

Think Tank: Autism Awareness: Misconceptions and myths

Speakers:

Amy Hopkins, LCSW

Paul Carroll, AutismDadadvocate.org Founder

Amy I truly believe that what makes you different is what makes you beautiful. If you've ever had the honor of knowing someone with autism, someone on the spectrum, you know, they are always unique. Totally intelligent and sometimes mysterious. I'm glad you're here. Welcome. To the Think Tank podcast.

Hi, everyone. Thank you for joining me today on the Think Tank podcast. This is Amy Hopkins. I'm a licensed clinical social worker and I am so honored to have a guest with me today who is the founder and creator of Autism Advocate Dot Org, a fellow podcaster and the proud father of a child on the spectrum. I'm so grateful to have you here today, Paul. Thanks for joining me.

Paul Oh, thank you so much for having me. This is such a treat for me.

Amy So, Paul, if you wouldn't mind, would you just share a little bit about why and how you became an autism advocate?

Paul Sure. I'd be happy to add first and foremost, just a huge note of gratitude for spreading the message around autism awareness. I can't thank you enough. But, you know, when I think about the journey of autism, to advocate it was born out of my own experience, you know, raising a boy on the spectrum. And really the catalyst for it was at one point, you know, after he was diagnosed, I really struggled.

I struggled to find information. I struggled to find support. I struggled to find a community. And if you can't find it, then you create it. So in spring of 2019, I created the website that you mentioned, autism advocate dot org. And then in 2020, I launched the Autism Advocate podcast.

Amy Yes. And I've had the pleasure of listening to some of those podcasts, and they're incredibly helpful. The one thing too that I love is that it's from a dad's perspective, which you don't see a lot when you're looking for podcasts on autism or information on the Internet. So I really love that So let's level set really quick and talk about what autism is.

Autism is a broad diagnosis that is a spectrum disorder because there are so many types and subtypes. Autism is influenced by genetics and by environmental factors. It can create challenges for people in their social skills. They can have repetitive behaviors. They can have issues with speech or communication. The way that they learn, they think and solve problems can range from being highly skilled to severely challenged.

And they may require support in their daily lives, or they can live and function pretty independently. What you say that's a pretty good synopsis of what autism is, Paul.

Paul Yeah, it's a great synopsis of I think what I would underscore in that definition is the spectrum. And you highlighted that, you know, at that at one end of the spectrum, you have fully functioning independent adults. If you think in the news we're hearing about Elon Musk and the actor Anthony Hopkins, and then on the opposite end of the spectrum, you have some who require really, really strong care and they likely will never be able to achieve independent learning.

So absolutely it is such a broad spectrum on autism spectrum disorder.

Amy Right. So I think that that's important too, for people to understand because I know in the first time I spoke with you, you talked about images in the media of autism that aren't always accurate. And so I think it's important for everyone to understand is that you may come across somebody with autism that you don't even know that they have autism.

Like Anthony Hopkins. I mean, he's one of the most brilliant actors. And then you can come across someone who is on the other end of that spectrum that may not be verbal. So I think it's important that, you know, people understand that there are so many subtypes, there's so many variations and there's so many different things that it can impact for each individual.

So what I understand, Paul, is that in the United States, one in 54 children have autism. So this is no small group of people.

Paul Yeah. And what I would add to that, Amy, is and I've been seeing that stat, that statistic for quite some time on my podcast and website community. Now, the CDC for 2021 is actually saying it's one in 44.

Amy Oh wow.

Paul One in 44 children in the United States is born that spectrum. Now that may be because there's greater awareness a lot more diagnoses but yeah one in 44.

Amy That is incredible and EYE-OPENING and again kind of links back to that spectrum right? There's people on one end and there's people on the other end and there's a million little segments in between. So I would love it if you would talk about the stereotypes around autism.

Paul There's so many there's so many. And that's why, you know podcasts that spread awareness like this are so important and so critical. Because Amy, I will share with you. Before my son, I had stereotypes myself just because I hadn't had exposure. So as a few, I'd love to share with you. Number one, and you highlighted our depictions we see in Hollywood, on television or on film.

And you and I were chatting even before this episode, like I've shared, I want to destroy the movie Rainman. I just think there is a lot of people that I assume because of Dustin Hoffman portrayal, that that is how every individual bit boy or girl is on the spectrum and it is so one dimensional.

Amy Oh, I had no idea. I have met people on the spectrum. I have colleagues on the spectrum. I have the sweetest neighbor who is on the spectrum. And so when you brought up Rainman, I literally had no idea that that was them portraying autism. And I promised you then and I promise you now, I will never watch that movie again.

