Transcript for Podcast Episode: 036

Autism Medication, Related Medical Conditions & Indicating Pain for Kids with Autism

Hosted by: Dr. Mary Barbera

You're listening to the Turn Autism Around podcast, and today's episode is all about medical issues in children with autism. Before we get there, I'd like to do a listener shout-out to Mapeach who said he or she was, "thrilled to find this podcast. This is a must have podcast for everyone who teaches, works or shares their time with folks that require behavioral support. Thank you. I can't wait to get through every episode. The information you share is vital to successful moments and your work is important." So, thank you so much for that great review. If you haven't given this podcast a rating and review, I'd love it if you'd do that wherever you're listening.

So, let's talk about what we are going to discuss on this episode. So today I'm going to talk about the medical issues that often occur with autism. I'm going to talk about something I just learned in early August that is going to be really important, especially to you behavior analysts and teachers out there. I am going to discuss the role of medications and supplements and why things often go awry when kids do start taking medications or a cocktail of medications, and how parents can take easy data in terms of keeping track of medical issues and problem behaviors all in one spot. And finally, we're going to wrap up with a very important skill that if your child or clients don't have it, it's going to make it really tough for them to describe or tell you if they are in pain. So big episode coming up, let's get to it.

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.

Welcome back to another episode of the Turn Autism Around podcast. I'm your host, Dr. Mary Barbera. And for those of you joining me for the very first time, welcome to the Turn Autism Around podcast. I've been doing this since January of 2019 hosting a weekly podcast. So, I hope that if you are new to this podcast, you'll become a, an avid fan and a listener. Now, I am both a behavior analyst as well as a registered nurse, but nothing in this podcast should be considered medical or behavioral advice. I am not able to give you actual advice, but I do use my podcast and my video blogs to give information to both parents and professionals in the autism world. So, as you probably know, autism is a medical disorder. It's a neurological disorder, it's a

developmental disorder, and it's a behavioral disorder. It does get diagnosed by developmental pediatricians, psychologists, neurologists, and some people are even now speculating that autism may be an immunological disorder.

So, lots of different specialties in terms of medical treatment and medical diagnoses for autism. And lots of kids and adults with autism have what we call comorbid conditions. And comorbid conditions mean that it's autism plus other things. So many of our children have diagnosed speech and language disorders and apraxia and they also, many children have ADHD. Many children and adults have depression, anxiety, there's autoimmune problems, there's GI disorders, there's sleep disorders, feeding disorders, all of that. My son has an autonomic nervous system dysfunction. So, all of those other conditions that aren't a part of autism often come with autism. And so, it makes the medical and behavioral treatment very complex.

I have done several video blogs on the topic of medical issues, medication, how to teach a child to indicate they're in pain, the difficulty and impossibility of quote unquote ruling out medical problems. And so, you can Google any blogs I'm talking about. You can always Google Mary Barbera plus whatever topic. So, medications, how to teach a child pain, you can Google that. We will also link all the video blogs that I've done on medical topics right here in the show notes. So, you can go to the show notes by going to Marybarbara.com/36. I also did two recent podcasts with physicians, with medical doctors, one of which is episode number 28. Again, Marybarbera.com/28 and that is a whole episode with Dr. Michael Murray, who is Lucas's psychiatrist who diagnosed the autonomic nervous system dysfunction and put Lucas on a medication that literally changed his life and my life. So, you want to check that out; Dr. Michael Murray.

I also last week had on Dr. James Coplan who is a retired physician, a developmental pediatrician who diagnosed Lucas in 1999 with moderate to severe autism. And Dr. Copeland has a vast amount of experience, decades of experience diagnosing autism, treating comorbid conditions, using medications, ruling out hearing loss, ruling out genetic complications and all sorts of things. So, you can check out Dr. James Coplan's podcast interview as well.

So, as an RN, a registered nurse, I know my son specifically who's in his early twenties as well as many of my past clients have medical issues. They are medically ill or have some kind of medical issue that's actually contributing to their problem behaviors. And I know this, I've proved this with Lucas and we're going to talk about keeping data and how I would suggest you do that coming up in a little bit. But before we get there, let me switch hats from my registered nurse hat to my hat as a board-certified behavior analyst. Okay.

