



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 008

Behaviorbabe (Dr. Amanda Kelly): Autism, Advocacy and Social Media

Hosted by: Dr. Mary Barbera

Mary: You're listening to the Turn Autism Around podcast, episode number eight. Even though we are just a few months into our journey here with the Turn Autism Around podcast, we already have dozens of five-star ratings and reviews and I just wanted to give a shout out to one of the people that wrote a review on iTunes.

Martina says she is already a super fan after listening to just the first few episodes. Mary is on a mission to reach 2 million people affected by autism by 2020 and this podcast is going to be perfect, easily educate yourself and put more power into your hands. I am stoked that I found this, so thank you Martina and if you are listening but you haven't subscribed yet, we'd love it if you would do that and leave me a great rating and review like Martina did, and maybe I'll give you a shout out in future episodes.

Today's episode is a very special interview with Dr. Amanda Kelly, otherwise known as Behaviorbabe, and we're going to get right into that now.

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: So today we have a very special guest. We have Dr. Amanda Kelly, otherwise known as Behaviorbabe, and Dr. Kelly received her doctorate in behavior analysis from Simmons University, and over the past two decades she's worked as a paraprofessional, a teacher a school counselor and a behavior analyst within home and school settings as well as in residential placements. Amanda has won several awards for her advocacy and dissemination efforts and became the very first licensed behavior analyst in Hawaii in 2016. Amanda and I have been friends for many years so I'm super excited to interview her today. Please help me welcome Dr. Amanda Kelly.

Amanda: Thanks for having me.

Mary: Oh, awesome. How are you doing today?

Amanda: Doing great thanks.

Mary: Is it sunny in Hawaii?

Amanda: I like to say... I have this saying where I say it's always Hawaii outside, but it's actually raining quite a bit. And so today it's a nice first day of sunshine in a few days.

Mary: I've been to Hawaii three times and every time I'm there I'm just amazed at how many rainbows I see. So, and you take beautiful pictures of Hawaii. So, uh, that is always nice to see online. So let's talk about your fall into autism and tell us about your background and how you got here.

Amanda: Of course. So I think fall is a really good word. I think that that pertains to both parents and providers. I myself am a provider. It was in late nineties, early two thousands that I was pursuing my undergraduate degree in elementary education. I knew at the age of three I was going to be a teacher. My parents laugh, my father was, uh, in the army. And so we were, we would move and travel and I would always recruit a group of students or neighbors to be, my students would grade papers, would give feedback, we would have recess. So I gravitated to quite a lot towards the educational realm and field. And it was when I was pursuing my undergraduate degree that I was looking for a part time job and they had jobs in the education wing posted up in the college.

Amanda: And this is a small university in West Virginia, about 20 minutes from where my parents were living at the time. So I didn't go too far from them. And I saw this job that said, hey, come work with our child. He has autism and we're going to do this thing called ABA based off of somebody named Lovaas. And really the thing that stood out to me from that, um, flyer was the photo and it was a beautiful little boy with these big blue eyes, wrapped inside of a snow suit and he couldn't put his arms down and I just wanted to hug him. So I, I thought this is something I could probably learn more about, but it had a lot of words that were very foreign to me. I didn't know what autism was. I didn't know what they meant by these letters, ABA. And so I went to my education professor and I asked the professor, you know, what is autism? What is behavior, what is ABA? I didn't even know it stood for applied behavior analysis at the time, and she was pretty dismissive of my question. And she, I, I've come to learn, they didn't know much about those things either, because her answer to me was, you know, autism, well that's just, that's a special need. That's like, um, like kind of like down syndrome. And it was really just simplified and tossed aside. And I, I think, I think I've thought back on that, and I think that's maybe because she didn't, she didn't really know. Um not a lot was known. And so then she told me behavior

analysis or ABA stood for applied behavior analysis and she said, you know, that thing Skinner did; that thing that we don't really talk about. The stuff we don't do anymore.

