

Adulthood on the Spectrum: Dealing with anxiety and navigating autistic spaces

Andrew M. Komarow

Welcome to Adulthood on the Spectrum. I am Andrew Komarow, an autistic Certified Financial Planner. I co-run Adulthood on the Spectrum with my co-host, Eileen Lamb. 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 like us 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 Lia McCabe. Lia is the founder of "Autism Wish" a charity initiative providing autistic children with sensory therapeutic items and parent resources. She is also the host of "Embracing Autism Podcasts," ranked in the top five podcasts worldwide, and certified in special need parent training and mentorship. She is an outspoken autistic advocate, and seeks to create a more compassionate and inclusive community.

Eileen Lamb

And thanks for joining us today.

Lia McCabe

Thanks for having me.

Eileen Lamb

So I know if you've watched our episodes, but we always start by asking our guests I would really like to identify. And by that I mean identity language as an autistic person or person with autism, and also your pronouns.

Lia McCabe

So across the board, whatever. So whatever suits your fancy, I prefer Your Majesty, if that's okay. But if not, I'll take it. No, she/ her and autistic is fine. But you know, if you say with autism or whatever, it really doesn't rock my boat.

Andrew M. Komarow

Speaking of the whatever, I helped some colleagues of mine with a book and they asked me how I would like to be credited. And I said, I prefer to go by my stage name "Candy, Delicious." I, they know me well enough, where I'm pretty sure they're assuming the sarcasm. But if there is an autism book

that comes out, and one of the credits is to "Candy, Delicious," that that would be me. But given it's very professional, I don't think they're gonna, you know, abide. But speaking to the whatever you want to call me, somehow that felt on topic.

Lia McCabe

I think I will start using that one.

Andrew M. Komarow

Yeah. Or you can come up with your own. So that one's mine. Anyway,

Lia McCabe

No, I mean to call you.

Andrew M. Komarow

Oh, I'm gonna second I'm gonna start rethinking this now. Okay. So can you tell us about when you were diagnosed with autism? what that experience was like,

Lia McCabe

Yeah, sure. So honestly, I've lost track of time, but several months ago, the process was really a long, extensive process. So it was probably overall about a six week long process. And we had three sessions, each of which were about three hours long. So it was spaced out, like every two weeks. So there were about a 10 or so assessments that were done 10 to 12, including, like an IQ assessment, executive functioning, all sorts of things kind of related in the family of autism as well. So there was a lot of paperwork and self self assessments, and then knowing your history and your childhood and all that stuff. So it was a really, really thorough process, I was kind of surprised I actually had to get help from my husband. Because I found that I didn't really know myself, well, like I didn't know myself as well as I thought I knew myself. So some of these questions were hard for me, because I was trying to read them a little too hyper-literally. And it was, it was really difficult to even understand what the question was asking. So I ended up leaning on him to kind of understand some of the questions. And then I ended up being able to answer it after getting some feedback on who I actually am around people versus who I think I am around people, which are never really the same thing.

Andrew M. Komarow

You have any good examples?

Lia McCabe

Yeah, sure. So one of those examples would be like in social situations where I'm gathering with a group of friends. A lot of times, I will be the person who is kind of like the caretaker, like, here, do you need a drink? Do you need a snack, whatever it is. And so I always thought that that meant I was really sociable, like, Oh, I'm a social butterfly, I got this going. I'm organizing the games, like we're all hanging out they are having fun. But what I didn't realize was that I wasn't actually partaking in the socialization itself. So it was like I was always the observer pretty much and like the organizer, but I

wasn't really partaking in that socialization. But I didn't really realize that until I was answering these questions on this assessment, I realized that some of these things were not really considered typical, which I didn't really know because I didn't hang around enough people to know.

Eileen Lamb

Did you or do you, do you have any other diagnosis other than autism? And what do you think that? Uh? Or do you think that autism is the correct diagnosis?

