

Adulthood on the Spectrum: Constructed language, job hunting and Pokémon

Andrew M. Komarow

Welcome to "Adulthood on the Spectrum", I'm Andrew, an autistic certified financial planner, I co-run "Adulthood on the Spectrum," with Eileen Lam. Hey, Eileen.

Eileen Lamb

Hey everyone. In this podcast, we want to highlight the real voices of autistic adults, not just inspirational stories, but people talking about their day-to-day life. Basically, we want to give a voice to a variety of autistic people.

Andrew M. Komarow

Today, our guest is Joy. She is an autistic writer with a particular interest in constructed language, professionally, she is seeking employment and developing some professional skills before returning to school for creative writing.

Eileen Lamb

Hi, Joy, thank you so much for joining us today.

Joy

Thank you for having me.

Eileen Lamb

So we want to, we always ask our guests that was the like to identify and I'm talking about pronouns, but also your identity as you know, autistic person and person with autism, on the spectrum, what are your preferences?

Joy

I use she/her pronouns. As for person on spectrum, autistic, I use all of them. It really doesn't matter to me.

Eileen Lamb

Us too.

Andrew M. Komarow

What is your diagnosis, diagnosis story? How did that affect your life?

Joy

I just I was in and out of therapy, they gave me medications and things nothing really seemed to help. And eventually, when I was a teenager, I got diagnosed misdiagnosed with borderline personality disorder. And to me, it was like, you know, this, I guess it sort of fits on the surface, but I don't think this is what's going on. I had an autistic relative, but even then I wasn't really putting together the dots. So I was referred to this therapist for the borderline personality disorder. And she looked at me, and she worked with me for a while and she pulled me aside after one session just said, you know, I don't really think you're autistic, or I don't really think you're borderline I think you might be autistic. So she referred me to the neuro psych, who was working in the same facility, and had the evaluation and surprise. It turned out I had been autistic for my entire life. And so at that point, I, she, I continued to work with this therapist, and she was with that approach, she was able to sort of teach me how to advocate for myself, helped me become more aware of what my needs actually were, I really got a lot more stable. Being able to advocate for myself was probably the biggest thing, and I managed to get through college, I don't think I would have if I had had the support of a therapist, and the self awareness that came from getting diagnosed.

Eileen Lamb

Did you keep the borderline diagnosis? Or did that go away when you were diagnosed with with autism?

Joy

I think that went away.

Eileen Lamb

Now you're just when you see her you're focused on like working on the autism part and not the borderline. Got it?

Joy

Yeah, and you know, the depression, anxiety, those, those are pretty constant. But

Andrew M. Komarow

And it is pretty common for a lot of people to be, you know, misdiagnosed with borderline personality disorder, you know, first, and there are similarities for a reason. But they also both exist. Not everyone who is autistic, you know, is misdiagnosed, borderline and, you know,

Joy

Right, and there are plenty of people who do have both it's yeah,

Andrew M. Komarow

What, what did she say were the main reason she didn't think you had borderline and she thought you were autistic, if you can remember?

Joy

Well with emotional dysregulation in general, I've been diagnosed with borderline when I was 17. And I wasn't presenting with that at all by the time I got diagnosed.

Eileen Lamb

Life is all about change. And you've had some major life changes. Recently. You got married?

Joy

I did, yeah.

Eileen Lamb

Can you tell us about how you made the wedding? And do you have any tips for having an autistic friendly wedding?

Joy

Um, keep it small. That is the vain tip I have for an autistic friendly wedding. Crowds are just really, really hard and everybody's going to want to come up and hug you and things. So if you keep it to just your family and really close friends who really want to be there, I guess there's the social obligation to invite literally everyone you know, but you don't have to do that. We just had ours and it was actually in the house. That was a funny story. That wasn't how he planned it. But his parents got COVID so,

Eileen Lamb

What was your plan originally?

