



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 013

Keeping Kids with Autism Safe

Hosted by: Dr. Mary Barbera

You're listening to the Turn Autism Around podcast, episode number 13, and in today's podcast, I'm talking all about how to keep kids with autism safe. And before we get to that I'd like to give a shout out to Spears who gave me a five-star rating and review for this podcast on iTunes, and I'd like to read that. She said, "I recommend Mary's podcast to all of the parents I work with as a BCBA." So thank you to Spears. If you have listened but you haven't subscribed and given me a great rating and review on iTunes, I would love it if you would do that. And maybe I will give you a shout out as well in a future podcast episode.

So let's get to how to keep kids with autism safe.

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 I am excited to be presenting today all about keeping kids with autism safe. Whether you have a child that's under five years of age at any functioning level, even children without autism under the age of five can get into very unsafe situations, but especially kids that are under five with autism tend to be very at risk. And also kids that are older than five whether, especially those kids that have moderate to severe autism, whether they are five or 15 or even 25 years of age, if they have moderate-severe autism for those older kids, teens, and adults, they can still be in very unsafe situations and this tends to be the population that I talk about a lot because my book is... was written in 2007 my online courses, my video blogs and of course this podcast.

We are addressing the needs of young kids no matter what functioning level. Because if we think about the VB-Mapp, which I talk about a lot, but that's the assessment tool that I use most of the time. We talk about the VB-Mapp that is kids with language abilities of a four-year-old or less. So a baby to a four-year-old. So even typically developing four-year-olds or five-year-olds could benefit from all of these lessons. But what happens is kids with moderate-severe autism who grow older sometimes remain with the language abilities and developmental abilities of less than a four-year-old. And so that's why the same techniques

work, whether we have a young child or an older child with more developmental delays. So it's all about safety.

As you probably know, if you've listened to anything I've ever talked or wrote about, I have two sons. One is in college, his name is Spencer, and I have Lucas who is an, they're both in their early twenties now, and Lucas gave me a crash course in safety from the time he was two before his diagnosis. I remember when Lucas was two and a half and Spencer was one. He was, they were both walking, you know, Spencer walked at 11 months of age, so one Spencer started walking, I was pulling my hair out because Lucas would go in one direction and Spencer would go in another direction. And I remember my friend coming over and I was literally chasing them all over the yard and she said, you need a fence. And I said, oh, my husband doesn't want a fence. And she looked at me, she's like, you need a fence, you will lose your mind or lose one of your kids. So we ended up getting a fence, which did save my sanity. And then Lucas was diagnosed as well a few months later. When Lucas was young, when he was two and a half and three, he was very darty, very curious, and would, would get lost.

He would wander away and dart away from us. I remember being at picnics before he was diagnosed and I would go in to go to the bathroom and I'd say to somebody, like my mom or somebody, you know, a good friend, hey, can you watch Lucas while I run into the bathroom? And I would invariably go into the bathroom and come out and Lucas would be away from the person who was supposed to be keeping an eye on him. So keeping an eye on a child with autism and keeping an eye on a typically developing child is two different things. And for many of us, we've seen where kids are getting in unsafe situations pretty quickly. As both a parent and as a professional, I've dealt with some serious safety issues with not only Lucas but with my clients. And I'm going to tell you about some of those safety issues throughout this podcast episode.

Just to organize the podcast a little bit better, we're going to talk about safety in the home, then I'm going to talk about safety at school or in a clinic, and then finally safety within the community. And we're going to talk in the community mostly about drowning, being safe around water, and then also being safe around cars because those are two very serious issues that many of our kids with autism face. So let's talk about the home and safety issues.

So we did have several issues in our home. When Lucas was two until about, he was 10, Lucas would leave the home. We moved when he was about seven years of age. So in our new house, we didn't have a fence anymore. And you know, when kids are five to 10 years of age, if they don't have the language and developmental ability and the cognitive ability of a, of the same age child, then they are big enough to get out of houses to turn, you know, the knobs or, not that Lucas did this, but you could climb up on a chair, move a chair over, unbolt the door.

