



**TURN AUTISM AROUND**  
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 003

*Lessons about Turning Autism Around:  
An Interview with Mom of 2 Young Boys with Autism*

Hosted by: Dr. Mary Barbera  
Special Guest: Kelsey General

Mary: You're listening to The Turn Autism Around podcast, episode number three, and on today's podcast I am doing a special interview with single mom of two, Kelsey from Canada. And Kelsey has taken all three of my online courses and is now our online community manager and the reason I wanted to have Kelsey on is because she has some great experience and advice all about her journey, getting both of her sons diagnosed with autism and getting early treatment started. She's a great example of how anyone, any parent can begin turning things around and Kelsey is also a professional in the field now, so I think you're really going to love this interview.

Intro: Welcome to the turn autism around podcasts for both parents and professionals in the autism world who want to turn things around for their children or clients, be less stressed and lead happier lives. And now your host, autism mom behavior analyst and best-selling author Dr. Mary Barbera.

Mary: Welcome to the show. Kelsey. I'm so excited to have you on the show.

Kelsey: Hi, Mary. Happy to be here.

Mary: Good. So, let's start with when you started feeling concerned about your oldest son Brentley's development.

Kelsey: Yeah, so I started being concerned pretty early about Brentley's development. He was probably about six months old and I remember going to the pediatrician and saying, I'm pretty certain he's deaf. I walk into a room, I say hi to him. I talked to him, he doesn't respond to any sound. And the doctor also noticed this at the, at that appointment. And

we began hearing tests and all of the hearing tests were normal. And so, you know, we kind of forgot about that. He continued to develop. He gained gross motor skills pretty young. He started walking at 10 months and then he started signing things like dog and saying dog at 10 months. And so, I kind of stopped worrying. Until he was around a year old, I think he was. And he was hospitalized shortly after his first birthday when he stopped walking and had a spell where he was totally lethargic for about a week. And after that kind of everything changed.

Mary: So, he was about a year, a year old when you started noticing?

Kelsey: Yeah. Yeah. Well, he was 13 months, 13 months when he was hospitalized and then after that the regressions started.

Mary: And did you have any background in development or you know, did you have any education on what milestones to look for or that you know, you even had to keep track of that?

Kelsey: No, we didn't. I didn't have any education in child development or anything like that. However, I had friends who were in the early child development field in Alaska. They start pretty early at well baby checkups, doing developmental screenings and I just looked online and found out the developmental milestones and just always kept track of that.

Mary: Did you, do you know what they did? What did they do? Like an M Chat with those 20 questions?

Kelsey: Yeah. So, I'm the one who originally did The M Chat, but earlier on when he was younger, they did ASP at every appointment. So.

Mary: So those are, those are really... Yeah, getting, looking at development. So, I guess back in, you know, two decades ago when I had my boys there really was, was very little standardized developmental testing at the well visit. So, it sounds like that's been an improvement over time that, that they are screening kids a little bit earlier and a little bit more standardized using things like the ASP. I'm not sure what that stands for. And then you know The M Chat that I talked about in episode number two, which is the modified checklist for autism in toddlers, which you can print out. So, you started to see another bigger regression when he, after he was hospitalized. And how were you feeling at that time?

Kelsey: Well, when the regression started, I was pregnant with Lincoln and I was in a pretty high stress situation and the regressions weren't overnight so it was a slow progression. So, during that time I was mostly feeling confused. Like what, did he have that skill yesterday? Like was he just saying dog now he's not saying dog anymore. But then maybe the next

week he would say dog and then it would go. It was a really slow regression and so yeah, I was feeling pretty confused and then I'd see things and I'd start to worry and some days I'd be really worried and other days I'd be like, oh, I'm just crazy. So, there was a lot of self-doubt during that time.

Mary: Yeah, it's funny because you know, I was pregnant with Spencer when Lucas started to have some regressive symptoms and I completely missed it. I wasn't even confused or concerned. I was just oblivious because I was pregnant and his... Lucas' regression was pretty slow too. So, what were the symptoms when you said his regression with slow but, but what? So, he was losing some words you said or not saying them as frequently. Anything else that was concerning?

