



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 059

Autism and Family Stress: Autism Dad Reflects on Marriage & Coping with Autism

Hosted by: Dr. Mary Barbera

- Mary Barbera: Welcome to another episode of the Turn Autism Around podcast. I'm your host, Dr. Mary Barbera, and I am thrilled that you're listening today. Today I am interviewing Jim Christy, who is an autism dad as well as an award winning playwright and filmmaker. And I'm going to tell you a little bit more about him in just a second.
- Mary Barbera: Before we get there, I want to do a listener shout out from someone who left me a five star rating and review on Apple podcasts. Her name is Sue's Good and she said in her a part of her review that she is a teacher of K to eight, and she's also a member of my verbal behavior bundle online course and community. So here's part of what she said. She said, "Mary is like my trainer. I listen to these podcasts to and from work and they ground me with insightful tips, offering a roadmap that helps me feel less stressed and stronger in my technique. Mary's always so positive in her approach and I just can't say enough about her as an incredibly vital resource."
- Mary Barbera: Thank you so much to Sue for thinking that and for taking the time to write a five star rating and review on Apple podcasts. If you would like to leave me a rating and review, it really helps me help spread the word. So I'd love it if you would do that like Sue did. Okay. Let's get back to the little intro about Jim and our special interview. So Jim, like I said, is an autism dad. And in the interview we discuss denial, coping, decision making on the types of therapies upon a new diagnosis, and how that changes over time, and the impact of autism or marriage and family life. Jim's son now is 17 years old. So we're going to talk about both.
- Mary Barbera: We're also going to talk about Jim's play that he wrote; Love and Communication about a couple raising a child with autism. And that play is now turning into a movie. And so we're going to talk about that a little bit later in the podcast interview. So let's hop into my interview with Jim Christy.

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: Okay. So I am so thrilled to have Jim Christy here with us today. So welcome, Jim, thanks for your time.

Jim Christy: Thank you. Thanks for having him.

Mary Barbera: So, yeah, I don't think we've talked for many, many years. So can you tell our listeners about your fall into the autism world and how it all started?

Jim Christy: Sure. So my son, Jimmy, was born in 2002. And he started fairly typically, but was late on some of his markers: sitting up and crawling. Walking and talking were both actually not far off. So he, you know, for his first 18 months of his life, there was no very clear difference with Jimmy. And when we would take him to, you know, when we'd go to doctors, you know, we had a very high end pediatrician in New York city and we liked her a lot, and she would, you know... My wife was noting that there were just differences, that kind of subtle differences between Jimmy and other kids. He didn't seem to want to play as much or interact and he cried more than other kids.

Jim Christy: And, you know, our pediatrician was like, different kids go at different times and have different schedules and, you know, was very much like don't worry about it. And that was what I wanted to hear, you know, and I think both of us wanted to hear, but my wife was continued to be more concerned. And you know, I remember at one point our pediatrician, when my wife raised the word autism, you know, she really ruled it out at first. And she, you know, it's just like, I have kids with autism in our practice and they can't even look at you and make eye contact. He can make eye contact, you know.

Mary Barbera: How old was he at the time?

Jim Christy: At the time, about 18 months, I would say 15 to 18 months.

Mary Barbera: And did your wife have any kind of early childhood background? This was your first child.

Jim Christy: Yeah, I mean, you know, it was one of these things where, you know, I just think she sort of noted differences between him and other kids. More kind of just day to day things that were not, you know, these kind

of clear markers. And it wasn't really until that period between 18 and 24 months, we actually started losing words. So he had some speech and he started to lose it and he did have, you know, regression and that's when everybody paid attention. Right? Once you've got regression. And our pediatrician, you know, referred us to a neurologist and we got on the path to get to getting a proper diagnosis. But it took, I feel like it took a lot longer than it should have. And you know, I think and hope the similar experience wouldn't happen now where a pediatrician would be sort of a little bit dismissive of that concept of autism just because a kid has certain skills and has certain levels of interaction he had. I think there were the warning signs were there.

Jim Christy: So you know... And then obviously you're in the the mold of just trying to get as much information as you can. And quickly we learned that we got him into an early intervention program and then once he turned three years old, we were living in Jersey city, New Jersey, and he was a part of that school. And we had a really difficult time with that. They had what they called an autism program and...

Mary Barbera: How old was he when he got his diagnosis?

Jim Christy: He was almost three, he was about two, a little under three years old.

Mary Barbera: And when did he start the early intervention? Right at three?

Jim Christy: It was before three. I would say it was about probably at two and a half. He got the early intervention before he actually technically got a diagnosis because it were some delays that made him eligible. But, you know, the diagnosis was closer to three years old and that's when we kind of got into the school system where it was like that was, that was going to be the pathway. And realizing very quickly that we had a really difficult situation with where we lived. And that they had a very clear, you know, they had what they called an autism program in their school system, and that's where they were going to send him. And we had him in that program for two weeks and it was just really not appropriate for him. You know, we're reading everything and talking to people like yourself where we're trying to understand. And we knew very early on that we wanted an ABA based program. We wanted something that was a one-on-one. We wanted 30 hours to 40 hours a week. This is, you know, all of the things that you read that you want, especially in that period between three and five years old. You want as many services you can as high level as you can.

Mary Barbera: What did the school provide?