Amanda: And I thought, I, I'm really perplexed by your answers, so, you know, so I thought, okay, well that didn't actually answer any of my questions. So what I decided to do was to go meet the family, call the family and just inquire as to what they were looking for and what it was they thought maybe I could bring, if anything, to their son's program. And they were real excited to meet me and as soon as I went to their house and talked them, I thought, this is related to education and teaching. Their son didn't have language, um, wasn't talking. They had a younger daughter, so their children were very close together in age. She was hitting milestones he wasn't hitting and that was making them very nervous and so...

Mary: And he was like three years old at the time?

Amanda: He was, I think two and a half. Close, not quite three. So yeah, they were really close in age.

Mary: And what state were you in at this point?

Amanda: West Virginia. West Virginia. Yeah. It's, you know, I, I think about it now, Mary, and I think, you know, in 2019 I am still advocating for children to access supports to get diagnosis, to get access to services, to get just an inkling of like what direction people should be going in. And to think 20 years ago, a child at that age had a diagnosis in that location and that the family had somehow stumbled upon what was still really kind of emerging as far as being an official profession or field.

Amanda: And so yeah, I, you know, I met with them and they just seemed like a very loving family. The father was a pastor and the mother was, um an art teacher and I love to do art, thank you for complimenting my photos. And it just felt like a really good fit and we kind of figured we could tackle the unknown together. And I still feel like that is a message I would give to people is that there's a lot that we don't know and there's a lot that can be done together and there's a lot we do know and you want to stick with those people who know kind of what direction to head in. So I worked with that family and with that child for three years in their home, I became essentially what is now viewed as a behavior technician. And, um, there were other girls, uh, therapist, uh, if you will. And they were either high school students or college students like myself. And we were trained by a consultant who I only remember as Valerie. And Valerie, um, the family was privately paying for these services, they cost shared with other families in the area.

Amanda: Valerie came from New York every six weeks and she would show us things. We had no video cameras and camcorders, like set up. And we would show her our videos of what we were recording. And I remember just trying to emulate Valerie. And so it's what I call the Valerie voice, and, um, people who have seen some work with children with autism or similarly, uh, diagnose individuals might have seen this in the past. So she would say things like, you know, clap hands, that's clapping hands, great job. And I, I thought that that's what we were supposed to do. So I tried really hard to create a Valerie voice, which is what I called it.

Mary: Now was Valerie... she wasn't a behavior analyst at that time because this is the late 1990s before there were actually board certified behavior analysts nationally, right?

Amanda: Yes. So the certification board I believe was was founded in 1999 but then started doing certification examinations in the early two thousands. So she was not a board certified behavior analyst even if she identified as a behavior analyst. Um, quite honestly I never heard her call herself that- that wasn't a title.

Mary: Was she providing Lovaas type ABA treatment? Was she part of a replication site for Lovaas or was she kind of on her own trying to do the Lovaas ABA Approach?

Amanda: You know, I have to kind of go back to that family who I'm still in touch with to kind of learn more because my memory on those details is probably a little fuzzy. I know that she worked for an agency and they had like, programs and program books and it was based off, I don't know how directly her connection to Lovaas and his research was, but that's how that family learned that they were doing or trying to be doing a Lovaas approach. We definitely had like, you know, the no, no, yes, procedures like, you know, or different kinds of things. Things that I feel, you know, when we were all trying to be Valerie, uh, in that way, like it was pretty robotic and routine and I can see how sometimes you get, or ABA can get that bad rap.

Amanda: But that was for me, that was 20 years ago, you know? So we're talking like, well this child still with our imperfect delivery, with you know, the best approach possible being funded out of the pocket of the family from age two and a half or three to age five and a half to six. This child was fully developed and met all of the milestones and was able to demonstrate all the skills that we were looking and that we had seen as deficits and he was considered by his physicians to be determined as indistinguishable from his peers and went into kindergarten a little bit later on the later end, but was able to succeed without additional support.