Lia McCabe

Yeah, so actually, what happened was a lot like, long time ago, my childhood like elementary age, I always needed help in school and academics. I've had a tutor since at least kindergarten that I can remember. And so throughout that entire time, I always struggled. And I never really knew why. I remember like, during recess and stuff, I would be at the picnic table. And I'd be drawing and writing stories, because I was, I was actually hyperlexia. And I didn't know it. And so as I got older, basically, after high school, high schools kind of became so difficult for me that I started having a lot of problems, because I knew that I was smart, but I couldn't access the information, right, I just felt like something was wrong, I couldn't keep up with my peers. So at that point, before college, I got assessed, and I was diagnosed with ADHD and executive dysfunction, and like a visual disorder and a couple other things, all in that learning disability family, but I was not diagnosed with autism at the time. So it wasn't until recently that I looked into that, because I felt like ADHD does explain certain parts of me. And executive dysfunction definitely does. I struggle with that a lot. But it didn't really explain the social aspect and the social part of it that I had struggled struggles with, and also a lot of the sensory stuff that I've always struggled with. So that's what made me want to kind of pursue that, particularly after both of my kids were diagnosed, my husband doesn't have any family history really of autism. So I felt like that had to be on my side, because I have a nephew who is also autistic. So I looked into it. And that's when I discovered I was autistic. And it all made sense, basically.

Andrew M. Komarow

So you have been involved with autism advocacy, your kids have been diagnosed with autism, you have other family members, with autism as well. Since before your diagnosis, you start your nonprofit, well, before your diagnosis. How has your ability to advocate changed since being diagnosed versus, just being a parent, I did quotation marks around just for anyone not watching the video.

Lia McCabe

Well, one of the things that I feel like that it's done for me is it's, it's made me feel more comfortable giving my opinion on certain things, in the sense that I don't feel like I always understood why my child was acting a certain way, or why certain things bother her a certain way, which is weird, because I still have sensory issues. So I still had that experience. And I knew what it felt like. But I never put two and two together, that that might be what she's also experiencing, until I got that diagnosis, then it like makes sense, because I was like, Oh, I connected the dots, this, this is around the same thing that they're going through. So if I didn't have that diagnosis, I wouldn't have really connected those dots, I don't think so it's kind of allowed me to basically be more aware and attentive to those needs, and be

able to advocate more for those needs. Because I can draw from my own personal experiences, and now feel confident that what that was, was essentially sensory issues. Like certain things I didn't know, other people didn't experience, like, I have really high sensitivity to sound, I can hear electricity and things like that. And I didn't know other people couldn't. So the diagnosis helped me kind of understand that better. And because of that I can now advocate for it better.

Andrew M. Komarow

No, I think it's interesting. I used to think that I wasn't anxious, because I never know not being anxious or that, you know, bright lights bother. But like if you've they've always bothered you. Right? So I think that's. Now do you think that you would have had that same understanding or same benefit if you had self-diagnosed yourself? Or do you think it was really through the long assessment process?

Lia McCabe

I honestly feel like I am the type of person that really needs that assessment and that process because part of the issues that I've struggled with growing up as because I've gotten late diagnoses on everything. I've always felt like, I haven't quite understood a part of myself. And then that gives you doubt of like, am I processing things correctly? Am I misunderstanding things? Am I doing things and following through properly? And I feel like the assessment kind of helps give you that validation that confirmation of like, No, you're not crazy. Like you. You get it like this isn't all in your head isn't the anxiety which for example, a lot of people tend to have a comorbidity of anxiety. So how do you kind of dissect what's the anxiety versus what's the disorder. Versus what's, you know, reality versus what's your inner thoughts telling you these things because you're stressed or overwhelmed or anxious or whatever it may be. So for me an assessment is basically imperative to be able to distinguish between the two so that you know, what it actually is.

Eileen Lamb

Can you tell us on the example of how your anxiety manifest?

Lia McCabe

Yeah, so one of the things that I noticed prior to getting my autism evaluation was that like, like you mentioned, going to the grocery store, for example, you were saying earlier, that it gave you or gives you a lot of anxiety, you don't understand how other people enjoy it. Very similarly, for me, I have an experience with like traveling in places that I've never been. So that whole routines and rigidity, when it comes to going to places like driving places, I always have to drive the same route. I lived in the same neighborhood for about 20 years. And I had my driver's license there for about 15 of those years, and I still would not stray to any neighbors neighborhoods that I had not driven through before without my husband. And then I would always kind of like refuse to take the beltway or things like that, because of the anxiety of like, if I take the wrong turn, I don't know where that's gonna go. And I don't know how to predict that or what to do. So that sort of triggered that. That notion, then I was like, you know what, maybe I do have more rigidities than I thought.

