



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 037

Autism and Grandparents: What You Can Do for Your Grandchild with Autism

Hosted by: Dr. Mary Barbera

- Dr. Mary Barbera:** You're listening to the turn autism around podcast, episode number 37 and today's episode, I am interviewing a gung-ho grandmother. Her name is Diane and we'll get to her introduction in a second. But before we do that, I'd love to give a listener shout out like I normally do and this one is also to a grandparent and she says having three grandchildren diagnosed under the autism spectrum was shocking and frightening. These podcasts are so very helpful to understand there is hope and resources available. I look forward to the ongoing series. So I hope that grandparent is still listening and if you are listening and have been listening and are becoming a fan of this podcast, I would love it if you would go on iTunes or wherever you're listening to this podcast and leave me a great rating and review like that grandparent. And so, as I said, this a show is going to be grant all about grandparenting and with a special interview from Diane who found my online course and community back in February of 2019 her grandson was recently diagnosed months later. So, he was diagnosed in June of 2019 but by that time, Diane had many tools in her toolbox, and she has seen major progress. So, we're going to talk to Diane, find out about her journey becoming a grandparent of a child diagnosed with autism. And we're going to talk to her about that role and the progress she's seen. So, let's get to that. Great interview with Diane.
- Intro:** 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.
- Dr. Mary Barbera:** Okay. So, I am so happy to welcome our grandmother to the show. Grandma Diane, thanks for spending some time with us today to talk about grandparenting.
- Diane:** I'm very excited to be a part of this, Mary. Thank you. Yeah.
- Dr. Mary Barbera:** So, I always start out my podcast kind of thing. So, can you describe your fall into the autism world?

Diane: Sure. You know, I, I really consider it more of a somersault. And when I say that literally a somersault right into your arms, you know, we had concerns that 15 months at 18 months, he was not developing as his mother had. And I kept questioning, is it a boy different than a girl? And I kept talking to the pediatrician and the pediatrician was not forthcoming on accepting what I was saying. I felt that I really had to talk specifics and those 10-minute conversations weren't getting me any confidence in his development at the 18 months. I really pushed the point and said, you know, he needs to be evaluated by a developmental pediatrician. And she wasn't, the pediatrician wasn't onboard with that yet, but she did the M Chat and then said, yeah, we have some concerns.

Diane: So, they were to refer us to EI, and we sat, and we waited, and nothing happened. And my husband and I living in central Pennsylvania in a wonderful township, a great county, said, you know what? Our county offers everything. We're going to call EI and do this. And that's how it started. They came in, they evaluated Jude and they said, Oh, he has a 25% speech delay. And we all went, okay, that's great. We can work with this. And our wonderful SLP therapist who immediately bonded with, with Jude and with me, because she was doing the therapy in my house about three weeks later, gave me the truth talk. And that was the beginning of understanding that he was going to be diagnosed with autism.

Dr. Mary Barbera: Well up until that point, were you thinking that it was autism?

Diane: Up until the m chat and the early intervention evaluation, we did think autism after the earlier intervention evaluation, we all went, oh, it's just a speech delay. I'm not fully understanding what we were saying.

Dr. Mary Barbera: Yeah. And then three weeks later when a speech therapist talked to you, she did she bring up the word autism. Did the conversation lead to the fact that yeah, he's, he's more than just speech delay.

Diane: Yeah. She basically pointed out that she is an autism specialist and she was assigned to him because of the red flags that were seen in the evaluation. But he, I never said, hey, these are red flags. They just said, Oh, 25% speech delay.

Dr. Mary Barbera: Sound. That early intervention professionals in general, they don't like to use the word autism. They don't push anybody for a diagnosis. And it just leads to a lot more waiting and a lot more denial and those sorts of things. So, before you go on so your grandparent, and it's your daughter's son now does it, sounds like you're really involved going to the pediatrician appointment. Does your daughter and Jude live with you? Are, you know, like what, what are the dynamics there that you are so active from the very beginning?

