

Think Tank: Autism Awareness: Episode 2

Speakers:

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Amy You've been told your child has autism. There's all sorts of emotions running through your mind. Maybe you feel sad knowing your child is going to have struggles other kids don't. Maybe you're relieved just to have a diagnosis and a starting point. Maybe you don't know how to feel. On today's podcast, we'll discuss parenting and self-care when you have a child on the spectrum Hey, everyone.

Thank you for joining me today on the Think Tank podcast. I'm here again with Paul Carroll, the founder and creator of autismdadvocate.org and the podcast Autism Dadvocate. Thanks for joining me again, Paul.

Paul Oh, I'm so delighted to be back.

Amy So, Paul, today we're talking about the parents' perspective and autism, something that you understand firsthand. Would you be willing to share your story a little bit about how you felt when your child was diagnosed here?

Paul And it's so funny. That sounds like such a straightforward question. It's actually a very complex one. So when I actually answer it in two parts. So my answer may shock you. I was relieved. I was relieved. And I'll tell you why, because I had self-diagnosed him in my head as having autism, and the diagnostic validated how I felt.

So I was relieved. But it could be any range of emotions that parents, moms and dads feel sadness, maybe even a little bit of a loss. Maybe like me, relief, or maybe just complete confusion. The other thing I want to add to this is it was such a journey to have him diagnosed so that when you ask that question, it's like, well, it really wasn't a moment in time.

As I said, there was a diagnostic and we were presented to it as a specialist. But it was such a journey just to even try to get him diagnosed to. So very complex answer to a very straightforward question.

Amy Yeah. And did you and your partner react the same way or have the same feelings?

Paul I think we did. So my wife Jen and I both had already diagnosed him as autistic in in our minds. So we shared, I think, the same experience. Interesting that you asked that question because I think it would be fair to say to a lot of our parents listening that the mother, the father or the partners may have different reactions.

Amy Yeah, I can imagine. I have a son not on the spectrum, but he does learn differently than, you know. The school system is set up for and I took him to a specialist when he was quite young thinking that he might be on the spectrum. And I had this sense of like dread and fear because I didn't want him to have to struggle and I didn't want him to, you know, just have a hard time.

 So I remember that feeling, wondering if that was going to be, you know, how was I going to be able to handle it? And I wonder a lot, do men and women typically handle the diagnosis or the process better or differently? Or how does that work.

Paul In terms of their reaction? I don't know if I can answer that question. But getting back to your own situation with your son, although he wasn't diagnosed with autism, you said part of your reaction was, I don't want him to struggle. And I think that's important for our listeners to hear, because any time you hear the diagnosis, that's the first thing that comes to all of our minds, right?

 Oh, my son, my daughter. What a struggle. They'll have in life being neurodiverse in an overly neurotypical world. So I think you're onto something there.

Amy Yeah. Which makes you think that it's time to alter that a little bit. So tell me what obstacles you had to overcome and maybe your partner had to overcome Once you did get the diagnosis.

Paul Oh, how much time do we have? So many. I'll share the top ones. So I think the first thing that comes to mind is letting go of my definition of normal and letting go of perhaps prescriptive dream I had for the vision of my, myself and as parents. We all do this right, Amy. As moms and dads, we have a child and we have this vision of them.

 Winning an Oscar and giving an acceptance speech or scoring a touchdown. So I had to to let go of that and just embrace his uniqueness and redefine success. So I'm looking at success in my son's terms. Not like my dad's dream of like what I want for him. And

here's one example I'll share with you, Amy. So like I would say, my son is friendly. My son is friendly. He's social. Yet he doesn't have any friends.

Amy

Oh.

Paul

He really has never had a playdate. He's never had a sleep over. But, you know, it's interesting because he's the happiest kid in the world. And so as opposed to me having a reaction like, oh, my poor son doesn't really have any friends. He's in a happy place. He's friendly, he likes chatting at school. But when he's done with school, he's absolutely fine. So that's an example of like an obstacle in my own thinking I had to overcome.

Amy

Yeah. And I had a visceral reaction when you said that you probably saw it on my face. You know, this is like, oh, that just breaks my heart. And but I think what I heard you say was he's happy yes. He's content. So again, that idea that you've got to have doodles of friends and you've got to be the quarterback on the football team.

