



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 020

Severe Autism

Hosted by: Dr. Mary Barbera

Special Guest: Amy Lutz

Mary: You're listening to the Turn Autism Around podcast, episode number 20. Today I'm interviewing Amy Lutz who is a mom of a young adult with severe autism, who has spent the last two decades advocating for her son as well as many others, and she gives us great insight on severe autism and the different needs that kids and adults with severe autism have.

Mary: So before we get to that interview, let me give a shout out to Lesfranz who gave me a five star rating on iTunes and said, "I was so excited when I heard Dr. Mary Barbera was starting a podcast after listening to lessons, which is episode number one. I am not disappointed. Great Information. I will be listening to all of her podcasts. Thank you Mary, for all of your hard work in the field of autism." Thank you to Lesfranz for giving me that great review. And now let's get to the interview with Amy Lutz.

Welcome to the Turn Autism Around podcasts 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: Okay. So today we have a very special guest. We have Amy Lutz who has a 20 year old son with severe autism, and Amy is a writer. She has written about severe autism for many platforms including the Atlantic Psychology Today, Slate and Spectrum. Her book: Each Day I Like It Better: Autism, ECT, and the Treatment of Our Most Impaired Children was published in 2014. Amy is the president of the E A S I foundation, which stands for ending aggression and self and jury in developmentally disabled, and she's a founding board member of a new organization called the National Council on Severe Autism. Amy is currently pursuing a PHD in history and sociology of science at the University of Pennsylvania. She lives outside Philly with her husband and five children. I met Amy about a year ago when she observed my son, Lucas for a paper she was doing as part of her PHD coursework, so please welcome Amy. Thanks for joining us today.

Amy: Thanks for having me.

Mary: Great. So I already let the cat out of the bag that you had a 20 year old son with autism. So, but can you describe your fall into the autism world? How you... what signs you were seeing and how you came to know that your son had autism? How old was he, what year? All that.

Amy: Wow, this is going into ancient history. Well Jonah is our first, our oldest son, so we didn't see any warning signs because he was our first child, so we didn't know what to expect. He was born in 1999 and you know, we read *What to Expect When You're Expecting* and what to expect the first year, and none of the things that are now taken as routine signs of early signs of autism in babies and toddlers were included in those books. Like, looking for a clear index finger point or the ability to follow one step directions or respond to names, you know, so we didn't see anything wrong with Jonah.

Amy: He was, um, he was very engaged, outgoing baby. We thought he was a super genius because when he was about a year old fifteen months old, he was crawling on our pool table, lining up the pool balls in numerical order. And we just thought he was, you know, on the road to be the next, you know, MIT professor or something like that. And then like many parents our diagnosis came at the age of two when Jonah wasn't talking, and our pediatrician said, you need to get his hearing tested to see maybe he's having a hearing issue. And I went home and I, um, I told my husband, Andy, I said, well, maybe Jonah is deaf and that's why he's not talking? And Jonah was watching a video, um, a Sesame Street video on the TV, and Andy just walked over and turned off the volume on the TV and Jonah took his hand and pushed it up towards the volume and Andy said, okay, he's not deaf, next, you know.

Amy: And that was the beginning of our journey to the specialists and the uh, kind of in home supports and the speech therapy and occupational therapy that I think is kind of very common trajectory for parents of children with autism. But it started when he was about two.

Mary: Okay. And you write a lot about severe autism. So what kind of treatment did you use over the years and, and was he always severely impacted and that didn't change, or did he regress later, you know, to become more severe or what... Can you describe that... You know his childhood and how we're at this point with him being severely impacted?

Amy: Sure. How long did you say this podcast is? That's really long story, but yes, he's was severe from a very early age. It's one thing though for to see severe aggression in a three or four year old. It's pretty easy to manage, you know, when they're knee high. But I do remember him being in speech therapy and the

speech therapist would have him in a highchair with a tray on the top to just keep him in place, and also to keep him from kicking and hitting her while she was working.

Amy: And I found out later, I didn't know this at the time, Jonah was in a special ABA preschool when he was three and four, and I didn't know, but it turned out that they would regularly have to clear out the classroom because of the rages he would, um, where he would be, you know, be very aggressive and self-injurious and throw himself on the floor and they just found it easier to clear out the other kids rather than, um, try to physically restrain him or prevent him from hurting anybody.

