



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 031

ABA Insurance Coverage & Funding Autism Therapy with Lorri Unumb

Hosted by: Dr. Mary Barbera

Mary: You're listening to the Turn Autism Around podcast, and I'm your host, Dr. Mary Barbera, and I'm thrilled that you're tuning in. Today we have a very special guest and I'm going to introduce Lorri Unumb in just a moment, but before we do that, I'd love to give some listeners shoutouts so today I'm going to give a listener a shout out to KellyH who left me a five star rating and review and she said, "Mary's podcast has been an incredible means of support for me as we navigate our early journey with autism. My son is 26 months of age and is not yet diagnosed. This podcast has provided education on such a wide variety of topics related to autism and the types of therapies, supports, ranges of services and the advocacy needs for the autism world. I'm also doing her online course, which has already made a difference in my son. I would recommend her resources to anyone trying to navigate this." So thank you so much Kelly for taking the time out to leave that review and to tell us that you're already doing my online course. Your son's not even diagnosed and you're seeing a difference in your son, which is just so awesome to hear. So thank you so much.

Mary: And if you would like to, if anybody listening would like to learn more about becoming a member of my online course or community, you can go to Marybarbera.com/workshop and you can sign up for our free workshop, which will give you some more information.

Mary: So now I would like to get to introducing you to our guest, Lorri Unumb, who is a lawyer, she's a professor, she's a mom to three boys, including Ryan, who's now 18 years of age. And Lorri fell into the autism world many years ago when Ryan, her firstborn son, was diagnosed with autism. She went on to do a lot of creative things, and one of the, one of the advocacy movements she started was the whole insurance reform movement across the United States. Lorri also founded the Autism Academy of South Carolina, which is a nonprofit year-round treatment center for children with autism. She's a big proponent of ABA and she has been featured on CNN and NPR and also is profiled in the American Academy

of Pediatrics 2013 book, Autism Spectrum Disorders: What Every Parent Needs to Know. So she has a wealth of information. I learned a lot about Lorri through this interview and I'm excited to get to that.

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: Welcome back to another episode of the Turn Autism Around podcast. I'm so thrilled to have Lorri Unumb here. Lorri as I said in the introduction is both an autism mom as well as an attorney and she led the insurance reform in the United States. I'm so happy that Lorri agreed to join me. So welcome, Lorri.

Lorri: Thanks very much. It's my pleasure to be here.

Mary: Yeah, I read about you in the past and then and I've seen you on social media, but it's, it's a real pleasure to get to know you personally a little bit more through this interview process. So I'm happy that you're here to share your wisdom. So the way I usually start my podcast episodes is I ask interviewees to tell us about your fall into the autism world and how you got started, and when that was and where you went from there.

Lorri: Well, I like the way you phrase that: fall into the autism world, because that's an accurate description of how I started this journey. My first born child was diagnosed on the autism spectrum shortly before his second birthday. And at that time I really didn't know what autism was. I had heard the word, but that's about it. And when the doctors recommended ABA therapy, I had no idea what they were talking about. I barely even understood the concept of therapy. I mean, I personally hadn't ever engaged in therapy, so I didn't even really understand what it was all about. It's just hard to believe how far removed that time is from my life now. But we were very lucky. My husband and I met in Washington DC. We were both young lawyers with the United States Department of Justice.

Lorri: He had moved from Boston down to Washington DC. I had moved from South Carolina up to Washington DC. We met there and got married, had our first child and you know, a year, year and a half, and he had no language and was a very difficult baby. So basically at his 18 month old checkup, he was referred to a developmental pediatrician for further screening and testing. And it did not take long because he was completely nonverbal. It didn't take long to get that diagnosis. I think we were lucky that we lived in the Washington DC area because we had access to some really very fine diagnosticians and we took advantage of three of them. I had been on the waiting list so long to get an appointment that

when I ultimately got one, I think the first one we got was at children's National Medical Center and we got...

Mary: And what year was this?

Lorri: That would have been 2003.

Mary: Okay. So, and how long did you wait for your first appointment?

