shopping for a bit. But definitely finding those things that you, you can do to unwind.

I did, you know, and I still struggle with anxiety and so... I think even I was with you when I had my first anxiety attack. Oh my gosh, I didn't know what was going on. I was so sick. I thought I was having a heart attack. And I ended up, I called my husband, I said, I need you to come watch the kids. And I called my doctor and they fit me right in and ran all these tests and it turned out to be an anxiety attack. And so after that I started seeing a professional therapist and talking to them. And I do have some medication to help when things are especially bad. But I mean, seek help and seek care and make those friendships, and take time to take a break and walk away if you have those supports in place.

Mary:

Yeah, yeah. And I mean, anxiety and depression are so common in just everybody, the general population that is, it is no wonder that probably there's a higher percentage of moms with kids on the spectrum.

Jenna:

Yeah, I can say all of my friends, you know, I'm not naming them by name, but all of my friends who have children on the spectrum have anxiety disorders and I think all if not most of us have prescriptions to help us with it.

Mary:

I did a video blog awhile back on that autism moms have the stress level of combat soldiers. Like they actually tested their saliva.

Jenna:

And that's what my diagnosis was, was PTSD from everything with Cody.

Mary:

Post traumatic stress disorder, which is, you know, it's just a shame that parents have to go through so much and, you know, waiting, worrying, there's not knowing what step to take. nd like Jenna has taken some of my online courses. She helped me by sharing videos, you know, what actually create, you know, I was creating the courses and you still are on the Facebook groups and somewhat serve as like a FaceBook adviser. You know, supportive of... but I think that's... I do agree like local friends are definitely, and I'm still really close friends with a couple of the autism moms I met early on. I'm still really close friends with. But you can find communities online.

Jenna:

Oh, absolutely.

Mary:

And you can offer support even without meeting people or without seeing them for years. And that, you know, it's not just the parents that are stressed, you know, professionals have, you know, maybe their own typical kids... and you know, parents who want different things and all different levels of autism and it's just, it's just a stressful thing. And I'm trying to get the word out for, with, you know, podcasts and video blogs and all that stuff.

Mary:

But in the end it does, it does take time to get educated. People are like, well, I don't have any time. Like, I'm so stressed now. Like I can't take an online course.

But in the end, learning how to reduce problem behaviors to zero, learning how to engage your child, learning how to get language up is just, it's just gonna...

You know, I heard a study or a statistic way back, you know, that \$1 invested in the early intervention period saves \$13, you know, in the long run.

Mary:

And so even though you're stressed, it's like you do need to learn how to do this and you can't just rely, if you're a parent, you can't just rely on professionals. Or one professional or your ABA team, because there's a lot of time in the day and on the weekends when you could be shaping up really significant dangerous...

Jenna:

And the work as a parent pays off. You know, I can take Cody out to the dentist, I can take him to get haircuts. He can take a bath, we can walk outside on a windy day and it's not tantrums and problem behaviors. And you know, especially with wind, I might get a quick, he's unsure about it, but he'll say I'm okay. It's just wind and keep, keep walking. So you know that hard work and those years of energy that we put on into it. And you know, I eventually quit my job and so sacrificing my career to work with him made a huge difference.

Mary:

Yeah. And you said from two to five, I mean that's when you were learning all this stuff, but those were also the best years of growth, so. So it is really reinforcing because a lot of these little techniques like even the Mr. Mr. Potato Head or something like that, I mean it's kind of silly, but that can make your day when your child says ears and eyes and nose and then all of a sudden he's touching his own body parts and it's like...

Jenna:

Well, and then it develops into he tell you where, what hurts on his body instead of just crying. He can now point to his knee that his knee hurts. So it makes a difference.

Mary:

And that's kind of why I'm a big Mr. Potato Head fan. You know, even for older kids, if they don't, they can't touch their body parts. They can't label their body parts. Like Mr. Potato Head is one of the ways because eventually we do really need them to describe their pain. And it's so important in the long run. Cause I know, cause you know, I've been on the road longer than my former clients. Um, you know, and, and now, you know, I get to, to work or I have worked with people like Jenna and Cody, and it's changed my life too. For child I worked with, you know, it is a different situation.

Jenna:

Yeah. And Cody could challenge you.

Mary:

Yeah, Cody was tough. He looks really cute but...

Jenna:

We used to call him Jekyll and Hyde.

Yeah, it's like, oh man, he's really pushing my buttons this week. But in the end, I think, I think the friend that introduced us.So I thank her for introducing us and I thank you for being so open with your story.

Jenna:

Well and I thank you. I mean for me it's been healing to know that by sharing our story and by letting you work with Cody and share the type of work that we're doing, that it might impact other families and help those families. And for me it's made it feel like our journey isn't in vain, that our journey isn't all negative. That this isn't, I'd hate to say a punishment, but a punishment on us. You know, good has come out of this not only through the work you've done. But you know, people recognize me now, not just through you but in groups of friends and that type of thing. And they'll come to me and say, Hey, this is going on with my child. And I've had several parents then that I've been able to help them find the path to get services, or to get therapy for their child, whether it was autism related or not.

Mary:

Right. Because in a lot of ways, like my toddler, of course it doesn't, you don't need a diagnosis. It would work like a charm for typical child. Like I just want to get people, if they're waiting and worrying, something that they can start doing.

Mary:

And so if you are listening and you want to check out any of my free workshops, which do talk about my courses and give you the opportunity to join, it's Marybarbera.com/workshop. So thank you so much again for joining us and I hope that you've inspired a lot of families and professionals out there to really strive hard to have each child reach their fullest potential and for themselves to have a great life too, and be a little bit less stressed.

Jenna:

So it's possible.

Mary:

Thanks again. Thank you.

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