Eileen Lamb

I'm the exact same way I was always driving. I just can't take a different route, even if there's like traffic and the GPS tells me. I'd rather like be on that route that I know then try to go around and Yeah,

Lia McCabe

Exactly. I tolerate traffic more than the unknown.

Eileen Lamb

Yeah, I hate traffic too, because I feel like I'm stuck and kind of makes me like claustrophobic. I started thinking oh my god, what do you do is on emergency Oh, am I gonna get out of there? Like, there's no exit and this and that and the overthinking part. But yeah, yeah, driving is a tough one, too. Like, it took me a while to be okay with like, I got my license fairly easily. Well, on the third try. Not that easy, parallel parking. Sorry, for another day. But like, getting out of there. And like driving, it's still you know, it's very overwhelming. You know, so many like things going around when you're driving. And yeah, a lot of people do enjoy driving. Like, yeah,

Lia McCabe

I don't. When I took my driver's test, my foot was literally shaking over the paddle the whole time, like physically shaking.

Eileen Lamb

Can relate. Can you tell us about your nonprofit organization? It's called The Autism Wish. I actually shared it on one of my, my blog posts. I didn't know It was you. But yeah. Can you tell us why? Well, yes, why its called Autism Wish and what you do, and just tell us more about it.

Lia McCabe

Sure. Um, so Autism Wish is kind of like a mom and pop charity initiative that my husband and I started basically, at the beginning of the pandemic. We started it because when the pandemic hit, our girls were going to full time therapies like four or five days a week. And when the pandemic hit, everything disappeared, they weren't able to go to their therapies anymore, they weren't able to have access to like the infants and toddlers program, which is that PreK developmental program that you get from your school system. So they started experiencing a lot of regressions, just as they had started to make some accomplishment. And so that was really heartbreaking and really frustrating. And I realized that, you know, after talking with their therapists, there were a lot of things that we could do at home to kind of maintain that therapeutic environment, maintain the fine motor skills, working on like OT and ST and PT type of things at home. But we needed tools to do that. And it got expensive after a while being able to buy these like toys and all this stuff that you can do that. But we did realize that you know, they are toys like they're they're things that you can get at Walmart that can help you practice fine motor skills, PT, OT, all sorts of stuff. So we basically, so we basically decided that we should put something together to help parents find those resources more easily. We created a way that would be easy to maintain and accessible. So just creating Amazon Wishlists and then finding

sponsors to match those wishlists with. So that was kind of like the beginning of Autism Wish and its since kind of grown into a bigger thing from that.

Eileen Lamb

That's awesome. Such a good idea. Yeah, we talked about how you've been involved with autism advocacy. Since before you were diagnosed, officially, do you think your voice? That's a tough question? Do you think your voice was any less valid a year ago before you had your official diagnosis?

Lia McCabe

So I will say, what I have experienced. I've seen this in other realms outside of disability as well. But it seems like with self diagnosis, there is an acceptance. So I was able to go into these autistic online spaces, or, I mean, I don't know who was self diagnosed or not. But I would go in those spaces. And without having a diagnosis. I was like, very accepted and welcomed into these groups. And honestly, if it wasn't for these groups, I probably wouldn't look to have looked into it, because I was suddenly relating to a lot of people. And I've never had that, like never, I've never been able to find a space that I was like, wow, wait, we have so much in common. This is weird. I didn't know people like me existed. So I do think that there's some value to that. But in terms of having to get that official diagnosis, for me, personally, I feel like that was an important part of my journey. I feel like it made an impact in terms of what I felt confident in saying, for example, through Autism Wish, which are our mission or what we're doing, because I wanted to make sure that it was like as inclusive and accurate and representative as possible. I kind of work at like research on the side, it's kind of like what my career is. And so for me, I try a lot to like, avoid biases. And so that was part of is like, I wanted to make sure that I was hearing voices from both sides, and not trying to put my own personal bias, even if I do have one, like I do have a thought and opinion. But I tried to distance that from my observations

Eileen Lamb

How about the research part of your job? I didn't know about that.