Amy: So that behavior was present from the very beginning. And as far as the list of things we tried, it is a very extensive, you know, of course we tried behavior modification plans, we went down the alternative therapy route also. We tried special diets, we tried vitamin injections, we did auditory integration training, we did oxygen therapy, we tried everything. We, I really just had this very deep seated fear that I would miss the thing that would transform Jonah and kind of would, I don't know how to say it besides, you know, cure his autism, you know, or at least really help him make great progress. And that, that fear of missing the thing is I think very profound in parents, especially when they're younger, this idea that there's a kind of a window closing and if we don't figure out what that magical thing is, it's going to close forever.

Amy: So we tried everything and um, and then including many, many medications. So from the age of six, we were in medication trials. Uh, we tried antipsychotics, we tried stimulants, we tried, I'm sure we tried to eye, whatever, you know, the psychiatrist could think of that might have an effect. And then as he got older, you know, the behavior got much more difficult to manage. And when he was nine years old he was kicked out, oh, I guess he was eight, he was kicked out of an autism school, a school just for kids with autism, and they couldn't manage his behavior, and so we ended up, he ended up going in-patient at the kinder institute for 10 months, so almost a year, and when he came out he was pretty stable, but within a year he was, his behavior was just as bad as it ever was.

Amy: In the year following, we discovered electroconvulsive therapy and that did a transformative job in managing the rages that Jonah was experiencing. And he still gets ECT regularly and that's the only reason why he's still living at home and going to school and going out in the community, I have no doubt that without the ECT, he'd be in a very strict residential facility.

Mary: Okay. So an ECT, and that's what your book is about. Your book is called Each Day Like It Better, and it is about your journey with ECT, which is electroconvulsive therapy, and that is a medical treatment. A lot of in the

behavioral field, you know are confused and um, don't understand that this is a medical psychiatric procedure. Right? Could you describe ECT a little bit for our listeners?

Amy: Right. So the first thing, you're absolutely right, I get a lot of, I get contacted a lot by people who are confusing ECT for the type of shock that's used at the Judge Rotenberg Center as a behavior modification punishment technique.

Mary: Right. Which we are not talking about that. That is, that is something completely different and something that we are not embracing here. This is a medical treatment for kids that, um, and it's not just for kids with autism, actually, it's more for, uh, people with depression and those sorts of, you know, adults and it's, it's used a little bit for kids. But go ahead. So ECT is a medical procedure.

Amy: Yeah, it's done under general anesthesia and ECT is used to treat about 100,000 Americans every year with certain, uh, very... untreatable psychiatric disorders. You're right, it's usually used to treat depression, often in the elderly who can't tolerate certain types of psychiatric medications.

Amy: But it's been very successful in treating kids with autism who's rages are, um, are provoked or by... Or caused by a Comorbid psychiatric disorder, most commonly an agitated form of Catatonia, or what Jonah has, which is kind of a rapid cycling bipolar disorder. So Jonah's rages, you know, we did the functional behavior assessments and they were not caused by anything in the environment. They were all internally driven due to some kind of, you know, some kind of internal activity in his brain and the ECT stabilizes that so it controls the bipolar disorder. It doesn't make him any less autistic, unfortunately. I was hoping the ECT might make him stop, like chucking his iPad out the window of an open school bus or shoving DVDs down the toilet and it didn't. But, um, but although we were able to implement the behavior strategies for these behaviors once his mood was regulated by the ECT, so he doesn't do those things anymore.

Amy: But ECT has been miraculous for us. And my book is also about several other families who use ECT with their teenagers, many of them with autism. But, but one case, it was a neuro typical teenager who had really psychotic of bipolar disorder and ECT really works as a very high efficacy rate with treating these types of psychiatric disorders.

Mary: And we'll link your book in the show notes for anyone interested in that. So you have five children in total, which is amazing. I can't even imagine having five kids and doing everything that you've been doing over the years. But, so what are the ages of your other kids and did you have any concerns about any of those, any of those, um, siblings have any developmental concerns or that sort of thing?

Amy: Well, my oldest daughter is, is turning 18 in a couple of weeks. And then I have, my middle daughter is 15 and then I have twins who are 12, and my middle daughter, Hilary, does have pretty severe ADHD. It's hard to know, you know, kind of trace where that comes from. She was a very premature baby with a lot of medical complications, but she's also in the gifted program at school so she's definitely not impacted the way that Jonah is, but I've certainly gone down the medical route with her as well.

Mary: Right. And I'm sure you've had to have your advocacy hat on pretty, pretty solidly for her as well and for all your kids. What about the dynamics within your family and with having Jonah with severe autism and he was hospitalized for almost a year and you know, I'm sure that affects your family dynamics a good amount.

