

Adulting on the Spectrum: Learning to be a self-advocate and what Disney can teach about being autistic

Andrew M. Komarow

Welcome to "Adulting on the Spectrum," I am Andrew Komarow an autistic certified financial planner. I co-run "Adulting on the Spectrum," with my host, Eileen Lamb. Hey, Eileen.

Eileen Lamb

Hey everyone. In this podcast, we want to highlight real voices of autistic adults, not just inspirational stories, but real people talking about their boring life, basically want to give a voice people like us.

Andrew M. Komarow

Today our guest is Jeff Snyder. He was born in Providence, Rhode Island has lived his entire life in Seekonk, MA, he was diagnosed with autism in 1990. And ever since then, he has achieved multiple successes in life in areas of education, long term employment, independent living, and speaking engagements in panels.

Eileen Lamb

Hey, Jeff, thanks for joining us today.

Jeff Snyder

Thank you. Thank you guys. Thank you very much for having me.

Eileen Lamb

So Jeff, we want to ask our guests what they identify us as far as autism identity go, you know, how some people prefer on the spectrum, autistic? So you tell us and also your preferred pronouns?

Jeff Snyder

Um, well, first of all, I'm usually I'm usually very open minded with, you know, identity and stuff. And I mean, I mean, I always use autistic. I use autistic, with autism in my talks and my presentations, and then my pronouns are he and him. And I'm also I'm also hashtag up actually artistic and hashtag neurodiverse squad.

Eileen Lamb

Nice. We like open mindedness on this podcast.

Andrew M. Komarow

What was it like for you growing up on the spectrum, you were diagnosed at such a relatively young age? And what was that like for you?

Jeff Snyder

Well, I was first diagnosed with autism in December of 1990. And at that time, I was 21 months old. And also at that time, at the time of my diagnosis, if the ratio was one in 10,000 of for an autism diagnosis, and nowadays, it's really shocking, it's 1 in 54. But to get back to what I was, to get back to what I was talking about, I actually didn't even know I had autism until 1998, when Nick News came to my house and filmed me for a subject on autism. And so, but before that, I knew I was acting differently from my from, from my peers and from other kids I went to school with, I knew I had something going on. I just didn't know what it was. So it wasn't until I was in fourth grade, that I eventually learn the truth via Nick News.

Eileen Lamb

Your parents didn't tell them?

Jeff Snyder

No, no, um, I, I was I wasn't told, um, I kind of had to learn for myself. So

Eileen Lamb

Do you know, why is it they decided not to tell you about your diagnosis? And how do you feel about it? Do you wish that they are told you?

Jeff Snyder

Well, I mean, it's, you know, I mean, they could have told me, but I don't really know. But that's fine. If I, if I was told that I had autism, then maybe they would have used an analogy, like you have magic powers, or you have a special gift. And also, you could also, um, and then you could also have a sense that. But yeah, that sort of thing. But, but yeah, that that was how, I mean, it would have been any differently than it would have been no different than when I was interviewed by Nick News. So, I mean, that's, I mean, ever since then, that's how I, you know, got my diagnosis. If I could, you know, offer one bit of advice for parents who are struggling to tell their child new newly diagnosed children, is that is that, you know, just ensure that, you know, say that autism is like, you have a special gift or say something like, you know, you're a wizard, kind of like in Harry Potter. And also, also, be sure to be open and honest. I mean, don't be scared to say to your child that you know, you're never going to succeed in anything. Say to them that you're going to, you're going to succeed in life. You're going to make friends. You're going to make a name for yourself, and we're going to be with you every step of the way.

Eileen Lamb

That sounds very positive, what would you say to parents of autistic children who, you know, might not be able to achieve these things, like, for instance, my son is eight, and is on the severe end of the spectrum, and is probably going to be one of those, you know, autistic adults that can't live independently and can't communicate on on his own. So that's, I, that's why I have such mixed feelings about the "autism is a superpower thing", because in some ways, for some people sure it is, but for some people, it will never be, you know?