Kelsey: Yeah, well, like I said at the beginning I didn't really notice and he was still gaining those impressive physical skills enough so that he was still passing these questionnaires at the doctor's offices because he just seemed like he was visibly looked like he was pretty advanced. The first thing I noticed during the regressions was in pictures actually. He used to always look at the camera and smile and respond to his name when I call for him when I was, you know, taking pictures like moms do.

And then I started to notice in pictures that he was withdrawn. He never smiled in pictures. He was always looking off and that kind of... So, his engagement went down a lot. His response to his environment went down, the tantrum started where he would flop on the ground and hit his head. And things that he used to enjoy doing slowly started to become really difficult for him. We did a lot in the community with large groups of people hiking and baby groups and he began to scream like constantly at all those events.

Mary: Did you think at that point, like this is like the early terrible twos or you know, were you like, thinking like he's just irritable? Were you thinking that he had autism at that point? Or were you thinking that it was something else?

Kelsey: Well, I wasn't. I definitely wasn't thinking autism at that point. Exactly at that point I was kind of thinking, yeah, he was just difficult and everyone around me to was like, oh, he's just going through a phase, you know, just don't worry about it. But I remember those pictures and I remember probably almost weekly like sending them to one of my friends and being like, it's different though, look at this and look at this it's different, like something has changed and I didn't really know what at that point. And then when he was around 18 months, that's when I started to get more concerned and my friend who is a BCBA pointed me in the direction of The M Chat and said, this is a screening tool that you can use.

Mary: Okay. So, you just so happen to have a friend who was a behavior analyst and she gave you some direction to go in. Look at The M Chat.

Kelsey: Yeah. Yeah. She was she's one of my closest friends and I didn't really know what she did until I got more involved in autism and what was happening. But I knew she worked in early childhood education for a long time. And knew about development and I was watching her son and I'd ask her a lot of questions and she answered a lot of them for me and was really helpful in getting me and helping me advocate to get Brentley into a developmental pediatrician.

Mary: So just to catch anybody up that hasn't listened to. Episode number two, where I do talk about The M Chat. It's a list of 20 questions, yes or no is the response. The parent can fill it out. You can download it for free and we'll link that in the show notes. And it's questions like, does your child point with his index finger, does he like to be bounced on your knee? Does he show you things? Bring you things to show you things? So how poorly did Brentley do on that M Chat? Do you remember?

Kelsey: Yeah, he scored a 14, which is high risk, high risk. And so, he basically failed everything and so. And he was already in early intervention speech therapy at that point, but they had not told me that I should seek an autism evaluation. So, I gave that to them and then I went to the pediatrician to and gave that to them as well, saying that I needed him to get a referral to be assessed for autism.

Mary: And had you not known your behavior analyst friend or not realize that you should do the chat and The M Chat. Was anybody else concerned or was it all just, you know, being pushy?

Kelsey: It was me pushing it and thankfully I did know my behavior analyst friend because she told me about a developmental pediatrician because when I took The M Chat to the doctor's office, they had a behavior specialist on staff who came in and you know, watched Brentley. And again, he looked advanced. He looked like a happy little boy. She said, oh well the doctor won't accept referrals until he's two and a half. And she was talking about a different doctor.

And I said, well, my friend who's a behavior analyst, told me that this developmental pediatrician takes children very young and she didn't want to send the referral in. And basically, I had to call the developmental pediatricians office directly and get them to okay the referral. So again, if I didn't know my friend, I mean I would have just been like, okay, I guess we sit and wait until he's two and a half and that would have been awful.

Mary: Did your friend tell you to read any books or did she tell you that about aba and that kids could recover. Did she give you any information about what could be done about autism if he was diagnosed?

Kelsey: Mostly she told me that it was important to seek a diagnosis early because the earlier the intervention, the earlier he can get insurance approval for the 40 hours of aba that insurance recommended that that was the best option. I believe in those early days I used to, she didn't give me any books but I used to scope out her library and I think one of the ones I brought home with The Early Start Denver Model and I read it and tried, you know, I didn't know anything at that point. Tried to do some of the things that I read in it. And at that point, yeah, not much of anything in that worked. He was just so withdrawn and I had no instructional control at that point. And so.

Mary: So, did developmental pediatrician...

