



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 070

*Finding Cooper's Voice: Interview
with Kate Swenson*

Hosted by: Dr. Mary Barbera

Mary Barbera You're listening to the Turn Autism Around podcast, episode number 70. Today I have a really special guest that I've been trying to get on the show for over a year. Her name is Kate Swenson, and she is the mom of three boys.

Mary Barbera Her oldest son, Cooper, has severe non-verbal autism, and Kate is the author and owner of Finding Cooper's Voice, a website and a community that shares the secret world of severe autism. Her Facebook posts on Finding Cooper's Voice reach 6 million people per month. Kate's goal is to create a community where parents of kids with autism can feel comfortable and understood, and she's currently writing her first book called Forever Boy. Please help me welcome Kate Swenson.

Welcome to the Turn Autism Around podcast for both parents and professionals in the autism world who want to turn things around, be less stressed and lead happier lives. And now your host, autism mom, behavior analyst and bestselling author, Dr. Mary Barbera.

Mary Barbera I am so excited to welcome you, Kate, to the podcast.

Kate Swenson Happy to be here. This is exciting.

Mary Barbera Yeah, we've had actually multiple requests to have you on the podcast. And I am part of your community, and I've had like four or five members of that community that I met through your community on the podcast already, including

Julie Hornak, Eileen Lamb, Deidre Darst, and so many people that I've met that are really helping me understand autism better. So thank you for that. So we're gonna get to your community. We're gonna get to your writing of your new book and all that stuff. But before I would like you to just tell me about your fall into the autism world when that happened and how that occurred.

Kate Swenson Yeah. So I knew nothing about autism. Nothing. And it's kind of interesting. I actually nannied for a while when I was in college, and it was a very challenging experience and very unique. And looking back, I know what autism is. It's just so interesting looking back now at things that I've encountered in my life and experiences.

Kate Swenson Cooper is my first born firstborn who was born in 2010. And, you know, pretty typical pregnancy. Everything was great. I gained a lot of weight, too, which was very fun at the time, hard after, but typical everything. Kind of a tough delivery, but you know, nothing out of the ordinary. He was born at full term and we came home from the hospital. And right away it was hard. But I didn't know if it was hard because I was a first time mom or if I was exhausted and no help. No one really tells you that when you're a first time mom, you just kind of getting through it.

Kate Swenson But he didn't sleep and he struggled to eat. And he was really full of anxiety as a newborn, which I didn't know it then. I do it now. Now I can articulate it better. And we just kind of, you know, we my husband, I just survived for, I would say two years trying to figure out what was going on. How do we get him to engage and start talking and how do we do the right things?

Kate Swenson We were, you know, seeking out resources and pediatricians and doctors. And we just keep hitting dead ends. And late one night after a glass of wine, I was doing some Googling on the couch, I think many moms relate to this, Dr. Google. And no matter what I typed in, the first result was autism. And I'm like, well, that can't be right. And then I'd type something else in and it was still autism.

Mary Barbera And what kind of things were you typing in?

Kate Swenson Nonverbal. I don't even know if I had the word then. No words. That was my most common one. No words at 2 years old. No words at 3 years old. I stopped at age 5. Just, you know, because it ain't pretty once you start searching for that age.

Mary Barbera And how old was Cooper at the time when you were searching these words? Two?

Kate Swenson 18 months? But I didn't know what autism was. And I wouldn't say it out loud. I just, you know, I just privately searched. And no one actually ever said to us that they thought it was autism because Cooper pointed. And he smiled and he waved. He greeted people. And if I could tell parents one thing, the M-CHAT, the tests that you do online that we can all get different answers to every time. I believe that that test and a lot of professionals are still asking the wrong questions.

Kate Swenson For example, you know, I think, does your child play with toys? And I would say, yeah, yeah, he does. He wasn't playing with toys.

Mary Barbera He was he was stimming. He was swimming with toys, he was repetitively building blocks over and over again, lining things up. And that is confusing.

Kate Swenson It is confusing. I always say it should ask more questions about like obsessions and different things like that. My girlfriends and I joke that we could write our own and chat and could help a million more people.