Jim Christy: Yeah, so it was a classroom with eight kids, one teacher and two support people. Those eight kids were all not necessarily autism. There were kids of different age levels and different skill levels. It was in a trailer. It was in a school that was so, I guess big and overflowing that they had sort of extra like pods of where the special needs area was in this kind of trailer and it was, yeah... Visually I have to tell you the whole thing just didn't, it didn't look good and it didn't feel right. So from a very early, you know, very quickly the vibe was just not what we wanted. And it didn't seem really right for him and for everybody we were talking to in terms of the level of services he needed.

Jim Christy: And so we took him out of that program pretty quickly and we found a private school and put him in a private school that was actually a pretty new ABA based program; that was good, but it was extremely expensive. And at the same time we got a lawyer that basically was like trying to help us convince our school system that he needed some more specific and better services than they could provide. And that process took a long time and was extremely costly. The tuition of the school, as you can imagine, was extremely high. And the lawyers fees were very high and we were doing it over a course of six and seven months. And we realized my parents had a fundraising benefit for us just to pay our bills. And, you know, it was very overwhelming. I mean I know that you know there's so much to that you're dealing with it at the same time. It just, the emotional thing of understanding your child has this diagnosis and where that's going to lead him.

Mary Barbera: So, yeah, let's talk more about that. So your wife was the first one to notice; the pediatrician and kind of poo-pooed the idea until he lost words. How were you, were you on board with your wife right away or were you like, she's probably overreacting? It's our firstborn. Let's not, you know... Like were you in denial at all?

Jim Christy: So it's interesting. You know, the word denial is a strong word. And... maybe I was, I still don't know if I would use the word denial about myself. I didn't have the same initial response as my wife did to his early not reaching his markers. And when our pediatrician was saying, Oh, it's not autism, that was definitely what I wanted to hear. The word denial... I don't know if I would say it because I don't know if the evidence was there to say, this child really has autism and you're ignoring it. And I will be honest that I've seen that. And you know, and I'm sure you've seen it and there's different levels I guess of denial.

Jim Christy: I'd say maybe I had a mild sense of denial because I was telling my wife, listen to the pediatrician, you know, kids go at different paths. Once the

information was more clear, I was definitely not in denial and we were all, you know, on the same page. I will say that my, you know, I think also about my family's response in that time... We've had a very supportive family experience on both sides. But I will say that in that early phase, before we had a diagnosis when we would bring up this concept of he's missing markers, or is there a problem here? Family would say there's no problem. There's no, you know, every kid goes at his own pace and from a very strong perspective. And so I don't know if I would accuse them of denial as much as people just want the best things and they want hope and they, you know, they don't want that word autism. And people will be dragged kicking and screaming before they, you know, they actually accept that word.

Mary Barbera: My husband first mentioned the possibility that Lucas had autism when he was 21 months old. And in my book I say, first page, my husband mentions autism. I tell him, what are you crazy? Like I never ever want to use the word autism again. I shut him down so hard for over a year, over almost 18 months. And in that timeframe, you can imagine how it's not good to be in denial for a let alone a year and a half. Lucas went into, he was in a typical preschool when he was two. So, you know, I'm just thinking he's speech delayed, he's going to catch up, you know, he's my firstborn. I think there's a lot to be said for that. But I shut my husband down really hard and we got a lot of false reassurance from very well meaning people, our pediatrician, because Lucas was going to typical preschool at two. He was, you know, he had some words; not a lot. I didn't know how to teach him words.

Mary Barbera: He wasn't doing anything weird. He wasn't stemming, he wasn't having problem behaviors. He was a pretty low key kid. So it's all confusing. And then, you know, I'm thinking because he actually, Lucas had really good skills early on. Like he was saying hi to people at eight months. So he had, yeah, he had a regression, but I had just had delivered my second son, Spencer. So I was like all like pregnant. I delivered Spencer, it's winter, they're both sick. It's like maybe it's just too much Barney, you know, it's confusing. And I, you know, we will get back to, you know, kind of the next steps.

Mary Barbera: But like, as you're talking, I'm thinking, you know, we have very parallel stories. And it's kind of funny because we're Facebook friends and we've been for many years, but I actually was contacted by you early on. So that was probably right when your son got the diagnosis. That was probably in 2005-ish when I was working for the verbal behavior project. And when I saw your name come up and the play and the movie that we're going to talk about later, I was under the impression that we were actually

related. So can you tell me, tell our listeners the story of how you contacted me and why I was confused about being related to you?

Jim Christy:

Yeah. It's funny because this is our unique kind of friendship. When you get introduced to somebody in such a way and then you're friends online and you forget a lot of the details. But I remember very much that you provided very... You're at a state when you get a diagnosis where you're getting so much different information from so many different people. And I think it can be paralyzing to parents. I really do believe that. I think, you know, that's why the play and the film I'm working on are really about that first year and all of the things that are swirling around and the different types of information people are getting. And in my play, INSERT TITLE, the experience of the parents is they're at really different polls about, you know, perspectives on that, on how they're handling that information.