He didn't do any of that. He would just get lost and wander outside of our house. He also, um, got lost in the community, which I'm going to talk about when we get to the community section. But he did wander away from our house and especially when we didn't have the fence, it was more of a problem. I remember one time we were on vacation and he got out of the

shore house that we were staying at. So one point is if you are in a new environment if you do switch house, you know, move houses or are on vacation, you want to be especially aware that even though you don't have any concerns at the moment, moving or taking vacation may present new safety concerns. But when he was about eight or nine, I remember I was presenting at the National Autism Conference, which is an annual conference at Penn State every year.

And I was presenting up there and I remember my cell phone ringing when Lucas was eight or nine at like six in the morning and it was my husband saying he can't find Lucas. And I'm like, really? I go away to speak at a conference and you lose Lucas. And you know, I was just like, can't imagine he would leave the house at eight or nine years of age. But he did. And then I could overhear my husband going, yes, officer. We checked there and I'm like, oh my God. Like they lost him to the point where police were called. Thank goodness I was on the phone and Lucas was found, he was in a neighbor's yard. I have no idea why he would leave the house, but it got me thinking like, I was probably always sleeping with an ear out for him. And it was very unusual for him to wander outside of the house at that point.

But it happens. And in a 2012 study, half of all children with autism wandered or bolted into unsafe situations. So I know it's not just Lucas and I'm going to tell you about some of my clients, um, to that that also had issues. So things that you can do... One of the things I mentioned was if you are in a strange environment or new environment that you have to even be more cautious, but it, if you're having any issues or you're worried about your child leaving your house or getting in unsafe situations within the home, you, if you can get a house alarm so that a chime can ring if a door's open, that's sometimes helpful. If you don't have that and you just want to put like a bell's, handbells, or you know bells you can wrap around your wrist, you can wrap them around a doorknob, make a bell sound.

When the child opens the door, you can use gates, especially if your child is younger. Outlet covers, doorknob covers so that it takes an adult's hand to open the door. Um, you can put bolts on doors. Another reason you want to use things like gates and outlet covers is you want to be as positive with a child as possible. And if you're constantly like, stop that Johnny, no, get your hand away from the outlet, stop playing with the outlet. You like, it's all these negative, negative, negative, negative. So if you put out like covers on or you put gates up, then you can be more positive and you don't have to do all this correction. It will also help you hopefully keep your child safer. So in addition to alarms and gates and barriers, um, you also want to notify your local police as well as, um, your neighbors.

There are some devices you can look into that can be bracelets or those sorts of things so that you can have like a GPS system. I do know a family or two that's um, gotten that. We never investigated that, but we did have Lucas wear a medical alert bracelet when was younger, and then when he became 16 years of age, for Lucas, he wasn't going to be able to drive ever. Some of my former clients are now driving, but for Lucas who has moderate to severe autism, he's not going to be able to drive. But we did take him to the motor vehicle office and we got him a

non driver's license ID, which I think is really important. We taught him to carry a wallet with that ID, so he always has his wallet on him.

Lucas also likes listening to music through wireless headphones, so we have an old iPhone that he uses as an iPod and we have the find your iPhone app on his iPhone. So not only does he have his wallet, but we also basically have a GPS on him all the time when he's out. Because, uh, we can, we can track the phone, which is always in his pocket, but he's also always out with a one to one person and we don't have any problems with him leaving the home at this point. He isn't leaving or darting, that kind of resolved itself when he was ten-ish. Inside your home, you can also put, I hook, um, locks on doors that are unsafe. There are unsafe things through different doors. You know, some kids get into things in a workroom for instance, or tool room with tools or whatever. You would probably want to have some kind of lock system.

Uh, so the child couldn't access that room. Also, if you have any cleaning supplies, make sure they're in cabinets with locks. And also one of my clients, um, Chino who I show in some of my videos and Chino, um, he was really young, probably three years old, but newly three and not a real big strong three-year-old either. He was a, he was pretty little kid and the mom was trying to get him dressed and she realized that Chino had no clothes in his drawers. So she asked Chino's dad, she's like, wear are the clothes? He, he's like has no clothes. Like literally no clothes in his whole dresser. Then the dad said, I didn't touch his clothes. I don't know where his clothes are. Here, Chino, the little three-year-old had opened his second-floor bedroom window, taken all his clothes and threw them out on the roof, and then closed the window.