Kelsey: It almost made it worse. I was like, wow.

Mary: Yeah. So, when you called the developmental pediatrician, you weren't whisked in for an evaluation, you had to wait, right?

Kelsey: Yeah. They basically just told me that yes, they would accept referrals at the age that he was. And so, I had to go back to my pediatrician and get them to write the referral and saying I talked to the doctor and he said he would take the referral. But yeah, it took until he was 25 months and this was when he was 18 months that we got the referral.

Mary: Okay so just under a year. So, and during that year you were doing what?

Kelsey: Well, during, during that time I was dealing with, I wasn't doing that much with him. I mean, I was staying home trying to live a normal life, trying to read these books and do as much as I could, but I really didn't know I was in a high stress situation at home. Things were getting worse and worse there and so while we were waiting for the evaluation, I actually left my ex and became a single mom and moved in with my behavior analyst friend for a fee and yeah, and started kind of planning the next stages, but I knew I wasn't going to leave Alaska until he had his evaluation. So, all the court dates happened. I got full custody of my kids and planned to leave the country. But we waited until diagnosis day and then we basically left the next day after he was diagnosed and moved back to Canada.

Mary: Okay. Because you're a Canadian citizen? So, you were your life was basically on hold waiting for that diagnosis day?

Kelsey: Yes. And I wasn't doing much at that time because at that time, I mean, you know, my behavior analyst friend ethically couldn't support, you

know, any therapy with friendly other than giving me some resources and I was just under the impression that I just needed to wait to get that diagnosis so that he could get 40 hours of aba. I just thought that was when my hands were washed clean of anything. I know, which is funny now, but I thought, oh that's the end. Once I have the diagnosis, it's done, it's fine. That's all I need to do. That was my, you know, most people say that they're upset on diagnosis day. I was relieved. I was like, okay, now we have this diagnosis, we can go get aba, we can go back to Canada. Court's done. You know, I was thinking it was good.

Mary: Okay. So, you moved back to Canada and then aba miraculously started, right.

Kelsey: I wish, that would be nice. No, in Canada. The system's very different. Every province is different. But in British Columbia, children who are under six get \$22,000 a year for the parents to basically do whatever they want with under some guidelines, but you can't access that funding until you're a British Columbia resident for three months. So, during that time I still, you know, we were adjusting to new life here. He did regress again.

He basically started just screaming as his form of communication. And he stopped eating a lot of foods. He was already pretty restrictive in his eating, but it got worse when we moved to Canada. There were lots of different brands, you know, I couldn't get Jimmy Dean sausage, which at that point was what he really enjoys.

You can't get that in Canada. So, we just waited. I had to pay for a private, a psychologist to confirm his diagnosis so that we would qualify for funding. But once all that wait was over, we signed our funding agreement. We got the 22,000 and...

Mary: Then ABA miraculously started right?

Kelsey: Well, I guess it kind of did. Yes, I, but it was not 40 hours, so \$22,000 does not go very far if anyone's wondering. It qualified him for about six hours, six to eight hours a week of therapy. Yeah, and there were no behavior analysts in my area. There were a couple programs saying they were autism programs and you know, that they were helping these children. But I knew from my history that I needed a board-certified behavior analyst that was really important to me. And so, I found one about an hour away. We met, I interviewed her the best at that time I knew how seemed okay. And then I started driving him an hour, an hour each way, three or four times a week to this it was a room in a community center and it was a type of preschool program where each child had a one to one.

Mary: Okay. So how old was he at this time?

Kelsey: Just under two and a half.

Mary: And then you also had Lincoln, your baby was, they were 18 months apart.

Kelsey: They're 18 months apart. So, he was, I mean, he wasn't even one yet, he was just about one.

Mary: Okay. So, when you started driving him to the clinic at two and a half after you've been concerned, I mean you were concerned at six months then you were really concerned after a year. Now it's your two and a half. He's two and a half. You're driving an hour each way? Not for 40 hours of treatment for eight hours of treatment; at best a week plus the hour each way commute. And your baby. And can you describe Brantley's behaviors at that point?