Jim Christy:

But what you really get is... You have to just start to pick and choose who you pay attention to, and what you pay attention to. You're truly reading everything. You're talking to these two different people. You're getting advice from people with letters after their name and PhDs and doctors that are saying the exact opposite. Right? And we got through you through my aunt who I think has a relationship to your husband, through other family. And I quickly, you know, having Googled you or the version of that 12 years, you know, 13 years ago, realized that you were a professional in the industry. And when we talked, you were very practical and very specific about the services, you know, getting the highest quality services you can as soon as you can. And you know, it was an ABA based program and why that's so important and why it's different from almost everything else that's out there. And you know, we can discuss, you know, things about ABA and our perspectives on ABA, you know, it can be done well, it can be not done well and there are always kind of different kinds of variances.

Jim Christy:

But from the beginning, my wife and I were very aligned that we wanted a science based approach to trying to provide services to our son, and that ABA was that. And I think you were part of a group of people that were on that side of things and we followed that path. And I'm glad we did. I think one of the hardest things about this, like I said, is understanding who to trust and how to make decisions that are rational. One of the things, I think parents who are getting that diagnosis, it is such an emotional time and it is such, it is difficult to make rational decisions, you know, because there's so much being thrown at you. And also that it can be combative that there's a school district or insurance companies or whatever it is that are not acknowledging services and things like that.

Jim Christy: All of that, I think, contributes to people not necessarily making the best decisions, and pursuing alternatives that might have some basis in reality or it might have some good things about them, but that could take you off of track of what the child really needs. So part of what my play, my film was about is that that tension; some of those alternatives have good things about them. And I don't think that there's, you know... That ABA is the absolute only type of thing or that you know, that somebody shouldn't necessarily be looking into. But when it comes to the day to day, most hours of the time that you want your child to be doing and trying to progress, that was the path that we chose and felt most comfortable with it. Like I said, you were a part of that.

Mary Barbera: Yeah, because it is... when you get the diagnosis or even before the diagnosis, when the child is just showing signs, you have conflict over denial, whether it's one of the two parents; whether it's the grandparents and other people. So all in your head about... It's not autism, or, you know, and then you have kind of the next step of then what services, you know, a lot of times people don't even have a choice. It's like, like you said the school district just enrolled him in this class, which actually I had flashbacks then when you were talking about the class that he was enrolled in for two weeks because we had a very similar experience. It's like I go from thinking my son is going to be a genius because he's saying hi to people at eight months to, you know, he's going to ride a special education bus and be in special education for the rest of his life.

Mary Barbera: I was just like, that's not happening. Like I am going to get an ABA program and he's not... The classroom that they recommended for Lucas to go into, that they placed Lucas in, was in the middle of the city, in a gun zone. So they couldn't do any outside time because they were worried about gun violence. I was gonna have to either send him on a bus completely not talking, not able to tell me what he was doing at the age of three into this, you know, gun zone, or I was going to have to drive him. And then I had Spencer too, so driving two babies into the middle of the city, into a gun zone and dropping him off. And then he was going to be there for six hours a day with 15 minutes a week of one to one time. I was like, what person would say yes?

Mary Barbera: You know, and I have an advantage. At the time I had a master's degree, you know, I had a car and a computer. I had the financial resources to fight it, but you know, a lot of these people... So I ended up in a legal situation right off the bat. I did have some previous podcasts with Gary Mayerson who's a pretty famous lawyer in New York city. So that's a really good podcast. I have a podcast interview with Lucas's developmental pediatrician who diagnosed him. So those are some

good... I also have a podcast, a podcast number two, which is all about the importance of early diagnosis and treatment.

Mary Barbera: But you know, I think, you know, a lot of parents are in different countries even that listen to this and there's like nothing, you know. It's like, it's so confusing and it's so heartbreaking. And you talked about, you know, you had other alternatives to ABA and, you know, more of like a social emotional approach; child led. Which a lot of people, especially if they've seen kind of quote unquote bad ABA, they are thinking that, you know, more child led, you know, programs like, I mean floor time, RDI, relationship development, intervention, sunrise...

Mary Barbera: Those kind of programs look more appealing if you have any experience or have heard the people in your ear say ADA is bad, which you and I don't think that at all, obviously ABA is the most evidence treatment for autism approved insurance wise in all 50 States now thanks to people like Laura Unum who is also on a podcast interview, and we're going to link all these in the show notes, all these different podcasts interviews.

Mary Barbera: But it's like even just linking those, you know, five podcast interviews, I mean, parents of newly diagnosed kids don't have time for all of this information. I mean, it makes me overwhelmed and anxious just talking about it.

Jim Christy: Yeah, yeah, it is. And so it's interesting in terms of that, those types of programs and why I think it's very, again, it goes back to a lot of things that come up in the film. It's very personal how people respond to the different types of programming, right? And so in my film, it's very, it's kind of a left brain right brain thing; where the father has, you know, the comfort of ABA in that it is science-based; it is rigorous; it is, there is a plan made, you have a behavior trying to fix and you take a scientific approach to trying to fix it. And he is almost too narrow in his approach and how driven he is that he starts to be very dismissive towards his wife and her. And she also approves of the ABA program and understands the importance of it, but is also wants to pursue other things at the same time.