So for him, for Chino and for many other clients that I've had, they actually need like window protection, so that there's latches that they can't open the windows. Chino also left the house once and was found by a neighbor. So for different kids, we have to look at different situations and Chino was never known to open a window before. So, you know, sometimes we just have to really be one step ahead of our kids in terms of protecting them. So those are some of the considerations that you could try to improve the home safety.

Now let's move on to a school or a clinic. Many of you know, um, Kelsey was on episode number three. If you want to go back to listen to that marybarbera.com/three, and Kelsey is a single mom living in Canada. She has two boys on the spectrum. And when she found my online course back when Brentley was only two and a half years of age, she at the time was driving Brentley to a clinic an hour away from her home and he was darting out of the clinic running into the street. I think she described in the interview that one time he got away from her just walking 10 feet into the clinic and he was like three blocks away. She was chasing after him.

So leaving a clinic or a school building, I know there's been reportings of kids, Uh, there was a boy in New York that left a school with moderate, he had moderate, severe autism. He left the school during the school day unsupervised and ended up drowning.

Um, we need to be, keep our kids safe, eh, even if they are not with us, if they're at a school or a clinic, again, we can encourage them or talk to them about possibly using barriers, although in

some schools, depending on where you're located, using gates at doors and stuff is not permitted. So a lot of times we just have to really talk to the school and see what is possible. Also, if the school, especially if they can't use a gate at the door, can't close the door for some reason, just positioning the child at the desk or at the table so that the adult is kind of on the outside. So if the child goes to, uh, leave the entire classroom, leave the building, um, we were able to, to block that and to be aware of that. We want to always be positive and we want to pair the room up the table up, the materials, the work, the, the staff up with lots of positive reinforcement because we, in the end, want our kids and our clients to be running to us for instruction.

So if they're constantly running away, darting away, especially if they're having any kind of problem behavior like Brentley was doing, Kelsey described, you know, she was, he was banging his head, he was yelling. That shows us that we need to go back to the drawing board. We need to figure out what is going on with the child, why they are not finding the room and the materials and everything we're doing reinforcing and we need to turn that around. Finally, lots of kids with moderate-severe autism need one to one support in the classrooms and the clinics.

This is not only important to keep them from a loping or leaving the room or the building, but also to protect them against any kind of abuse. I've been reading all kinds of, you know, reports and articles about kids getting abused from other kids, being wandering, being left alone. Um, we need to make sure that our plan or IEP or whatever kind of plan you're using does address any safety concerns. And if you have safety concerns, like the child goes to recess, he doesn't have a one to one. There is no fence. It's near a highway. He's been known to run, you know, those sorts of things. Then that not only you need to bring that up verbally, but you also need to put that in writing so that we can get the needed protection in place so that the child does not get injured. I've even had IEPs where we write down that the one-to-one needs to be within arms distance or the child needs to go to the kindergarten playground area because that is fenced in. Whatever the child needs to keep them safe is what they should get.

So now that we covered some considerations for the home and the school, let's talk about keeping kids safe in the community, which is very tricky. So one of my clients, uh, we'll call him Andrew, but he was with his family. He was an only child at the time. He was about six years of age. They were visiting New York, the Statue of Liberty. They were getting ready to go on the ferry over to the Statue of Liberty. Mom and dad and Andrew were going through security. Dad had to take his belt off. They got, you know, a little jumbled by that whole thing. And they looked down and Andrew was gone and they didn't know if Andrew went on the ferry, went out to the street... you can imagine the panic and this child has moderate to severe autism. He's an intermediate learner through and through. And um, luckily within five minutes they located Andrew outside on the sidewalk, not in the street. And they were able to, um, you know, get him back and take him to see the Statue of Liberty. But you can imagine the panic and, you know, just losing your child for five minutes.