Jeff Snyder

Yeah. Well, I mean, I will say this for, for parents who are struggling to who will, who are struggling with their children that may never end up where may never end up being independent. And, and I gotta tell you, I mean, the thing is, when in life, we all want to be independent in some way. But there's a lot of components that come into being independent, there's financial independence, there's more, there's transportation, independence, and all these things can really, and these are very, very critical steps. And if you can't, and if the child cannot obtain that independence, then you know what, it's not the end of the world, the important thing is, we have to be there in the child's life. However, they can't be very, they cannot have any, they may not have the independence that a normal person would have. It's just, you know, it is, the key factor is to always, you know, be there and say, you know, I'm you are not alone, you are, we're going to be with you every step of the way. And we will help you in any way possible for you to obtain some level of that independence that you want to have. Because you have to also remember, some people may not or may not end up being, some people may not end up ever driving a car, or may not, may forever lack the skills to live on their own. So that's one thing you really have to, to keep in mind is just because someone doesn't achieve that level of independence, then it's okay. And it's also a good idea to connect with other parents who are in the same boat as you, you would have to, you could get their perspective from their point of view. And also you can, you can, you can connect with a parent with parent parents and families in one way or another because they know what you're feeling and, and you know, what they're feeling. So it's kind of like a duck, it's, it's more about being on the same page when it comes to being there for your, for children and adults who are neurodiverse and are struggling to an or who may never have independence that they want to have.

Eileen Lamb

Yeah, I like that. The message that you're not alone. That's something that I try to tell people on social media to, because honestly, it feels very lonely sometimes, and just knowing that other people are going through what you're going through, helps you know, it in some ways, you know, it doesn't take all of the struggles away, of course, but it's nice to connect with other people and find our tribe, like we say, so you describe yourself as an autism advocate. I think I got that. Right. So what does autism advocacy mean to you?

Jeff Snyder

Well, for me, autism advocacy, well, autism and neurodiversity self-advocacy is meaning that, you know, you're getting out there and you're reaching out to individuals and their families who are who may not realize that, who may not fully understand what they are really going for. And because a lot of a lot of family, because you and I were talking Eileen before the before the interview, that when I was first diagnosed with autism, it was one in 10,000. That was the diagnosis ratio. Now in 2021, nearly over 30 years after I was diagnosed, it's now one in 54. So, so, being a self-advocate is a field onto itself because you're going to be You're getting your name out there to say to families and individuals that you know what, I've been down that road, and I can help you out. And I also am I'm also a public speaker. So I've done talks about growing up on the spectrum. And I've actually done that through a presentation called "Autism and Disney Characters". There's two volumes to that. I've mostly been

presenting Volume One and hoping to send Volume Two at some point. And each of those, those two presentations identify certain Disney characters that may display traits of autism that we may not be able to see or understand. However, those traits that the characters demonstrate they are the same traits that neurodiverse people will display in life, whether it's being clumsy, or being prone to wandering or having routines disruptive, or a lack of personal boundaries, all these things can really be identified through Disney characters. And, and then also, another thing that I'm very passionate about is include is workplace inclusion, because I've worked in retail for over 15 years. And I've seen and one thing that I, I've started to try to do is, is to try to reach out to retail companies to try to see if they can make their stores inclusive, because at my place of employment during the pandemic they operated they set aside the, the first 90 minutes of the business day for senior citizens and people who are susceptible to the coronavirus. And if and, and I said to myself, why can we do that for people with like sensory issues or who are neurodiverse? So that would be the goal that I would, that I would that I would have is to reach out to companies and say, You know what, you know, for like an hour or for 60 to 90 minutes, once a week, have your store, be be sensory friendly, lower the fluorescent lighting, lower the music. And also also turn off any unnecessary noise, whether it's the checkout the beeping of the checkouts or, and also also have train your staff to be neurodiverse, friendly, and train them how to help out individuals who may be having meltdowns. So that would be something that I would like to see in retail companies accept but um, but again, you know, there has to be you know, there has to be a two sided moment here, both sides will need to win. And they will do whatever and, and if they do if they do that,

Andrew M. Komarow

And and I saw something just this week in Vogue Business of all places, and I was through the roof excited that was talking about you know, neurodiversity and retail. And something that I was so pleasantly surprised that the article mentioned was a smell as well. And you know, it's a combination of all of the, again, sensory overload. And it's sometimes it's not just one thing, but it's a combination. And what they found, too, I think, when it comes to the retail stores is that if they, you know, other people like coming in, during those senior hours, right, it's the very definition of universal design. Right, which should mean if it's good for one person with autism, it should be good for everyone. Right. So I, I think that, you know, I think that it's moving in the right direction with awareness and advocacy. And one thing I really liked that you said is your definition of advocacy, because I think you've been an advocate for a long time. Some would argue since the day you found out you had autism, but your advocacy with Nick Jr. Right? But how, you know, what I really like is how that you separate advocacy is about helping others and being kind and spreading a message and awareness and not just, you know, talking about you know your story. You you have a change You have things that you want to share, and not just to share a story by, you know, very specific goals and things you could relate to. So I want to say thank you. Because that's that's quantifiable, right? Everyone, almost everyone needs to go to retail stores, and almost everyone would want them to be sensory friendly. And the more people working on that the better. Is advocacy, your career, because there are many, you know, some I consider myself an advocate, I am not a paid advocate, and I consider it, you know, a privilege to be able to have a job that allows me to also advocate. And there's nothing, but I think there's many who would like to be paid, and compensated and make their advocacy a career. And it

sounds like you've made it at least a portion of your career. And could you talk about that, and maybe some advice for others who would like to do the same?