Mary Barbera And for those listening, I did do a video blog on the M-CHAT, which we can link in the show notes. And I did a video blog on pointing, which we will also link, and this is gonna be episode number 70. So you can go to MaryBarbara.com/70 for anything we mentioned here, we'll link it in the show notes. Because, you know,

pointing is definitely early... You know, if they're not pointing by 18 months. Now, if they're not pointing by two or three that see... But, like you're illustrating, some kids, you know, they have the point, but it still could be autism. So one little sign is not enough. It needs to be the whole picture.

Kate Swenson

So as he aged between age 2 and 3, there was no more hiding it. There was no more... And people sometimes feel weird about that term. But it wasn't that I was hiding it. It was just like you can have a toddler having a tantrum on the floor and it can be just a tantrum. But this was not... This was lining up chairs and then being really upset when there were no chairs to line up. It was just different. There were different things to it. And I called a place, we lived in rural Minnesota and there was no place to go and diagnosed around there, so I called the city, which was three hours away, the bigger city. And I did it on my lunch break in my office with my door shut. And the intake process, I still joke about this, it was like a 45-minute intake process. I don't have time for this. And the man on the phone was like, well, it's a six to nine month wait for the appointment. And I'm like, oh, that's fine. We won't needed by then. I'll be fine. And I said that. I was like, oh, no big deal. And the appointment came and we went.

Mary Barbera

And did you have to wait six to nine months?

Kate Swenson

We did.

Mary Barbera

Yeah. And I have a video blog on waiting, too. I mean this is just the tragedy because, you know, once up parent, I have a video blog on denial. I mean, once the parents both get on the same page, both agree that the child should be tested, then you get in line and then you wait nine months. I've been hearing two years in the United States. And during that critical window, a lot can be done. And that's kind of been my life's work is I was in a very similar situation when Lucas regressed and started showing signs. And I was in denial. I was in denial for fifteen months. My husband first mentioned the possibility. I shut him down and told him I never want to hear the word again. And so I was in denial for 15 months. Once I got out of denial, that was two decades ago. You know, we got an appointment and it was moderate severe autism. But, you know, that's why I really want to catch people when they're starting to worry because the

same things parents can do to help. And that's just so important. So I'm glad that you're you know, that you're telling me the story, because I think it's gonna help a lot of people. Because it is so confusing back at that time when you're starting to notice things.

Kate Swenson

Cooper could've been diagnosed at 18 months. And I was told by many professionals that nothing could even happen till age 3. And I have a lot of regrets which we can get into. You know, but it's like between 18 months and three years, we could have done a lot more things, but we just kept hitting dead ends. You know, it's like he's too young and he's a boy. He's just late developer, early talker and only child at the time. And I was like, I don't know about that. So it's like, what could we have? You cannot beat yourself up as parents. But it's like, oh, we could help one mom now get in at 18 months. That's a big difference.

Mary Barbera

Yeah. And that's why my new book, Turn Autism Around, it is for the little kids to 4 years of age, because what I've learned over the past two decades as a behavior analyst is like, there is a ton you can do and not wait in line. So I'm excited that you agree with me.

Mary Barbera

Now you do have two other kids, too. And were you worried about their development? Because this you know, if you have one child with autism, the rate of autism in a language delays and developmental delays, which is really scary.

Kate Swenson

I get hundreds and hundreds of emails a week, and the most common question is moms wanting to have more children and they're scared. So Sawyer, my 7 year old, they're almost two years apart. So when we got pregnant for him, it was very much a surprise. And it's a blessing that it happened that way. I want to be clear because I don't know... The years were hard for so long. And he was born right after Cooper turned 2 in December. We knew something was going on. He was born in January, Sawyer was. And I never had a second to worry about him. I never had a concern about his development.

Kate Swenson

What I was scared about and concerned about was not being enough for Cooper and not being enough for Sawyer. So I put the guilt on me like I was like, they're both, you know... Cooper's having a lot going on, but Sawyer is fine. But can I give them both what they need? And that was hard. I was stretched very, very thin. And I have a lot of regrets that, you know, times that I would shush Sawyer's beautiful voice for talking because I just couldn't handle any more noise. I think about all the times we downplayed his development, you know, he would say hit a baseball and, you know, Cooper would touch a blueberry and we'd have a party. You know, the times we had to leave places or not go. That's what I have regrets about.

