

Adulthood on the Spectrum: Passing legislation and changing perceptions

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 host Eileen Lamb. Hey, Eileen.

Eileen Lamb

Hey, Andrew. I'm Eileen Lamb, an autistic author and photographer from France. And in this podcast, we want to highlight real voices of autistic adults, not just inspirational stories, but the stories of people talking about their day to day life, and we want to give a voice to people like us and like you.

Andrew M. Komarow

Today our guest is Jillian Nelson. Jillian Nelson is a queer, autistic activist from Minnesota, she has dedicated her life to changing the perspective of autism and creating a better world for the tiny autistic humans. She lives solo with her sidekick pup, but has a cast of characters including partners, PCAS, and a delightfully quirky neuro-diverse social circle. When she's not working tirelessly, she can be found at local breweries, WNBA games, or anywhere else that promises an adventure.

Jillian Nelson

Hi guys, thank you so much for having me here today.

Eileen Lamb

Hey Jillian, thanks for being here. We always start our podcast by asking our guests, how's they like to identify themselves as far as autism identity go? A person who has autism on the spectrum? How do you identify yourself? And what are your preferred pronouns?

Jillian Nelson

My preferred pronouns are she and her. I lean towards autistic first identity-first language, but I'm pretty open to on the spectrum or are people first-identity. I tried to be really fluid with that in our community. Because I understand that, we can't just normalize one identity, we have to make sure that we're really leaving that expansive for people to choose how they identify as autistic or on the spectrum or as an adult with autism. There's no one right answer, so I embrace them all.

Eileen Lamb

Nice. You know, every time we ask this question, we get such great answers and such good perspective on it. I love how, you know we say of autistic people that we're not like flexible, and it's hard to see the other side. But I feel like all the answers we got in this podcast were very middle of the road and understanding of both sides, or all sides of this issue. So that's really great. Can you tell us more about your autism diagnosis? How did you come to be diagnosed?

Jillian Nelson

Oh god, it's a great story! Um, for being a female of my generation, I was actually diagnosed incredibly early. And by incredibly early, I mean at 21, but I grew up in the 80s. Like, they weren't talking about autism and individuals that weren't the stereotype like "Rain Man", like we were completely off the radar back then let alone females with autism. They were even farther off the radar. But I have a little brother, he is 23 now, and he was identified very, very early as autistic in preschools when they started doing the testing. And then he got a medical diagnosis shortly after, then the same doctor that diagnosed him, treated me for everything, but autism, when I was growing up and mentioned to my mom that, "Hey, this is something that can run in families, maybe you should let your doctor know about this.". And I started reading books about that my mom had purchased from my brother. And at that time, there were no adult books. So it was all like supporting your child with Asperger's syndrome. But I've seen so many things that were my life. So I went out and did a whole lot of hunting. Because in 2002, there were very, very, few doctors that were diagnosing adults. There were even less doctors that knew how to diagnose adults who were women. That the first assessment I ever had, they told me that there was no way I was autistic, because I was too visual to think. So even from the little amount I had read at that point, I knew that that was a load of crap. And I got a second opinion, and then magically, my mom hit two out of three kids on the spectrum. And I consider myself incredibly lucky to have been diagnosed as early at 21 for being my generation. A lot of my friends and my peers, they're being diagnosed now at the same age that I am now for the first time ever. So I feel blessed to have that 17 year insight to why I am the way I am.

Eileen Lamb

Yeah, I mean, I'm a female, so I relate to this a lot. And I grew up in France where I mean even now, a child will not be diagnosed with autism unless he or she is very severe. I was diagnosed at 26, and it's like such a textbook autistic child growing up. I feel like in the US now, I probably wouldn't be missed, but I still feel very thankful. I was able to get that a professional official diagnosis as an adult.

Jillian Nelson

I'm just gonna add into that. Like, I think diagnosis is something that he I've heard so much debate about in our community lately about what's valid. Like, do you have to have a medical diagnosis to belong to our community? Is self-diagnosis acceptable? What about the people that only had educational diagnosis coming into the community? I think it's really important that we recognize that like France, and you guys have a way better healthcare system than we do over here in America. As far as access to healthcare, but like there's so much privilege and being able to access the resources and services to get an appropriate diagnosis. I mean, you talk about things like simply do you have the health insurance? Does your health insurance cover it? And even things like geographical privilege? Like do you live in a place where there's a professional that can reasonably and accurately diagnose an autistic adult? And I think it's a conversation that as we start talking about identity and diagnosis that as a community, we need to start kind of thinking about. How do we be more accepting of one another? Like, is there really a right or wrong way to come about this title of autistic? Or can we just accept one another? I mean, most of us knew we were autistic before someone handed us that official

piece of paper, right? Why does that piece of paper make us more autistic than someone who's self-diagnosis?