Jeff Snyder

Well, to be honest, I've actually, this particular, my advocacy I've actually been doing, the bulk of this has been for the past two for almost two years now has been the main portion of this advocacy prior to that I was in the I was in the Brony fandom. And for those of you who don't know, bronies are fans of My Little Pony Friendship is Magic. And I would go to Brony convention, so and I would see people, you know, give presentations on aspects from that show. And that was kind of my formal training, if you will. And I was also a fanfiction writer, I was also a fanfic writer. I was a freelance fanfiction writer for the show. So that was kind of my formal training. And then, and then, after the Brony fandom died down, I decided to take what I learned from, from being in the Brony fandom, and bring it to autism, self advocacy, and the some of the things I brought in to work, the sense of community because the Brony fandom was a community of people with the same interests and the same goals as I had. And then also you had, and then also, there's the matter of speaking in front of speaking in front of your peers was another one, because you can speak and talk about whatever you want to share in front of an audience. And then it actually goes further than that, because I also did, I was also a gifted public speaker, when I was in school, I did a lot of times, I had a time create presentations for some of my classes when I was in school. So that was, that was one other key aspect to my training. And then, and then I actually, and then I start sort of built this advocacy from sort of like a business, if you will. I mean, I've already done I've done two paid speaking engagements this year, which I have been compensated for, made about upwards of like, \$300 already, for those two events. But yeah, I mean, I would like to try to, you know, get, but it's more about, I would like to get more, you know, engagements where I get compensated. However, it's more about getting the message out there. It's more about getting people to come. And listen to what I have to say, because some of the things that I say, are things that people have never heard about before. So that could be something that's more of the message that I have. And yes, this is, this is kind of a career. For me. It's a career that, as of right now, you know, it doesn't get it doesn't, you know, pay very much. But again, it's more about getting the message out there. And I also have a profile on Speaker Hub that I sometimes go on to look for, like paid speaking engagements there. So. So, like, if I want to apply for a paid speaking engagement, I'll go on to Speaker Hub, but it's more about them coming to me, rather than me going out to them. It's about it's not just about getting your name out there. It's just about how can you bring them in and listen to what you have to say. And it's one of the thing and another thing I have to keep in mind for in terms of being an advocate and a public speaker is you got to have rhino skin. Because not everyone is going to want to hear what you have to say. You have to you're going to get people who are going to say no, I don't want you to speak for this event or I don't watch, we think that what you're presenting is not going to be acceptable. That's one thing that I have. That's what if I could give someone who's trying to be a self advocate and a public speaker for the autism and neurodiverse communities, that is trying to get that sort of who's trying to, you know, become a public speaker, that's what you're going to have to contend with is, you got to have rhino skin when it comes to having when it comes to, you know, doing your advocacy and stuff, and also some people may also be very opinionated with can also be extremely opinionated.

Eileen Lamb

Because yeah, let me ask you about that. I know you've spoken about autism and bullying before, you know, because some people have very strong opinions on social media, and they share it, they will let you know about it. And it can be hard sometimes to be an autism advocate, when people are so eager to share their views, and they feel so strongly about them. So can you tell us more about autism and bullying and how you feel about it?

Jeff Snyder

Well, I mean, and I'm going to say right now, I was never bullied in, in school, but some of my friends who are also neurodiverse, have been bullied. And, and there's and honestly, and also, in the first two characters, I talk about my autism and Disney characters presentation, talks about you know, being easy targets like the character of Gus, from Cinderella, he is very, very, he's very, very prone to bullying from, from Lucifer, the cat. And he is very, very prone to bullying because that what Lucifer and Gus represent are individuals on the spectrum that are very, that are, that are very vulnerable, they're very vulnerable to specific bully they're, they're vulnerable to bullies. And that's what Gus represents, in Cinderella. So that's one thing that you really have to, you know, keep in mind is that what you see in characters like Gus, is what you're going to see in real life. And unfortunately, in the age of social media, we're seeing online bullies, you know, target their victims from, from, from the, from the comfort of their own home. And that is a very, that's a, that's a major problem. So you really have to keep in mind that bullying can happen, not just nowadays, bullies can happen, not just in schools, they can also target, they can also happen online. And that's a major problem that I think a lot of organizations will have to contend with. Um, going forward.