Lia McCabe

Yeah, so I am a UX researcher. And that's my day job. And a UX,

Andrew M. Komarow

For people who don't know UX is?

Lia McCabe

Yeah, yeah. Nobody knows what it is ever. So a UX researcher is a user experience researcher, I basically research how to best design websites and interfaces to make them most user friendly. And basically, it's kind of like my job is to make you not hate using your tech devices, it's to make it as enjoyable as possible. So if you see yourself like wanting to smash your cell phone, you probably have a bad UX person there. If that makes sense.

Eileen Lamb

You know, when I started writing about autism online, was like eight years ago now. I wasn't diagnosed yet. I was diagnosed, I think two years later. And, you know, people used to tell me, Well, you can't talk about us design, because you're not artistic. And then I got my official diagnosis. And people, you know, when I say people, you know who I'm talking about change from where you can talk about autism, because you're not autistic to? Well, then you have self internalized ableism. So it's like, there's absolutely no winning, in my opinion. So I know your diagnosis is fairly new. But have you seen any changes in the hate you're getting is it better, or as your experience being the same as me, just that the criticism is different?

Lia McCabe

Honestly, so far, I've been able to not receive a whole bunch of hate, because I feel like you're a little more in the public eye than I am. So you're gonna get hit with it a lot harder. There's been little moments, I basically have not seen a difference pre and post. I honestly don't think that that matters to many people. I just feel like there's this monolithic view. And it really doesn't matter. How how you try to kind of talk about it. It's kind of like it's set in its ways. It's interesting for me, because I've experienced, I've experienced the same phenomenon being a Latina, because I am a Latina, who does not think like many do, supposedly, according to the monolithic view of what Latina should feel like. And I have received hate for that, even recently, being called like, not a real Latina or things like that. And it's been interesting for me now going into this autism world, and seeing the exact same phenomenon. So getting the same sort of response of like you're not really autistic, then mmm, it's just weird because I see it very much. So from a cultural lens. And because I see it cross these lines where it's not just about autism, it also goes into other fields like my race, my gender, things like that. I don't take it as seriously now, because it's all encompassing, which makes me feel like it's less real, if that makes sense? Because it kind of spans too much for it to be real. For me, I'm starting to sense patterns, like the researcher in me is like, hold on, this seems more like a bias thing.

Andrew M. Komarow

What do you I feel like there's a difference with the autism community for some of the other communities where there is some of that, you know, for not thinking like the crowd? Is it because there's a large portion of the autism community that can't think for themselves? Is there or is it not actually that different, but I feel like there there is something a little bit more unique and different, you know, about it, but that was a good parallel, what do you think?

Lia McCabe

I think it's the nature of autism. So like, the nature of autism is, you know, like me, just how I am typically I have a lot of communication problems, which means I misread people a lot, people misread me a lot. It leads to a lot of arguments and discussions, even with people that you know, you care about, and they care about you and have an intimate relationship with. So to have these types of conversations with people, you have no idea who they are, they're on another side of a computer screen, you don't get to see each other's faces and reactions, you don't see anything, it's just text on

the internet, I feel like that's just bound to go bad, you have even less context than you have in real life.

Andrew M. Komarow

So now, something you said was interesting, and that you try to always do the middle ground, right and see things from another perspective. And one of the diagnostic criteria for autism is not seeing things from other people's perspective. And, you know, theory of mine, right? So, question for you, do you think that you, it's not so much the middle ground is it's that you don't necessarily see things from other people's perspective, but you see from everybody's possible perspective, so it's almost like, you know, empathetic isn't the right word. But you can always see why somebody might feel that way or you. It's not necessarily putting yourself in that person's shoes, but you putting that person in anyone else's shoes and seeing if they fit. I'm totally not describing me here looking for validation, by the way. Sarcasm again. Okay, continue.