Mary: Months and months. I cannot remember the exacts, but it was many months. And you know, that seems like years when you don't know what's going on and you can't get an appointment with somebody to tell you what's wrong with your child. So, you know, we got that first diagnosis and it, there was really no question. They said he has autism, but then I think it was Kennedy Krieger that called next and we had come up for an appointment and I said, well, let's just go ahead and see if their doctors agree and if they recommend the same thing. So we went for another diagnostic evaluation and they said yes, this child has autism and gave us recommendations. And then Georgetown called, we had been on the waiting list for all three. So we went ahead and talked to the doctors at Georgetown as well. And really, I'm not just a neurotic parent, I just thought, you know, we'd been waiting that long, let's get advice from all three different institutions.

Lorri: And I look back and I think how fortunate it was that we did get advice from a variety of people because they all mentioned ABA therapy. And again, I didn't know what it was, but I was like, you know, Georgetown mentioned this, Childrens mentioned this, Kennedy Krieger mentioned it, let's figure out what that is. So, you know, we fell into the world of trying to figure out and understand ABA. And again, we're lucky that we were in Washington DC because there were ABA providers around. I think so often about people with children older than mine who were diagnosed earlier before there was as much access to intervention as there is now or as there was in 2003. But we were lucky that we had access and we went down the path of the path that so many parents go down, you know, first grappling with the diagnosis and then next step is figure out what do you do? How do we give this child the best shot at a functional future? And that led us down the ABA path.

Mary: And back in 2003, did you read any books that persuaded you that ABA was the right way to go?

Lorri: Well, like probably every other parent in that era I read, Let Me Hear Your Voice and... Did you read it?

Mary: Yeah. That was... Lucas was diagnosed in 1999. So Let Me Hear Your Voice was the book that got me out of denial. And I was shocked and horrified that a decade after the Lovaas study in 1987, that, you know, I didn't know that there was any... I thought autism was a death sentence. I didn't know that there was any chance of recovery or even major improvements. And so Catherine Maurice's book, Let Me Hear Your Voice, which I do mention and talk about in episodes number one and number two I believe of the podcast... But you know, talk about like I found that out and now we're three decades later after the Lovaas study, and the majority of people even with autism... The parents that are getting diagnosed, they're not going back to a 1993 book. They're going to more current books and the Internet. I mean back then, well in 1999, the Internet was not, you know, in place really. I mean the search and Facebook wasn't around and so it was much more like go and read a book. I think now it's like more online and a lot of parents are not reading Let Me Hear Your Voice.

Mary: One of the reasons I wrote my book is because I was recommending Let Me Hear Your Voice, which had been my bible, but I was doing it a totally different way. And so I realized that I needed to write my book. But anyway, yes. Let Me Hear Your Voice is still a very good book for parents to read just to get an idea that autism is not a death sentence and the earliest signs of autism need to be treated aggressively, which is kind of my whole movement but... So you got involved and I'm thinking, and I don't know you as well as I know some of the other people I've interviewed so far, but I'm thinking that since you led the autism insurance reform in the United States, that my hunch would be that, yes, you got a diagnosis and you got a three diagnoses and all said the same thing, ABA. And I'm assuming that that was private pay or not well funded and you know, and then that's what prompted you to go, like, this is ridiculous.

Lorri: You're exactly right. So I recall when we brought ABA providers into our home to kind of explain what it was and how it worked and you know, how there'd be people coming into our home. And then we got around to the point about cost. And again, our son is very severely impaired, so he really had been recommended for a very intensive program. We were looking at a 40 hour per week program, and the ABA professionals just basically laid it out and I was doing the math. I'm like, that's going to be like \$70,000 a year.

Lorri: And I remember turning to my husband and saying, oh my gosh, thank goodness we have health insurance. You know, what would you do if you didn't have health insurance and you got this diagnosis? I didn't know that health insurance would not pay for one penny of it. I just assumed, you know, the doctor diagnosed my child with autism. The doctor said this is the best treatment that's out there. I have health insurance. You know, I had no idea that we were going down this path where we would have no assistance from the insurance that we had been paying premiums for our whole working lives. And that just seems

really, really unfair to me, honestly. Initially my first concern was not, oh my gosh, I've got to go change this law. My first concern was, oh my gosh, how are we going to get this for Ryan? Right? Initially I was just concerned about, do I quit my job so I could be home with Ryan? But then if I quit my job, how are we going to pay for the therapy? It's a very difficult conundrum.