Andrew M. Komarow

Eileen, you should ask the next question, even though I was kind of because we got to see the puppy.

Eileen Lamb

Oh. So what do you think about the actually autistic autistic hashtag? And why do you use that hashtag when it's often associated with, you know, hate, and sometimes hate that is directed at you too?

Jeff Snyder

Well, it's more about, um, it's more about, you know, letting people know that I'm on the spectrum. And, you know, I'm autistic, I'm, you know, I'm a smart, smart person, but, you know, I do have the flaws, and I do have, you know, the work, I mean, I'm always going to be a work in progress, I've got dents, I've got quirks, but I've got flaws that make this work. And for those of you who don't know, that's actually, um, lyrics from a song on "My Little Pony," called "We're not Flawless," from season seven. So that that is a good example right there of you know, nobody's perfect. And, you know, you can write, you can write down your mistakes on there, written in ink. So, that, to me is something that will, I mean, it's okay to, it's okay to show your identity for who you are, you know, you're, but I'm also a member of the Neurodiverse Squad. That's the other hashtag I use, because I know what it's like, I know how it is. I know what it's like to go through, you know, being on the spectrum. And dealing with

critics that you may not be able to understand what they're saying, or you might or you might translate that is something like being something offensive. So so that's where that's where things, you know, really go. So

Andrew M. Komarow

I think those hashtags is especially actually autistic, in particular, for people who may not be aware, are commonly associated with very bullies who you mentioned? Are you just kind of doing your own thing? And knowing that you're doing things right? Are you afraid that, you know people will maybe associate you with bullies? That some might? Or do you think that the hashtag is here to stay? So the best thing to do is kind of reclaim it with your kindness? And how do you stay so genuinely nice and kind in the state of everything? And just the face of adversity and challenges in hate? How are you so nice?

Jeff Snyder

Well, the important thing is that I try to be a good role model for people. I mean, I have to, and also, part of the reason why I got into autism, and neurodiversity self advocacy is because I have two nieces. One is one is four years old, and my youngest is one. So part of the reason why I became a advocate is because they are going to be growing up among people who are on the autism spectrum. And the last thing I want is for them to grow up and end up being being bullies to other to other students who are neurodiverse are on the autism spectrum. And if by doing this advocacy, I'm kind of teaching them for what they're going to expect later on. And when they when they get older. But then also, the fact of the matter is that, you know, and the fact is that, you know, I can always, um, I can always change from actually autistic to something else, maybe that might be the best, maybe the best way to get attention, but I do I do disclaim that, you know, I don't want to offend anyone. And I'm really doing this for the, for the common good.

Eileen Lamb

That's, that's really good. You know, we've been trying to get some traction on other hashtags, which I've been very controversial, like, actually diagnosed. You know, because we, we feel that sometimes self diagnose people tend to control the narrative around autism. And they've been, there's been a big increase in self diagnosis with, you know, social media, TikTok, Facebook, Instagram. And, and sometimes, I mean, obviously, out of all of these people, some of them are not going to be autistic. It's just, they can be, yet they speak for the entire autistic community, as if we all speak, we all think the same. First of all, that's an insane thing to think, because we're all individuals, you know, and we're not all gonna share the same views on autism. But yeah, my point is we we tried, like using the actually diagnosed hashtags. And maybe that would be too on the other extreme, and there is somewhere in the middle, because, you know, we don't want to exclude people who don't have access to a formal diagnosis, because it's too expensive, both who are actually on the spectrum. Yeah. But it's a fine line between the two, like, how do you feel about self diagnosis and including those people but at the same time, making sure they don't speak over? Or speak for the entire community? How do we do that?

Jeff Snyder

Well, if you want to do a self diagnosis, I would probably seek out like, like a psychiatrist or a psychologist, and they can and will lead and they will be the ones that will officially make the diagnosis self, people who self diagnose that's kind of walking the fine line in terms of, you know, you know, you want to share your story with the world but how are people going to react? What is the one story because people who say, you know, hashtag self self diagnosed with autism or a neurodiverse condition, some people may view that as gaining a form of attention or, you know, this person is doing this to, you know, try to be better than somebody, but it's better to get diagnosed by a professional, medical professional than just say, you know, Hey everybody, I'm I'm on the autism spectrum. So, I mean, that's, uh, yeah, that's, I mean, if anyone on here, anyone's listening to this interview that wants to get on, wants to, you know, find out if they're on the spectrum, if they're neurodiverse or not, then I would seek out, I would seek out a doctor, I would seek out a medical professional, and let them be the judge of whether you have autism or not.