Andrew M. Komarow

So, to challenge you, and I'm not disagreeing with you. I think there's a line and I don't know where the line is. But I because I would cross it if I did. But I think there are definitely is one. So for example, you know, at what point is somebody I guess, a lot of the hatred, and I'll call it actually autistic on the internet. Is a lot of self-diagnosis, looking for an excuse for their own behavior. And I think that also really hurts the people who are legitimately self-diagnosing. Like, I remember watching a YouTube video of somebody who attacked me and Eileen on Twitter. And she had a YouTube video, where she just diagnosed herself a couple weeks ago. And that autism is not a disability, it's not like diabetes, a doctor can diagnose you. And she's saying all the, I'll call it the stereotypical hateful things, right? Regurgitating them for lack of a better term, and I feel like a self-diagnosis should be to help you, right? It shouldn't be a public excuse, for bad behavior. I actually don't think an official diagnosis is I don't think there's any, but I think if you're telling parents, this is what autistic people want, or speaking for autistic people publicly and socially. I do think having an official diagnosis of some sort is appropriate. Right? Where do you fall on that?

Jillian Nelson

I'm going to challenge you back. Because, I believe that our medical system is incredibly flawed right now. How many people are out there being diagnosed with autism that aren't actually autistic, because medical professionals don't really understand? Or how many people are autistic and being told by medical professionals that they're not because they don't understand? Where I work, we have a counseling team, and they do a lot of assessments. And a lot of the assessments that we do get our people that have been assessed by other professionals in the cities that do not have the same understanding of adults with autism. So they were told, even though their textbook presentation of autism, they're told, "Oh, well you're not autistic, because you don't flap or something small." So I like to err on the side of caution and believe that, yeah, there's gonna be some bad eggs out there with self diagnosis. But if we embrace self diagnosis, then think of all the people that don't have access to the privilege that is medical care, and that is diagnosis that really need to be embraced by the community. And if we embrace them in the community, we stop all the infighting in our community, we can do more to change the perspective of autism to the outside world. So that when we do get those bad eggs that are self diagnosing, so they have an excuse, if we educate the rest of the world on what autism really is, and who we really are as people, then the outside world would be able to look at those bad eggs and be like, Nah, I think you're full of crap. Like, I know, like 73 people with autism, and that's just an excuse. And yeah, you should go get some therapy.

Andrew M. Komarow

I don't think we are at the point where we have enough people doing that yet and feel like they can speak if you're not autistic, right? One of the things is, well, then you can't speak to me because you're not autistic. So I agree with everything you're saying, by the way I can, which also makes it really hard. Right, because there's so much validity, but I feel like also Well, if you have somebody

who's not really autistic saying they are, and they're saying what they think it means to be autistic, right, then that we're just, I'm afraid of it going too far. And it just hurting to any people, I think, what is the reason you're self diagnosing? What are what are? What is the reason? Right? And what are you looking to get out of it? Right. And I think if it's, you know, to, to have Twitter wars, right, I don't think that's a good reason. But there are so many valid good reasons, the diagnosis is hard, which is also the challenge. And it also makes me angry at the people who are essentially taking advantage of that, right there. They're using that it's hard for some as a reason for an excuse for their behavior, which if it's not hurting our community, yet, well, well. So yeah, I mean, I think as a whole, like, as a community, we need to step up, we need to stop with the infighting. Like, why do we have Twitter wars of autistic people? Like because they're not actually autistic people pun not intended. But like, yes, we do, testing people to like we do, where everyone has a medical diagnosis, and they're still attacking each other to get through. If we spend all this time attacking each other like my, in my work, I spent a lot of time on Capitol Hill fighting for things for the autistic community. And every single person that's fighting each other on Twitter over semantics or opinions. Were to join me on Capitol Hill, we might have a very, very different world. But instead we're busy that like fighting over the most ridiculous things on the internet.