Mary: Wow. So he was in the best outcome group. Um, we talked about that in previous podcasts about the Lovaas studies and that in, in Lovaas' original study it showed that 47% could become indistinguishable from their peers by first grade. So it sounds like this little boy with your intervention really made tons of gains and, and was in that best outcome group. So you said you're in touch with the families. Is that little boy still indistinguishable or does he have some issues?

Amanda: Um, I know around middle school the family experienced some challenges and ended up with uh, developing an IEP, uh, for some social supports and for some counseling support but relatively, um, is functioning quite well is my understanding, has since graduated high school. And I know that that's not every outcome but I have to say it was a really powerful first encounter and it changed my life and it's why I'm here talking to you today. It started there.

Amanda: Um, I never went into teaching elementary education officially. When I graduated in 2002 I, I pursued, uh, I looked for jobs in behavior analysis and at the time with dial up internet, I looked on Monster.com and only found two jobs, two positions that I could even apply for. And one was in Massachusetts and one was in, um, on the west coast at Morningside Academy.

Amanda: And my, my mother didn't really like me living far away from her even though I was in my twenties and said, you know, I really would prefer if you're going to move that'd be 500, not 3000 miles away. And now the joke's on her because I live in Hawaii, I'm quite far. Or maybe the joke's on me because now she lives in Las Vegas so we're not so far. But anyhow, I, so I ended up moving to Massachusetts and I worked, uh, at residential placements and I was working in different capacities with different teams, different skillsets, and it was a whole new, you know, it was a whole new game. I was getting injured, I wasn't seeing best case out, you know, outcomes. I wasn't seeing systematic applications of what I thought we should be doing or what I understood what I had done that I thought could maybe generalize. But all of that led me to want to know more about behavior analysis and why, what happened there wasn't happening here, and why that outcome for that boy isn't necessarily going to be the outcome for this next child.

Amanda: And so I wanted to learn more about it, and I just sat back home...

Mary: At the residential placements they tend to have a lot older kids, and kids that didn't have great ABA provided early on. And so you really saw the backend of what happens when this type of therapy is not implemented and it gets really scary. Um, I know in podcast number three I interviewed Kelsey, um, who has two young boys with autism and Brentley was only two and a half. He was banging his head on hard surfaces a hundred times a day. And the behavioral analysts said, well, if you want to bring him back, he's going to have to wear a

helmet. If we start needing a helmet at age two and a half, you know, what's going to happen to these kids as they get older? And luckily Kelsey didn't believe her and pulled him out and now he's, you know, much better with no head-banging or very little. So I'm sure in residential... I've never worked in a residential placement. I have done some independent evaluations on kids in residential placements and um, you know, it's just, it becomes a tough situation for the parents who need to place their kids there as well as for the providers who are really now working with kids that are older, who have histories of, you know, all kinds of issues that are hard to address.

Amanda: Yeah. I think you make a really good point there and that's part of what motivated me to advocate and to continue advocating is when I see what the outcomes are without supports and services. I have to do everything I can to prevent that from happening to future individuals or to do everything I can to allow them to access services as soon as possible. Um, what I know now is that what we were doing at that, at that time on that team, and granted it was going through transition and it was a lot of variables that just didn't make it the best situation at the time. Um, what we were doing wasn't behavior analysis and I, you know, left that position and ended up working. Like I said, I didn't want to, didn't want to go home. So I ended up looking in the neighboring area and I had to drive an hour and a half to get to the next closest, you know, opportunity to work in behavior analysis.

Amanda: But it wasn't 500 miles. So I started working at a, um, at Melmark New England and they, on my interview said, you know, so you've had this experience with this best case outcome here and then you've had, you know, injuries that have hospitalized you. What is it that you think behavior analysis is and why do you still want to do it? Um, and I remember thinking like, those are great questions. And what I know is I saw somebody... My first encounter with autism was a two and a half year old in West Virginia with big blue eyes and a loving family. And I had never seen a child who wasn't talking, who wasn't showing that he recognized you when you walk in a room. And when I met him I thought, well, he's going to have these challenges for the rest of his life. And when I saw that we were able to relieve or develop skills that were going to allow him to succeed in ways that I didn't know were possible, I had to do everything I could to make that an option for everybody else.