I mean, I played soccer growing up. I was on competition teams and I loved it. And I had these two kids that had no interest whatsoever. So I kept giving up that that dream, you know, that idea. But understanding that happiness has different definitions for different people, I think is, you know, key to what you just said there.

So, all right. Now, how would you say having a child on this spectrum has impacted your marriage?

Paul

So this is such a great topic to address. And before I jump into this with my autism dadvocate work, I have a podcast. One of the episodes was where I brought in his name was Eric Feig, and he is a marriage counselor. And his niche is counseling couples who have a child on the spectrum. I thought it would be a great idea.

It is unequivocally the most downloaded podcast in all of art. So it's clearly an issue in the community. It even surprised me, like, wow, look at the number of downloads. And so I'll tell you why. Amy, this is my own experience and what I've seen through the autism dadvocate work. When there is a child on the spectrum, the roles between husband and wife partners, they become very archetypal.

And what I mean by that is typically the mother is overwhelmingly the primary caregiver. Not only the primary caregiver, but the coordinator of any medical appointments, doctors' visits, therapies. It is a very overwhelming role that father can pivot and then become wholly

focused on being a breadwinner. Occasionally in the autism, in a family with a child on the spectrum, you can't have a dual income household.

It's just impossible. So one person has to make a decision to be a primary caregiver, an unfortunately in our culture, it's still primarily the mother. We have to change that. So the father becomes a primary breadwinner and primary caregiver to neurotic Michael's siblings. So the dynamic you have, Amy, is a mother and a father doing completely different things in a complex family dynamic. And I think that's what leads to marital strife and can lead to separation and divorce.

Amy

Yeah. Because I could see because it it can be overwhelming depending on your child's limitations to be a caregiver. Being a caregiver in general is exhausting its emotion. All it's triggering. It's all of these things. So I could see where there would be kind of a built up animosity for the person who gets to disconnect from that and go out in the world and be the breadwinner.

And I could see where that would lead to marital issues. So what my question kind of came up with this was when there are other kids in the home that are not on the spectrum, are they? How do they manage and how do they how do they get by? Because there's going to be one kid that gets more attention because he needs it.

Paul

Yeah. And ironically, I have a podcast episode on this as well from an amazing guy named Jesse Morris, who is, if you can believe this, to sound like a story about out of Hollywood. He is one of four triplets, not one of four quadruplets. Oh, my God, I can't. And one of his four paternal brothers is on the spectrum.

And I hate to use this terminology, but let's say just a little lower functioning. And so the experience he shared and he did share that he felt neglected. When I say neglected, obviously his autistic brother got a lot more attention and care. And he also moved into a role of caregiver himself as he got older and he became a little bit of a surrogate parent to his brother, who while they were quadruplets. So they were the same age yet in different classes at school.

Amy

Oh, I can imagine that being hard for any kid. I have twins and a girl and a boy. And it's amazing to me the pressure that you feel when you have kids that are the same age and learn differently and behave differently. So, again, I can relate to how that must have felt. But I still think that there has to be like and a huge weight for everyone in the family to have somebody that requires more time and attention.

Paul I would agree. And it's still even here in 2022. Autism is still a very great space. And you and I discussed in our last podcast one in 44, that is the latest CDC guidance. So it is a little bit of a shock to me that this is still such a great ambiguous space, given how common it is. One in 44.

Amy Yeah, that's just wild to me. But okay, I have another question. How do dads get more involved do you talked about you've got moms usually take on this role and dads usually become the breadwinner and go out and have. But how do, how do we get dads to want to be more involved if they're not the primary caregiver?

Paul Yeah. And so I'll add it's a great question and I am going to make some sweeping statements around gender norms. And you and I were talking about this in my experience, just my experience. Mothers and women tend to be stronger and better in this space. And what I mean by that, Amy, is mothers tend to be better at.

I need support. I need to connect. I need to reach out. What are the resources? What are the community with this complex situation that just, I think tends to come a little more naturally to women and mothers than they do for fathers and dads. I think that's underlying what I'm trying to do with autism dadvocate. And I think step number one is creating a really safe space where fathers can show up authentically.