Kate Swenson

Then the time for the third baby came. I wanted a third baby so bad. I mean, I wanted it more than anything. I wanted a little girl... My husband and I know we're open about it. I'll talk a lot about this in my book, too. But we had a doctor tell us not to have a third baby, that it was too risky. And that just pissed me off that someone could tell me what decisions I could make with my own body and my own family. And my husband and I had a lot of fights, a lot of discussions, drink a lot of wine. And talked about there are lots of pieces that go into it that I don't sugarcoat. I mean, what if we gave Sawyer to siblings with disabilities? What if we had two children living with us for the rest of our lives? There's so many parts and we went for it. And he's 18 months and he's perfectly on track. But I wasted a lot of time being scared. Don't do that. I was scared a lot?

Mary Barbera

Yeah, we had a very similar trajectory because Spencer is 18 months younger than Lucas, so. And Lucas regressed. So he was developing on track. We got pregnant. Surprise, you know, with Spencer. And then it was really it was actually Lucas's reaction to the baby that scared my husband... A lack of reaction. Like we could have literally brought home a baby doll and put it in the crib for how much he was aware. You know, most 18 months old... And my husband's a physician. So he was used to like where he should be. And so was his lack of responsiveness that worried my husband. And that's when he first said it.

Kate Swenson

Yeah. We could about home babydoll, too. It's funny that you said that. Because people always assume that Cooper was mean to the baby. That's the kind of the assumption. Like when you have severe autism, they're like, oh, you know, is he mean or aggressive? And my kid doesn't even know there's a baby in my house. I mean, didn't even pay attention to him for years. There was no mean or aggressive. Sawyer didn't exist, which I will tell you, I think was very emotionally

hard for Sawyer. I remember the moment he realized his brother didn't even see him. It was crushing.

Mary Barbera Yeah, yeah, yeah. But it is hard... With Spencer, we didn't know there was any problem with Lucas. And then I actually don't write about this or talk about it much, but we did actually go try for a third. And I got pregnant, but I had a miscarriage very early on. And this was when Spencer was three. So I also understand that whole debate. And, you know, is it something you should do? And, you know, we finally got off the fence and then I had a miscarriage and then, you know, we decided against it. You know, months later, which was fine, because then I became a behavior analyst and wrote my book and, you know, had a different trajectory. So, you know, it is decisions that you have to make and sometimes you just go for it. And I know from following your group... So now Cooper is how old? Nine?

Kate Swenson Nine. Nine, seven, and one.

Mary Barbera Nine, seven, and one. And I know that you write in your group that, you know, the baby, Harbor is his name, has been such a blessing to your family. And he really helped you, you know, in many ways.

Kate Swenson When we went to the hospital to have Harbor, we actually had a safety plan for coming home. That's how many behaviors Cooper was having at the time, we were actually in his hardest time. It was right before we started meds for him and we actually had a safety plan. Because we, you know, we decided that the boys could never ride in the car together. The baby could never be on the floor. The baby's room door is just different, different things because we were so scared. And we have never had a problem. I know that sounds it... Cooper hates babies crying. He doesn't like many people. He doesn't like anything on the floor. I mean, we joke about it, but we've never had a problem with the baby.

Kate Swenson And Harbor has just... He saved our family. And that'll make people annoyed. I don't care. He was just this joy. Sawyer, after a month told me he's like, I'm not lonely anymore, mama. He said that to me. You know, we're gathered around

this baby where he's laughing, he's bringing us together. It's really the best thing that's ever happened to our family. The other part of it, though, where I thought you were going with that was the baby's 18 months now, and he's passing Cooper in a lot of areas. And that is an emotional trip that I knew would happen. I wasn't fully prepared for it. It's hard.