Jim Christy: Right. And this was actually our path that we looked into some of those more social types of programs because we just wanted to experience... We wanted to know everything. And we'd heard, so some people had had positive experiences with this. We wanted to learn ourselves, you know, how do we best interact with Jimmy? Right? And that was attractive to us. There are, you know, like you said, because if like anything can be done in a not great way, if ABA has been done in a not

great way, it can come off as a little bit impersonal, right? You've got people with charts and writing notes and things like that. It's so data-driven that sometimes that can be a turnoff to some people in terms of, you know, I want this to be more natural, I want this to be more organic.

Mary Barbera: And also, you know, I have two online courses now and I have a lot of members in my toddler preschooler course. And one of our just said her child was doing well with the online course and, you know, interacting with her child, he's happy. He's starting to talk within two weeks of purchasing my course. I was like, Oh my God, you know, this is amazing. You know, I'm getting all excited. Well in my course, I say, you know, start ABA, like my course is part of it, but you know, I'm going to teach you how to advocate and how to make a sense of this maze. Right? And so they get ABA and the ABA providers, BCBAs and therapists are like, you know, they're telling them about my course and how great, you know, they're making progress and he's happy sitting at the table. He's smiling, he's talking and you know what they said: you need to stop doing that. We're gonna, you know, use his bedroom, take him in there and expect a lot of crying in the beginning.

Mary Barbera: Well, I don't care what people are doing, if it's a social, emotional, you know, model; if it's whatever they're doing, if somebody says something is working with a two year old within two weeks, I don't care what it is. A reasonable person, whether you're a behavior analyst, speech therapist, other parent, doctor, should be like, what are you doing? Yeah, find out, well how, you know, show me we can incorporate this. We can mesh this. Why don't we sit at the table together and, you know, you transfer those skills to me? Not stop what you're doing. That's what gives ABA a bad name.

Jim Christy: Right. I mean, that's great. Yeah.

Mary Barbera: Kids crying is not good.

Jim Christy: Right. And if you're going to put them in a situation like that to sit, because it fits your narrow definition of, Oh, this is the steps that we need to take to teach. Because if it's not in this room in this structured way, I totally agree. I mean, it needs to be centered on the child and it needs to be. And you know, one of the things when going through this process for us of looking at these alternatives and, you know, what you start to recognize is that it is about how it's done. Right.

Jim Christy: And that ABA based program... You probably know Bridget Taylor and you know, she did an assessment of Jimmy a long time ago. And we were

talking about, I think I'd raised getting opinions about some of these different types of programs. And she was like, you know, this concept of making an emotional connection with a child to try to bring them out, that's just being a good therapist. Right? But that's not, that's not like, Oh, ABA doesn't do that. You know, that's not just in some other world. A good ABA instructor will be all about making that connection with that child as they're working. It's just that while they're doing that, they're doing it while taking data, while having specific goals, and trying to reach them this specific way. So that was a marketing point for me of just like that... It's not all or nothing, right? It's not that there's this left brain approach and this right brain approach and that, you know, never between. It's about finding the right people who are really going to be centered on that child and paying attention to what that child needs.

Mary Barbera: Pairing yourself with reinforcement. You know, my approach is just very positive. And, you know, I'm sure, read the book *Let Me Hear Your Voice* and what's gunning for, you know, recovery or as close to recovery as possible because that book, you know, motivated all of us in the 90s and early 2000s and right now, like hardly anybody's reading that book you know, but it's a very black, I think when you get a diagnosis, just like if you got a diagnosis of cancer or diagnosis, you know, it's very black and white thinking, okay, how do I fix this? How do I get it all better? It's not like, Oh well I guess I'm going to have to live like this for the rest of my life. I mean it's just a very black and white situation in a lot of cases.

Mary Barbera: And then you've got the husband and the wife in two parent homes who are all doing their own black and white thinking, and that often causes conflict and it's not about this approach or that approach. It's about focusing on the child and making it structured so they get enough trials in the right order of the right skills to make them... which are my goals as safe as possible, as independent as possible, and as happy as possible. With or without advanced language, conversational skills. You know what, we have to focus on the right things. And I think hopefully the behavior analysts out there, I mean it's kind of preaching to the choir because people that listen to my show and watch my videos and are part of my online courses are all on board. But if you are working somewhere where that is being told, like expect the children to cry and just make sense of the table. Like it's not a good approach. I don't care what you're going to call it. Please don't call it verbal behavior because it's not. Or don't call it my approach because my approach is not that.

Jim Christy: Well, let me kind of ask you a question referring back to our experience. And we talked about the stress levels. One of the things that I do think is very difficult to deal with is the pressure of the amount of hours and

when you're first getting that diagnosis, especially in that early part, three to five years and older is what I remember of it was, you know, 30 hours a week at least, and ideally more, right? And there's this intense pressure. I mean, you know, we were adding up hours, you know, we were like, how are we going to get us from this to that, you know? And I will tell you in sort of looking back on the longterm, Jimmy's, you know, 17 years old now and things like that. In his path, I worried that we over did the stress about the amount of hours at that, you know what I mean?

Jim Christy: And I feel like that, you know, we can talk about that kind of the pathway as your child gets older and you know, and obviously changes based on how severe the issue is... but that's something that was a stress point to us and I think is to a lot of parents is that number of hours and getting those services and adding those all up, and feeling that if you don't that your child is going to miss this opportunity for recovery, you know? And that is, you know, I really remember this kind of day by day feeling of like, weeks are passing and I'm not getting 30 hours, you know. And so anyway, that's a thing that I think about and I'm curious for your perspective and where that is now cause I'm not in that game.