Typically, my experience with fathers is resilient. Feel the need to care in a breadwinner fashion. That's how we as dads define care and reluctant to seek support. Share or truthfully don't even know where to begin. That's my own experience. Like when I started to see the signs, I did what every dad did. I'm just going to do a Google search.

And boy, let me tell you, that is not a good first step. Given how complex the Internet is. But I think creating a safe space for dads to share the challenges of being a parent on the spectrum and the challenges of one, maybe wanting to be more involved in that primary caregiving.

Amy And maybe just not knowing how to get involved. In typical male female relationships, women kind of just step up and take charge and the man or the dad, you know, they kind of just let allow that to happen. And so maybe it's like creating a norm that you step up and you say, I want to be a part of this. I need to be a part of this and making it okay to step out of those typical gender roles.

Paul Yeah, I think my advice to anyone is when you look at your spouse, your partner always approach their perspective in the dynamic from a place of pure curiosity. Like, if I think about my own experience with

my wife, I have to go in and understand that she is the primary caregiver and I need to enter that situation. Curious curious because it's very different than mine.

I typically default to breadwinner and other responsibilities, and it's great that we're seeing this, Amy, but let me just share a story that really brings at home. I was coaching and talking to a father of an autistic child, and he had a pretty demanding job. I would say it's probably more on the blue collar side, and he had to log a lot of hours.

He worked like 55 plus hours a week. He was a truck driver and he said, Paul, when I go home from my job, my wife is just depleted. It has been overwhelming for her for her to be a primary caregiver to our daughter. But I'm overwhelmed, too. I'm exhausted from my workday. You have two parents that are completely exhausted and looking to each other for support.

And I think all of us who are parents, you know that when you're tired, you're fatigued, maybe deprived of sleep, it's hard to bring your best self to your partner.

Amy And it's easy to argue.

Paul Yes, it's.

Amy Easy to start arguments when you're tired and you're depleted and point fingers because you have that animosity. She's home with the child and is worn out and he's on the road dealing with all of that and worn out. And then you just come back and it's it could be a ticking time bomb if you don't practice some self-care.

And get some support. So, okay, that's my next question is what are some tips that you can give to the people listening that have a child on the spectrum that they can do to increase their overall wellness and their mental health What do you think is like key for them to do to be able to, you know, manage all of this? The physical, the emotional, all of it?

Paul Hmm. I think step number one is to practice a little bit of self-compassion, first and foremost. This is a complex, dynamic you've entered. And I think mothers and fathers can both do this. Just understand it is a challenging situation. And however you feel is completely acceptable. The other thing I would advocate for, and I think this is true of just mothers and fathers of children but I think, Amy, the volume is dialed up.

If you have a child on the spectrum is to really try to make a distinction between yourself as a person and your identity. And I'll use moms if you're the mother of an autistic child that can just consume your identity completely. That is all you are. And it's easy to lose yourself in that identity. So understand, yes, I am a mother, but I'm also a person.

And as a person, I have other things I need to do outside of the mother role. So you mentioned physical, mental and emotional wellness. What are those things that you can do, even if they're small, that will incrementally recharge the batteries? And the same is true as fathers. You can overwhelm yourself in that identity. But what are those other things that tend to feed your soul and recharge the batteries?

Now, this sounds great. Amy, we're talking about this, but we know like well, if you don't have time, if you've got multiple kids and like there's like we know that for moms and dads or moms especially, there's zero time to really think in earnest. What are those small things I can do that can help me get through the day and keep me in a good place?

Amy

Yeah, I can see the idea of it being great, like I'm going to take 10 minutes, but it may be the 10 minutes that he's having a meltdown or she's having a meltdown. I know that when I was researching this a little bit, there was comments about, you know, everybody needs a rest, but everybody needs help and support. But finding people who are comfortable or capable seems to be like the biggest issue.

So how do people or how did you wrap yourself in support?

Paul

Hmm. So I think you're on to something really important in that. If you want to keep yourself in a good place, you have to have connection and you have to have community. Now, some mothers and fathers get it through a larger extended family. Some feel the need to completely align to those in the community, because what I hear is they get it.