Amanda: And so what I will tell families and what I have told family since working at that residential facility, and I again, I work in residential after that, so it didn't deter me from that setting, was like, you really need to have all your ducks in a row. You need to know, you know, kind of what the system is when you're working in those situations you need, you're competing with those histories, all of that stuff. But what I tell families is, I know what can happen if we don't do this, these next steps. And that might mean like getting a social worker on board, it might

mean making sure they have the right supports at the school. It might mean going out into the community instead of avoiding it, you know, whatever that means. But when I took the job at Melmark New England they said to me, we have some classes since you're interested in the ABA and if you want we can drive you there after work and you can take these classes at the University of Massachusetts.

Amanda: Um, so I like to learn. So I was like, cool, I'll take some classes. And I had no idea really at the time that I was starting coursework to become BC ABA. So an assistant behavior analyst. So it was the best, best way ever that I wanted to be there, but I didn't know I was actually pursuing a certification at the time. Uh, at first; I certainly learned that within like the second class, that's what we were doing. And I remember taking my BC ABA exam, it was paper, it was scantron and I was so worried. Remember those, those little bubbles?

Mary: Yeah, I took the exam in 2003 and it was all bubble fill in with a number two pencil. And my distance learning program from Penn state was literally like a box of VHS tapes and binders full of PowerPoints. And so even though it was distance learning, it really wasn't online because the online situation was just emerging. So I mean, so when did you take your BCA BA exam?

Amanda: Um, I took that exam in 2005.

Mary: So even then it was, it was still the bubble.... Filling in the bubbles and, and scantron and everything like that.

Amanda: And I remember my number. My certification number was, um, the last number was 1828, which meant there was 1,827 BC ABA's prior to me. So that's kind of what happened in the first five years of the certification. So to look at the growth now is really kind of astronomical. But after that, I...

Mary: So when you were at Melmark, were you in home settings or is it another residential or a classroom or what, what was the setting there and what was that a lot better than your residential experience?

Amanda: Great question. So at Melmark, it was a day program for a lot of, um, I was teaching at the day program for students who most, um, we're in a residential program. So they were also part of Melmark's residential living in the housing. They had, you know, schedules and visitations and things, some with their families. Um, most children had their families involved, but not all. And so I was working in a classroom. I worked with, actually the age was 15 to 19, so I was still working with older individuals, not, you know, a two and a half year old. And his home, there were other people doing what I was doing and all of the neighboring classrooms. So essentially you had lead teachers, second teachers,

they called us and I, at the time I remember I had my bachelor's in elementary education. I was a licensed, uh, elementary education teacher and was just, uh, pursuing, um, my BC ABA while at Melmark.

Amanda: And then they had this great opportunity where they were looking for someone to work as a one on one, essentially a one to one for a child in a preschool setting. Um, they were looking, hopefully not for their lead teachers because they wanted to keep the program they had. So as the second teacher, I was a prime candidate and I applied for that and um, was assigned. I, I got that position. So I was in a unique situation where I was a Melmark employee, but I was working in an integrated preschool setting in a neighboring district.

Amanda: And the child was four and a half years old at the time and it was a classroom full of about 20 children. They had three adults teaching and uh, myself, so I'd be the fourth adult in the room and I was there to help him attend at circle. Um, you know, socialization, um, develop all the skills that you would in that setting with those peers. I did have a board certified behavior analyst who was overseeing me. I was a board certified assistant behavior analyst at that time. And at first the other staff wanted nothing to do with me. They really welcomed the child quite easily into their classroom, but they saw me as somebody who didn't bring expertise or additional insight into their classroom. They thought, you know, she really knows that child or she knows autism and they never really asked about my teaching background or anything like that. And um, I'm of the firm belief that you don't tell people you can help them, you show them. So I just did my part to volunteer and read books and when other children were taking naps, this child and I would be doing some intensive teaching and they, you know, helped us carve out a space.