Eileen Lamb

Yeah, and I but to challenge you, again, I would say that a lot of the people doing the fighting are the ones who are very set in their way of like with terminology. Because people like me, like I don't care if you prefer autistic person with autism. I don't care if you don't like ABA, you know, I respect that other autistic have their own views about autism, and I'm not gonna go attack them for those views. But those actually autistic they come after everyone's they disagree with I witnessed it today. Again, just because a mother asked for ABA therapy suggestions. There are like 20-30 comments ganging up on her, she had like 10 likes on the post. I mean, she was just a mother. And I feel like this is just not helpful. And another thing is that these people often use the word "we" as in "we autistic people", as in this peak for the entire autism community. And that's where it gets really tricky. And it really bothers me. Because you know, we are all different from each other, and to use "we" to speak for an entire community is just not right. Because their opinion is valid, my opinion is valid, yours is valid, you know? And we should say, "Well, as an autistic person, I feel like I'm not we autistic people", you know what I'm saying?

Jillian Nelson

Oh yeah, absolutely. I think there's so much irony in the fact that we have spent so long as a community fighting for the world to see us as individuals, that we are a whole spectrum of people that are all completely different. Like we have that if you've met one autistic person, you've met one autistic person. But then there's also the same fight that we all believe this because we don't like even my best friend is a blogger in the autism community. And I love her to death, like her children are some of my favorite people. But there are things, there are things that are hot button issues in the autism community that we don't agree on, and that's okay. We don't have to hate each other, we don't have to start an internet war. Like, we can just like each other and agree to disagree and recognize that we have different lived experience and different opinions, and that's fine.

Eileen Lamb

That's, that's good. Yeah, I agree.

Andrew M. Komarow

Let's focus on what we can agree on. Right? Instead of what we can't.

Eileen Lamb

Maybe we shouldn't focus on what we disagree on. If it's respectful too. You know? like we just did in this podcast, you see? We're not like fully in line with each other. But we talked about it and it was respectful. We don't hate each other, we're still talking and, that's good. That's what we shouldn't be doing, yeah?

Jillian Nelson

Yeah, good. We can keep growing and seeing more of that in our community. I think it's important.

Eileen Lamb

Yeah, I agree.

Andrew M. Komarow

So, you mentioned you do a lot of advocacy. Is that what you do for a living or working assuming that you work?

Jillian Nelson

I do, I work for the Autism Society in Minnesota, and our community resource and policy advocate. Really long title on to say that I run our information and resource service and then I also lead our public policy agendas. So I get to talk to people all day about the challenges of their life. And then I get to go to Capitol Hill and try to change the world. It's like the best pairing of responsibility, because I know that I get to take the voice of the community with me because I'm talking to them all day. So it's, and like, we are actually the only affiliate in the country that has a paid policy position that is being held by an autistic person.

Andrew M. Komarow

That is awesome.

Eileen Lamb

Oh, yeah. And Andrew was telling me about the law enforcement law that you passed. Can you tell us about that, too?

Jillian Nelson

Oh, yeah. So on August 31 2019, a young man was killed not far from my hometown. His name is Kobe Heisler, and he was having a meltdown. His grandparents called for help. They then called and said they didn't need help, and the police came anyway. And they really escalated the situation. And

they ended up shooting and killing Kobe Heisler. And it was kind of the turning point for us. So we decided it wasn't time to just ask for money for law enforcement to consider having autism training that this is the final straw. And we were going to ask for a mandate. So I sat in my office one night, and my co-chair from our board was like, sit down, write down some ideas on what you want this law to look like. And I wrote this bill that would create a mandatory training every four years, every single licensing cycle, every single officer has to be trained. But we've seen that bill in the country before, like there's several other states that have that, we took it one step further. Our law actually states who has to be involved in training and creating the training, with autistic adults being number one on that list, and family members, number two. And then we also created a list of what had to go into that training. I didn't want to set our community, I didn't want to pass a law that would set our community up to have law enforcement being trained with information that wasn't going to be helpful, because that's not going to save our lives, right? It's not going to give like if they know that, you know, eight year olds with autism like trains, how is that going to keep them from shooting autistic adults? So we outlined what has to go in the training. And then we set to work on passing it. Sadly, and also very, very excitedly on there was a lot of civil unrest here in Minnesota that brought this to our Senate attention very, very quickly over last summer. With all of the George Floyd aftermath, and they passed a major piece of police legislation. And the POCI caucus, the people of color and indigenous Senate and House members, they put together this super comprehensive bill and we talked with them and worked very tirelessly with them to really recognize that intersectionality between race and disability, and they included the autism language, and it passed with flying colors. And in fact, in just a few days, on July 1, the law goes 100% into effect and that a single officer in Minnesota won't be able to take their licensing test without having four hours of autism training.