So other mothers and fathers totally get where I'm coming from, like my extended family. They just don't live in that space, so they don't know it. But I think I may hesitate to answer your question because I stumbled and fumbled because I was looking for it and I was looking for something specifically for dads because I found a lot of great stuff communities and online forums and research, but it was not geared towards dads. And when I investigated it overwhelmingly, the memberships and community were mom based.

Amy

And so I saw that too. I saw that too. There seemed very little. That's why I was so excited when I did find your podcast because it's one of the few that is focused on kind of the male perspective, how you can

take care of yourself as a dad. But it just seems like there is this huge void out there of people who can step in and offer that respect to parents that are exhausted.

Paul Mm hmm. And so therefore, it's exactly why I created autism dadvocate. So a higher power spoke to me and said, if you can't find it, you create it. So that that was that was the birth, the birthplace of autism dadvocate. Yeah. And you talk about a respite or support. It really is about connection, because sometimes what I hear from dads, imams is I don't really need a respite.

I just need someone who gets it and that I can talk to and connect to and gets me and gets my situation. And as I said again, I don't mean to stereotype, but I think women typically are much better at this than men. And so if there are any male listeners, it takes a step of courage to reach out to somebody and share where you're challenged. It may require some vulnerability. It may require to show up authentically, but let me tell you, it is the best thing you can do for your mental health.

Amy Yeah. And that's in life, you know, that's not just as a parent, that's as a person. Having to be vulnerable and allow yourself to just feel what you're feeling. Right. We especially men, I did private practice for a long time, and the men really struggled just to, I think, just feel safe enough to say I'm sad, I'm depressed. I'm whatever. Because they have this idea that they have to be strong all the time. So I love that. I love that finding people that understand what you're going through. It sounds like a huge need, right? You need people that understand your story and support you through it.

Paul Exactly. And the key word you said, Amy, is safe. It has to be a safe form. Just because of some cultural stereotypes. So, Father, if there are any fathers listening to this podcast, please go to autism dadvocate that is your safe space for you. And if we have mothers listening and you feel like your husband or your boyfriend's or your partners need a place to please drive them to autism, because it's created uniquely for fathers to have. As you said, Amy, where is that safe space where I can show up and be a little bit more authentic?

Amy Right. And it's so good. I'm not I'm not fangirling here, but I've listened, and it's it really is good. And as a female listening to it, I got so much out of it. So I cannot recommend your podcast high enough. So just to kind of go back over, I think that we were talking about self-care and finding just even little moments in the day where you can take care of yourself.

And I think that that, again, is probably harder for you, but so important. And so anybody listening, if you feel like you need additional support, if you feel like there is something that you need to talk about, that you don't feel like there's a safe space, please talk to someone, talk to your doctor or talk to a counselor.

Talk to somebody because there is help available. Go to these podcasts, go to autismdadvocate.org. Get this support because we need you and we need advocates. We need people that are out there talking about autism and supporting each other. And if you're like me, you are a parent of kids, but they're not on the spectrum We need to step up, too.

We need to be out there offering support, offering, you know, safe spaces for people I just think that there's so much more that we can do as a community for people on the spectrum.

Paul

Yeah. And Amy, here's what I would say I love what you're saying about, you know, if you don't have an autistic child, how can you be an advocate? And this is what I would say. You can never go wrong from a place of curiosity as a father or even mother, as if you came and just said, tell me more about the uniqueness of your son.

Like, I can't even tell you the gratitude I would feel if you came in from a place of curiosity. What doesn't work? I'll share with our listeners is when you come in and you say something to this effect. I saw this amazing Internet article about autism, and I have to tell you about it. I saw this amazing thing on television. It was on America's Got Talent, a blind autistic. But when you do that, it shut me down because it's what I call shooting on me. It should the word should you should look into this Internet article. You should look into this TV program. You should look into this therapy come from a place of curiosity. Don't feel the need to tell me what you've seen on the Internet.

Amy

Because you've seen it all. You've seen it all. You've researched it all. Yeah. That that idea that we become experts when we're outside of the circle does not go over well.

Paul

Yeah. Amy, my favorite story, the you say the expert, the armchair expert. My favorite story is where somebody in my very close circle said I saw an article that said Diet can cure your child of autism. So have you thought about going gluten free with your son? Oh.

Amy

No, not.

Paul A shut down completely.