Amy: Well, it's interesting that you asked because I have to say I don't see it. You know, my kids, maybe because they're all younger than Jonah and they don't know, they had never experienced life without severe autism in the house... they roll with it. You know, when, uh, when Jonah went to Kennedy Krieger they adjusted to that, and when he came back, they adjusted to that. They've never asked, can we have a birthday party and Jonah not come? Can we do this outing and with our friends and have Jonah and do something else because he embarrasses us or I mean they are, they're rock stars when it comes to that.

Amy: And you know, that's kind of the... My oldest daughter is a very stereotypical sibling of a child with special needs, and she's very nurturing and she engages with Jonah a lot and knows exactly the right scripts to use with him, and she cares a lot about that interaction. The three younger ones are a little more all about themselves, you know, which may be more typical of their ages, but they don't, they just kind of operate in a different universe. And you know, we do a lot of things as family. We have to do a lot of things not as a family because of Jonah's disability and split up a lot. But it's also because my kids are at ages where they all do different activities and like to do different things.

Amy: So I think that's also very common in families affected by autism is that one parent will take the autistic kid to do one activity and the other parent will take other neurotypical kids to do different types of activities. And our family is no different, but there's no tension about Jonah or a desire for some kind of normalcy. My kids have no idea what that would look like anyway.

Mary: Yeah, that also sounds like my family. Yeah. Because Spencer is 18 months younger than Lucas, so he never really knew anything different. So, so most of your writing and your work and your advocacy work has been surrounding severe autism. And I know there has even been a lot of people, um, the media for instance, really does feature more high functioning... like The Good Doctor

for instance. People are like, oh, have you watched The Good Doctor? I'm like, no, I don't watch The Good Doctor because, you know, for me, autism looks a lot different than The Good Doctor who might be 0.0001% of how a person with autism could possibly even function.

Mary: So do you also agree that like the media's portrayal and also funding, which I'm sure you're more expert at the funding allocation, but I've heard that funding allocation is much more for the higher part of the spectrum. And so can you describe like your views about media and funding and um, some of the disparity between high and low function. And I did an episode podcast episode on high and low functioning and like I don't even like to use that term really. Um, and that's episode number four. So you can go to marybarbera.com/four to listen to my views on high functioning, low functioning. But you know, when we're talking about severe autism, we're talking, you know, very impaired and my son is also in that same realm of very impaired. So can we talk a little bit about the media and funding and just some of the issues involved?

Amy: Yeah, I completely agree with you that the media focuses on extraordinarily high functioning cases of autism. So yes, The Good Doctor, the Big Bang Theory every year around this time I see forwarded these famous celebrities have autism, you know, advance of autism awareness month in April. So like Dan Aykroyd and Daryl Hannah have autism, you know, and we should, you know, this is how much they have accomplished given that, and to me one of my prime motivations is to get kids like Jonah and Lucas into the public's eye. So as we as a society decide what types of supports and services we need to provide to people with autism who are dependent on these types of services, we have a clear picture of the population that we're talking about.

Amy: And it's not Dan Aykroyd, it's our kids and the media doesn't want to focus on autistic kids that are engaging in self-injurious behavior or might still be wearing diapers at the age of 12 or have to wear helmets like some of the children of families that I work with because they hit themselves in the face so many times an hour they're at a risk of detaching their own retinas. Like, these are not stories that the media wants to tell. So they focus on, you know, the kid with autism who can sing with Katy Perry or um, you know, riff with Jon Stewart or sell their artwork for \$5,000. You know, but these and those stories are good. And then it's important to have positive stories about autism and as with all disabilities in the media. But there needs to be some balance. And I've seen, I, you know, I know about and I appreciate, people's uncomfortableness or lack of comfort with the high functioning, low functioning binary, but I think it's essential that we not forget that there is a big difference in functioning between people who are very mildly affected by autism and people on the severe end. And I haven't yet seen other terms that I feel do as accurate a job as describing that difference than high and low functioning. So I'm living with that for now.

Mary: And what about funding? Do you know anything about the disparity with funding of research and, and those sorts of things? Like, I don't have the statistics in front of me, but I do, I have heard that the majority of the studies are on the high functioning kids.