Kelsey: Yeah. At this point things had gotten, had gotten pretty bad. He essentially had a lot of tantrums and anytime he heard no. Anytime a routine was different. Anytime he didn't get his way or you know, we had to clean something up, he would flop to the ground, throw himself back and slam his head on hard surfaces and he hit it hard. I mean.

Mary: How many times a day?

Kelsey: I mean up to 100 times a day. Sometimes more. I mean, it would depend on the day and the kind of stressors that were happening for him. He still wasn't communicating very much.

Mary: So, he had some words?

Kelsey: He had some labels, he had some labels, he was using anything to communicate.

Mary: Did you know how to teach him language at that point? Teach him new words?

Kelsey: No. I was trying to find ways? But no.

Mary: And how was... because you were a single mom at this point... You had your baby, you had him, you know, and you like to go hiking and go out in the community. So, can you describe what that was like right when you started ABA treatment?

Kelsey: Yeah. So that was a scary. It was hard to take both out. Brentley would need to have a backpack on with a leash because he wouldn't hold my hand. He would often bolt away once, when we got to therapy, actually he decided he didn't want to go and I didn't have him on the harness because it was like a 10-foot walk into the building and he ran three streets over. He was gone and I, and I could see him a lot of the time, but

he was, you know, I didn't really expect that to happen and outdoor activities I would normally either wear him in the pack on my back and Lincoln on my front or I would have him in the harness. But even that sometimes didn't work. I mean he would flop to the ground like we would call it the wet noodle and we couldn't even walk into a store from the parking lot. Luckily in Alaska they gave me a handicap sticker so that we could be closer to the doors because Brentley is not a small guy. He never has been. And so, trying to manage dead weight of an over 40-pound kid at this point was, was very difficult.

Mary: Okay. So, the aba clinic that you were driving to that did have a board-certified behavior analyst there, was, were you seeing, a lot of nice gains with that or what, how was that working?

Kelsey: No, there was not very many gains with that. So, his first assessment, they did there, they did the Ables Assessment, which is a type of verbal behavior assessment. He had about one box filled, maybe not even that. I mean he didn't respond to people he didn't respond to anything. And then they began teaching him colors and we're trying to teach them through play and building and having him engage with different toys, which actually Brentley has always been very good at. He's good at engaging with objects in his own way. So, it was really just allowing him. It was really almost just like babysitting. And you know, trying to teach them skills that were pretty beyond him. I mean, I'm not sure why you would teach a child who can't even request what he wants colors.

Mary: Right. So, and he was still having the major problem behaviors. They weren't even coming to your home a little bit, but he was still, they weren't really helping you to solve this immediate safety issue of you even going to the grocery store without major safety issues.

Kelsey: No, no. They, you know, and the behavior analysts came once and watched me at the store with him and you know, but really, again, no strategies that were, that were helping or that we're working. It was just difficult to watch and it was frustrating to watch because they didn't really want me that involved either and it was like, well I'm the one who was with him all the time, I need to know what's happening.

Mary: And so, they just wanted you to drop him at the clinic and go and busy yourself for a few hours while they taught him and then to come back. And so that, which is common in schools and in clinics, you know, they can't have the parents sitting there the whole time because well you also had a baby with you and that would be very disruptive. But there is that fine line between like how much parent involvement is needed, especially when you're having all these safety concerns.



Mary: So, about that time, you found my online course and you began to take it and you, so how, how did you feel once you found my course and started watching that?

Kelsey: There was mixed feelings. There was happiness that I found it because I was learning a lot and it was all click and was like, oh, okay, now I know I can do this. But then there was intense anger and intense frustration, which, and not at you obviously or at the courses. But just that like...

Mary: Who were you mad at?

Kelsey: I was mad at the programs in my community for not providing, you know, this kind of information to parents. I was mad at the program he was in that even though they were verbal behavior, that they weren't teaching him like this because it seems so simple. And then I got frustrated when I tried to show them your videos when I tried to educate them and try and get them involved in what I was learning. And they kind of shut down at that point.

Mary: And they pretty much asked you to leave, asked you like, we're not going to do it Mary's way or the way you think will work. So, you know you can go elsewhere and find therapy. Is that what they basically said?