Diane: Well, my daughter's single mom for the first two years, I had Jude three days a week and we had him in an in-home daycare situation two days a week. So, I was very much a part of seeing him develop day to day. You know, I was the

grandma who cooked all organic foods for him and fed him. And you know, it was my joy three days a week to have him. I was in the position of taking him to doctor's appointments because she worked during the day. She works during the day, 8:30 to 5:30 and there's just no opportunity for her to get these well checks done. So, we had to do a little bit of work on that with the pediatrician, with, with the different doctor saying, hey, you know, I'm going to be your point of contact. Please accept phone calls from me, please, you know, allow me to bring him in. And there were a few hiccups in the beginning, but we finally got that smoothed out.

Dr. Mary Barbera: And were you the one who was talking to your daughter about the signs and are you the one that noticed his delays before your daughter?

Diane: Definitely. you know, she's a new mom. She had no idea what was normal and what wasn't normal, and she was a very fast learner. So, I was even a little cautious because I thought, well, maybe he's just not as fast as his mom was, you know? And how many times did we have conversations late at night? My husband and I saying, is he autistic? You know? No, he's not autistic. You think he's autistic, you know, all those conversations back and forth that were really getting us nowhere. But when it all, when the truth talk happens and we had to accept it, my husband and I were immediately on board. It took Audrey a little bit longer, my daughter.

Dr. Mary Barbera: And how old was he when, when the SLP told you that it's probably autism? How old was he at that point?

Diane: He was just 22 months.

Dr. Mary Barbera: Okay. And then how much longer did it take to get the actual diagnosis?

Diane: We just got our diagnosis in June.

Dr. Mary Barbera: So how old was he then?

Diane: 28 months.

Dr. Mary Barbera: Okay. So, it took another six months. But you've had been having concerns since 15 months. So really, you know, over a year to really get the actual diagnosis, which is very typical. I mean, then you got a super early diagnosis. But you see how, how long it takes, how much, you know, there's denial within the parents, the grandparents each, you know, and then you have Jude having some good days, some bad days. He's an only child. He's a boy. He gets ear infections, whatever the situation and how he didn't sleep well. Oh, the family moved. I mean there's so many variables that, you know, mom's working full time, you know, it's just, it's so confusing for both parents and grandparents, you know. So, I do want to point out that in preparing for this podcast, I did do a little bit of research, not much.

Dr. Mary Barbera: And so, I found the autism speaks has a pretty good guide that I downloaded called the grandparent's guide to autism. And I know I sent it to you when you looked at it too. And they do have some interesting stats. Like 30% of parents were the first to notice that there was a problem with their grandchild's development, which is in your case near nearly 90% felt that the experience of facing their child's situation together, grandchild's situation together had brought them closer to their adult child. Did you experience that? Yeah, definitely. 72% of grandparents said they play some role in making treatment decisions for their grandchild, which is you. Right? And then more than 7% said they actually combine households with their grandchild's family so that they could help manage all that's involved and then 14% had moved closer but not into the same house for the same reason. And I think you told me that you were moving

Diane: We are looking for a bigger house really with Jude in mind. Audrey does not want to live with us. We offered that. We, we were gung ho to just start looking for multifamily residences and she said, no, you know, I need my independence and you know, we respect that, but you know, there's a lot more overnights with, with grandma and pop after Tom and, and we want to be able to do that. We live in a one-bedroom cottage right now. So, it's really not conducive to grandchildren.

Dr. Mary Barbera: Yes. Okay. A couple more stats before we go back to learning more about your journey. Over 34%. The grandparents said they take care of their grandchild at least once a week and 6% of grandparents said that the family situation had become so difficult that they had taken on the role of parents. So, you've experienced a lot of these moving, moving to accommodate, you know, the caregiving, being really active in treatment decisions. I'm noticing the first signs and, and actually, I mean, you sound like you and your daughter you've done a good job with, with keeping that relationship really intact and, and better than it was before. And so that's, you know, I take your off, I take my hat off to you for, for, you know, because that's tough. You know, she's working full time. You're, you're kind of taking charge to some degree and, and you know, for Jude and she sounds like she's appreciative of that, at least at this point.