Amanda: And one day we had a particularly challenging day and I needed to just to take a break, I needed to step away. And so I asked them if they could just hang tight with the client and the student, if I could leave, I needed to regroup myself. And when I came back they were like, you know, you were really upset. Are you okay? Can we help you? How can we switch with you if you need a break, how can we cover you so you can go to the back? And they just, they just shifted their perspective. And so not only did they welcome this child into the classroom, but about six months then they really, really welcomed me. And we were there for another year together. So it was a year and a half total. And it turned in to be one of the most formative shaping experiences really of my career because I got to see how we take the in home, or in the residential applications of this intensive science and, um, apply it in an educational setting.

Amanda: And that's kind of where my initial background and training had been. So it felt like a really perfect blend. And from there I went and got a teaching classroom teaching position in a special education school. I then decided to pursue my BC

BA because why not keep learning more. Got a master's from Simmons College, now university. Um, I'm still in Massachusetts. Um, and then I decided to, while pursuing my BC, I ended up with a consulting position and I was consulting to Cambridge public schools, eight of their 13 schools at the age of like 25. Um, so I knew I didn't know what I needed to know to support that school, um, and those, that district, but I was really fortunate to be partnered with the professors at Simmons and to have mentors come in and support me in that really unique role. So, and, uh, I decided again to keep going to school.

Amanda: Um, apparently it's what I love. I thought I wanted to be a teacher, maybe I wanted to be a student. Um, or both. So I ended up pursuing my PHD, also at Simmons College, and decided to get a doctorate. And during that time I started working for an organization that was publicly funded but kind of got to operate a little bit like a private or a collaborative. And what we did was I coordinated school and homebased ABA Services for 10 public school districts, um, outside of Boston and Massachusetts. And they would come to us when an expert or an advocate was going to go and critique their program. They would say, help us not lose this child to an out of district placement. And what that meant was if they weren't doing what they, the child needed, the family's in Massachusetts were pretty well educated and had access to lawyers, very affluent communities, and they would hold these school districts accountable. So I think it started as a, as a threat or as a fear of the districts to start asking for our support. But it really turned into them asking for embracing and then adopting the practice of behavior analysis as the go to educational approach, at least in those school districts for the time that I was there. And I know that they're still, they're still doing that.

Mary: Um, all along you were, you know, you learned what, what kids needed and then you were really on a mission to get this ABA technology into public schools where the majority of kids with autism were. And that's a similar background to my background with being involved with the Verbal Behavior Project, trying to get those, those technologies out to regular ed teachers, special education teachers, paraprofessionals, speech and language pathologists and collaborating with parents all along the way so that we make sure that everybody reaches their fullest potential.

So, I mean, and your, your background is fascinating and even though we've been friends for years, I didn't really know how it all transpired. So when did you become Behaviorbabe? And like what, what was that about? I remember meeting you at a poster session with the little Behaviorbabe icon. Like who is this Behaviorbabe? And, and you were like, that's me! So we became fast friends after that. But, but how did that all come about?

Amanda: That actually happened while I was in my PHD program. Um, in 2008 I think I had just started the program prior to working at... When I was working in one of the school districts prior to coordinating all these services for multiple districts. I had gotten injured on the job as is a hazard of our job. But sometimes, you know, people are just klutzy and so it may not have been too fully connected to just my, my day job. But I got injured and when I was out of work, um, what happened is I sustained a shoulder injury and ended up needing to have a surgery. And when I was out of work the teachers who had me as a support in their classroom, they didn't, they didn't have somebody replace me and the children who had my support written into their IEP that we had fought so hard for in those districts, they didn't have somebody to fill in for me.

So it was while I was there, they were getting the supports and services, but while I was away they just put them on hold I guess. And so the teachers started reaching out to me and saying, Amanda, can you send me that data sheet? Can you look over this information? Can you help us? And of course I want to help these teachers. I mean these are teachers in year before who they don't take data and they didn't want me in their rooms. They were, they had a misconception of what they thought my support or behavior analysis would look like.