Mary Barbera

It's hard. And Spencer, you know, only knew a life with autism. And he became like a little junior therapist right away. You know, I remember him being really little and being like, look at the moon, and taking Lucas's face and move it, you know. And he was also a kid magnet. Your boys actually remind me a lot of my boys. And, you know, I know it's scary for a lot of people, but it's great, you know, in any way you slice it, having siblings can really bring a lot of joy. And it was nice because... And I know some families are listening and they have, you know, three out of three kids all have autism. And it's painful, you know, but if you do have a typically developing child, it does provide you with like that, you know, normal parent teacher call and that or parent teacher conference or the concerts or whatever. And it's like, you know, I have my autism friends and my autism journey. But I also, you know, celebrating like Spencer's graduating from college. He's going to med school next year and like all those things. And he's been such a great support for Lucas. So I think you'll find that as they grow it, it's going to even get better.

Kate Swenson

I always say that I have a foot in each world. The autism world and the neurotypical world. And this may surprise people, I feel way more comfortable in the autism mom world now. It's just the safe place with the friendships that I've made, the village we built for Cooper, this safe place. And then I go out in the real world and I don't even know what to say sometimes. I feel like I've lost my ability to chitchat and like small talk and like, oh, okay, you're not talking about like specialty strollers and constipation, like this is weird.

Mary Barbera

Or you're saying, you know, I remember vividly Lucas would take a whole can of soda and just take it and dump it out on the floor. And meanwhile, I'm on the phone with somebody who has typically developing, you know, girls. And she's yelling at them, like screaming at them for running up the stairs with mud on their shoes. I'm like, really? Like, don't you know don't have white carpet? Like do not yell at your kids, you know, put them in time out for stupid stuff. You know, it's just like, come on. And it really does make things very real and make

things very much like... Your purpose in life. How to treat everybody and you know how it changes your whole world view.

Kate Swenson

It does. And I, you know, I will never less than anyone struggles. I will never... Hard is hard. We all have our version of hard. It's where we are in life. But I always I love when someone's telling me, like, you know, their kid only made it into three colleges like, oh, you know, it's just so sweet. It's like, I will never lesson anyone's hard. And I understand. But, you know, I think about the hard that Cooper has and the hard that we went through. I think it would knock some people's socks off. They would just not believe it. So I'm a much better person going through what I went through. It's made me a better human.

Mary Barbera

Yeah. So I know you identify Cooper as having severe autism, was it always severe? Like, did you...is it still really hard or is it getting easier? Now you described like the baby and you don't have any aggression problems. You don't have any safety issues. And you kind of alluded to meds, help to medications. So how is it now? How is he doing now just overall?

Kate Swenson

He has always been severe. But I will tell you, some parents will chuckle at this, before when he was like three and four I would be like, but he's high functioning. Like I would say that sentence, that phrase and like, oh he's high-functioning. I don't know why I did that. I laugh at myself because... I don't know. I was like trying to convince myself, I was a nut. He's always been nonverbal. And people sometimes get mad at those type of terms. You know that. But the reason I use them is not they're not negative to me. It's not a sad thing, it's not a negative thing. It just describes him and helps him get the services and the resources that he needs.

Kate Swenson

We had really, really hard years where we only had regressions or we didn't have any steps forward. And I know a lot of parents can relate to that. Ages four to six were really, really hard. We had lots of health things, too. Pretty common, you know, constipation, ear infections, really bad anxiety, really bad ADHD. And no one seemed to really care because he was autistic. And one of my messages that I would like to just drill into people's brains, if you go to a doctor and you say my child is struggling with an ear infection or constipation, and they say, well, that's just severe autism. Get out of there. Pack your kid up and walk right out the

door. Do not even look back, because I think Cooper suffered for many years with struggles that should have been addressed, but no one cared.

Kate Swenson And, you know, we couldn't leave the house. There were all those things. Aggressions really built up and the kid felt like crap, but he couldn't tell us. And no one cared. And it wasn't until he had a speech device and he said it head hurt, head hurt. And that was the moment where I really turned to quality of life. And I was like, we're going to I don't care about therapy. I don't care about talking. We have to get you healthy. And I drove into health anxiety, ADHD, getting those things under control. And at age, I can, you know, talk about meds too, at age eight we finally started meds.