Dr. Mary Barbera: And so those hurdles of those first months after diagnosis and stuff are even before diagnosis are super important. Okay. So, did you also in this, in this parenting guide, grandparenting guys gives me they talk about like the stages of grief that grandparents can go through. And I really, you know, I know about those from my nursing background and parenting background, but I don't think I've ever thought of grandparents going through the common stages of grief, like denial, fear, anger, guilt, confusion, powerlessness. And I mean, it makes total sense and I feel like so, so you, you did go through those feelings as you progressed through the process.

Diane: Again, Mary, you know, my, my fall was soften so dramatically because the day that the SLP gave me the truth talk, I contacted my dear friend Jamie, whose son had been diagnosed a year earlier and she gave me, you, she gave me your

program immediately. She said, this is what I'm doing, and it seems to be helping. And, and I knew Jamie to be a very no-nonsense person. She had done all the hard work. She had done the Google searches. She had talked to all the people. She had done all of the hard work and handed me her prize, which was your program. So...

Dr. Mary Barbera: So, you joined my toddler course and community before Jude was diagnosed. So, two months old when the SLP told you that it's probably autism. And my toddler of course as you well know is four kids with autism diagnosis. But also, while they're waiting, if parents are worried if it's just a little speech delay, all the better cause the kid's gonna fly through the program. So I really am trying to capture the wait list people because waitlist in the United States right now are, I've heard now, I don't know any research on this, but I've heard that it basically every time I turn around its nine months to two years. And that is ridiculous because if you thought your child had cancer and you were told, well just for an evaluation you had to sit and wait for nine months. I mean no one would do that.

Dr. Mary Barbera: And so with, with its delayed development and stuff, I think it's just such a, such a large amount of kids that are showing signs that it is scary because we know, especially the members of my online course and community know that there's a lot you can do to teach talking, to teach, teach following directions, to teach sleeping in their own bed, eating, getting over, you know, if they're addicted to a bottle or a pacifier. There're all these things that we can change, and the brain is most plastic or moldable at the earliest signs. So, so it, it really is crushing. The people are waiting and missing the critical window of time. So, you found out through Jamie. Jamie was in our program as well. And then you joined right away and, and what did you, and at that point was Jude speaking? What, what, what was Jude's baseline?

Diane: We had no words and you know; I refer to this finding your, starting your program as I was devastated for 24 hours and then I became empowered knowing that I could do something was huge. So, when I started the program, Jude had no words. He was flapping his hands. He was having, he was a runner. We were having tantrums and I didn't know that all of that was the scope of autism. The characteristics that I was looking at, you know, a lot of this has been, is it two-year-old activity or is it, you know, a spectrum activity. So, I just felt that immediately I had some answers. I had a direction, I had something I could do to smooth away. And I watched modules one through four, three times before I did anything. I, you know, hold up Amazon, which I'm really good at Amazon shopping and had everything in my basket and on its way.

Diane: And, and while I waited for it to arrive, I studied and listened and took notes and I got your book. And again, I studied, I, you know throughout the process, the way that I've been reading books I've always been someone that will consume a book. I'm a speed reader. I have the ability to understand when I'm reading that fast. But with the books on the spectrum that I had been introduced to, I learned to read a chapter, take notes, read the next chapter, take notes and

understand, see if I was building, my understanding, my education was so little that I, I felt like, you know, I was studying for a life exam and that I had to master the understanding in some way of what autism was and how I was going to be able to affect this.

Dr. Mary Barbera: And so, you started working with Jude using the strategies for my course and for those of those people out there that are listening it's not, we have a toddler course and then we also have a verbal behavior bundle. And it's not just for parents and grandparents, it's also for professionals. We give continuing education credits for behavior analysts. So, it is pretty meaty. Even the toddler course, which is our most basic course, but it is pretty meaty, and it is, it's not just like Rah, Rah or put my arm around you. It's like we're going up the mountain. It's going to be steep, like get your backpack on. Like we're not sitting around complaining, we are going up, we're not going to go fast. And if you fall behind, you know we're going to support you. But it's not just like watch a five-minute video or listen to a 30-minute thing. And, and your good, this is a lot of work to undo some of this stuff. So, through the it through the six modules, which is a 60-day program, did you see progress?