So, I want to talk about the four functions of behavior. And I want to just describe this very in Layman's terms, as Layman as I can get. So, we have four functions of behavior and one function is the child cries or hits or, you know, hits, bites, kicks, screams. So, let's just say child bites his hand. The first one function is what we call socially mediated positive reinforcement, which means in the past when he's bit his hand, it has meant that something good happens. He has received positive reinforcement that has followed biting his hands. So, this might be the

child bites his hands because he wants something. And in the past, he's gotten it. So, this could be child wants candy in the candy aisle at the grocery store. Okay? So that's the first function. Socially mediated, positive reinforcement. Socially mediated means people are involved and positive means he's, he receives the candy, he's given the candy.

Then we have socially mediated negative reinforcement. Let's take still... We're talking about the same child, Johnny, he bites his hand when he doesn't want to do something to get out of something. So, it's time to take a bath, bites his hand, and then mom says, well, you know what? He got a bath last night. He's not that dirty. Let's not do it. And now Johnny has learned, okay so I bite my hand to get things. I bite my hand to get out of things. That's socially mediated negative reinforcement. So, both of those functions, people are involved. We tend to see those functions a lot in the classroom setting and home settings. And this isn't just for children with autism, this is children, adults. These are functions that have been proven as to why behaviors occur. Okay, so we have the two socially mediated functions and then we have two additional functions that are called automatic, which means people don't have to be involved.

The adults don't have to be in the picture, they can be included in the environment, but it's not that they are adding or taking away. So, we have the automatic positive reinforcement. So, it tends to feel good or sound good to the student or the child and Johnny may bite his hand just to stimulate himself. I know that sounds weird because you would think that that would cause pain, but you know, even, let's just say he's not really biting on his hands, he's biting the cuticles of his fingers and he's biting them kind of raw. He's doing that because he likes the way it feels potentially. Let's use another example, like self-stimulatory behavior where the child might be rocking, might be verbal stemming like blah, blah, blah, blah, blah, blah, blah, making noises. Because either way, this positive reinforcement, this stemming or this biting on the cuticles or this rocking, some headbanging may occur, is because the child doesn't have the language, doesn't have the play skills and other skills that are needed to occupy his mind.

Okay. So that's automatic positive reinforcement. And then we have the automatic negative reinforcement, which is pain attenuation. So, a child might bite his hand if he's in pain or stress. And this is what happened to Lucas. He, when he was 13 or 14 years old, he started to bite his hand, and he also at that point was able to tell us he had headache. And so, he's biting his hand and he was saying head hurts, and it was like stabbing pain that I think the biting actually drew his attention to the pain in his hand. And then the headache miraculously went away even before I could run downstairs to get Mottram. So, it seems like it... Why would that be?

So, the thing I learned in early August, I went to the national autism conference at Penn State University and I've been there many times. It's a great conference. It's always in early August and it's always great. And they do live streaming and they, some of the three-hour lectures are recorded. And I saw Dr. Tim Bohmer there who's an expert in these four functions of behavior. He was talking a decent amount about automatic positive and negative reinforcement. And so, I am going to link that in the show notes so that you can watch the lecture by Dr. Tim Bohmer if you are interested. I think it's fascinating lecture, and I asked him the question... I was interested in studies on automatic negative reinforcement, the pain attenuation, because I

have a strong interest in this. I know that over time it's been proven that Lucas's self-injurious behavior and aggression was related to pain and distress. And so when I asked Dr. Tim Bohmer about the studies on automatic negative reinforcement, he said right away that there are zero studies on automatic negative reinforcement and that he also added later in the lecture that all animals like monkeys and birds and rats, they bite on things when they're in distress, when they're in pain or stressed.