Joy

We were gonna have just a little small ceremon in the prayer chapel on his campus. And that would have been you know, more of the same, just tiny with the people who are most important to us.

Andrew M. Komarow

That's important. Eileen, did you see the Reddit: "Am I the Asshole," for the people who paid for like a Mickey Mouse like costume person instead of having food at their wedding it was, oh yeah. You, I thought you read "Am I the Asshole, " a lot right?

Eileen Lamb

Yes.

Andrew M. Komarow

That was good they spent like \$6,000 like their whole food budget on like, like an official Mickey Mouse something and people were mad there was no food,

Joy

I would be mad, I would be mad.

Andrew M. Komarow

Yeah, I think the food is important. How did you, how'd you meet your spouse?

Joy

Especially if you are gonna invite people right around meal time. I met him online actually, through Facebook, we were in the same Facebook group together.

Andrew M. Komarow

So what the hell is conlanging, what I can?

Joy

Conlanging, yes.

Andrew M. Komarow

And can you give some examples?

Joy

Sure. So conlanging is short for constructed language. A conlang is it's a language that's not it doesn't it hasn't happened organically. It's been designed by a person or a team of people. And that can be either a fictional language like how Tolkien has the Elvish languages like Quenya and Sindarin. It can be like that, or it can be an auxiliary language. For the to facilitate, facilitate communication between people who speak other languages, like Esperanto is an example of that. And that's one that's actually designed for people to use. I do fictional languages, I don't actually attend anybody to be speaking fluently. It's just to enhance my world building in the stories that I write mostly.

Eileen Lamb

So what is what in your expert opinion, do you think of made up words like neurodiversity? Neurodivergent, neurodiverse, especially the term lately, that now everyone is neurodiverse?

Joy

Ah. I personally don't really use the term neurodivergent neurodiverse. I don't feel like they're very useful. Just, they don't give you very much information, like by the current neurodiversity paradigm, you've got, okay, so just people are divergent, and so are people with ADHD, and so are people with any mental illness, and so are people with chronic pain, so are people with trauma. And so if you tell me your neuro divergent, I don't know anything about you. And as for the distinction between neuro divergent neuro diverse, I guess I see the argument, that nerodiverse has to describe a group rather than a person. Like I see the argument, I just think it's silly, because the, you know, the word doesn't mean all that much to begin with.

Andrew M. Komarow

No, we were definitely yeah. Curious, given your thirst. Again, just, you know, on language. And I would agree with you that, you know, in general, if you try to include everybody, right, then you don't

end up really well. You know, there needs to be descriptors, like you said, it doesn't, you know, it becomes almost meaningless, the more people, you know, described or under an umbrella. So. So you mentioned that you had some obstacles to employment?

Joy

Oh, yeah.

Andrew M. Komarow

What obstacles have you faced? And what do you think can be done about it?

Joy

Yeah, I really struggle with the interview process. I am. I haven't found anyone who's like, explicitly autistic friendly yet. And I think that's the reason I don't really get called back after interviews. I just, you know, I get nervous. I don't like to make eye contact. I don't, I can't really anticipate what sort of answers people are expecting of me. So as the interviewer that gets me a lot of the time. Also, I struggle to pick things up, like during training. So when I do have a job, I can make mistakes at the beginning, because I'm not quite grasping. You know, things that people would pick up on pretty quickly in general. So I think the employers get frustrated and they get let go. I'm just trying to brute force my way through applications at this point as for what can be done about it, I applied to a tutoring job online recently, and I haven't heard back yet.

Eileen Lamb

Yeah, I mean, struggle, struggles with unemployment and adapting to life changes, as you mentioned, can be difficult. However, you also believe that the key to moving forward is to avoid negativity online that many of us can get sucked into. Yeah. Tell us about that.