Diane: Oh, huge. So, our timeframe was I had three, two and a half weeks before June started full time daycare. Once I'd started the program. And the importance of him starting full time daycare was, he was really just getting too active for me. And we needed to put them in a program. So, I had two weeks to teach him through your modules, to give him the ability to man for items. Because at this point now I understood he can't even ask for these things. You know, as a grandma, you anticipate everything. So, the kid never had to ask, you know, I'm, I'm an Italian grandmother. I, there's always food. There's always juice. When I got the idea that, oh no, he's going to be, you know, in a classroom where he's going to have to vocalize is needs, it is needs across in a very short time. Right. we were able to make some massive progress in those two and a half weeks and Jude was able to, oh, start vocalizing words and pointing and matching was immediate. So, by the time we got him into the daycare, he was already on the role of learning and wanting to learn. And this was the big takeaway was this kid would sit at the table for hours if I let him because he wanted to learn so much. All of the behavior stopped because he was eagerly waiting for what I was going to teach him for those flashcards to come up to see those pictures, to have my attention devoted towards one action. You know, we would play together. He would play with his toys. But table time was different and special and exciting. And so, he needed very little snacks at the table or juice. He wanted to be there. He wanted to be doing the cards. And he very rapidly started learning and it was beautiful to see the light bulb go off behind his, his eyes like, yeah, let's go for it. Let's, let's, let's learn. It took six weeks before I would say he, he had a good amount of words and could point for most items and, but six weeks come on. You know, we had spent six weeks discussing EI every year. We were making no major progress.

Dr. Mary Barbera: Were the early intervention professionals surprised in his progress?

Diane: Hugely. We have three therapists that we work with now. At the time there were only two during this, this initial window. And literally they just, every week they would come, they would just be amazed that this little boy was number one, happy to see them social, you know, wanting to be involved with them. And then of course they started seeing the progress very quickly and...

Dr. Mary Barbera: Getting words that quickly is, yeah, it doesn't always happen, but when it happens is it's almost miraculous and you're like, wow, this really works. Okay. So, you talked about table time and for listeners out there, I am a huge proponent of table time and we... I had the pleasure of meeting Diane and her friend Jamie who, who told her about my course as well as another member of our online course and community at the national autism conference at Penn State in early August. And we had a chance to meet in person and that's when I decided that Diane would be great on the podcast. And so, we met there, and we met after a lecture where a behavior analyst was talking about how table time and intensive teaching... that's the thing my table time is different than what you might imagine to be like a strict discrete trial table time.

Dr. Mary Barbera: Like my table time is actually mandating natural environment, teaching, pairing and a little bit of early learner matching and imitation and stuff along the way. So, it is a very different kind of table time. And so most professionals including me would say that for a childlike Jude, two years old, major, you know, struggles with no language, no imitation, no receptive touching of body parts, all that, you know, really in essence, no skills, little, little to no skills with what we're talking about. You should not be bringing them to the table and trying to drill stuff. That's not what I'm suggesting. But I have found over my 20 years in the autism world and my methods are very much like don't chase the kid around during your hour of early intervention trying to pair and they're all over the place they are like little tornadoes. I find that getting these certain materials that I recommend getting a small table and pairing that into my unique program is not just Diane's grandson.

Dr. Mary Barbera: It is literally everyone who does the program and gets through it. I mean, you know, some people buy the program and they don't watch it and they don't do the homework. And then you heard Diane, she watched it, watched the first four modules three times each before she even intervened with anything. I mean that takes a lot of time and energy. But what we're seeing, it's even amazing to me because I'm not giving Diane feedback on her videos. I'm not giving Diane step by step advice for Jude. I'm simply saying these procedures work and they may have to be adapted. Not everybody is exactly the same. And that's where our community really helps get people unstuck if they, you know, I remember Kelsey who's featured in podcast number three, they go to Dr. Mary Barbera.com four slash three is a podcast interview with our community manager, Kelsey, you is three boys on spectrum...