Paul I will say there is progress in Hollywood. But unfortunately, I think in the larger population, there is a perception in that, oh, Rain Man, or I've seen that movie, Temple Grandin. So, yeah, I'm very familiar. And surprise, surprise, you're not you know, Amy, you talked about the spectrum. This quote in our community that I love to share is when you've met one child on the spectrum, you've met one child on the spectrum.

Amy Yes, I saw that in that. And I think that is a great way to look at anybody. To be honest, I mean, anybody with any kind of limitation in how they learn or how they interact, really, we just need to learn how to be aware of what they need and how to help and how to stay out of the way, too.

Don't you think sometimes we get in the way?

Paul I would agree. And I think what you're basically underscoring is what we use in the community called neuro diversity. It's just a different type of diversity. We hear that everywhere right now across corporate America, around how critical diversity inclusion is. And it applies to autism with the term neurodiversity.

Amy Yeah. What would you say was another stereotype out there of people with autism?

Paul Oh, there's so many. And I should just share. This is so cathartic for me. So I really appreciate the forum. There's a few more I'd love to share. You know, the second one that comes to mind is and because of stereotypes, is that those with autism, they're emotionless or they don't show any empathy and certainly there are a few on the spectrum that fall into a category of being somewhat mechanical or expressionless.

But I can share unequivocally that is not accurate. Those on the spectrum are very emotive and can absolutely demonstrate empathy. I just look to my son as a great example of that, a few others I'd love to share. Another stereotype is that autism can be cured. Absolutely not. It cannot be cured. It is essentially it's such a farcical argument because it's almost like me saying to you, I can cure your left handedness, right?

I was born left-handed. It is just part of you who you are. So there is no cure. There are therapies that absolutely can improve the quality of life, but no cure. A few others that I really want to emphasize to listeners, especially if they're new to autism, is one is there is a belief, especially with high functioning, that if they just tried hard enough if they coached, they could be normal.

And this is a frustrating one for me and something I always address in autism advocate because there's a belief that it's purely behavioral. They just need to learn that is not true. And here's the metaphor. When I've heard that, I say, if your daughter had epilepsy and she had a seizure, would you look at her and say, you've got to try harder not to have seizures?

You would never say that to a girl with epilepsy. It doesn't make sense. We should have the same thing with autism when they engage in repetitive behaviors. A meltdown or challenges with their fine motor skills. It's not that they're not trying. It truly is part of the neurological condition.

Amy Right. I say a lot about every like any condition. When you talk about people that die by suicide, are you talk about people with depression

or whatever you wouldn't say to them with somebody having a heart attack. You wouldn't say, you know, if you just didn't eat that that bacon. You know what I mean? So I love that you brought that up because it's a huge misconception out there that if you just tried harder, if you just worked harder if you just read the right books, if you just took more care, that there would be this, you know, recovery.

But, you know, there are therapies to help people with autism become more capable with their neurologic and environmental factors. But it doesn't remove the condition. I love that you brought that up. I just I want to thank you for bringing that up, because I hear that all of the time. That it can be cured. What would you say are some myths around autism besides it can be cured if they just tried harder?

Paul Yeah, a few more come to mind in terms of myths. One is that all those on the autism spectrum disorder, they're good at math. And so natural. There's a belief that those with autism have like an X-Men superpower. What's his superpower? What's her superpower? And certainly there are some that have savant like abilities that are incredible, but that is a very, very small minority.

Amy And again, wouldn't you say that anybody could be born with a genius level in playing the piano? That doesn't necessarily mean Again, it's that idea that we throw out the net and include everybody in this idea. So what's another one you would say out there?

Paul Yeah. And I think the last one I'd love to comment on is a myth or a stereotype. That man, they're difficult to employ. And this is probably going to be the new frontier for autism advocate because hiring and the workforce of the future for those on the autism spectrum disorder is a huge new opportunity both for employers and those on the spectrum.

There is just so much this is new. So it gets me really, really excited to think that those on the spectrum are an untapped workforce and typically 75 to 80% of young autistic adults are either unemployed or underemployed. So we have a lot of work to do in that area.

Amy What you why do you think that is? Do you think that people just see their behavior or the condition and rule them out? Why do you think that is?

Paul It's a great question. I can answer in two ways. Number one, if you think about those on the spectrum, typically social interactions can be challenging. So it presents a challenge in two ways. One. Typically, they don't interview well in this classic interview fashion that we still

have in 20, 22. We really should be saying, is this person a fit for the job or do they interview well?