Kelsey: Yeah. Basically, I wanted, I started asking. I was like, okay, I can leave Lincoln here. I want to come. I want to see what's happening. They got mad once that I took notes and it wasn't. It was like notes of things to ask the behavior analysts like why are they doing this? Like can we do it this way and why are they working on this goal? And then everyone got upset that I took notes. They started saying I couldn't attend the center anymore. They didn't want me there and that if Brentley was to continue on, I couldn't come or be involved and he had to wear a helmet because he was a liability.

Mary: And so, at that point you just decided to withdraw him from that clinic?

Kelsey: Yes. They weren't doing what was working for us at home. They wouldn't listen to, you know, what I knew as a mother, what's helping him.

Mary: Because you started, you started to do your own aba therapy just using my courses and, and what. How is that working? Was that working?

Kelsey: Yeah. I mean it was hard at the beginning. I'm not sure if you remember some of my early posts in your Facebook group. It was hard to get him to sit at the table. It was hard to get him to do anything but run away from me. It was, it was hard, but as I learned more and learned more about, you know, instructional control and how to get him to want to be with me and work with me. That's, that's the real turning point. That's the real turning point for Brentley that, that moment, once we figured out how to

work together. And so, once I started doing that and I started realizing, oh, we can teach this kid once we just, you know, get him to want to learn. And I, that's when I started to try and tell that to the, to the program. And, and say that I didn't want to use, you know, traditional escape extinction and all that kind of stuff that they were using. Yeah. They weren't that open to it

Mary: And it only really took you maybe two months to realize that there was a better way. Right. I mean you've been with our courses for you, you know, two years now over two years, but it only took you about 60 days to realize like, wow, I can. And even though you had funding to pay for that. And when you pulled him out, it was just you. So, you weren't even using any of that funding, right?

Kelsey: No, I wasn't using any of that funding. I was using about twice a month I had a speech therapist come in and work with me on some play goals with him. But not like language building, just some play goals. And that was about all I was spending my funding on. Yeah.

Mary: So after about 60 days you saw what kinds of changes you were. He was sitting now?

Kelsey: The biggest change for me is he wanted to be around me. I could not only teach them at the table, I could also play with him more, like he wasn't just running away from me. That was big in our relationship I think because before that I was like, well, this kid wants nothing to do with me or anything about me or the environment. So that was a big change.

And also, a big change was his receptive language, which is his understanding of language. He didn't really understand anything I said before or didn't show that he did. He may have, he couldn't, like, you would tell them to touch an apple when there was only an apple in front of him and he wouldn't touch it. He would look at you like, I'm not sure what you're trying to say to me.

And so, he started following simple directions, which as you with two young toddlers was really helpful. He started to get better outside, not flopping as much. I don't know, when I say he got better, I got better at knowing what to do. And so, we didn't deal with a lot of those problem behaviors as badly, but some of them were still happening, and some of them were challenging to get rid of, but they definitely decreased. And his language, you know, was increasing pretty rapidly. He was starting to request things he wanted and needed, which he had never done before or hadn't done in a long time.

Mary: Right. And was it overwhelming for you to learn online?

Kelsey: Actually no, I really enjoyed watching videos and learning. I liked watching examples. I think I'd read so many books and I even read your book and it was like, I still don't know what that looks like in real life. I still don't know what that looks like for me, you know, I would try bits and pieces from all these books and it was like, just so frustrating because it was worse. I mean it was like, okay, well this book says this works. It certainly does not work. And so obviously he's, you know, he's never going to learn. And it would just send me into different panics and I didn't find that about watching the videos online because I could just rewatch over and over videos of you sitting at a table teaching and just emulate what you were doing. And so that was helpful for me.

Mary: So. So, you basically had to become an expert, you know, at least for your own kids you were, you're kind of forced to learn. I mean you said you were angry, you were angry at, you know, the people who made your wait, the clinic that wasn't working on the right things. And I'm, we're not, you know, I'm not trying to throw people under the bus and you know, but there are prerequisites to teaching a child colors and there are things you can do besides putting a helmet on a two and a half year old, you know, because if we're going to use a helmet at one a two and a half year old, then what's he going to be like at age eight or age 16?

And we really have to do the, do the type of aba and collaborate really well with parents in order to have each child reach their fullest potential. And so, I'm always on that soap box. But what do you say to parents who are either in denial on wait lists or just want to leave treatment to the professionals?