Kate Swenson And I will tell you, I was so against meds because I was supermom and I could help him without meds and meds are giving up. Clearly. I'm winking for anyone that can't see me. I was like my kid will never need meds. Oh, goodness. I was crying one time at my mother in law's house because I couldn't do it anymore. It was the first time I said out loud, I can't do it anymore. And she's a nurse. And she said, you have to help him. He doesn't feel good. He's full of anxiety. His brain can't stop. Help him. And I made the appointment and I canceled it. And I made the appointment again. And we started Cooper on meds and we have had the best year of his entire life. The first year, the first year we have lived since he has been born.

Mary Barbera Wow. Yeah. A couple things I want to point out here and we can put these in the show notes. I have a podcast, a podcast number four is on high-functioning versus low functioning and how that is just, you know, kind of nonsense because with any child or their strengths and needs and, you know, you can't really just lump everybody together in terms of high functioning, low functioning. And Lucas looked a lot higher functioning when he was little. He attended preschool on his own. He had some language. He didn't have any self-injurious or aggression. And now, you know, as he's older he looks more impaired.

Mary Barbera I also did one of my favorite podcasts, episode number 28, with Dr. Michael Murray, who's an autism dad, and he is Lucas's psychiatrist. And I waited 18 months to get him in. And he finally got in at the age of 18, and Dr. Murray put him on a medication that literally changed his life. I talk about that in episode

number 28. And also, I'm a registered nurse and behavior analyst. So I have done multiple blogs on the importance of rolling out pain and how that's really impossible with kids that are minimally verbal. And I also have video blogs on how to teach a child to take medication, how to label when they're in pain, and all kinds of stuff.

Mary Barbera

So I really do, and I am all about, you know, I have a video blog on medications and supplements. Like there's a lot of people in the behavioral world especially that think that if you say biomedical or supplements, that's bad. And medications, if you say that or you say medical intervention, that's good. But I give examples in that video blog where I gave Lucas multivitamins that had copper in them and he got agitated. And I have, you know, he's had other medical issues that I talk about in the Dr. Murray blog that, you know, needed to be treated because behaviorally, it wasn't a behavior thing, it was a medical issue. And I think there's so many kids out there with serious medical issues. So, yeah, I'm glad we had that little discussion.

Mary Barbera

Let's move on to your writing, your group, your community, and just things in general that you're finding with the moms, mostly moms in your groups. So when did you start blogging and started Finding Cooper's Voice and how did that evolve? And I know you have some viral videos like how does that even work? Because I mean, I've been in the online space for five years and I know what a viral video is, but I don't quite know how that happens.

Kate Swenson

No one does. So I started writing and I've tried to remember this. I think it was when Cooper was two. And I knew something was going on, but no one else did. I couldn't say it out loud. So I just started writing. I started a blog on my couch and I started writing and it was really healthy for me. So I just poured everything out that I wanted to say. My fears, my worries, my concerns. And I recommend writing to anyone that, you know, feels comfortable doing so. Just write for yourself. It's so helpful. Wrote for a lot of years, on and off, and then started a Facebook page three years ago.

Kate Swenson

And I didn't start it to have a big following. I didn't start to have any following. I started it for two reasons. I wanted a place to share, you know, when you're scrolling through on Facebook and you see an autism resource or an event, you

share it to your page and it's like crickets. Like, it's just I needed a place to kind of have all that stuff. So I started it for that. And I started it to try and find some moms that had kids like Cooper, because Cooper was five or six, I didn't know any. I did not know any parent that had a kid like mine. We couldn't leave the house. You had three locks on every door and window. And it was really at that point, a lot of parents all relate to this, kindergarten at age five was a really pivotal point where some kids start to improve and some stay the same. And I felt like our circle got even smaller. So that was why I started. I'm like, I'm going to find those moms.