Paul Yeah, right. And then secondly, if you think about the world of work these days, it's nothing but interpersonal interactions and those on the spectrum can easily trip up be very little will be very direct. Some supervisors and managers get frustrated with some of the social limitations, and that also presents a challenge.

Amy And on the flip side of that, it also presents a huge opportunity because there are lots of jobs that I reference my neighbor a lot. He is more on the severe end. He has issues with the sound. So he's he always has his headphones on to the sound blocking headphones But he is the hardest worker you'll ever find.

He is very perfectionist. He does great work. He's always on time. He's just the greatest guy. And I know I went to see him at his work. And as just kind of when he first started there just to support him. And the manager said to me, I am beyond lucky that he's here. He is the best employee I have ever had.

So, again, I think there's this idea of what they can do and what they can't do. And that's putting a limit on their potential.

Paul Yeah. Typically, what the research has shown is those with autism tend to be fiercely loyal, huge hugely loyal to their employer and great retention. And if you think about what's happening right now in the labor market in 2022, we're seeing the great flight, the great resignation, huge numbers of attrition. So this is a workforce you want to tap because they're so loyal and want to stay with their employers.

Amy Right? Right.

Paul Yeah. And I think there are some important statistics for those listeners who are still learning about autism. In the autism community like you and I had shared. The really accurate number now is one in 44 versus one in 54. But there's some other sobering statistic. So boys are four times more likely to be diagnosed with autism than girls.

And there's still research. Do identify why is there apparently a gender link to autism? A few other things I want to share with you is 40% of those diagnosed with autism are either nonverbal or very limited vocabulary. So that's certainly a challenge with this very, very broad spectrum. But I think the last statistic that I want to share with you that I think is so critical and it was part of the catalyst for my creating the

autism advocate community and podcast is the huge marital stream that having a child on a spectrum can cause.

So it's very hard to get reliable statistics. But anywhere between 75 to 80% of marriages where there is a child on the spectrum either are separated or divorced. And that is a very, very alarming statistic for me. And so part of the Autism Advocate Mission is giving those fathers a forum where they feel safe, where they feel heard, where there's community to say this is a challenge and you're not alone and you shouldn't forge ahead alone.

One observation I've made in marriages where there's a child on the spectrum is the role has become very archetypal. So what I mean by that is that typically the mother becomes primary caregiver and therapy and medical coordinator and then the father becomes primary breadwinner and maybe a single parent to the neurotypical children. So there is a very, very complex dynamic in the family when you have a child on the spectrum.

Amy That actually breaks my heart that 75 to 80% of marriages are you struggle with when they have a child on the spectrum. It goes to show, I think, the level of dedication and devotion and energy that you need to have when you have a child on the of the spectrum. But it also goes to show the lack of support that's out there.

Paul Oh, my gosh, you nailed it.

Amy You nailed it. I'm so grateful that there are people like you that saw a void in the support and created something so powerful. I want to make sure that people know where they can find you. But I also want to let the listeners know that this is going to be a series. Paul has way too much information and knowledge to share.

So we're going to do a series on this, and we are actually going to be talking about the impact of autism on marriages. So please tune in for that again. But Paul, please tell people where they can find you and find more information about autism advocate.

Paul Yeah. Oh, thank you so much. So the website community is www.autismadvocate.org. Again, a community where we share stories, blog entries and the links to the podcast. The Autism Advocate Podcast is on iTunes and Spotify. There are currently 24 episodes and I am so excited Amy to share. I'm going to leave our listeners on the edge of their seat.

- Paul We're going to have our first celebrity guests at the end of the month. I'll leave that as a mystery. And then lastly, if you want to follow me on Instagram, it's autism advocate on Instagram. By all means, please follow. I include really inspirational quotes and also links to the podcast episode. Again, to create this online community of support.
- Amy And your website. I love to and I just want to spell this out, dad for Kate, it's a diva o c at its very it's very creative, by the way, but I want to make sure people can find it. Even though I am not a dad, I found a lot of information on your website that link to support.
- So if you're a dad or your mom or your sister or your brother, of someone on the spectrum and you're looking for support, this really is a good place to go. So, Paul, thank you so much for being here and for your commitment to spread awareness and acceptance for those on the spectrum.
- Paul And thank you again. A huge note of gratitude for spreading autism awareness through all these different media channels. Thank you.
- Amy April is Autism Awareness Month, but we really need to be talking about autism awareness all year round because we don't just need awareness. We need acceptance, understanding and inclusion. I hope today we all became advocates. Thanks for joining the Think Tank podcast.

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