Eileen Lamb

I think we share the same views. It's, it's nice to be able to talk about these things, because these are important topics in the autism community. And I don't hear actual conversations about it very often. So I appreciate you sharing your your thought on that. Is there anything else you want to share about Disney some really cool facts that you're just burning to tell us?

Jeff Snyder

Well, well, like I said, I, I create I've created two presentations based on autism and Disney characters. Hopefully, I can present Volume Two at some point. But um, but I'm also a big Disney buff as well. As you can see. Just above my shoulder, you'll see the original Tinkerbell from "Walt Disney's Wonderful World of Color,". So but but I've been I've been a huge Disney fan all my life. And, you know, I've been to I've been to Disneyland. I actually have a cousin that works at Disneyland. I've been to Walt Disney World once, but I kind of prefer Disneyland because it's the park that Walt himself walked on. And it's also very easily navigational. So but but yeah, I mean, I collect you know, all Disney movies I've collected. I've collected any Disney related material growing up, and and then you know that, that sort of thing. And then I'm also I'm also I've written a fanfiction, and for those who don't know what fanfiction is. Fanfiction are stories based on movies, cartoons, books, any form of entertainment. So I've written plenty. I've written several Disney fanfics that are currently on fanfiction.net and also on deviantart.com. So my username is Twilight Sparkle 3562. If you're interested.

Eileen Lamb

I'm sure some people will. I know Disney is a special interest of a lot of people, even those who are not on the spectrum. So you'll you'll get some. It is reading you it's stories that you wrote or is it's audio.

Jeff Snyder

It's stories that I've read.

Eileen Lamb

It's written. Okay, cool. Yeah, I like creating. Alright, we, we want to ask you some quickfire questions now. So we, I, I asked you a question and you tell me the first answer that comes to your mind.

Jeff Snyder

Okay.

Eileen Lamb

Good. What is the best piece of advice you've ever been given?

Jeff Snyder

Basically, just just to be myself and, and don't let others you know, doubt me for who I am. I mean, I'm, you know, I I was born. I was born this way and I live this way.

Eileen Lamb

Beautiful. What do you like to do to relax? Let's think I know.

Jeff Snyder

Ah, well for one thing I'd like to you know, play video games. I like to watch. I like to watch movies. I have a large physical DVD collection. And I also like to you know, go for walks and stuff and

Eileen Lamb

VHS?

Jeff Snyder

DVD.

Eileen Lamb

You don't like VHS?

Jeff Snyder

I used to have VHS but there at my folks house.

Eileen Lamb

We just had a guest who was so happy because he just got a VHS tape and he was so excited to have it in his hands. Hi Seth if you see us! What is your favorite food?

Jeff Snyder

My favorite food is there's a whole gosh, there's a whole variety of there's like pork chops. Rice Pilaf. I like chicken parm so

Eileen Lamb

Oh good. What's your favorite movie? TV show?

Jeff Snyder

Uhm favorite moviei, as a kid. it was . "Snow White and the Seven Dwarfs" And as an adult, it's Fantasia"

Eileen Lamb

Oh, good. Okay, tricky question. What is your favorite Dreamworks movie?

Jeff Snyder

I would have to say probably Shrek, the Shrek films.

Eileen Lamb

Yeah, I've seen those Andrew (all laugh) Well, Jeff thank you so much for joining us today it was really great to, to chat with you. And if you want to tell our followers where where they can find you on social media, I know we've kind of touched on that but if you want to tell them again, tell tell them now.

Jeff Snyder

Um, I am on Facebook, I am also on. I am on I'm on Facebook, I am on LinkedIn, I am on Twitter, and I am on Instagram and I'm going to put into the into the chat wall for you guys to to share. In a follow up I'm on WordPress have a blog called "Going the Distance," it is the website is Jeff Snyder, autism, neurodiversity, self advocate.wordpress.com. I update blogs every Monday through Friday. And then you I also have listed my speaking services, volunteer services if you ever want me to come out and speak to your organization or also, if you want me to help out with like any be on a panel or help out with like any volunteer events, fundraisers, you can also reach out to me that way. In addition, I am also a contributor to a book called "This is Autism," by Jessica Leichtweisz and Allman-Cooper. It is currently on Amazon.com for \$19.97. And if you ever want me to sign you a copy at a future in person event, please bring your copy and I'll be happy to sign it for you.

Andrew M. Komarow

Thank you so much. Thank you for coming on the podcast.

Jeff Snyder

You're very welcome

Eileen Lamb

Bye.

Jeff Snyder

Thank you for having me. Bye