Joy

One thing is, you know, there's nothing wrong with venting online about how about when you find things difficult, but it's easy to get in this sort of, I don't know, can I call it a feedback loop? Where you complain about how hard it is, and people just validate? Oh, yeah, it's super hard. And you get into this mindset that the world is never going to change, you're never going to get a job, because this is just how everything is. And I found myself getting into that mindset, like, I didn't even want to apply for jobs for a while, because I just thought, you know, there's no way there's no way they're going to want to hire someone like me it just because I get in this. I don't know, you look online, and you kind of can reinforce your own negative thoughts. If you're not careful.

Eileen Lamb

Yeah, definitely. And I think it's the problem of many groups, is I can echo chamber, whether it's like just my opinion, or feelings, and it gets really bad.

Joy

And many times, it isn't even on purpose. It's people want to be validating, but they validate the wrong thing.

Eileen Lamb

Oh, yeah, that's very true.

Andrew M. Komarow

I'll validate everything you ever say? Eileen, don't worry. I'll always be there to argue with you. Okay?

Eileen Lamb

Thank you Andrew.

Andrew M. Komarow

Yes. Well, I don't even know if that sarcasm that might be mostly true. Right. Half sarcasm, maybe Eileen?

Eileen Lamb

Its needed,

Joy

But it's good. It's good to be challenged.

Andrew M. Komarow

Yeah. So you are going to college not just as an autistic person, but during COVID-19? And can you tell us what that was like? I mean, again, talk about change. And uncertainty, there must have been quite a bit.

Joy

Oh, man, it was so it was sudden, we that March of 2020. We, I went to my brother's wedding, in a different state. And you know, the place was packed, it was huge wedding. I remember dancing, you know, to Taylor Swift songs or whatever. And we're like, you know, life doesn't get any better than this. And then as soon as we came back home, it was, you know, we have this pandemic now. And we went straight to lockdown pretty much. My classes were suspended, because our spring break got extended, they didn't know what to do about the classes. And then we just went online for the rest of the semester, is like I left campus and then just didn't go back. And just I remember just the contrast between that wedding and just nothing I went and I, I lived really close to my campus. So I would just I would go walking, just to give myself a semblance of routine, I would walk around campus to like, I wouldn't go into the buildings, but to where my classes used to be just completely deserted, it was just me, because you know, I would have fallen apart. If I wasn't out there going somewhere. Like I had been before, I just had to hang on. It was really hard. Just the starkness of it is gonna stay with me forever. We had the COVID cases in my home state were not as severe as elsewhere in the nation. And so our governor decided to open things up a little sooner than some other states. And that was a

bit of a controversial decision. But regardless, I'm just zoom in person classes the next semester. So there was sort of that return to normalcy, but it was just a little, everyone was on edge, it just wasn't the same. And I ended up feeling like I lost half of my college experience. Because of it because of COVID-19. And all the measures that had to be taken, it really was a rotten time. That's how that lost three family members not of COVID but around that time, just in quick succession. So it was just it was a really hard time. I think it would be hard for anyone but on top of that, I just you know, we're autistic, we resist change.

Eileen Lamb

I know that you like video games. Did that help you cope in any way?

Joy

Oh, yeah, I played Stardew Valley all throughout the pandemic that really helped. I just get away from it all Stardew Valley. It's this little Farming Simulator RPG thing. It's very cute. Very wholesome. It's not like serious gaming at all, but especially during that time you just need something light and fluffy to get you through your life.

Eileen Lamb

I like video games like Animal Crossing, Pokemon.

Joy

Yeah. Stardew is right in that genre along with Animal Crossing.

Eileen Lamb

Oh, that's cool I need to check it out. I've never heard of the game. Mystery Dungeon Explorers of Sky but do you know about it?

Joy

Yes, that is my all time favorite video game. It's this really obscure Pokemon game. I've only met like two other people who have ever played it. It is wonderful. It's a I think primarily the gameplay you describe it as a rogue like. I think that's just how you would classify it. But the story is quite good. And the music is excellent.

Eileen Lamb

So what do you do in the game, like compared to the other Pokemon games?