Mary Barbera: Yeah, happy to answer that. I think that's a great question. So Lucas got 40 hours of therapy, you know, at three years. I mean as soon as I could get myself together. Luckily we were in Pennsylvania and at the time I could get him on medical assistance. I remember regardless of family income, like as a secondary health insurance and like there was a way around the back alleyway, which I figured out pretty quickly from other parents and I'm just like, I remember saying, well I don't want him on medical assistance. I mean why would I put them on medical assistance? We have insurance, you know, well this is pretty much the only way you're going to get it. So I'm like, okay, you know, so we got 40 hours. I remember we used the Lovaas approach, the Lovaas replication site in the beginning.

Mary Barbera: And I remember them saying, you know, they wanted us to stop preschool, which he had just completed his two year old preschool program. We decided to hold him back in two year old preschool so he'd have less, you know, less kids and he'd be going now with a one-to-one support person who would be also doing ABA. They wanted us to stop that, stop speech, stop OT and just do 40 hours and my husband and I were like, that doesn't feel right. I mean he was already not causing a fuss and he's not hurting other kids. You know he's going to be with the same teacher like we want, you know, Tuesday and Thursday for two hours each time to be an ABA person going with him to preschool. And so we were strong on keeping that. We kept OT. I think we kept speech. We

may have gotten rid of speech for a little bit, but now as a behavior analyst, a lot of my kids were only able to get 20 hours. I know a lot of my online participants aren't able to even get any of that.

Mary Barbera: One of my online participants, Kelsey, who is in podcast interview number three, Marybarbera.com/three... She tells a story. She's a single mom of two. She tells a story how she got ABA in Canada; drove him an hour each way to the clinic; and he was banging his head so hard, they were doing the wrong things. They're trying to teach him colors. He didn't even have requesting down. He was totally unsafe. She had to bring him on a leash and a harness, you know, and she was taking my course and when she started to question the ABA that was going on there, they basically, you know, told her they had a waiting list for other kids and you know... so she withdrew or got kicked out. I'm not sure which, but she brought him home and taught him herself.

Mary Barbera: And so even though insurance will pay now, you have to be careful that you're still, you know, like... So in my opinion now it's not about the hours, it's about the parent becoming the captain of the ship, learning how to do it across all environments in the home early on. And then, so there's a lot of debate, a lot of discussion within my own community about, well now he qualifies for, you know, the school where Jimmy's getting or an ABA clinic... but it's like, you just have to learn to ask the right questions; learn who to trust; learn what to do, what goals. Like even parents, like I was a nurse and a nurse manager. I worked in rehab, so I was used to multidisciplinary goals and how to, you know... But most parents have no idea.

Mary Barbera: And so you have to make sure you have the right assessments, the right goals, the right program, the right people, the right materials, the right structure. So like, it doesn't matter about hours. I mean, ideally each child should be engaged with the right procedures, the right pairing reinforcement throughout every waking hour. So it kind of worries me, even if you had 30 hours at a clinic or a school, or 40 hours for a three year old, that it wouldn't be near enough parent training.

Jim Christy: Yeah. I mean it's really the parent training part of it. And that was part of when we were looking at the social stuff and trying to learn the skills, I think it's so variable how ready a parent is to do that stuff, to really take it on. Right? I mean, and you know, I feel like we got to it decent skill level or whatever, but there were times where you would recognize that your child's been at the school, you know, once you got into what we, you know, the school is in, where it's really, you feel really good about it. And we've had afterschool programs with people coming out from the, you

know, ABA based programs in our home. But sometimes we have done some of that ourselves. And there are times where I've been like, I don't want to be a drill sergeant to my kid. He's tired. He's had a long day already. You know what I mean?

Jim Christy: So we struggled with that, even still. I mean the amount of directed time and the amount of, you know... how much you're overwhelming him, you know what I mean? And that's I think another thing where your brain shifts a little bit over time.

Mary Barbera: So he's seventeen now. How's he doing?

Jim Christy: He's doing well. I mean we're, you know... He has severe autism, you know. Jimmy's, you know, his language is very limited. He has some. He, you know, the school's focus is on, you know, skills. It's, you know, it's on, you know, things that lead towards independence. It's on things that could be in theory, job training from a very simple perspective. So, you know, we work with the people at our school. We really love as teachers. We feel like they're very much about making plans that are flexible based on where Jimmy is at any given time, you know. And so his progress, we look back and we think about what would the path be if he had been at a different program or whatever. We for the most part feel nothing but gratitude for where he's at, and what he's had. And I think it's a really important point for parents to be thinking about that the level of services and care that the child gets is not necessarily going to mean translate into a lockstep amount of progress that you think that you should get from the child's perspective of, you know, his Jimmy's cognitive development I think has limits on where it's going to go.

Jim Christy: But it's his skills and his ability to learn those skills and bring them home into our home and the community, very much I think is going to be based on how good the level of instruction is both at school and at home. So you know, it's a shift. It's a mental shift from where we were when he was three to six to even eight years old and where he is now from 10 to 12 to 14 to 17 years old, where you are thinking less about recovery and you're thinking more about, I want a happy young man. You know what I mean? I want him to be supported. I want him to have as many skills as he possibly can, but I also want accept who he is. And I think there's a tension there. You know? Of course the word acceptance is like...