Andrew M. Komarow

That is amazing.

Eileen Lamb

Yeah, well, congrats.

Jillian Nelson

The only autism training bill in the entire country. So I'm hoping to see more states, follow in our footsteps, take our language and run with it.

Andrew M. Komarow

So what what can other advocates do in other states who would like to either advocate and use some of your model legislation or your legislation as a model and or advocate for other change in general, we got introduced for politic reasons. I served on Connecticut's autism waiver committee and involved with I would call it our equivalent of an Autism Society and Connecticut, we don't have that here. Because not even they want to be in Connecticut. I like to insult Connecticut every chance I get. But politics on the state level and advocacy. And the change, it's so complicated, it's so frustratingly slow. And it's really hard to, it's political. It's like the worst type of like social game there is like talking about just like lying straight to your face, having the senator who sits on the committee with me being like, "I

know people with autism, I understand you, I don't need to speak to anyone, but I'm the reason that this has been messed up for the past 15 years." So but again, like by yelling at them does not accomplish anything. I also speak from experience with that because I've done that too. You know, so how, how can you help others? Do what you've done? There's 49 other states, there are not 49 of you.

Jillian Nelson

I got, there is not I wish there was. I got involved in politics actually through a program called Partners in Policy Making. And there is a Partners in Policy Making in all 50 states, or at least.

Andrew M. Komarow

There's at least one in Connecticut. So I assume it's probably a national thing.

Jillian Nelson

A really, really great advocacy training program that is typically like I know, here in Minnesota. It's sponsored through our Governor's Council on Developmental Disabilities.

Andrew M. Komarow

I think it is too, because every state has a DD Council.

Jillian Nelson

And I serve on our DD Council now. But I went through that very, very young. And then I kind of I got involved slowly but surely like things like serving on councils, I'm showing up to a lot of town hall meetings, find civic engagement classes. One of my favorite things that I do outside of work is I teach civic engagement for special, or for Special Olympics. So I'm teaching athletes how to do all the things how do you go to Capitol Hill? How do you write a bill? How do you change a law? I am so proud that one of my first athletes in my very, very first class has a bill being introduced in January that's going to create a study to look at obesity rates and people with developmental disabilities. Which is long overdue, then why hasn't it happened? Because no one suggested so now someone suggested it. And she's working with her representative and senator to carry this law forward. And it all started with someone taking the time to teach her how to change the world, as I like to call it. But yeah, like there's classes, there's, like programs like act up and like there's there's a million different disability organizations with self advocacy programs that really look at that political work and then finding other people. My inbox is always open to any autistic adult that wants to learn how to be more effective in the policy world. I will help anyone, I may not understand all the nuances of every single state, but I can tell you how to make a difference and how to negotiate.

Andrew M. Komarow

You think that reaching out to a state's DD Council is in? Could you talk about the DD Council? And I didn't know you were involved with that, I think they're amazing. And most people don't know who they are or what they do. So do you mind giving a plug for DD Councils?

Jillian Nelson

I love my DD Council, and I am lucky enough that I am in Minnesota and RDD councils head up by the legendary Dr. Colleen Wick, who is one of the foremost historians on disability culture and disability history, and she's just amazing. We do a lot of work like funding a lot of other programs within our states and deciding what does and doesn't get funding on things like self advocacy programs or anti-bullying campaigns. We've been doing a lot of work in cultural outreach to expand cultural understanding and minority groups in Minnesota. We are still a lot of research. So we do a study, we have a five year study cycle, we do studies like on what is the public attitude towards developmental disabilities? What is the quality of life for people with developmental disabilities? How are we doing with our own set goals? We just are in the process of commissioning, five more years of studies that are going to look at racial disparities in the disability community and services and experiences so that we can get some data to hopefully start closing some of those systemic racism gaps that we see in disability services. And then we we just get to meet so many amazingly cool people and really have great conversations about disability culture, and the changing climate. Shout out to my my really great friend Brittany, who has a physical disability, but as my co-conspirator on the council, we're really trying to push new conversations about Disability Justice into the traditional DD Council model, so that we're not just doing the same old things we've always done for the last 50 years, we're gonna change it.