Joy

Sure. So a difference is you wake up on a beach at the beginning of the game and discover that you have turned into a Pokemon but you have no memory. So you are exploring dungeons with your Pokemon partner. There aren't any other humans in the game, just Pokemon.

Eileen Lamb

Well, that's cool. What a console do you play it on? Nintendo?

Joy

It was a Nintendo DS game. Yeah.

Eileen Lamb

Oh, it was a DS game. That's cool. I have a DS. I need to check it out.

Joy

I think they released it. I think they released it for Wii U as well as a digital download. But you know, I never had a Wii. So

Andrew M. Komarow

Or let alone a Wii U like yeah. Actually, one of my employees and friends actually does know the game. And he does have it for DS. So there are three people.

Joy

Wahoo!

Andrew M. Komarow

So he plays a lot of Pokemons. I asked him yesterday, I'm like, do you know this game? He's like, Yeah, I have it for DS. So,

Joy

Yeah, it's so good. I think it had some mixed critical reviews. But I don't let that sway me.

Andrew M. Komarow

What did you like so much about it?

Joy

Mostly the story. I thought it was excellent. It I replayed it recently, actually, with my husband because he had never heard of it. And the story holds up pretty well. Like I was impressed as a kid. But kids are easily impressed. I really thought it held up.

Eileen Lamb

That's awesome. All Pokemon game hold up pretty well.

Joy

Right?

Eileen Lamb

Like you're playing Pokemon. Like "Let's Go", which is basically the newer version of what it used to be when I was a kid. Love it.

Joy

Yeah, I think the first Pokemon game I played was Yellow.

Eileen Lamb

Yeah, Mine was red.

Andrew M. Komarow

Did I tell you, Eileen that, that's how I bonded with my wife, Jessica. Like, yeah, over a video game that I lied and I said I played. I hadn't played it yet. It was Portal. Portal Two had just come out. And I did end up playing both of them. But I pretended I liked it more than I did.

Joy

Those are pretty fun. Yeah.

Andrew M. Komarow

So what did you study in college, and why?

Joy

Oh, so I was initially a Music, Music Education major. But I changed over to English pretty quickly. I had a particularly good British literature class that I just adored. I was captivated by Sir Gawain and the Green Knight and just Middle English in general kind of kick started my interest in linguistics and, and literature as well. So I switched my major over. It's a little bit frustrating, I think, because people expect autistic people to be really into math and engineering and that kind of thing. And I just never was I was more of the creative type. But then I never quite felt fully at home in the English world, either. Because there's just so much subjectivity, and especially literary criticism. You know, I always want there to be a meaning of the text and there's this, you know, the death of the author, there's, you can't say that the text is what the author meant it to mean, And, and there's just a whole lot of interpretation. And that always really frustrated me as someone who, you know, I contend a little towards black and white thinking, a lot the time and I just want there to be the same objectivity that maybe there is in music theory, which is what I did before. And so that's kind of why I gravitated towards the systems of conlanginG, rather than literary criticism, because I like things being they're not necessarily perfectly regular, but they're systematic and to me, that is where the beauty of language lies and that's why that's why I majored in English to begin with.

Andrew M. Komarow

Did you know that there is a college scholarship for speaking Klingon?

Joy

I didn't know that but that is awesome. I wonder if there's one for Quenya?

Andrew M. Komarow

I don't know. I, we I give presentations like sometimes on like college planning and people getting ready and like, you know, weird scholarships and Not so was the one that like stuck with me that I like to mention is that if you can speak Klingon there's, it's like a \$500,000 scholarship.

Joy

But that's, that's awesome.

Andrew M. Komarow

Maybe you should start by learning another language that you've mentioned that I can't repeat. So.

Joy

Yeah, Klingon is fun. Quenya is Tolkien's one of his two. Well, yeah, more than two, I think one of Tolkien's Elvish languages.