Lorri: And we as a family ultimately decided I would not quit working. My husband and I would both work full time. We would live on his salary, and my entire salary would be used to pay for Ryan's ABA.

Mary: Wow.

Lorri: And we did that for a few years, but I've got to tell you, I could not sleep at night thinking about, okay, so we have made it work because I'm a lawyer and I happened to make enough money, and my husband makes enough money that we can live on his salary and fund an ABA program with mine. But obviously that's a very small fraction of families that can just handle it that way. And I thought, you know, that is just very unjust. And I kept thinking about the kids whose parents weren't in that kind of financial scenario, and they had no shot. You know, I knew from the Lovaas study, from researching online, I knew that this wasn't going to magically recover my son or whatever. But I knew that there was at least a 50% chance that he would do so well he might be mainstreamed in school. I knew that I wanted him to have a shot at being one of the best outcome kids. And I kept thinking about again, all the families where their children weren't even in the pool of kids who had a shot at achieving best outcomes because they couldn't, they couldn't access the intervention. So that, that motivated me.

Mary: Yeah. I compare it to, you know, you find out your child has leukemia and then you find out that there's this chemo that's, you know, 50% chance that they could, you know, live a relatively normal life or even completely go into remission or whatever. And then people are like, yeah, well you can't have that. You just have to take this crappy chemo. And fortunately, and I don't know if you know anything about Pennsylvania, but back in the 90s, shortly after the Catherine Maurice book came out, a small group of parents lobbied and got some loophole so that kids like my son Lucas could go on medical assistance regardless of family income and get 40 hours of treatment. So all of a sudden I find out about ABA and then I'm like, okay, who's going to pay for this? And then I find out, well, the only way to get it paid for is to sign Lucas up for medical assistance. I'm like, well, I don't want to sign my child up for medical assistance, I have regular insurance. Oh no, this is the only way.

Mary: So I mean, we stood in line and got the medical assistance for Lucas, and I mean it was a godsend. And even with all the insurance reform over the years and

everything, Pennsylvania, became a complicated state for insurance reform because of that loophole, and because, you know, it was already out an infrastructure in place like no other state. And so it was a little weird, but I think you and I both realized me in 1999 you in 2003 that this was a ridiculous system. You know, it's like, well, it's a medical condition until it's time for treatment and then it's education, but the education is like, no, it's not education, it's medical because it's so expensive. Nobody wants to pay with it. It was like a hot potato. Like somebody else is going to have to pay for it.

Lorri: That's exactly right. And when I got kind of to my boiling point that I was just so frustrated on behalf of the less fortunate really, I thought about, well, I'm a lawyer, maybe I should sue to under IDDA to get better services educationally. But I remember having a flip chart in my office and I kind of drew out all the systems. I'm like, education has a role to play. Healthcare has a role to play. State social services has a role to play. The family has a role to play. And I looked at all of those and I said, well, this group is trying, I mean, they're not living up to the best standards, but they're trying and this group is doing something. And I looked at the healthcare system and I said, well, they're not doing anything in my mind. They were not contributing to intervention for autism in any way. In fact, they were doing the best they could to stay away from it with a 10 foot pole.

Lorri: And so that really kind of focused my mind. I could spend the next few years suing under IDDA, or we could look at the health insurance industry and try to figure out a way to get them into the mix again, because they were just not helping at all. So that was, that was part of the decision making on that front. But you're absolutely right that everybody just wanted nothing to do with it. And I am familiar with what Pennsylvania did, and, and really it was pretty groundbreaking. When I first started researching the healthcare component of it, I thought that Wisconsin had taken some steps to create funding. Maryland had, Pennsylvania had, but that was, well and you know, Massachusetts was funding it through the education system. California had the regional care system, but most people in the United States had no access; either they couldn't get it through their school system or... You know, in my state, my son could also get on medical assistance without regard to family income, but that still didn't allow him to access ABA. He could get a Medicaid card, but ABA was not a covered service. And that's the way it was in most of the country until very recently.