Kelsey: Yeah. So, I don't believe in leaving treatment to the professionals ever. Even if I'm the professional, don't leave it to me. I, you know, I believe in, you know, as a parent, we're the only ones who are there. We're the only ones there all the time, you know, your provider could leave, who knows, government funding could change, insurance, could leave, and what are you going to do? I mean, if you're, you know, if you don't have professionals and you don't know what to do in high stress situations or you don't know how to teach your child, I mean, that's a hopeless place to be. And I'm not interested in living in a hopeless, hopeless place that's not, that's not where my best me lies.

Kelsey: But, you know, I understand some families can think, well I shouldn't, I just want to be mom or I just want to be dad or I just want to be grandma or whatever you want to just be, you can be. I mean me and my children have great relationships. Me and Brentley especially, and I think that's because we just have a really good working relationship both in therapeutic settings and outside. He trusts me and I think without building the kind of teaching instructional control we did, we wouldn't

have that kind of trust and we have a ton of fun teaching and learning doesn't have to be, you know, upsetting for the child. It shouldn't be, it should be just part of your day and it's part of typical parents' days. So why shouldn't it be part of ours?

Mary: And you've learned to be your kid's best teacher and advocate for life. So, okay, let's move on really quickly to your younger son, Lincoln, at some point started to show some signs of autism or some signs that were concerning to you. So, can you talk quickly about when he started to show signs that were concerning and what those signs were?

Kelsey: Yeah. Lincoln was a very late walker, so that was definitely on my radar pretty early. He didn't say a lot of words. He said a lot of sounds and he but he didn't say words until close to 18 months. So that was concerning. And he was very on edge a lot. He and he was very obsessive about balls, about certain things. He would get very obsessive and to the point of hysterics. So that was between 12 and 18 months and then closer to two he started tantruming about 80 percent of his day. Six or seven hours. I mean, it was insane.

Mary: So, it sounds like his signs were a little different than Brantley's.

Kelsey: Yeah, way different. I would say Lincoln is more high functioning autism if we want to put. He's, he's very, very rigid. He gets very upset very quickly, but he has a ton of language, but for a long time he also didn't use it to speak to people. He would tell you what he wanted, but he would yell it at the fridge or at the wall or at his toys. And no one really knew who he was talking to. He didn't understand to come to adults, which was another big red flag.

Mary: So, when did you put him on a wait list then?

Kelsey: I put him on the wait list when he was 13 months old. Mostly because he's a sibling, which is a risk factor actually. It was a year wait.

Mary: You knew it would be a year wait. So, you, you wanted to get in the queue as soon as possible. And siblings, you're right. There was a study a few years ago. It showed that if you have one child with autism, the chances of a sibling having autism are 19 percent. So that's really high. So, you, you were concerned enough to put them on a wait list knowing that in that year. But that year was different for you because you already knew how to teach Lincoln, right?

Kelsey: Yeah. Yeah. I already knew how to teach Lincoln the levels of tantrums that Lincoln was experiencing were just way out of my scope, that's for sure. It was insane. But I knew how to teach them language. And so, I did

do that to the point where I was actually concerned that I taught them too much.

Mary: He surpassed, he surpassed Brentley with his language, right. Even before he was diagnosed?

Kelsey: Oh yeah. He's, he's actually, he actually scores as advanced in language. He's three years old and he scores are much higher than that in language testing. Wow.

Mary: So, you, before this point, when you were concerned about Lincoln, you had taken my early learner course and then my intermediate learner course and then two years ago I started my toddler course for parents and you right away were very interested in helping me. You volunteered to be a community manager and sent me some videos of Lincoln and did the steps with the other parents in the group. And you would say like, I mean I could see it on the videos that you sent me, like the step by step guidance was really helping Lincoln even broken down to a very basic level.

Kelsey: Yeah, I mean the games with Lincoln were quick and it was much easier knowing what to do with him.

Mary: And so, you waited how long to get Lincoln diagnosed? Was it a year like you expected?

Kelsey: It was a year. Yeah. And at that point his tantrums were pretty out of control and yeah, he got diagnosed when he was 25 months old, the same age as Brentley was.