Jim Christy: You know from the beginning you accept your child, but there is a tension there because you are from the beginning trying to shift that child's focus. Acceptance does not mean, Oh, that's okay that he doesn't want to look at anyone, he doesn't want to speak, you know? No, we don't accept

that. Right. We want an intervention for that. We want to bring him out as much as you possibly can. And we still do. We still do want to bring him out as much as we can; but when we have a party with our family and friends and you know, it used to be that, you know, eye contact with mom and you know, grandma and aunt and say the name. And now it's less that, you know, we do the high five and "hi" and then you can shift, you know, because it makes him unhappy, you know, at that party to be having to do every... Look up at, you know, take his nap, you know, take his chin, Hey, make sure we're not in that space right now. You know what I mean?

Jim Christy: Like we want him to be at that party and to be integrated and to be a part of it, but also to not be forced to do things that aren't going to make him happy. So, you know, it's something we struggle with and I think we'll always struggle with to an extent, but it is something that where he is now and where his progress is at that now, you know, I think we still want to focus as much as possible on things that are practical and that can lead him to a happier and more independent life versus things that are more geared towards, you know, what we would call recovery. You know, we're looking at that when he was much younger.

Mary Barbera: Right, right. Yeah. There definitely is a shift over time and you know, your goals and you know, and even if you're married, you know, marriages in autism families have a higher divorce rate... And I think it's because of all these conflicts and tensions and shifts that have to happen. And plus the requirements of, if your son were 17 and typically developing, he'd be driving, he'd have way more independence. And just the sheer level of supervision that's required gets draining over time. And the family unit, you know, you can't always do things together and, and that sort of thing.

Mary Barbera: So I did want to jump in quick about eye contact. I did do a video blog on eye contact and I never recommend you know, moving somebody for eye contact. I'm pretty opposed to that. But I agree it's like you, whatever it is, whether it's a high five or whether it's, you know, him just playing iPad during the party; you don't have to worry that there's going to be problem behavior or anything like that or getting a respite provider or whatever to take him out so that you can...

Mary Barbera: We just got back from vacation where we didn't bring Lucas. And you know, some people might think that's mean or odd or whatever. But it's like, he's not going to tolerate the plane trip. He's not going to tolerate just hanging out and relaxing. He actually thrives in structure. I remember bringing him down to Disney when he was really little and it was the first time he like had any self-injurious behavior. I was like, you know, he was

so overwhelmed by sensory input. And then when we got home, I remember bringing him to like Kmart and he was like, run up and down the aisle, smiling from ear to ear squealing and it's like, wow, you know, you bring them to Disney and he's really not doing well. And then you bring him home and he's like thriving with the structure. So, you know, sometimes during parties and stuff it's just too much.

Jim Christy: Yeah. Yeah. And you have to do what's right for your family. I mean, part of this is you're a family unit and you're going to bring the best to Lucas every day if you're grounded. It's gonna define you to some extent, your relationship with your child with autism, but it shouldn't define you completely. Right. And you need to have your own life. You need to, if you have other children, they need to have a focus, too. And they need to have time with you, too. And you need to have time with your, you know, with your significant other, too. And that stuff is all, I think a part of an organic family. And so pursuing things that are outside of that.

Mary Barbera: Do you have other children?

Jim Christy: We do, we have three. So it's really interesting hearing you talk about having your second right off of your first because we did as well. And I think that, you know... so Philip was born 15 months after Jimmy, and I was just thinking as you know, preparing for this is like how much that must've changed our mindset, like you said. And you know, just understanding we were getting this diagnosis when we're dealing with a very, very small child at the same time. And just what that throws at you in terms of, you know, your ability to make decisions and your ability to literally deal with going to, you know, visit different services or have people in our home and we're trying to feed Phillip at the same time, you know. Apically insane stuff.

Jim Christy: So Angela is, I think, you know, maybe four years, five years younger. And so that decision to have a third child, the decision to have Philip was really not, you know, we were thinking two or three kids and you know, we had Jimmy, Phillip right after. And there was no decision about that. We didn't know about Jimmy's diagnosis, but we did before we had Angela. And that was a very hard decision, you know, to have the third child when you obviously know the risks are higher and you know, your time on your ability to focus on, you know, on Jimmy. That decision was a really tricky one. And it was...

Jim Christy: Obviously when you have a child, you never look back. And Angela, what she brings and what, you know, our unit of five for us... something that was a very, like I said, a very difficult decision to make, but one that I feel

really good about in terms of not isolating Jimmy to a degree and not isolating Phillip to a degree. And that having this third child created this new set of dynamics and this kind of new set of support. So where there's kind of bigger group and I feel like that's more support for Jimmy in a way, you know, and that's just our path.

Mary Barbera: Any kind of delays? Worried about anything?

Jim Christy: No we did not. And you know, but obviously that was always the concern and you're terrified of it. And you know, you really, you can second guess yourself about everything. She actually did have a seizure and Jimmy had had seizures, so that was really scary. You know, we were into this different world whenever she blew by all her markers. I always feel like young girls... for us we had two boys and Philip was good, but he was just on his markers. And Angela was, you know, has always far exceeded hers and stuff like that. So from a pretty early age it seemed different.