Eileen Lamb

Nice. So cool. It's funny what you said about like, oh, what people expect autistic people to like maths and engineering. And I was the same, I was always into like, languages, you know, obviously, my first language is French. And, yeah, I've never been into math or science and all of that. And I don't know why that cliché of it is sticking so much, the idea of people have autism, because it's not true for so many people. I mean, then you have people like,

Joy

But there's this idea that we can't be creative. And I wonder if that's why I was missed as a child, just because, you know, I was in my own imaginary land all the time. And, you know, they look for things like the lining up toys and quote, unquote, inappropriate play. That was actually my brother. He would line things up. And he's, he's, uh, he has his PhD. Does he have his PhD? Yet? He's getting his PhD in mathematics. Somehow he doesn't have a diagnosis.

Eileen Lamb

Well, okay.

Joy

I wonder, I wonder if this is a male female thing. If just women tend to be more imaginative, even if they are autistic? I don't know.

Eileen Lamb

Yeah. Yeah, that might be true. Because you know, all of the people I know, are autistic and creative or more. Yeah, that they're all women actually. And then they are other people that are into math, who are boys. Might be a gender thing.

Joy

And then I know autistic, I know autistic women who are into math, too. But

Eileen Lamb

It's more rare. Yeah, it's interesting. I'm sure the criteria for diagnosis are going to change. Over the years, they're already kind of picking up on. Yeah, those things like how, you know, girls have less restrictive interest and all of that. Or less obvious, I guess what I read that really stuck with me is that girls, their special interest are more what would be considered normal?

Joy

Socially acceptable? Yeah. Like the horse girls. Yeah.

Eileen Lamb

Yeah. So so that's how it can be missed. Like, oh, she really likes it. But you know, well, you know, who doesn't like horses or like, I was really into soccer. When like, boys, it's more like yeah, maybe like trains or something a bit more unusual. So it's more obvious,

Joy

Right? I think for girls, sometimes it's boy bands or things that are not necessarily abnormal for a teenager. For me, it was Pokemon when I was little. And then I had when I was in high school, I was obsessed with sonnets, the poetic form, and I wrote 300 of them in my four years of high school. And I think people just saw that as me being nerdy and quirky. And maybe a little bit obsessive. It doesn't it's not. It doesn't seem like the same thing as the boys who really like trains, for instance.

Eileen Lamb

Yeah.

Joy

But it definitely was it was pretty rigid, pretty restricted.

Eileen Lamb

Yeah, looking back, I mean, I feel like it's so much easier to see now that you know, we can look back on these things. But, yeah, I am going to ask you some quickfire questions. So basically, it's just like quick questions, and you tell me the first answer that comes to your mind. What is your favorite memory as a child?

Joy

Going to the pool with my dad.

Eileen Lamb

Oh, that's so sweet. What's your favorite Pokemon?

Joy

Pikachu. That's everyone's favorite Pokemon.

Eileen Lamb

I like Eevee.

Joy

I do like Eevee. I like all of them.

Eileen Lamb

What's your favorite drink?

Joy

Water.

Eileen Lamb

What's your favorite portrayal of autism in the media?

Joy

It's an unpopular opinion. But I do like Shaun from "The Good Doctor".

Eileen Lamb

You know, I've only seen a few episodes but yeah, I've heard it so like on the cliché side.

Joy

It is, but I like him.

Eileen Lamb

What's your dream? What was your dream job as a child? Do you have a dream job now?

Joy

Dream job as a child. Um, I actually wanted to be a software engineer like my, like my brother. Dream job now, I would love to compose music for video games.

Eileen Lamb

Well, thank you so much for joining us today. It was great. Speaking with you. Do you have a social media anywhere you want people to find you online?

Joy

I tend to keep to myself online. I do have a writing page, but I never post to it. So. Yeah, well, thanks for having me.

Eileen Lamb

Yeah, of course. Have a good night.

Andrew M. Komarow

Thank you. Bye bye. Thank you.

Joy

Bye