Mary: Right, right. So before we get to your work with Ryan's Law and going over the country, you also have two other sons and can you tell us about Ryan now? How old he is and what level of functioning and what services he gets and then your other sons as well?

Lorri: So Ryan, my first born, has recently turned 18. And that leads, as you all know, as you know, very well to a whole new set of issues, which I have not yet

successfully dealt with. But he has had a lot of ABA. He's made enormous progress. He is still considered pretty severely impaired. He's essentially nonverbal and occasionally has some aggressive behaviors. We've made a lot of progress with that and we've made a lot of progress on the communication front, but with the combination of his autism and pretty severe apraxia he is still essentially nonverbal. But you know, I always like to put the positive spin on it too. Through years and years of ABA, his life has changed dramatically and our lives as well, because when he was young we definitely like couldn't go to a restaurant, couldn't go to the grocery store, stop going to church, there were too many outbursts. You know, we were one of those families that felt pretty confined to our home.

Lorri: Now we take him everywhere. He travels on the plane with us. We take him snow skiing. It's amazing the kind of activities that he's been able to access, and the life that he's now living. Even though he's this nonverbal individual, but he's acquired the ability to participate in life with us and that's been incredibly meaningful. I do have my younger boys, 11 and 15, the youngest one has now also been diagnosed on the spectrum. He did not get a diagnosis until after first grade and people are like, oh my gosh, you already had a child with autism, you work in autism, your husband works in autism. Why wasn't he diagnosed until he was seven years old? But we really did not detect autism in him because he is so completely different from Ryan, our firstborn son. He is the polar opposite end of the spectrum. And that's just a very different condition than the autistic disorder that Ryan was diagnosed with.

Lorri: He is extremely intelligent. He has a vocabulary that's far more sophisticated than my own. And the social deficits just didn't appear in preschool or kindergarten or first grade.

Mary: So he didn't have a speech delay or repetitive interests or lack of social awareness? Nothing?

Lorri: I mean, maybe lack of social awareness, but we didn't pick up on it. So anyway, we got the diagnosis and it was actually a little bit hard to decide whether to even or how to discuss it with him, because unlike most first graders, he knew quite well what autism was. He'd known his whole life and he knew it as this condition where you can't speak, you can't make your needs known. You might bang your head, you might pinch your siblings. So he knew something very different from what he had been diagnosed with, but it had the same name: autism spectrum disorder.

Lorri: And so we had to be very cautious to talk to him about the really diverse nature of the spectrum. We actually, even though his diagnosis was under the DSM five, we still refer to it as Asperger's using the DSM four terminology because that

was a critical differentiating factor for him. So he is now very conversant in his Asperger's diagnosis. If anything, I would say he's pretty proud of it, because he excels in school and he believes that's part of the reason that he's able to excel in school. So it's been a very fascinating journey personally and professionally to have both ends of the spectrum in my household.

Mary: Yeah, I bet.

Lorri: Right. When, when people would all these flare ups happen between the ends of the spectrum and the self-advocacy community and the severe autism, I'm like, got it. I'm living it, all of it at my dinner table every night. But it's been good for me. It's been good for me to understand both ends and I think it's shaped my advocacy, my professional work as well.

Mary: Yeah. Yeah. I did a podcast episode on number 20, I believe, with Amy Lutz from the National Association for Severe Autism I think is the title of her organization. And, and she's a writer for psychology today and she has a son who's a young adults with severe autism. And, you know, we talked a little bit in that episode about how high functioning autistic people who are identify as self-advocates and stuff, they're sometimes in some occasions... and I would happen to say most people that are vocal about it, they are against ABA and they are against, you know, guardianship and things like that. It just doesn't make sense. Like they, at least in their writing their emails to me, you know, I've gotten some, some pretty nasty emails like 'anti-ABA' and this is not what Lucas would want. Of course, you know, I'm trying to get Lucas to reach his fullest potential to be as independent, as safe and as happy as possible. That's all I want for him and for all of the children I work with, and with my typically developing son; it's just that the, everybody reaches their fullest potential. And to do that we use the science of ABA and that's been proven. So like how do you respond to people that are anti-ABA?