Kate Swenson

And I had a lot of things happen right away. We went to a special needs park and Cooper was yelled at by another guy. A dad. It was terrifying. And I did a video about that. And that got me kind of viral in Minnesota because the news channels contacted me and it was very stressful and shocking. I didn't like it, but it was fine. And then I started writing for other sites and my page started growing. But I still knew everybody that commented. Like I knew their names and their kids. I'm sure you remember that when you only have a few hundred people follow you, you're like, hi. You can be very honest. And then I had my super viral video where I cried in my car. The one and only time after seeing Elmo. And that just blew up and that was a really scary time in my life, because when you go viral, you bring a lot of crazy you into your life. A lot of evil, a lot of...

Mary Barbera

And what you were saying, describe that video and we can post that video in the show notes, episode number 70. But I saw the video, but I don't remember. So what? How old was Cooper? What about Elmo? Why were you crying in your car?

Kate Swenson

He was six. I worked for PBS and we got invited to a special meet and greet with Elmo at the Mall of America, which is in our backyard, it's huge. And Cooper couldn't go to places like that. We would never dare bring him. And this is a big challenge we still have today. He loves Elmo. He loves him. I want to bring him, I want him to have fun and I want him to experience things. So we went. My husband and I and he, you know, it's like he can't wait in line. And he ran up and he rolled on the ground. And he was self-injuring, and he was crying and he was laughing. And it was just really, really manic manic behavior. And that's Cooper. Okay. But it was the first time I had seen Cooper through the lens of everyone watching us.

Kate Swenson And I looked around. I had this out-of-body experience. I looked around and everyone's holding that little baby and is like whispering; whether they're saying good or bad or supportive, it doesn't matter. I was only one with a 6 year old there who was struggling to that level. And I came home and it was the first time in my life that I had realized this isn't going away. It's forever. It's not going to be easy, because I had always truly believed that at some point this would be okay. Meaning he would maybe... I knew he'd be autistic forever, but I thought maybe he would improve a little bit. I thought he would be able to leave the house and he would have some words. And it was just a really low point. And I let myself go to that dark place. That was the first time I'd ever let myself go there where I thought about after I die, who's going to take care of him, even though I was dead? And then I kept going. I let myself keep going. I'm like, will anyone go to his funeral? Who will even know him besides his brothers?

Mary Barbera Were you posting that on Facebook live? Like you went on your page and just started talking?

Kate Swenson No. The next morning when I went to work. I published it and I walk into work and I came out and I was like, oh, my goodness. I never expected anyone to watch my video.

Mary Barbera And how many millions of people watched it?

Kate Swenson Well, when it was shared by the Today Show, it was something like 30 million.

Mary Barbera Wow. All right, let's talk about your Finding Cooper's voice community, and you also over a year ago started a private group that is a paid membership group. It's only for 4.00 a month. And I've been a part of it since the beginning because I love what you do and I love your writing and your community. So at some point last year, and I think part of it was because you were getting a lot of backlash from people in your big community. Is that... Then you transitioned to a lot of

more really real videos and blogs are inside of Coop's Troops. Is that is that accurate?

Kate Swenson

Yeah. I had reached that point and I thought someone had told me about this, but I never thought that I would reach that size of a page where it was just too big. You're too vulnerable, you're too exposed. You're reaching too many people. And I had actually thought about quitting. I was like, I'm going to shut Finding Cooper's Voice down, the Facebook page, one year ago here in a couple of months now. I think I'm done. I just had a baby. I was like, I don't need this. I'd wake up in the morning and I would take one look at my Facebook and like, I didn't need it. It was too stressful. And I was approached by Facebook and they asked me if I would be able to test whether there are supporter platforms. So for anyone that's on Facebook, you've seen it by now. It's pretty big now. So, you know, it's a paid subscription group where you get, you know, special content. And what's been really fun... Oh, so first I'll say I said, heck no. Who would ever pay to listen to what I have to say, I don't know anything. But then the bullying got so bad that I said, I'm doing it. I'm doing it. And I launched it. And it has been the best thing I have ever done professionally, personally, emotionally. I chat about, you know, how do I describe it? It is a safe space to ask questions.