And so, he hypothesizes that some of the biting behavior, biting on your hand or biting others, could definitely indicate that the child is in some kind of distress and possibly pain. He also added that in the past before anesthesia that humans were taught or given a towel to bite on. My dad said like in the cowboy movies that to get a bullet out they'd often show a towel on a person biting on a towel. So, so just after seeing Dr. Bohmer and him talking about biting and other species and that... I just was more interested in, in doing this episode for this podcast. And I'm also trying to tell behavior analysts, like we can't just use bite guards and use helmets if the kids are having self-injurious behavior. We really need to get to the bottom of this and we are, by our ethical code... behavior analysts need to have these medical conditions ruled out before we go treating problem behaviors with keeping the demand on procedure, which I don't recommend hardly at all. And all kinds of behavioral procedures we need to figure out what's going on medically. And it's really impossible when children are either not speaking at all or have limited language.

And I'm going to talk about ways we can get kids to indicate they're in pain. But I think a big issue is that we, you know, you'll read a report and you're a behavior analyst and you'll read a report, oh, that the mom took Johnny to the doctor and there are no medical concerns. So, we need to just treat him like it's all behavioral, but nothing's just all behavioral. I mean, there's so many things going on within each child and this is a big problem. So, if you're a BCBA, the other thing I want to mention... Or a teacher or part of an IEP team, there tends to be a lot of talk of, you should put Johnny on medication. And in my video blog where I talk about Lucas's journey with supplements and medications, I tell people at the end, I'm like, do not say this child should be on medication. If you are a nonmedical professional, you can't even imagine.

I'm a registered nurse, I'm a behavior analyst, I'm married to a physician. It is complex and each child is so different. What's going on medically? And it's so hard to tell, so don't be too quick to blame it on just get them on a medication because it's very, very complex. Just very briefly, I just want to tell you a little bit about Lucas's journey with supplements and medication.

Lot of behavioral analysts and education professionals think supplements are all bad and pseudoscience and regular traditional medicine are all good. But from my experience early on, Lucas was a very picky eater. He had to be treated with a feeding disorder at Children's hospital. But somewhere around the time of his diagnosis, before he was treated with a feeding disorder, I was told, you know, put him on a multivitamin. So, I don't know what Multivitamin I put on, but 20 minutes or 30 minutes within administration of this Multivitamin, Lucas would become agitated. And so, I started to like really to question like, what is in in the supplement

multivitamin that might be causing agitation? And at the same time, I started to learn about some work done at Hershey Medical Center on the zinc to copper ratio.

Now the zinc copper ratio was really out of whack in many children with autism. And so, we had some blood tests done, the zinc level, the copper level, and we found that Lucas's zinc was low, and his copper was too high. And so, we added a zinc supplementation and he's still on that two decades later. But the other part of the zinc to copper ratio is that we need to avoid copper. And there was copper in Lucas's multivitamin and in fact, many multivitamins contain copper and that was just enough to get him agitated. And who would have thought, you know, that is just bizarre. So, then a few years later, Lucas started having acute onset tics. He had tics and were treated with antibiotics. And eventually was diagnosed with PANS, pediatric autoimmune neuropsychiatric syndrome. I did a video blog on PANS. And then with Dr. Murray when he was 18 years old, he was diagnosed with an autonomic nervous system dysfunction and he's been doing really well on a beta blocker, which is a cardiac medicine for that autonomic nervous system dysfunction.

So obviously very, very complicated and I don't want to bore you with Lucas's story, but within each child there could be a real a journey with medical issues and medications and supplements that involves lots of twists and turns. So, I do want you to realize that it's, it's extremely complex.

Okay, so how do we keep data on problem behaviors and medical issues all at the same time? And one of the things I found, and I used to do this all the time too, is we would get these clickers, these tally counter clickers. I got these on Amazon, these colorful ones, but as a behavior analyst and I've seen many behavior analysts continue to do this is they count problem behavior on this clicker. And they might have actually five or 10 clickers all rolled together, and rubber banded together, and they might keep track of there's two kicks and there's three bites or bite attempts and there's hit and all this focus on problem behaviors clicking.