Dr. Mary Barbera: Two, two boys on the spectrum. She had her older son and she joined my course and she couldn't get him to sit at the table for three weeks. And you know, with pairing and everything, and so, you know, we helped her figure out

what was going on. It's not like it's a cookbook where you just apply it. You do the homework; you assess where your child or grandchild is at and then you make some bold moves. So anyway, so we, we happened to be at the lecture where it was a lot of focus on not table time, like you basically taught the skills in the natural environment and then it generalized at the table and there were pretty good videos. But you came up to me afterwards and you actually, you know, messaged me with another lecture too. And I'm assuming this was your first conference that you went to in the autism.

Diane: Yeah.

Dr. Mary Barbera: And so, what, what were your thoughts on tape? Like my table time or my approach after seeing these, these highly skilled professionals speak?

Diane: Well, Jamie and I both felt we did most of the classes together. Throughout the classes, we would just look at each other and go, we know this Mary's program taught us this. And not only did your program teach us what we were hearing at the conference in that lecture, but also the pitfalls to avoid, which was the huge takeaway. You know, I was the, the one class I had said specifically to you was the, the poisoned Q with Jesus Ruiz. And after watching that video of him with the dogs, because his research is based on showing the ABA techniques, but showing them in dogs and seeing the results, which was remarkable because you saw it instantly, whatever he was affecting you saw instant movement of those animals. What I learned in that lecture was not only that your program had prepared us so well that we would not have made those mistakes, but I understood the bigger picture behind the pairing of the table and the items, which I don't think I understood as well before. Hearing the lecture, the poison Q brought everything home. And again, Jamie and I looked at each other and wet. Wow. Not only do we know this subject, but we were able to avoid this. And that was so affirming for us that we were doing what we should be doing, you know, using your program correctly, learning and helping our, our, her son and our grandson to be their best.

Dr. Mary Barbera: Yeah. And I do. The poison Q was at the Penn State autism conference. It is Live Cast. I'm going to try to link it in our show notes here for this podcast because it, I got a lot of feedback that that was an excellent lecture and I also want to watch it myself and I think it's a good idea to link it in the show notes. It is a three-hour lecture. But I, I will try to get that linked in the show notes. So, what are you, where is Jude at now? How old is he and how's he doing? First of all,

Diane: Jude is doing tremendous. He's imitating his peers. He's really having no true behavior issues. The he's no longer a runner. He now walks with us and holds our hand. He, the biggest issue I would say we have is still picky eating. And as the Italian grandmother, that's a big hurdle for me. But we continue working on it. The Sunday before that I left for conference, he said his first sentence, and we have heard multiple sentences.

Dr. Mary Barbera: What was his first sentence?

Diane: Oh Gosh, you're going to put me on this? Yes. I want to jump. Wow. We, we have you been taking him to the pool almost every day and he's become a great swimmer this summer through some private lessons and with working with him. And I really think that biomechanical conditioning of swimming has also helped is language ability because you know, building that pyramid from the bottom up. This week we're hearing, no, I don't like that regarding food.

Dr. Mary Barbera: And he's only 30, 32 months?

Diane: He'll be two and a half at the end of this month.

Dr. Mary Barbera: Wow. And you just joined my course in June. Did you say that?

Diane: February.

Dr. Mary Barbera: Oh, back in February. Okay. All right. Wow.

Diane: So, we're hearing that he, his daycare teacher said yesterday, I like you. And he said, I like you too. So, we're, we're getting really amazing things. He's pointing, he's drawing attention things he wants us to be involved with which is, you know, so great. He's anticipating, which it was a little remarkable to see because he had not anticipated things before. But now he's walking into our house and going, hi Pappy expecting his grandfather to be here even though he's at work and you know, so that was kind of neat to see that, you know, it's all there and...

Dr. Mary Barbera: And then I mean those using contractions using "no", like that is all coming for free. That that was not part of my toddler course. And that's what I find is that if we build the base really solid and you start applying the principles of ABA folks at the table, at the grocery store, in the bathtub, at daycare or wherever you go for a walk you start to see, you know, in many cases an explosion and some really great skills. So, what are you, what are you hoping for in the future or how do you feel about hope now?