Andrew M. Komarow

So I'm gonna give my summary of the DD Council for early in their Developmental Disability Council, which includes autism, etc. What's very cool about from my perspective, is it allows advocates to really be advocates. So the DD Council in my state, he's a father, he's probably even a more fierce advocate than even I am. For, you know? Just again, empowerment he was, he's amazing. His name is Walter Glom. He's helped me so much. What I love about his position is he's a pure advocate. So he works for the state. He's paid by the state, but he only reports to the federal government. Right? So there they can do what needs to be done. Essentially, they can piss people off without being fired, but in a way that gets things done as being an advocate. Every state has one day do fund causes that are good, especially for self-advocates, especially and they've had a request to increase their funding for autism self-advocacy as well. So for example, in Connecticut, they read reached out to me and they said, "We need a new self-advocacy group in Connecticut. Right? You know, can you put some people together just amazing advocates with amazing experience?. And I think you're right that they do sponsor the Partners in Policymaking in all 50 states. We'll post a link below but you should reach out to your DD Council."

Eileen Lamb

Yeah, I asked you to come to Texas.

Jillian Nelson

When the day that we vote on partners and policymaking is the funniest day ever. Because if you are a partners graduate, you have to abstain from voting because you benefited from it. So you have this council of like 30 some people and at the end of it, like only like five can vote, to abstain it's kind of

tradition that you say I abstain class at 25. And like, as everyone's abstaining, you announce what class you are. It's incredibly cool to experience and I get goosebumps every year. So but it's Yeah, it's been an amazing ride and really getting to kind of shape what our state's attitude is towards disability. So they call out the people doing the research and be like, why did we ask this question? Next year, we need to do better and to see those changes happen? Even if it is incremental and slow? It's still happening, and that's pretty cool.

Eileen Lamb

That's what it always says that it's super slow. Good advocacy is very slow, right Andrew?

Andrew M. Komarow

Yes, and I remember it. And I always like to assume that, you know? For the most part, they have good intentions. And I find that a lot of legislators, they just have no idea. They're very busy. This is our lives, but it's a very small portion of theirs. We were talking about PCA waivers, and I'm like, Oh, yeah? And then it's not as great waivers. And you're like we do, and this random person in Connecticut knew that. But

Jillian Nelson

Still incredibly impossible and maddening. And so frustrating to try to navigate the system. But its better than most places.

Andrew M. Komarow

Yep, so for research, you mentioned research, and we I see a lot of a call it "hate". As Eileen would say, at organizations spending money on research. Can you tell me why research is important for funding services for autistic adults?

Jillian Nelson

So I think, where we see a lot of hate towards research. I'm going to I'm going to explain this first and why what I think when I talk about the need for research, I want research about lived experience. I want research about what is the actual day-to-day life of a person with a disability like? Where are people disabilities experiencing ableism and discrimination? Where our service systems failing people? That because really important with a research that I think that gets a lot of hate? Is the scientific research. Does it actually matter why I'm autistic? No. What matters is how life with autism unfolds and what isn't happening to support autistic people. You do, I think we actually need to know where autism comes from. Nope, I think we've done enough research to determine that we're probably not going to figure that out, and that's okay. There's a lot of things we don't know where they come from, like I don't know why garlic exists, but everyone's okay with garlic existing, right? We're not researching to figure out where garlic came from. So why do we have to figure out where autism came from?

Andrew M. Komarow

Unless your a vampire? I guess. Right?

Jillian Nelson

Well, thankfully, we don't have the Vampire Society of America or the Vampire Society in Minnesota. Maybe a membership thing?

Andrew M. Komarow

And Medicaid can't experiment, right? So one thing I say is, in order to get funded funding for services for an adult, there needs to be studies that seem useless in order to make that happen. So advocating for good research is advocating for funding, right? You can say that, so I'm not putting it in your mouth.