Amanda: And we had worked really hard and collaboratively together as you mentioned, teachers, SOP's, OT's, PT's. I have had such a wonderful opportunity to do that in my background having been in school settings, a psychologist, a psychiatrist. So definitely it's very important to collaborate. And I was answering questions for them and then I guess the powers that be found out and said you cannot be on a work, you know, work related injury and still be working. And so they told me I either had to stop helping the teachers or I had to forego my salary being paid while I was recuperating. And neither one of those felt like an option to me. So what I did was I was on my couch, I had one functioning arm and I looked up how to create a website and I found a site that was free and it wasn't fancy and you didn't have to know how to write code and you can just insert a title, insert an image.

Amanda: So what I did was I put up data sheets and I put up an email system and I password protected the website and I sent it to all the teachers and um, just said to them, hey, you know what? I think the answer to your question might exist in this online platform. Check it out if you want to. And um, that's how it started. And then I was supposed to be working on my dissertation and I just started resource dumping on this website as well. Special analysis, uh, you know, ethical codes, the first red flags and signs, different things I was looking for. I'd start to just put them in categories on this. It essentially functioned like a Google Drive for me before I kind of really knew how to use that software. And then I ended up no longer in that position and I was able to make the website public.

So originally the website was, could it be found at ABama.webs.com so as you can see, that rolls right off the tongue. Um, but it stood for applied behavior analysis in Massachusetts and webs was the free hosting site. But anyhow, for a year or so I had the website going, um, started to again, resource dump, find information. I started to ask like paraprofessionals working with me or students and my colleagues in my program, my classmates, if they would check it out and if they thought it was accurate and if they understood it, if it seemed like a valuable resource. And then about a year or so later, 2009, I think it was that Twitter started to kinda come out and everyone had screen names and it was like Miss Behavior and A Stem Function and just some real clever ones. And I was scrolling behavior girl, behavior woman, behavior lady, behavior babe, and went with alliteration. And then it wasn't until 2010 that when Facebook pages came out, I remember thinking like, she's a cartoon, right? Like it's not a personality, it's not a public figure. Am I even allowed to make a Facebook page over this?

Amanda: I had no idea what I was doing. And um, and that's okay. So by having no idea what I was doing, but being driven, I think with a good purpose, starting to put information out there. Um, I changed the website to Behaviorbabe because it was easier for people to remember. For some people a little controversial, you know, you're not, you're not, you're Dr. Kelly. Why would I want to be called babe? Yeah, that's a good, good point. Good question. But nonetheless, it's memorable and I think it's really drawn people to access the information and it's everything that I do and offer is free. I will make my money some other way. Right now it's about getting this information in the hands of the aspiring providers and trying to find, give some help to parents and Mary, you know, for the families and providers that I know have been involved in through your work and through the involvement I've had in being able to join online, like it's powerful and people need to hear about it.

Amanda: So I'm happy to be a part of it. And then I moved to Hawaii and all of a sudden everybody wants to hear about what the cartoon characters are doing in Hawaii. And it was just a way for people to stay in touch with me and for me to communicate with them, not feel so isolated out here. I moved to Hawaii because I had spent 11 years in Massachusetts continuing to go to college. By the time I was finally done, I decided I needed to make up for all the vacations I never took, which is a joke because I feel like I've never worked harder than since moving here. And because I do have a hammock.

Mary: You do have a hammock.

Amanda: Yeah, I do have a hammock out there.

Mary: So, um, you got to Hawaii and I know you've since then done a lot of advocacy work and I know I'm an advocate for my own son as well as, you know, all the

kids that I've worked with and, and try to help. Um, but you don't see professional advocates, like professionals in the fields who are as much of an advocate as you are. You, you actually really got to Hawaii and said funding needs to change. At the time, different states were um, mandating ABA insurance to start paying for ABA. But Hawaii was kind of behind the times. And so you, you really spearheaded that effort and that's why you were able to become the first licensed behavior analyst in Hawaii. Were people surprised that it, that the advocacy was really being done by professionals as opposed to parents or did you have a lot of parents to help with that effort as well?