Mary: Were you given a, of like moderate, severe, mild, high functioning, low functioning, did they put any kind of Brentley or for Lincoln? Did they give you any kind of gauge as to where they were on the spectrum?

Kelsey: For Brentley they definitely gave him a diagnosis of severe classic autism. He failed everything pretty, pretty seriously. Lincoln, they did not give me a level. They actually could not get full assessments and a lot of areas because he spent close to two hours flicking and door handle and screaming and kicking the door. But the things they saw in that moment, the fact that he never came to me for comfort or even look to anyone else in the room for like, you see what I'm doing here, which is what a typical toddler looking for attention or looking for something might do. He was just doing it. No one really knew why. And so, they didn't get a whole lot of assessment out of him.

Mary: Okay. So, you got some start with my courses and you're still heavily involved, but you did all along. You were trying to get professionals involved and that goal of, you know, maybe not 40 hours because the

\$22,000 a year wouldn't cover it, but now. But at some point, you did find some, some more help, right?

Kelsey: Yes. Yeah. I was lucky that I found a behavior analyst in your courses. Not Locally, but she was able to get on the approved list of providers so that we could use her on our team. Because Brentley's behavior was pretty severe and Lincoln's behavior got pretty severe and it was, although I could teach them language, they both definitely needed some individualized support and so I was very lucky to have connected with her and to learn that there was a whole network of behavior analysts doing distance consultation, which I didn't even know was a thing.

Mary: Right. So, she could help you just on the computer through Skype or Zoom or something like that. And she could actually watch videos and give you individualized support. And that's where like the online course, you know, I created it. I know my three online courses are really helping people turn autism around. But legally and ethically and even time wise, even if it was legal and ethical, I can't give you specific advice about Brantley's head banging. I didn't even know he had head banging the first 60 days of your course because like, even for me to advertise my courses, it's not for kids that are banging their head 100 times a day, you know, that's really severe.

You do need somebody and everyone would benefit from having a behavior analyst on whatever your child's case. Certainly, the online courses aren't, aren't enough to provide that kind of intervention. So what kind of, how much and what kind of aba therapy are both your boys getting currently and how much of it are you doing?

Kelsey: I'm still doing 98 percent of it, no. So right now, they are both. Lincoln is actually a daycare with no one to one support. He only has consultations with one of our behavior analysts. She writes him behavior plans and supports me in supporting him mostly with extra practice at home so that he can take that to different environments. Brentley, he goes to daycare with a full time, one to one support who is trained by our other behavior analysts who is local and he has been great and he goes in and he trained her on how to teach Brentley throughout the day and to support him and daily living skills at the, at the daycare and interacting with peers. And then once he comes home, I'm supervised by my behavior analysts that I met through your courses and she takes care of all his language goals. So basically, I have behavior analysts and then I do all the implementation for him. He does not have a therapist outside of me.

Mary: And so that whole 40 hours a week or 25 hours a week of individualized one on one time. You basically replaced that with providing your boys

with good aba during most of their waking hours. But it's not as intensive as you know, is recommended.

Kelsey: No. And you know, sometimes I do talk to one of my behavior analysts and I say, you know, maybe he's not gaining skills quick enough. Maybe we do need to rethink this maybe, but at the end of the day, the skills we've taught Brentley and continue to teach Brentley are changing his life. You know, the me being able to help them in the community, me being able to go hiking with him with no leash and harness, you know, a lot of the things we've taught them are just things to make his life and my life easier and you know, there's no reason to sit and teach rote skills. Which I think is probably where a lot of programs would have gone with Brentley. So, it's been really invaluable to me to have a team of strong behavior analysts supporting me because that's how my kids are making the most game.

Mary: And are you feeling what's your stress level and your happiness level like compared to what it was two ago when you were, you know, had a friendly at the clinic?