Lorri: Yeah, I mean I guess it's kind of what you just said. You just can't assume that you understand another's experience because you have the same diagnostic label. Because the experience of my oldest son and my youngest son could not be any more different, and the youngest one wouldn't assume to know how the oldest one feels and vice versa. So I think it just, you know... I would never force any particular kind of treatment or therapy or intervention upon someone who was able to make a, you know, an informed decision against it. But my son, my oldest son, you know, he would be at a very poor level of functioning and at a not good place in life right now where it, not for the ABA. I'm confident of that and I'm confident that it's been nothing but good for him. So I, you know, I just, until you've walked a mile in my moccasins, I just can't allow your thoughts about it to influence what I do for my child.

Mary: Yeah. Yeah. So, you were very involved... You spearheaded the effort, in South Carolina initially and got Ryan's Law passed, which was insurance reform, then for the state of South Carolina. And then you went state to state and you worked for Autism Speaks, did you work for Autism Speaks from 2007 on or at what point did you start advocating in other states?

Lorri: Right. So initially I just had the idea that I thought insurance should pay for ABA and, and whatever evidence based treatment is recommended by a physician for autism. And I had that when I was living back in South Carolina. By this point we had moved from Washington DC back to my home state of South Carolina and I, I researched it, I learned that insurance is typically regulated at the state level. So this is something that had to be addressed at the state level. So I wrote a piece of legislation and asked a state legislator to introduce it for me in South Carolina. It was a very long, difficult two year battle to get it passed. But I really didn't have my sights set on this grander kind of national reform movement. I was just trying to fix in my state what I knew was a problem.

Lorri: And I did not work for Autism Speaks at that time. I actually was a law professor teaching at a startup law school in Charleston called the Charleston School of Law. And I was just kind of doing this on the side and the, the faculty at the Charleston School of Law was kind enough to support me in that endeavor cause I kept having to drive two hours to our state capitol. You know, every time there was a hearing or a meeting or whatever. But no, I, I was doing it purely on a volunteer basis as a mom because I thought it was the right thing to do. But after it passed, I started that in 2005 it passed in 2007, and shortly after that Autism Speaks reached out to me and said, you know, we think that's a really neat law that you got passed down there in South Carolina. That's good policy and that ought to be in the law everywhere. So why don't you come work for us? And make that our mission to replicate that law in all 50 states.

Lorri: And I actually, I took a few months thinking about whether I wanted to give up my career in law to go work full time in autism. But I'm really glad I did because Autism Speaks really just gave me an amazing professional platform to do this work. Like I would have gladly on a volunteer flown all over the country and help families all over the country to get this law passed if I could have, but I couldn't have because I'm not independently wealthy. You know, I had to have backing, I had to have an organization that would pay for my travel to various places and would allow me to make it a career.

Lorri: So I'm super grateful that the founders of Autism Speaks, Bob Wright, Bob and Suzanne had the forethought to say, let's support this as part of our organizational mission. And so yeah I joined Autism Speaks in 2008 and just took off and had a couple of team members who work with me, Mike Wossner and Judith Orstudy primarily who, also traveled the country working in various state

legislatures. And really it just took off. In 2008, like I think five more states passed it that year and then seven more states the next year and eight more states the next year. So it was a whirlwind. I have Delta frequent flyer miles out the wazoo. It was a whirlwind running around the country, but it was such an idea whose time had come and just meeting the parents, the moms and the dads who said, yes, I'm going to take this on for my state. I'm going to make this happen in Kansas. I'm going to do this in Washington. I'm going to do this in Colorado. It was just an amazing, amazing professional journey.

Mary: That's neat. So when did you leave Autism Speaks? It wasn't very recent.

Lorri: Just a couple months ago and I really wasn't looking, I wasn't looking to leave Autism Speaks. I still was very much enjoying my career there. But an opportunity came up with the Counsel of Autism Service Providers, which is a national membership association of nonprofit and for-profit autism service providers. So they, they were looking for some, some leadership and I thought, you know, this is kind of a logical progression in my career because I spent the last decade with Autism Speaks helping to pass these laws that created a consistent funding stream for ABA, which has allowed many, many entrants into the field of ABA. I mean, obviously there's just been a proliferation of ABA clinics and businesses all over the country, and they can set up shop and make a living because of the laws that have passed that require both Medicaid and insurance coverage for ABA.