Amy: Right. That's true. And uh, Matthew Siegel who is a psychiatrist that's on the board of the NCSA, the national council on severe autism with me, recently published a review of the research on autism and found that people with severe autism are increasingly excluded from research. And it's obvious why... It's really hard to put somebody with severe autism in a scanner for example, or have them follow directions on some kind of assessment. And so it's just easier to say we only are looking at people with autism with an IQ of 70 or above. You know, that's kind of a very common statistical, I mean that's like a common criteria and study in the study guidelines and we need to do better because the people who need the, you know, the research the most are the ones who are most effected. And that's the people on the severe end.

Amy: And as far as funding, well, I would say what's happening is how, how is that funding being allocated? And you know, we've talked about how, you and I privately have talked about how a self-advocates have succeeded in kind of nudging policy to reflect the, their primary goal, which is only funding, fully included settings in the community. So I'm not saying that the funding is changing so much as what kind of supports and services are available to people who get waivers from the state has changed a lot. And right now, for example, in Pennsylvania where I live, my son would never be able to choose a residential setting, you know, larger than three people because that's considered institutional. Now, even though Willow Brook for example, had 6,000 residents, now we're defining institution as anything larger than four. So this has been the, um, the inclusion advocates have been very successful in nudging policy to reflect their particular agendas. And I think it's, that's been detrimental to, to kids like ours who might need more structured, larger settings.

Mary: So Jonah is now 20 years old and in in the United States, kids with severe disabilities can go to the educational settings until they're 21. So Lucas is 22 so he's over that hump. So can you, um, describe what Jonah is doing now and what you foresee him doing? Um, in a couple of years after he transitions away from the educational setting,

Amy: Jonah goes to a wonderful school called the PAAL Program in Downingtown, Pennsylvania. It stands for Preparing Adolescents and Adults for Life and he's been there... it's the secondary community based school. He's been there since he was 14. And PAAL does have, um, an adult program and nothing would make me happier than for him to just kind of stay doing what he's doing now. He really

likes going there. He spends all day out and about different work sites, different leisure activities, restaurants, shopping, you know, he has a blast.

Amy: And as far as residential settings, that's a great question. I mean, I know he can't live with us forever, but there's really nothing that I'm seeing that I think would be appropriate for Jonah. And because honestly, nothing scares me more than the idea of Jonah alone in an apartment with one caregiver who's being paid like \$12 an hour and can't be bothered to take Jonah out to do his favorite activities because that's a lot more work than letting him sit at home and stem on his iPad, and there's nobody to make sure that you know that any kind of great programming is implemented.

Amy: So I'm a big fan of, I think Jonah would enjoy more being in some kind of community, not necessarily like, and definitely not thousands of people big but maybe like 20 or 30 people, um, with autism and IDD who um... Where there's like a real emphasis on quality of care, where direct care staff is paid a living wage and offered lots of opportunities for training and advancement and for perusing a meaningful career where there's lots of supervision and structure, lots of therapeutic services and lots of options for how to spend the day. And you know what, I think that other parents trying to build these types of communities, I am in touch with several different groups and I'm kind of waiting to see that hopefully these groups will get off the ground and be able to, to change the debate as they show, you know, really positive, enriching experiences.

Mary: So these communities, some people refer to as intentional communities, and they would be a group of homes or like a development or something where, or an apartment building where you could have activities and support and oversight by maybe a behavior analyst and oversight maybe by a nurse, almost like a, like a assisted living for older people. You know, like those sorts of, you know, it's a little bit different than that, but you know, to have those supports kind of in one place.

Mary: Because right now the way the laws are in terms of waiver funding, it's like you can't be even next door to another group home. Like you have to be... you know, one house here with two people, you know, and that's... It's a lot of support. It's a lot of, you know, if there's turnover and those sorts of things, it is just a real concern because Lucas is still obviously living at home and he's 22 and you know, I have relatives and friends who are in their seventies who have 50 year old children living with them. And it's like at some point, you know, it would make me happy if I could get Lucas somewhere where he's happy and safe and as independent as possible and not living here constantly.

Amy: Yeah, I agree. And I, and I just want to point out that that's, that's not the rule across the country. This is just the Pennsylvania rule that that where you have to, you know, they're so strict about the size of residential settings, how many shared walls the person who's receiving a waiver has with another waiver recipient. There are, there are some states that are encouraging parents and providers to do these public private partnerships and build something great.