Jim Christy: But yeah, it was a very difficult decision, you know? And it was, you know, it is one where I feel like the happiness of the whole family unit is so important. I feel like to support your child with autism and should not be overlooked. You know, this idea that you, if you're coming at everything with your child with autism from the perspective of stress and strain, I don't know. I feel like that comes across somehow, you know? And so just, yeah, I don't know. It's a priority for us, you know?

Mary Barbera: Yeah, no, it's priority for us. So before we end, I do want to talk a little bit more about your play and your movie. So you are a writer by day, and you work for a healthcare company. And then you're also a playwright and you've written a few plays in addition to this play. This play is called Love and Communication and now you're making a movie based on play.

Jim Christy: Correct.

Mary Barbera: And so Love and Communication is a play about a couple's struggle with getting a diagnosis of autism, making the decision, all of the things we talked about, the false reassurance, you know, dealing with the proposed placement which was not good and was going to result in great things you're finding, you know, ABA versus social emotional programs. And so, well we didn't really talk about the play very much... We did because that's what it all is. And it's not exactly your life story. It's kind of created from it. Like you weren't as in denial as or as focused on ABA only as the guy in the movie. And we'll post the trailer for the movie in the show notes. And you know, the play won awards. And so you wrote the play 10 years ago.

Jim Christy: Yeah.

Mary Barbera: So why this play? And it was received really well. Right?

Jim Christy: Yeah. So it's interesting cause when I first wrote the play I was definitely in a different head space in terms of closer to this moment that we're talking about that I feel is that, you know, kind of two to five year period when you first get the diagnosis and you're trying to handle that. And like you said, it's so emotional and it's so kind of difficult in terms of, I think, you know... In recent years obviously we're hearing more about autism in the media in general, and it's being reflected a little bit more on movies and TV; and you will see characters and things like that, which never was, you know, happening ages ago. And I think it's great. I still don't think what you see as much of is how it impacts families and how it impacts parents and the sort of almost Kafkaesque stuff that we're talking about, about how all these different things being thrown at parents on all these different strains and all these different types of information, and what that does to the family.

Jim Christy: You know, in my wife and I, our experiences, if anything, it's brought us closer together. Not that we haven't had conflicts, we certainly have, but for the most part we've taken all these different things in different parts and, you know, parts of advice and we've talked it through and we've thought about what it's, what's right for Jimmy. And we've made decisions based on that and we've, for the most part, been pretty aligned on it. But we have seen, and we know of a lot, as I'm sure you do, a parents where that stress and that strain released us starts to break them apart and that they have different perspectives on what to do about it and how to handle it emotionally. And that's what I felt like hadn't really, hasn't really been explored. And so the play and the film, you know, kind of go into what happens when these two parents really are coming at it from different perspectives.

Jim Christy: They both want so much to do what's right for their child and they're willing to do anything to do it. Cause we all are, right? But they're wanting to do it in different ways and what does that do to that family? What does that do that unit as they go in and explore these different directions? You know, one of the other things that it's also come up, it came up in our conversation that's a little bit more in the film than it was in the play, is this of the services. So in, you know, very much like we did, they're in a situation where their school district has a very narrow perspective on what is right for that child and they're not willing to explore a more deeper one-on-one type of, you know, ABA based approach and the financing for all of that.

Jim Christy: And like, like in our experience, they have their child in a program that clearly is not the right fit for them for a very short period of time before they pull them out. I think a lot about the kids that were in that school that we yanked Jimmy out of after two weeks. I just, they stay with me and my head. You know, those parents that put, you know, have those kids in that school, do they have options? You know, and we've had the resources to be able to say this wasn't good enough for my child and I am going to hire a lawyer. We actually ended up moving because that was the best thing to get him into a program. We had bought a house. We had only lived in it for five months and we ended up moving five months after we moved into this new house because we just realized the best chance for the better services were to get to move to another town.

Jim Christy: And that worked for us. We got him into the school we wanted because we were able to establish residency in an area, you know, where they were more supportive. Those kids in that classroom where we lived at that period of time, I would assume they didn't have the resources to make those kinds of decisions. That's another thing that I, you know, wanted to reflect and it's been very satisfying to reflect and film the experiences of another family that are going through a similar thing with a child that's a little bit older and just don't have the resource to make that kind of fight. And so these are things that, you know, have been very gratifying for me to try to address because I think that there are along the fringes, but there are things that aren't... We're not really seeing, you know, we're not really seeing and hearing those stories as much.

Jim Christy: And when I did the play, I will say that it was profoundly gratifying for me to share those stories and to have people who have been through it and, you know, come up to me. I have people, you know, give me hugs that I'd never met before and said, I've never seen our real experiences reflected this way. And that was, you know, just very gratifying for me personally. And then also people would never know about autism and have no idea about, you know, no history within it that really responded to the story. And you know, I'm not making a film because I want to raise awareness about autism in general. I feel like there's autism awareness is a thing and that's been great. I want to tell a great story, I want something that people find impactful and find funny and find relatable.