Amanda: In Hawaii we have everywhere, wherever you are, you have to look at the local climate and culture. And in Hawaii we have a lot of being Native Hawaiians and we have a lot of individuals of Asian descent. And there is this idea if you will, that it's a personal matter to talk about, right. We don't disclose our family history or um, something that people are maybe still a little bit unknown really. It's not as much talked about, um, here in Hawaii in general. So the parental role was that parents were relieved to learn.

There was something that could help their children that they were hopeful that somebody was here or that people, we're here to advocate for them. Um, but they were afraid to say anything publicly. So it put us in a unique position as providers where we almost had to be a voice in a way that we felt we don't, we are not trying to speak for other people in place of them, but we were able to consult and meet with and interface with a lot of individuals and then be able to be kind of, I say the microphone for other's messages.

Amanda: Um, so I am the face of a lot of advocacy that's happened here. And a part of that is because I'm fearless in a way. Like it does take thick skin. People will come after you if you're trying to achieve change. I think it can be unnerving and uncomfortable and scary for a lot of people. So Hawaii became the 42nd state to pass insurance reform. We were the last blue state to do so and when we were advocating for insurance, we did have, um, a self-advocate, Luke Pinnow and his mother, Geri Pinnow, who are at almost every single hearing. And Luke really became the face of the fight, if you will. Um, and our law is named Luke's Law in his honor, it was enacted at the time in 2016 with an age cap of 14 and a dollar cap of \$25,000 a year, which for anybody who is aware of some of the intensity of the services that tend to be provided, the projected costs can definitely exceed that and supports are necessary, needed and effective for individuals much older than 14.

Amanda: Fortunately, we continued our advocacy efforts and those age and dollar caps are no longer being imposed by our commercial health plans, even though our state law still says that. So we do see individuals like Luke and others who are much older starting to receive services here. They wanted our insurance

companies, uh, requested that we have licensure. They wanted to regulate the profession who was going to be providing the support and so that put us in a position to then design and develop licensure for behavior analysts in the state. We used resources from the behavior analyst Certification Board and the association for the profession of behavior analyst, um, their model licensing act. But we made two distinct deviations from all other states in our licensure. And these were made for very localized reasons. The one is we required any direct support worker or one to one who is providing this instruction to become a registered behavior technician, which is an official credential offered by the behavior analyst certification board.

Amanda: And the reason why we did that is because we felt that that level is necessary given the amount of bleeding, harm and injury and insult that we were hearing on the news on a daily basis. And so we wanted to at least put our ethics and our protection for consumers out there in that way. Um, the second thing that we did that no other state has yet to do or yet to imitate, is that we did not carve out our Department of Education. So, and other states licensure laws have gone into a place; they have supported the insurance, um, rollout and the individuals who access insurance, but they have excluded public school settings saying unless you're in a public school, which to me offers up behavior specialist consulting teachers, resource experts, you know, and they may or may not have a license or a training or credential.

So we chose to go that route here because Hawaii is consistently rated the lowest in the nation for the care of our special needs children. And also because we are one school district, meaning that if we can make change with the powers that be, it can trickle to the entire state much more quickly than Laura, than many other states.

Mary: What are some ways we can make the autism world less stressful? And you know, do you have any, any advice for parents and professionals who want to be less stressed and happier and not spend their entire life in fight mode?

Amanda: Um, find your champions and support them. Ask them if they need, you know, uh, if you can pick them up lunch or if he can cover their [audible] and their gas costs or their parking pay sometimes. I think everyone can help each other in that way. Create verbal communities, know that you're not alone, try to triage what you're working on as a provider. Um, we really made our state ABA chapter in the Hawaii Association for Behavior Analysis as robust as we could, and we made it look as fun as it as we thought others needed to see so that they would come and join our efforts, and we really have been able to kind of find it's, it's centered us, right? It's given us a common theme to come together about. And I find sometimes when we're fighting against something, the benefit is what's what we're pulling together for.