Amy: So you have first place in Arizona, big intentional community with lots of kind of training and different types of programs just open. The Ark Village in Jacksonville is a big community. Um, it's basically, it doesn't prevent... I don't know if they provide service, but it's a big kind of gated type community for people with milder forms of IDD who are a little more independent. But there it provides a strong sense of community with easy access to Jacksonville and you know, I can, I'm just hoping that Pennsylvania takes a look at what other people are building, what other states are doing and families are looking for and kind of backs off from this policy, which is way more... It's stricter than then CMS, which is the Centers for Medicare and Medicaid Services, uh, requires.

Mary: So it looks like people like you and I, Amy, are going to have to get on that because really the only way things are going to change is with parents like us who can gather other parents like us and force the change. I mean, it's not just going to be somebody from some department saying, yeah, that sounds like a good idea. It's going to be us advocating and for something better. So we'll get on that. So you, speaking of advocacy and getting on that, you recently became a founding board member of the National Council for Severe Autism. And can you tell us about that organization and what you do there?

Amy: Yeah, I'm really excited to be part of the NCSA. This was the brainchild, primarily of Jill Asher, who is a California based advocate. She's the president of the Autism Society of San Francisco. And she's someone I've connected with through the world of advocacy for severe autism. And there were several, you know, very public advocates who I had the pleasure to meet while I was, for example, researching my article in the Atlantic on housing called Where Should Autistic Adults Live? That was my first foray into the world of adult services. And I met so many amazing advocates and through them they would always say, well, you need to talk to so and so. So I met Jill through that. And also Alison Singer, who is the president of the Autism Science Foundation is on our board. And so is it Feda Almaliti who was another California based advocate. And Jill pulled... Oh, and Lisa Parles from New Jersey who is an amazing advocate and a lawyer for, you know, for this population.

Amy: So at least, so Jill pulled all of us together and said, you know, basically we're all working independently on these really important issues. We need to have a national presence to kind of balance the conversation and make sure that our

severely impacted kids are included and the issues that we care about are highlighted in these debates. So we launched in January and we've had an amazing kind of reception. So many families have reached out to say, thank God someone is representing our kids because no one else is really focused on the very specific needs of families who have kids with severe autism.

Amy: So for example, guardianship, you know, you have organizations like the Autistic Self Advocacy Network fighting against guardianship, you know, period for anybody. You, the United Nations taking a stance, um, that guardianship is like genital mutilation. This is what a United Nations official said at an autism awareness event day, I believe it was two years ago, the idea that guardianship is an infringement of civil rights. And meanwhile, parents like me are saying, my son can't even cross the street on his own without being hit by a car. How on earth can he survive without guardianship? He would be extremely vulnerable, just he cannot make medical decisions even with the highest levels of support. It's, I mean, I, you know, so we take a stance on guardianship and how that it's necessary for a certain population that made certain criteria. And we also have position statements on our website about housing, we have it about vocational programs.

Amy: So, um, you know, the way I met you, Mary, was through my research into the sheltered workshop. And I actually think this is maybe going back a little bit to your previous question about advocacy is and how parents can make a change. That sheltered workshop, you know, debate in Pennsylvania was I think a great example of how families and providers can shape public policy. Because in Pennsylvania they, the opposite developmental programs try to basically eliminate sheltered workshops with one new policy that would've required, um, adults in day programs to spend 75% of their time out in the community. And the IDD community in Pennsylvania really responded and almost immediately within a couple of months that law had to be retracted because of the amount of backlash that the state received. And I feel that if people at ODP and the governor's office here could get that kind of feedback about their residential policies for people with IDD that similar changes might result. So I do think that families and providers and people care about this population can have an impact if they can organize and um, and kind of make their opinions known. So and so sheltered.... You know, having a range of vocational and residential settings is something that NSCA is very invested in. And we want to counter, you know, organizations like the autistic self-advocacy network that represent the highest end of the autistic spectrum and, but kind of claim to represent the entire spectrum where we are not making any claims to represent the entire spectrum. But we are saying that we, the parents and, and some providers and the practitioners who work most closely and love this population are the ones who should be making decisions about their future.

Mary: Yes, I agree wholeheartedly. Um, when Lucas was 18, we, we went had to go to court and get guardianship and you know, even just the process of getting guardianship, you know, it costs money and time and you have to like get on it. But I had heard from other people that if we didn't get guardianship, you know, if he were hospitalized and stuff after 18, you know, they didn't... Hipaa laws and stuff, they couldn't even share... He can't even make a decision reliably. He over answers yes to things. So if you say, you know, did you have a good day? Yes. Did you have a bad day? Yes. You know, are you an ax murderer? Yes. Like, you know, he can't cross the street. He can't be alone by himself. So why in the world would I not see guardianship for him?