Amy Oh, I bet. Oh, I bet. Yeah. Oh, no, I didn't think about that. Yeah, there is a cure here now, so. Yeah, and that was another thing that I was reading a lot about was this, you know, people getting so frustrated with people outside of the, you know, the knowing coming in and saying there's a cure, there's a cure.

You just have to do this. You just have to do this. And it's like, how deeply can you punch a parent in the gut by saying you're not doing it right? I mean, every parent is trying to do it right and be good enough. And, oh, there's just an article I missed. I must be you know.

Paul I know, Amy, in essence, what you're doing is your mom shaming and dad shaming. Yeah. That person. Like how? Here I am. I'm not even the community. And yet I've. I've discovered the miracle. Yes. And boy, Amy, are there so many things wrong? So many levels of wrong when you talk about an article that says cure in quotation. Right? There's so many things wrong with that.

Amy Right? And that's not where anybody should go, especially those outside of that. I keep calling it the knowing, you know, I know what you're dealing with. I don't know what you're dealing with. I have ideas of what you're dealing with, but the only thing I can do is, like you said, be curious and ask, you know, tell me about your son.

Tell me if there's things that I can do to help So, Paul, we've been talking a lot about couples and two parent families, and we've also been talking a lot about the marital stress that it causes. And you and I actually talked about this in the last podcast, that the numbers of separation and divorce for couples who have a child on the spectrum is really, really high, somewhere between 70 and 80%. Depending on where you look. So what are your thoughts on that?

Paul Yeah, it's a disturbing statistic. It is anywhere between 70 to 80%. And you and I even discuss there is it's even hard to get good data on the divorce or separation rate with autistic couples because we are such an invisible demographic. But when you think about it, so if that is a statistic is true and I think it's fair to say it probably is pretty close to accurate.

Well, now you've got this dynamic of potentially a single parent household raising an autistic child, so. Oh, my gosh. Now we're adding further complexity on an already complex situation. So I think a few things that come to mind is then then the need to have broader support and community, maybe starting with the extended family, a

tight circle of friends and community becomes even more absolutely critical for that single parent. Being a mom or a father.

Amy

Yeah, and that's community, extended family, that's neighbors, that's the school system, that's health care. That's all of that that you've got to kind of spread that. Now, wide, because I can't imagine I mean, I really honestly can't imagine being a working mom, working all day, coming home and having all of the pressure on top of that. Like we talked about your friend, the truck driver who gets home and he's exhausted.

Well, that's what they're doing every day. They're doing that every day. So I love that idea that they need to cast the net wider and get additional support. But it's also going to be equally important that they find time for self-care, that they have to have that in their day. It's that old you know, the old airplane story.

You know, you've got to put the mask on yourself before you put it on the person next to you, because if you're depleted, you have nothing to give. So I think that's really a good point there, Paul.

Paul

I completely agree. I use the airline metaphor all the time. And the other one I use is that the gas tank. So if you're constantly putting gas in everybody's automobile, who is putting gas in your car? And so you do that through the community and the support. And what I would also add to this, Amy, is one thing that really concerns me when I think about some of the challenges of single parent households and let's be fair, it probably unduly affects mothers is mental health challenges.

And that is a that is an opportunity I want to explore with autism dadvocate work as how do we how do we bring about the conversation around mental health for this really, really unique situation?

Amy

Yeah, we need to normalize getting mental health, just like getting your flu shot. You know, it really needs to be a part of everybody's daily life is taking time for your mental health and working on your thoughts and your feelings and your behavior. So again, it's easier said than done and I'm sure it's hard, even harder for parents that have a child on the spectrum.

So, Paul, I just want to thank you so much for being here. Again, and sharing your story with us and helping us learn about being a parent of a child on the spectrum. And thank you for all of your information and tips If you are a parent of a child with autism and are struggling, please give yourself the opportunity to feel, to acknowledge how you're feeling.

Talk to someone, talk to your doctor, or talk to a counselor. But also take time to practice self-compassion, self-care. Take time every day to fill up your bucket, to fill up your tank. If you are a person that is outside of the knowing, outside of having a child with autism, reach out to those parents with curiosity. Offer support where you can.

Next week we'll be talking about just that, the community perspective and what we can do Even if your child is an autistic. Until next time. Thanks for joining the Think Tank podcast.

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