Kate Swenson

Because if you're in the autism mom community, there are not a lot of safe spaces to ask about meds, to ask about potty training. To ask about self-injuring behavior aggressions. Because if you do, you're going to get a lot of odd, weird shaming and parents just give up. And see for me I stopped asking questions. I didn't want to be shamed. And in this group, it's small and its tightknit. And, you know, we do interviews and lives and we laugh. We cry. It's just wonderful. It's wonderful. The other thing is there is so much value in having a face to face conversation, having someone you can text at 3:00 in the morning. And I'm really pushing now, before Corona, it was meetups in the community and they were happening all across different states. Now it's Zoom chats and I'm doing phone calls every week, face timing, sometimes two a week with moms that just need to ask questions. And it's life-changing for them and me.

Mary Barbera

Yeah, that's great. So how do people if they're interested... And you have you also have professionals in there and not just autism moms; you have grandmothers, you have just supportive people that are interested in autism. It's not all autism moms, but I would say it's predominantly autism moms. So how

do people find out about that, too? Like, how would they join something like your support group?

Kate Swenson

Yep. So go to Finding Cooper's Voice the Facebook page and it's this giant blue button near the top of the page that says Support Now. It's pretty easy to sign up. You just click and they bill you through Apple or Google. You can unsubscribe at any time. A lot of people come and go. They'll come for an interview and they'll come again later for an interview. There's no questions asked. But there have been a lot of women that have stayed the whole year because it's become a safe space for them to ask questions, judgment-free, and to give support to what I love. My favorite part is the mixture of parents with newly diagnosed and the parents of older kids, because that's who needs to come together. And also, I would love to... If other, you know, it's not just autism, like you said. You know, parents of kids with other disabilities and different abilities join, too. And that's starting as well, because we can all help each other.

Mary Barbera

So what are three to five things that you think from looking at your community stress mom's out the most?

Kate Swenson

The number one is having another child. That decision. That is the most common thing all the time. Potty training. My advice about potty training is they're not ready until they're ready and they might not be ready till six, seven, eight years old. I stressed out so bad. I was like I'm going to have the only boy in kindergarten and diapers. He went to get to kindergarten in diapers. It's fine. He's potty trained now. That's number two. I'm trying to think of other ones. Lack of services. Struggling to find the right services. Another one that I preach a lot is you have time. And what I mean by that is I... Professionals would do this, too, but I would do this to myself; if he's not at a certain pace by age four, if he's not doing this by kindergarten and that's the society we live in: milestones. Cooper is a lifelong learner.

Kate Swenson

And I will tell you, I've been told dozens of times by parents of older kids that a lot of learning with our kids starts at age 20. Then once they get in their 20s, they're really learning. Cut yourself some slack. You have time. And then, you know, another thing is they come to me and they have so many regrets. And I talk about those still, too. They feel like they failed. You haven't failed. If you're

searching on Facebook and the Internet for resources, you're obviously a good parent. You're not failing.

Mary Barbera Right. Right. And when you know more, you do better. And, you know, I could kick myself for being in denial for 15 months. I probably would have a different trajectory. But, you know, life is life and you just do the best you can and put one foot in front of the other and... Yeah. I do have a whole podcast, I believe, on potty training and a free guide at MaryBarbara.com/potty. I know we talk in Coop's Troops, you talk a lot about lack of sleep and sleep issues, which is also common in not just kids with autism, but typically developing kids and that sort of thing too. So I do have a sleep guide as well.

Mary Barbera So I think we kind of covered it. But just to summarize, like what are some pieces of advice you would tell your younger self when Cooper was first starting to show signs or when he was diagnosed, like, looking back what advice would you give yourself?

Kate Swenson I wish I would have an easier on myself. I was so hard on myself. I was really hard on my body. I was just so focused on helping him and making his life easier and catching up and all those things that I... I worked all day. My job. Phone calls, you know. And then I did everything for Cooper. And I was a mom to the little boy. I let my marriage go. I wish I would have given myself grace. I wish I would have been kinder to myself. I wasn't kind to myself for a lot of years. I thought I failed. Prioritize time with your family and your spouses. Be good to your other kids. I wish, I mean, Sawyer was always the light of my life, but I was just... I don't know if I had enough to give him at the time. I mean, it was just the part that no one ever talked about to me was the emotional side, the emotional journey you go through as a mom, no one talks about that. And it's not easy. I'm a completely different person. I've reinvented myself for the better. But, you know, your child's gonna be fine. Cooper is going to be fine. It's me I shouldn't worried about. Yeah. And then give yourself grace.