Amanda: So when I look at even just the language of how I talk about things, I'm not fighting against the Department of Education. I am fighting for our children. I'm fighting with our families. I even sometimes like to take the word fight out of it and say I am trying to be a champion for our children. Right? We are going to rally together. I think just shifting that language, I also think it's really important to know that, like you can take a break and the world is still going to need you when you come back. But it's also still gonna keep going without you for a minute.

Amanda: And I do take a break. Sometimes it takes me 60 days before I take a break and then I might take three or four days off if that's what's needed. Some people might need to take a break every single day. That's okay. I tell parents, um, and I, for providers, I want them to remember that this is not just a job. Obviously the providers who are advocating know that, but for our families, this is their lives. I say this is their heart walking outside of their body and we are here to help protect it.

So I, I find in Hawaii people are hugging each other a lot and I think that comes naturally with just the sense of Aloha, but don't underestimate the benefit of physical contact and just kind of reaching out literally physically, sometimes touching, touching someone or letting them know that you're there or that you need to know that they're there. I think that's incredibly important. Um, and we couldn't get everybody to agree that, you know, applied behavior analysis is what every child needs.

Nor are we saying that, well we are saying is that it's an evidence based effective intervention that we know is effective and for individuals who choose to pursue it, and should be available and if they are paying for their insurance, if they are going to schools, this isn't a right that is afforded to them and not a privilege. And so I do think we need to kind of all remember that what would we want for ourselves is what we want for, for others. And for people who are sometimes on the other side of the advocacy efforts. I just want them to know like, we're coming at it for a really good cause and uh, we're always trying to achieve a more happy, productive, sustainable outcome for these children, for adults, for these families, for ourselves and for our, all of us, I think just in general.

Mary: Well I think that is all good advice. I think we do need to advocate, we need to take breaks and we need to advocate for the good of not only these children who are diagnosed, but in future children that will get the diagnosis. I know advocacy efforts from two decades ago that I did for my son has helped other kids that come after and, and we all just want everyone in the autism world to reach their fullest potential, to be as happy, to be as safe and to be as independent as possible. And I know you and I have strong feelings about not only that kind of view, but also how important it is to disseminate this

information out to the world. And we were both doing that through social media efforts.

So I envision a long history to come along, future years of getting the word out about how we can turn autism around. And as you said with your first client that was turning autism pretty much completely around, or almost completely. And for other kids it's just, it's lesser gains, but it is all trying to get them as independent and safe and happy as possible.

Mary: So thank you so much for your time today, and I look forward now, how can people follow you? You still have your website behaviorbabe.com?

Amanda: Behaviorbabe.com still exists. It's gotten more and more robust so it's there. Um, Facebook is a great way and if people want to reach out and just email or ask a question, its behaviorbabe@yahoo.com so.

Mary: Okay, great. Well, and thank you for that. I know I visited your site and your social media sites. Um, Amanda was also interviewed for... I have a four part ethical series within my verbal behavior bundle and we give type to BACB use, so I know you have watched many of my videos within my courses. You're on our online community as well and you can find out more about that at marybarbera.com/workshops. I hope you enjoyed this episode and I hope you tune in next time for uh, another great podcast. Thank you.

Mary: I hope you enjoyed that interview with Amanda Kelly, otherwise known as Behaviorbabe. I've known Amanda for over a decade and I learned some new things about her awesome efforts to advocate for kids with autism and families as well as for professionals.

Mary: And one thing that I don't think we mentioned at the time of the recording was that Amanda started her own podcast called Behaviorbabe. It's available on iTunes and her podcast is also really good. I did an interview with, with Amanda, and she released that podcast on January 22nd, 2019. So go search that out. You might learn a thing or two about me and my efforts, but if you could support her podcast as well as my podcast by subscribing and leaving a great rating and review, it does help us get our message out to more parents and professionals. So thanks for tuning in and I hope that you also listen to next week's episode.

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.