Jim Christy: But at the same time, I also want to draw them into what's happening in the experiences of people, families like ours and what we're doing, what we go through on what people continue to go through. You know, as I mentioned, I'm in a very, you know, a different space now that Jimmy is 17 years old. And we are looking towards this future and there's a whole different set of, you know, challenges... but this is that period when that

first diagnosis happened and those stresses. And I don't think people really know. I don't think people know what that's like, you know? And I think it's important that they do. Because there's so many people that are impacted and they have so many, there's such a variance in the way that people can react to that based on their resources and their emotional state and stuff like that. And I feel like it's really important that those stories are told and reflected.

Mary Barbera: Yeah. I think it's great. And I'm even trying to get to people for my toddler course, and I don't know if I told you, but I did tell my listeners, but in case they missed it... I am writing a second book and it is going to be for parents of kids with signs of autism, or a diagnosis. So one to four year olds, one to five year olds. During that critical window of time when they need to learn how to control tantrums, teach talking, teach potty, sleep, eating, socialization, who to trust, how to make decisions, how to make sure that the goals are really are about the child and not just some pack goals that are wrong. And those sorts of things. So it sounds like your film and my new book are going to really be, you know, very similar.

Mary Barbera: So, what's the process? How soon can we expect the movie out? Yeah. So you know, with independent film it's a, a process to find a distribution that we want. We're still finishing the edit of the film and I would think that I'll be finished, you know... The movie will essentially be finished I would say the early part of this year, March, April, May. And then we'll submit to film festivals and the film festival kind of run and how that goes will really dictate what kind of distribution I have. If you hit the home run, that means, you know, you could try to find a distributor that I'll bring it to a theater near you. And that's certainly the goal. If that doesn't happen, we're in an era right now where there's a lot of options in terms of self-distribution and iTunes and Netflix.

Jim Christy: And one of the things that I appreciate is you're putting people to our website and our Facebook page and stuff like that because even if we don't get that big level of distribution we really think we can find an audience with this film because I think there's a lot of people, I mean already just with a trailer, we've had pretty remarkable response to it. And and so my hope is that even if we don't get that large distribution that we'll find our audience through social media and through these other two platforms, cause we'll definitely screenings. It might be an online distribution and that will be about, you know, finding a groundswell of people to say, Hey, this is a story that really is about something important. And hopefully that kind of takes on a life of its own if we go that route. So that's where we're trying get out there and talk about it as much as possible.

Mary Barbera: Okay. Somebody might be listening with some connections, who knows? And so your website is LoveAndCommunication.com and we'll link that in the show notes. We'll put the trailer for the movie, which is great. And I think it's going to be a great movie. I'm happy to support it. And maybe we'll have you on again once it comes out.

Jim Christy: I appreciate that. That's great. Yeah, we have a really fun group, great talented group of people. And once we're sort of at the stage where it's actually out, you know, those are people we can talk to as well. I don't know if you've seen the Americans, one of our stars was in the show, and he's really great and a very funny guy. And there's a lot of great people involved. And so yeah, one word closer on. I'd love to share more detail. We'd love to come back and talk about it.

Mary Barbera: Awesome. So we're going to wrap it up. I usually end interviews, we'll do this really quickly. Part of my podcast goals are for parents and professionals to be less stressed and lead happier lives. And we've given some, you know, you talked about your family. Are there any specific things that you could recommend for parents and professionals to be less stressed?

Jim Christy: I mean, I think one of the things, a lot of things we were talking about in terms of your vacation story, I think that it really is important that you're grounded with and connected to your spouse and other children if you have them. And not blaming yourself for that, you know, and I think the word blame is a word that people, especially in that first few years need to address and think about, because I think it's very easy to blame yourself for what's going on. Right? I mean, I think a lot of us know that in terms of causes, I don't want to get into causes, but you do start to think about these things. And it's seemed clear that most of those causes are genetic, but we are reaching out and we want to blame something. Right? And I think that's where people get into environment factors and all these different things. And we start to, I think, blame ourselves. And I think it's so important that we look at our child and sort of accept the child again, while also pushing for as much as possible, the best possible results for them. But not blaming and accepting as much as possible, you know. And you know, we try to do things that are, you know, as much as possible that Jimmy likes. And you know, Jimmy likes to hike. We have a beautiful nature preserve here in Princeton. We take long walks almost every day. He leads us, you know, and he knows those trails really well. Things like that that are together and that, you know... it just, it makes you feel good to spend time with him and in a place where he's comfortable and happy.

Jim Christy:

And you know, I also think it's just important to follow your own passions and you know, that can be a real challenge. But my wife and I are very supportive and I try to give her as much time and, you know, solo time to do the things that she's passionate about. Obviously she's let me, you can only make an independent film on top of having a job if you've got support. But also just things that you're doing together... finding ways to connect. Obviously you mentioned respite. It can be really hard. I know that it can be a struggle to find, but just those little pieces of time, day to day mindfulness, things like that for solo time I think are also really important to just keep yourself grounded and connected. Cause if like I said, if you're happier and you know, coming at things from a more positive frame framework, I think your child is going to kind of get that and let it soak in.

Mary Barbera:

Great. Alright, well thank you so much for your time. LoveAndCommunication.com and if you're listening and don't know about my free online workshops, you can attend one at marybarbera.com/workshops. So thanks again, Jim, for your time and we'll talk to you hopefully after your movie is produced and out there. We'll have you back on.

Jim Christy:

Thank you so much, Mary. Appreciate it. It's been great to talk.

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