Kelsey: Yeah. It's definitely, I can't imagine where my, let's just say I'm still stressed. Every parent with a child with autism is stressed to some extent. I mean the roller coaster is stressful. I mean, watching your child, doing great one week and watching them maybe not do as great the next week is, is challenging. I'm not going to say it's not stressful. But the fact that I know what to do if a headbanging episode happens, the fact that I know how to... If we go to the community, I know how to prepare situations to stop things. I know how to deal if something happened. I can't imagine my stress levels if I had no idea. I don't even know how parents survive. I don't know how they survive day in and day out, not knowing at least some of what to do. And so, and the nice thing is when you're feeling stressed or you know, frustrated with something is I can say, okay, well I know how to teach them. Let's just teach it to them. And that's really helpful.

Mary: You've also made the transition to becoming a professional in the field. You know, I know we don't want to take up too much of your time, but can you just briefly talk about like why you went to work and what you do and those sorts of things?

Kelsey: Well, as a single mom it was never an option to stay home forever, although I love that time with my boys, so I had to go back to work and the company I now work for brought in a really strong behavior analyst who has, who does verbal behavior and I actually learned about in your courses. And so, I decided that it was a good time to go back to work and I work as a behavior interventionist with children with autism and

different disabilities supporting those behavior plans. Luckily the company I work for believes in heavily in parent training and actually train parents to be their best teacher. So, it was a company I felt very aligned with and I wanted to help more kids than just mine. I wanted to show parents that there was a better way, that the way that all the children in this community were being taught previously wasn't necessarily the best way and we could really make a difference and I want it to be a part of that.

Mary: That's great. And you do have plans and hopes and dreams to become a behavior analyst one day, which I wholeheartedly support. So what advice do you have for parents of young kids on the spectrum? Just a couple of pieces of advice. Like if you were in that state back in Alaska, what are a few things that you would tell yourself back then?

Kelsey: Don't wait. Don't wait because it doesn't matter what you wait for. No one's going to do it for you. The earlier you can learn what to do to help your child, to make your day easier, to teach language, do it early. My second piece of advice is never it's hard to say never trust the providers but never trust them so much that, that you just handed off to them. I hate to say there is no handing it off.

Mary: You need to become the captain of the ship and stay the captain of the ship.

Kelsey: Yes. You need to become the captain of the ship. So that's and really enjoy your chill time. If you need to take some time for that grief then take it. But the end of the day, our kids are kids. They're really awesome kids and you know, learning what you can to help them gives you hope and it gives you hope that it's okay, you know, he has challenges and that sucks, but I know what to do and I can help my child and I can teach my child and that hope carries me through every day. And I think if I had that hope sooner, there would've been a lot of better days of me enjoying my child earlier in his life.

Mary: So, you were having a lot of hope and it's, it's hard to imagine, you know, five years or 10 years from now. And do you even ever go to that place where you're trying to envision what Brantley and Lincoln are going to be like?

Kelsey: I actually don't, I live my life and their life one day at a time, one moment at a time. You know, I actually don't even really make goals for the year. I mean, I tend to make. This is what's happening in our life right now. This is what needs to happen to make them happier and me happier. How are we going to get there? That's where I live in my life because I don't know what's going to happen, you know? Nobody knows.



Mary: Nobody knows outside of the autism world how their kids are going to end up. And that is a big lesson I think we autism moms learn early on is you know, hope but not expect, you know, you can be very hopeful and your goals and everything may change over time. But I think you've, you've shown, you've shown me, you've shown everyone that you can, you can single handedly begin to turn autism around and we don't know if that's turning autism completely around for either of your boys, but it's turning autism around so that you and your boys can lead happier, less stressful lives.

And so, I think this was just a great interview. I'm really happy that we're able to spread the word that moms and dads and professionals can, should really work together and that we can really make a difference. So, thank you so much for your time.

Kelsey: Thanks for having me on Mary. I really enjoyed it.

Mary: I don't know about you, but I loved hearing about Kelsey's journey and getting her insights for other parents and professionals. For the show notes, you can go to [MaryBarbera.com/three](https://MaryBarbera.com/three). And if you would like more information about my online courses and community, you can go to [MaryBarbera.com/workshops](https://MaryBarbera.com/workshops) to sign up for a free workshop today. I will be back next week for another episode of Turn Autism around. Have a great week.

Thanks for listening to The Turn Autism Around podcast with Dr. Mary Barbera. To join Mary's mission to turn autism around for 2 million by 2020, go to [MaryBarbera.com/join](https://MaryBarbera.com/join).