Diane: Oh, I feel I have so much confidence for his future. I feel that, and the therapists also feel that Jude will go to first grade unassisted, unsupported. And you know, I'm not naive enough to believe that, you know, we've got this, and you know, it's easy selling from here. I realized that, you know, there'll be tutors in the future and he's gonna have needs educationally. That I'm, I'm not worried about emotionally. I have more concern for him then because I don't know. That's one part that I don't know yet is as he grows and his body changes, what are all of those emotions that he's going to experience and how can we prepare him for that? You know, just because a child looks normal on the outside and Jude is a beautiful boy that doesn't indicate the struggles that he could be going through internally. And I saw this with my daughter growing up. She was a beautiful girl. She had a severe learning disability that you couldn't tell from looking at her. So, people assumed she was capable and whatever titles they put on her, they assumed all of that because of how they viewed her. And I want to make sure

that going forward, Jude has the emotional maturity and coping mechanisms that he's going to need to live in our world successfully.

Dr. Mary Barbera: Yeah. And nobody has a crystal ball. You have no idea how it's all going to turn out, but you, you sound like you have the tools now, you know, you need to keep learning. This isn't a once and done 60 day and you're out kind of. I've learned all I can. I mean, you've gone to the autism conference at Penn State, you're continuing on with our membership and you're, you're continuing to learn so that you can continue to help him at the next step, whatever that next step is. So, I think there's a lot of reason to hope and I'm so glad that you found my strategies and my courses as early as possible. So that makes me very happy. So, part of my podcast goals is for parents and grandparents and other caregivers as well as professionals to be less stressed and live happier lives. So, do you have any advice or tips on this?

Diane: Oh, absolutely. You know so anytime I spend with Jude is, is my joy time. However, prior to Jude, we traveled a lot. We like to travel, we like to do a great vacation four times a year, which is a little crazy. We have continued traveling. I have a bucket list that I want to see all those places. So that's very important to me, to my wellbeing, whether it's dreaming about the next trip or actually being on the next trip. It helps to keep me going, keep me involved in, in something I really, really enjoy. And when this first came home to us, what I would do throughout the day that were my stress-free things, I probably narrowed a lot of them. You know, I spent a lot of time doing the modules and reading the books and, and doing, you know, a little bit of research. So, reading became more functional for me and the enjoyment kind of went out the window at that point. And I had been such an avid reader, but that was just initially, you know traveling, sometimes we can take Jude with us. Sometimes we go on our own. Traveling has always been my, my, Oh Mary, I'm losing words now. Traveling is my big "hurrah".

Dr. Mary Barbera: Yeah, that's good. Just to, you know, the thought of planning the travel, looking forward to the travel, being on the travel and you do it, you know, four times a year. I mean, that sounds like a great way to reduce stress and lead a happier life when you're constantly kind of looking forward to the next trip, which I think is, is great. So. All right. So, we are at the end of our time. Thank you so much for joining us and sharing your journey with your precious grandson. I am so thrilled to hear about Jude's progress and your involvement as a grandparent. And hopefully this will give other grandparents ideas on how they can be involved and how, you know, learning language, learning pointing, learning matching, all that stuff can be taught and it can, doesn't have to be a professional, it doesn't have to be a teacher.

Dr. Mary Barbera: It could be anyone with the motivation to learn. So, thank you again for your time. If there's anyone listening, parent professional or grandparent who wants to learn more about my online courses and community, you can go to marybarbera.com/workshop to attend a free workshop and to learn more strategies and also to learn about our community, which I think is really the best

place for me to help you. I mean, these podcasts are great and thank you for listening, video blogs, but really to have a comprehensive program I think is the best, quickest way to see progress like we're seeing with Jude, which is awesome.

Diane: I agree. Thank you for doing what you do, Mary. I don't know where we would be without your, your program.

Dr. Mary Barbera: Oh, well thank you. All right. Have a good weekend. I hope that you listen in next week. Thanks again, Diane.

Outro: Thanks for listening to the turn. Autism around podcast with Dr.Dr. Mary Barbera. For more information, visit marybarbera.com.