Lia McCabe

I think for me what it is, is, because I know that I struggle with understanding people. And because I am a researcher by trade, what I tried to do is assess things holistically. Because I know that my nature is to look at the small nitty gritty details. And I know that my nature is to be very black and white. And I know that because of that in the past, I've made inaccurate assessments. So what you're seeing now is like the version of me that's already gone through years of troubleshooting, and kind of figuring out like, everything isn't always black and white, like you have to pull back the curtain a little bit and like give people the opportunity to give both sides and try to make a more overall like assessment. My instinct is to think very black and white. So I'm like consciously working on pulling that back.

Eileen Lamb

Really helpful to see, to try and see things from another perspective. To me, it's really not natural, because I'm very stubborn. And I always feel oh,

Andrew M. Komarow

No, I don't believe that.

Eileen Lamb

Andrew knows. My way, the right way, but it's a good exercise to try and do that and they'll be so black and white. Yeah. And, you know, I feel like all of the autism stereotypes, how autistic people are like, you know, they can put themselves in. What's the expression can't put themselves into shoes?

Lia McCabe

People shoes, yeah, yeah, I can if they're right there on the floor I can slip them on.

Andrew M. Komarow

Unless they're crocs then I'm not gonna do that. So

Eileen Lamb

It's just like, you know, I feel like it's a bit outdated. The same as like the the empathy and, you know, it's, yeah. Anyway, so your job. See now I can't remember what it's called?

Lia McCabe

UX, UX research user experience.

Eileen Lamb

So that's a that's a visual job and technical, and seems kind of boring. And that okay? But do you enjoy it? And do you think it's because you're autistic?

Lia McCabe

I actually think it's really great for the autistic brain. It's both a combination of like needing certain rules and guidelines, but also having the flexibility to be creative. Because I'm designing things. So I'm like designing websites and stuff like that. But at the same time, it fulfills my need to have meaning behind things. So like, I'm always asking questions, I always want to know why something needs to be built a certain way. And we all know, one stigma that happens often is the little kid who's in the class, and keeps asking why the teacher says, do this, why do this, but why? And that kid who just always needs to know why. So this is a good opportunity for that kid, because this job is all about asking why you don't get in trouble for it. But also, it's it's about getting to know why people think a certain way you ask them questions, you basically try to find out if they all think the same way they think differently. And then you make conclusions based off of those discussions, to design something that will meet their needs. So I feel like that's actually kind of worked with my advocacy work as well, because it's helped me a lot with my mindset of approaching these conversations, when I don't necessarily agree with them. I'm like, Okay, pull myself back. I'm going to be the researcher right now put on the researcher hat. And I'm going to see why, like, why do they feel this way? What's What's the root cause of the issue? There's this assessment, it's called The Five Why's and basically, it's like, you have to ask why five times to get to the original root cause of that original. Why? Because what's at the surface might not be what the actual problem is. So that's something that I've learned that I also like, apply into the world of autism.

Andrew M. Komarow

That is super interesting. And also, there are a lot of a few companies out there that I've recognized, especially when it comes to UX and testing work. You know, I think, for example, you know, Aspiritech, that's something that they do, and they hire specifically for, again, among a few others, right? So it seems like, it's definitely a skill set. You know, avoiding a stereotype but something that, you know, again, uniquely beneficial for probably sounds boring to a lot of other people. But so, so does a lot of jobs, I guess. So what struggles have you had at work? So you were had ADHD, you work from home, but now you're autistic? Have you, what has helped you, you know, what hasn't working from home and a move and things like that?

Lia McCabe

I just laugh at the but now you're autistic, it jumped up on me.