Again, back to Brentley with his mom, Kelsey, when he was only two and a half and he was darting and streets and banging his head up to a hundred times a day, to keep him safe she would actually have to have a harness and a leash on him, um, which, you know, a lot of people would really give her a hard time about. But you know, if that's what it takes at least until you can teach the child to want to be with you and learn about reinforcement, we need to keep our kids safe. Lucas got lost a fair amount at malls, at our home mall with my husband. He also got lost in malls that we weren't familiar with, um, once or twice. And so getting away from you within the community is always something we have to worry about.

And as I said earlier, I'm going to talk about two big things that big community dangers that almost always, uh, are a problem when a child or even an adult with moderate-severe autism wanders away. And that is water and streets, but mostly water. I do have a former client and he was two and three when I worked with him. And then when he was six, he wandered away from his home and he drowned in the neighbor's pool. And you know, this was a summer, sunny day in the middle of the day. He just took off and they found him, and it was horrible as you can imagine. And so that is just a real indicator that teaching safety and teaching children to want to be with you and reinforce, hey, this is life or death kind of strategies.

We, we, you know, can never 100% prevent all of the tragedy from happening. But it was a real wake up call for me even though I hadn't worked with that client for a few years, I was in touch with his mom, and his mom has been great. She's been trying to get the word out that accidents happen like this and to be present with your kids and his mom also since he drowned in a pool, she also has advice to get kids with autism swim lessons and to start as early as possible even when, when kids are babies if possible and not to rely on floaties because if we just rely on floaties, that child, you know, has been used to floaties and used to just being able to jump in and float. And when he wandered and jumped in, he didn't float and ended up drowning.

So there was a 2017 study that I read that showed that kids with autism are 160 times more likely to die from drowning than typically developing kids, and so it's just a huge, huge concern. If you own a pool, you want to make sure you have good security on the pool, that the gates lock, you want to, if you have neighbors with pools, you want to make sure that they know that they really need to be careful with their gates being locked at all times. We also need to be aware that kids can even drown in hot tubs and bathtubs and those sorts of water accidents too. And sometimes that's related to kids with autism having seizures. So we're going to have to watch our kids a lot more around water even if they do know how to swim.

We also need to be aware that teaching street safety and traffic rules isn't always possible with kids with moderate-severe autism who are functioning within level two or three of the VB-Mapp.

You know, I had a question come in from a member a while back and she said, well how does she teach, you know, a 10-year-old to cross the street or 12 years old with severe autism across the street? And I said, well where... what's his functioning level? You know in terms of the VB-

Mapp. And she said, well he's a level two VB-Mapp learner. And it's like, level two VB-Mapp learner is map 18 months to 30 months old cognitive language ability. You cannot teach a child of that age, anybody within the VB-Mapp level, learner, level, to cross a street. It's just not physically possible.

One of the reasons we can't leave Lucas at home is because we can't teach him the decision making involved with emergencies, such as when and how to call nine one one, what strangers are, we can't teach him elaborate traffic rules. We can't teach him to cross the street, it's just not possible. So we need to provide supervision when he's out in the community. We need to provide some level of supervision when he's at home and we need to be especially careful if we go into a new environment like on vacation or those sorts of things.

So in summary, I think it's, we've illustrated that it is, it is just crucial that we focus on safety for kids with autism. We focused on safety at home, at school, and in the community and that we need to assess the situation and really teach kids language skills to help them get more and more aware of their environment until we can totally make sure they're safe. We might have to use physical barriers like gates and bolts and maybe even harness' and leashes, but as a temporary measure until we can really make sure they're safe.

We can also use things like house alarms and bells and make sure our neighbors and police departments are aware of our unique situations. We will probably need to advocate for one to one support and supervision at school and clinics, maybe just for parts of the day when it, uh, presents when unsafe situations like recess present themselves. But for some kids, it might involve a lot more supervision than they're currently getting.

This is an ongoing process and keeping kids and adults safe is not just like a once and done thing. We're going to have to continually assess the situation and provide things to help kids reach their fullest potential and to be as safe as possible.

So hopefully you've learned some things through this podcast episode about keeping your kids safe. If you liked what you heard, if you have more ideas, I would love it if you would leave me a rating and review, share this episode with others who can benefit and if you would like the show notes with the additional resources I mentioned, go to marybarbera.com/13 and I hope that you tune in next week for another episode of this podcast. Have a great week.

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