Lorri: So it seemed like a logical next step to me to then work with this membership organization that they belong to, to help ensure best practices are utilized by all of these organizations and to make sure they're committed to evidence based care. You know, I'm not a clinician. You're a mom and you went and got your BCBA. I'm not a clinician, but I bring the family standpoint to this association to help reinforce and remind all of these providers: There's a reason you're doing what you're doing and it's to ensure that each and every one of these children reaches that maximum level, that maximum capacity. So it seems like a logical next step. And I'm really enjoying working with all the providers from this perch with this account full of autism service providers.

Mary: And are you able to work back in South Carolina?

Lorri: Yes, yes I am.

Mary: Cool. So part of my mission with the podcast is to help both parents and professionals be less stressed and lead happier lives. And as you know, as an autism mom, it is very stressful. And also in your advocacy work... Do you, so do you have any tips or ways to keep you less stressed and try to bring more happiness into your life?

Lorri: I do. I would say my mantra and my advice is lower your standards.

Mary: I've never had that advice, but I like it. So go ahead and tell us what you mean by that.

Lorri: Very counter to what you might expect. But I just believe in keeping standards low in my family life, my personal life. It doesn't mean... I work super hard. I try to accomplish a lot every day. But, you know, I guess it's partly in my family. Like my kids when they go to school, some days the homework is completely done. Some days it's not. Some days their clothes match, some days they don't. You know what, who cares? Right. I don't mean to say that I neglect my kids. I don't, but our lives are not perfect. Our household is not perfect. Our family is not perfect and I've just decided I'm okay with that. Sometimes if you come over to visit me, you will find dirty dishes in the sink and piled up laundry, and I'm okay with that. So it really is just kind of, just deciding that you can't do it all and just deciding that you're going to take some of the pressure off of yourself.

Mary: Yeah. My mantra has always been, you know, better done than perfect. And I actually am very grateful that I've never been a perfectionist because I think I wouldn't have gotten a lot done in my life and my career. Because like you, I mean, it's just like don't sweat the small stuff. No, it doesn't have to be perfect. It doesn't have to appear perfect. It's like life is messy and autism is even messier.

Lorri: That's right. And, you know, my children don't have perfect table manners, but you know, there was just a point where... When most parents would be teaching their three year old better manners at the table, my concern was making sure that Ryan didn't jump off the refrigerator or run out the front door. And so I just decided, you know, I can't do both of those all the time. And so let's deal with the safety issues that my older child presents. And then if my younger kids don't develop the best table manners because I'm not there correcting them all the time, then they don't, I mean, we'll work on it, we'll try to get better. But I mean that's a silly small example, but you get the concept that I just allowed myself to accept that you can't do everything perfectly. Yeah. Somedays I will brush my hair, some days I don't. And that's just...

Mary: Okay, that sounds great. So how can people follow you and your work and stay in touch to see the exciting things you'll be doing over the next how many years of your career. But yeah, I mean you've done so much for the autism field already, so how can people keep up with you and see what you're doing?

Lorri: Well, thanks for asking. I'm actually terrible at social media. I am on Facebook and CASP is on Facebook, so we welcome people to follow myself or CASP on Facebook and our website. I think I have a profile on Twitter and LinkedIn, but I

don't check it or utilize it very much. I do enjoy speaking at conferences around the country, I do a fair amount of that, so I welcome people to follow that way.

Mary: Okay, great. And we will link your email address in our show notes so that if people want to contact you regarding speaking or something like that, then they can do that by going to the show notes at marybarbera.com/podcast. So I'm looking... I'm so happy that we got to chat and learn more about you and your important work over the last decade; first helping your son and then also in helping lots of families and providers around the country. So I thank you on behalf of our listeners for all of your work in the advocacy efforts. So, I look forward to seeing where your career, your new career and your new position is going to take you and I hope to continue to collaborate for many years to come as well. So thank you again for joining us.

Lorri: Thank you, Mary.

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