I would not recommend clicking problem behaviors because the child can hear it and it is an audible marker. I'd since I've been TAGTEACH certified, I did a recent podcast episode with Teresa McKeon all about TAGTEACH. I'm very careful to now use clickers like this for pro-social good behavior we want like language and great skills walking with me not darting all the positive behaviors, writing your name, participating hand raised. Those are the behaviors I click cause the child can hear that we can after 50 points we can get a reinforcement, do whatever, but I find that clicking problem behaviors is not what I'd recommend. I do recommend more of a partial interval data collection form, which I explained within my online courses. But real briefly I do recommend, and I did a video blog on this, is for parents to keep a calendar, a dedicated paper calendar with everything that's going on medically.

Now we keep a calendar now for Lucas's staff is in pencil. We have two writing instruments in the front here. One is a red pen and that is all medical issues. So, some of the medical issues we keep track of here are allergy shots, because we do notice that when an allergy shot is due or

when he's on antibiotics or when he has a fever, we can correlate that usually with agitation and potentially SIB. Using this calendar system, I brought this calendar just this week. We had a one-year allergy appointment, brought my calendar. I was able to say, oh, when was the last time? How many antibiotics has he had this year? How do you feel like the allergy shots are working? And we use Lucas's behavior, keep track of agitation, SIB, allergy shots, antibiotics, those sorts of things.

Some people in their calendar keep track of supplements, medications, any change. If we up a dose goes into this calendar and we use this calendar to make database decisions going back years. And so, I would highly, highly recommend working with families if you are a professional or if you're a parent getting a dedicated paper calendar and start keeping data.

Now I did, as I mentioned, do a video blog about how to teach kids to indicate that they are in pain. And one of the most important skills for kids, if you have a child or clients that cannot label and touch their body parts on command, like touch your head. What's this called? Label nose, label mouth. Be able to touch shoulders, touch you know, maybe some kids can learn neck and thumb. Maybe some kids can just learn the basics, head, belly, you know, toes, those sorts of things.

But we need to always prioritize body parts. And I am a big fan of Mr. Potato Head. It's one of my favorite tools. So, I'm a total fan of Mr. Potato Head and people say, well, that's not age appropriate for our teenager. If the teenager cannot label and touch body parts, then using Mr. Potato Head and other things to teach body parts is an absolute must as far as I am concerned. You can also use stuffed animals, larger pictures of a boy or a girl, and you can use real Band-Aids, to then teach, you know, booboo on his elbow, or booboo toes, or booboo head. The best time to teach a child to indicate they're in pain is when they have a visible injury. Like they fall down and they skinned their knee. That's when you want to be saying booboo on my knee.

So that is a big tip. And then hopefully that will generalize to more internal pain. The way we keep data on Lucas's effect his speed of response, any mild agitation, we don't wait just for self-injurious behavior to keep data. We keep a lot of data to make sure that he is as happy as possible, as safe, as possible, as independent as possible. And he has some language but not enough language to say the pain is stabbing here and it goes behind my ear. So, we really need to be proactive and help him. So now we have from all the calendars and working with the physicians who've been wonderful, especially Dr. Murray who he's on that podcast number 28. We have been fortunate to get his aggression down from about once a month to once in two and a half years. We've gotten his self-injurious behavior down from say once a week to about once a month. And we have adjusted medication. We are on our seventh year of allergy shots, even though most people would have ended at five years.

So, it's just an ongoing process to keep him medically stable to keep him behaviorally stable. And it all is intertwined. So if you have a child or clients who don't know body parts, who are having self-injurious behavior, who need help, the best way I know how to help you, I mean these podcasts and video blogs are free and that's awesome that you're listening. But the best

way I know how to help you, whether you're a behavior analyst, a speech therapist, teacher, parent, grandparent, is through my online courses and community. And there we are all likeminded parents and professionals on a mission to help our kids reach their fullest potential.

So, you can find out more and get a free workshop at marybarbera.com/workshop. In summary, I hope you now know how complicated medical issues are in children and older children, teens and adults with autism. And I hope now you will consider more so these comorbid conditions that may be interfering. And I hope that you will work with medical professionals and learn more about how you might be able to help parents keep easy data and help them work with their physicians and medical care providers to get their children to the best level possible. Hope you enjoyed this podcast and I hope you tune in next week for another episode of the Turn Autism Around podcast. Have good one.

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