Mary: There'd be no way. And um, yeah, so I think it's good that you all have founded this organization to represent the needs of children and adults on the severe end of the spectrum because it is, there are very different needs. And I think with, with the research being done on people with IQs above 70 with the, um, the media portrayal of kids higher on the spectrum. And it's like, these aren't like fun, nice topics.

Mary: Like even for the podcast, you know, we want, we want it to be positive and happy. But the thing is, is that we're showing that our kids can be safe, happy, as happy as possible, as independent as possible. But it's our job to get them there and to keep them there. It's not all once and done thing. It's a lifelong goal to have our kids stay at that level and it takes a lot of work and a lot of advocacy.

Mary: So, well, I'd like to, this podcast is not just to improve the lives of, of children and adults with autism to get them as safe, happy and independent as possible. But also one of the goals for my podcast is for parents and professionals to be less stressed and lead happier lives. So any advice for parents and professionals, and also collaboration? It sounds like you do collaborate a lot with, you know, professionals in the field. Maybe they're also parents and all these people on the board, but any advice for helping those moms out there or professionals who are working or living or loving someone with severe autism to be happier?

Amy: Living with severe autism, I don't know that there's anything harder. I don't think that there's anything more difficult than caring for someone who is a constant threat to hurt him or herself or somebody else. And the only reason that I'm here and have been able to pursue these advocacy goals, to go get a PHD, to write a book is that we were extraordinarily fortunate to have a lot of support between support from our county, you know, the hospitalization when we needed it. And to have honestly the financial wherewithal to supplement with um, you know, private help for Jonah. Honestly, that's what families with severe autism need more than anything else is just support. They need somebody to say, I will sit with your child, you know, for an evening so you can go to the

movies with your husband or you can go just go get a manicure or just have a break.

Amy: I think so many of the families that I see in my Facebook groups or who reached out through my advocacy work and are interested in ECT or want to talk about something I've written, they're living in constant state of crisis and they can't leave their kids alone for a minute. And it's incredibly taxing on mental health and quality of life. And I don't have any good answers because it's really hard to get that support. You know, if your kid is aggressive or self-injurious, you can't just get a babysitter and you may not even be able to ask family members. You may not feel comfortable leaving your child with anybody because you'd be afraid that someone would get hurt.

Amy: So I think part of what drives me is trying to make sure that other families get at least some of the support that I had the privilege to enjoy and make sure that those needs are highlighted in these public conversations so that we don't have families who have to give up everything, all their own, you know, parents... and it's honestly, it's often the mothers having to give up their jobs and their hobbies and their friendships because they have to be on 24 hours a day because let's not forget kids with severe autism that are not medically stable, often don't sleep regular hours. You know, I've certainly met several moms who kind of sleep on a mattress outside their kids bedroom door because their kid might get up at two or three in the morning and just leave the house, and that's a tremendous fear.

Amy: So just bringing some peace and some, you know, some peace of mind and increasing the quality of life of these families is hugely important to me. And I wish I had, you know, an easy way that we could do that. But I can't think of anything harder. So I guess I would say if your listeners are, um, you know, family members or, or friends of families in the situation, anything you can do to reach out to those families and make them feel less alone is... But we would say is a huge mitzvah a huge great thing that you could do.

Mary: Yeah, that's great. And also, um, I provide weekly video blogs and so I'm a registered nurse and a behavior analyst. So I do have some video blogs, um, should you medicate children with autism? And, and just kind of go through in that video blog, I go through Lucas's journey with medication and with supplements and some of the side effects and some of the, some really, you know, one medication that's been truly, uh, you know, almost miraculous for him and his aggression and self-injurious behavior, which is now near zero levels, and, and it was like the journey with him. So each journey is going to be different for each child and, and the more you can learn about behavioral strategies as well as medical issues that might be at play, I think the better. So, you know,

listening to these podcasts, checking out my video blogs and also, I offer free online workshops and I also have an online community of support.

Mary: So it's an ongoing process. It's not like a once and done. You go to one training or your child takes one medicine and everything suddenly is better. It's an ongoing process to get them to this level and to keep them as safe, independent and happy as possible. So thank you so much for your time. I look forward to knowing you for many years and continuing to advocate for our kids. And for other kids who are on the spectrum and more on the severe end of the spectrum. So thanks for your work and your advocacy and I wish you all the best.

Amy: Oh, thanks. Thanks for having me.

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