Mary Barbera Yeah. Yeah. I love that advice. How about some things for professionals that you would tell professionals in your life now or in the beginning, like... You said, one thing was if they say the constipation is severe autism or any other medical

issues, obviously you don't want, you know, to keep going to that professional. But any other words of advice for professionals that you could give?

Kate Swenson One thing that I would say is we have encountered so many therapists, so many doctors, nurses, all of it. There will be doctors, nurses, teachers, therapists that you will encounter in your child's life that are wonderful, great. But they might not be the right fit for your child. And that took me a lot of years, I think, back to this amazing therapist we had. But she wasn't right for Cooper. Cooper just wouldn't work well with her. And it took me a long time to find my voice for that. I'm from Minnesota. We're always nice. So it was hard for me to speak up about that. But on the same side, while it probably would have hurt my feelings, I would have loved if that therapist would have said this just isn't working, but here are some resources that might. I feel like there's a lot of dancing that goes on in the beginning, it was just kind of dancing around. We weren't really having a conversation.

Kate Swenson For a lot of years people just didn't see Cooper. You know, I'd bring him to the doctor and it would be this challenging little three year old melting down and they would not even examine them. They just didn't take me seriously. And it's like, get on the floor. Help him, help me. And I also for a lot of years, I didn't feel validated. I didn't feel heard. And I lost my voice for a long time. And I think, you know, we just have to just... Just see us, see that we're struggling. And then, you know, give us hope. Give us hope.

Mary Barbera I think that's great. Okay. So to wrap up part of my podcast, goals are for parents and professionals listening to be less stressed and lead happier lives. Do you have any self-care tips or things that help you with stress reduction?

Kate Swenson That's funny. I struggle in that area, but I try to go for walks. I try to just to get little breaks away. Walks are really important to me. One thing that really causes me stress is the sound of Cooper's iPad. Lots of sounds. Find tools and resources that will help, meaning don't live in chaos if there's help that you can get. So, you know, example for the iPad is a volume restrictor app. If your kids escaping out your house, put extra locks on your house. If your kid's going in a room that they're not supposed to go in, put a keypad lock. So, you know, one thing that's

really helped with my sanity is making our house safer, making our life safer. Don't live in chaos. You can't live like that. What else? I don't know.

Mary Barbera

I like that. I just wrote down the volume restrictor app. I didn't know there was a thing Lucas is really good at wearing headphones, but he's still will turn it up to loud and then he'll be extra stimmy. So I wrote that down. I learned something new. So I will definitely investigate that. But I think that... I mean, our whole talk today was pretty much like how, you know, how you cope, how you look for the joy, find hope, you know, really be there for your family, for your spouse, for your group members to support each other. So it sounds like you really came full circle. And now especially with Coop's Troop and your new book, which won't be out for a while, you just started. You just got a contract and you're writing now or soon. But that book is gonna be called Forever Boy. And so maybe once that's published, we'll have you back on. I would love to keep... I'm going to stay in Coop's Troop. I'm finding a lot of value and I'm sure some other members will come along for some fun. It's a great place to really have your hand on the pulse of what's going on, both with moms, with younger kids as well as older kids. It's a super supportive, positive community, which I love. So congratulations for building such an incredible community and your writing is beautiful. So I look forward to years of continued collaboration and help for both parents and professionals in the autism world. So thank you so much for your time today, Kate.

Kate Swenson

Thank you.

If you're a parent or an autism professional and enjoy listening to this podcast, you have to come check out my online course and community where we take all of this material and we apply it. You'll learn life-changing strategies to get your child or clients to reach their fullest potential. Join me for a free online workshop at MaryBarbera.com/workshop, where you can learn how to avoid common mistakes. You can see videos of me working with kids with and without autism. And you can learn more about joining my online course and community at a very special discount. Once again, go to MaryBarbera.com/workshop for all the details. I hope to see you there.