Andrew M. Komarow

I know right? So everything must be completely different, right? (all laugh)

Lia McCabe

Honestly, one of the things that also helped me kind of realize that, hey, I should look into this is because the last two jobs that I've had, I mean, I was there for years. So this is probably like the last 10 years of my working life. I consistently got the same feedback during that yearly evaluation. And every year, I would try to like fix it. But I could not understand how to me I was like, This is not a fixable problem. And the problem that I had, the feedback that I consistently got back is that I wasn't delivering what they were asking. And I've never understood that because they would send it to me an email verbatim what they wanted, I would do what they I would design what they wanted, I'd give it back to them. And I'm like, how does this? You literally listed these things out? And I literally delivered this to you, how am I not meeting those expectations? And the feedback that I got from my supervisor was like, oh, yeah, well, you gotta read between the lines, like there's other contexts and dah, dah, dah. And that to me, I like it's stuck with me for years. Because every job that I went, it was the same issue. And I couldn't ever understand that. I was like, what, how do people do this? How do people just magically know what's supposed to be in here if it's not written down? So that was before I knew that that was related to autism. So it was just driving me crazy. And I thought I was like, I don't know, maybe I'm just dumb. While everyone else gets it, I don't get it. So the autism evaluation really helped me figure that one out. So now, what's worked much better is that I'm in a fully remote place. Everything is like through slack and email. So there's a written record, which helps me a lot with like my executive functioning issues. I can always refer back to the notes. And because it's a more IT type of field, everybody who's there's more of a techie, it tends to attract more neurodivergent people. So there are more people like me there, which makes it a more empathetic place. So that's been really helpful.

Eileen Lamb

Tell us where we can find you online?

Lia McCabe

So I have a few social media accounts, Facebook and Instagram at AutismWish. I also have a YouTube channel where I do our video podcast series "Embracing Autism IRL", you could just search that keyword because we're not cool enough to have a cool URL yet. But we also have our podcast "Embracing Autism," you can find that pretty much anywhere you listen to podcasts.

Eileen Lamb

Let's do the quickfire questions. So we'll ask you a question then you tell me the first answer that comes to your mind. Are you ready?

Lia McCabe

Sure.

Eileen Lamb

Do you have a favorite quote? And if so, what is it?

Lia McCabe

Ah, I do and I can't remember it because you're asking for it. No, my favorite quote is, if you "If you try to judge a fish by its ability to climb a tree, it will always think it's stupid." I think that's something that stuck with me forever because of my disability and always being judged by different standards.

Eileen Lamb

Okay, so fun fact, I love this quote. And I posted it the other day, and I say it was from

Andrew M. Komarow

Albert Einstein. Yeah.

Lia McCabe

They say it is but they can't actually verify that.

Eileen Lamb

Exactly. So my post got removed like a fact checked by Instagram and removed because what was wrong? Because it's not,

Lia McCabe

I posted it on mine and they didn't take it off.

Eileen Lamb

They hate me. But I was like, what? And then I Googled it and apparently yeah, we don't really know where the quote is from.

Lia McCabe

You know, you can repost it and put Albert Einstein with a question mark. Just to troll them.

Eileen Lamb

I don't know what they would do. What's your favorite comedy movie?

Lia McCabe

My favorite comedy movie? Well, I think that it's basically "Pineapple Express," because I love James Franco.

Eileen Lamb

Have you seen it Andrew?

Andrew M. Komarow

I have I watch movies, unlike Eileen.

Eileen Lamb

I'm just waiting for the day where someone's gonna like answer like a movie or TV show and you're not gonna know about it.

Lia McCabe

I am not really into rom-coms. I'm into like weird silly coms.

Eileen Lamb

"Pineapple Express." Okay,

Andrew M. Komarow

Like "Harold and Maude".

Eileen Lamb

Right and what's what is your favorite alcoholic drink?

Lia McCabe

I actually don't drink alcohol. Shirley Temple.

Eileen Lamb

Who is your favorite comedian?

Lia McCabe

Uhm, Ricky Gervais. I think he's hilarious.

Eileen Lamb

What was your dream job as a child? What did you want to be?

Lia McCabe

I wanted to be a neonatologist.

Andrew M. Komarow

Oh, what's a neonatologist?

Lia McCabe

A doctor for newborn babies.

Andrew M. Komarow

Oh, okay. I didn't know.

Lia McCabe

That was that's what I wanted to be as a child.

Eileen Lamb

Well, we did it. Thank you so much for joining us today. It was great having you.

Lia McCabe

Yeah.Thanks for having me.

Andrew M. Komarow

Thanks for letting us be a little extra all over the place.

Lia McCabe

You no? (all laugh)

Andrew M. Komarow

Me never right?