Jillian Nelson

Everything without data, we don't have anything. I mean, I'm I have, as you can see, my board behind me it has all of my bills that I'm working on. One of them is an entire accessibility. What did I call it an accessibility? Like, we're gonna do an audit of the entire state and county systems to figure out where accessibility isn't. And they're like, well, we already know that they're not accessible. Why do we need to do this? Because I can't get the senate and the house to make the changes to make these services accessible, if I can't provide them with hard data. Data is everything in system change and in funding streams. So it's so important, but we also really have to make sure that we're advocating for appropriate research and that that research is being done from an equity lens and not from a systemic ableism lens. I did a research study, I've heard one of my fun hobbies is I like to participate in research studies. And then when I tell them why their study is completely screwed up. So I did a social research study that track 30 days of like my social activities and like, who I did things with and where I went and what I did. Well, I only had two choices every day in this automated survey. Did I do it with staff? Or do they do with family and friends? Like, "Hi guys, I'm polyamorous, I have four partners. They're neither staff nor family or friends.". So I started just putting really snarky things in the other box. To like really kind of reflect that I'm an adult individual that does adult things. I don't just go to the bowling alley, or the movie theater, or a community rec class. Like no, I'm going to the bar, I'm having an overnight date, like these things. And then I blasted them at the end in the feedback like you are going to present this, this is going to damage independent autistic adults, because you're going to present this information that we were only given these choices that this does not accurately reflect the full potential autistic adults have to socialize in this world. Because I do a lot more than what was on the list they offered me.

Andrew M. Komarow

And by the way. Thank you for your volunteers research. I live very close to Yale, New Haven, Connecticut, and all the studies are still at the at the child study center. Right? Because while that's still how it is, although, like one of the largest autism research labs and you know, even like drug experimentation, PET scans, all that stuff, they really need people for good research. I'd like you giving that feedback, because if it wasn't you doing it, then who would it be? Right? So, thank you.

Jillian Nelson

I have a commitment that you will appreciate Andrew. I refuse to spend any money any stipend I get for any research study on the expected things. Usually I use spend it on things like cocktails.

Eileen Lamb

That's good.

Jillian Nelson

It's my it's my, my non compliance.

Andrew M. Komarow

I should do that. So have you ever done a drug study yet? Or?

Jillian Nelson

Not done a drug study? They're kind of terrifying. So fun fact, not actually a fun fact. But I like to introduce it that way. Um, I am one of those autistic people that is horribly hard to medicate. I was actually institutionalized when I lived in Illinois, because of drug induced psychosis after people put me on a whole bunch of psych meds I shouldn't have been on. So after that institutionalization thing, I kind of tried to steer clear from anything that can really screw me up like that again.

Andrew M. Komarow

That's, that's fair. I think that's probably a good thing, yeah.

Jillian Nelson

So then we've closed all our institutions. Still don't want to go back there. There's 36 states that that's still happening in so,

Andrew M. Komarow

Yep.

Eileen Lamb

And you mentioned that you were poly. I just want to say poly. I cannot pronounce the entire word. Polyamorous. I tried. Is that something you're you're open to talking about you. I know you do a lot of advocating. Do you do anything in that space?

Jillian Nelson

I'm starting to this it this year is the first year I came out openly as polyamorous. Um, I was actually laying in bed with one of my partners. And it was like a charmingly adorable moment and I wanted to post about it on Facebook. I was like, oh, we'll nobody knows yet. And it just kind of gave me like this really gross feeling in the pit of my stomach that like my whole life. Like I am openly autistic. I will tell someone I'm autistic when buying broccoli at the grocery store. I am openly queer. Like I have rainbows tattooed on my body. None of these things are a secret. So why was I keeping this other thing a secret? Because I'm open about autism. I'm open about being queer. Because I want to

change the perception. I want people to understand what queer people are like what autistic people are like, and that were not just the stereotypes, so I decided it was time to also be openly polyamorous to change their stereotypes of what a polyamorous lifestyle looks like. There's a lot of ideas that it's just a lot of kink and a lot of sex and in reality, it's sending a lot of text messages to a group of people telling them how much you care about them and encouraging them and making sure they drink enough water and a lot of calendars.

Eileen Lamb

Because I don't hear about it. I mean, barely ever it's so rare. Like you know I hear about people being gay like everything but like being poly is something that is still not talked about a lot. I have a friend who is poly so I know a little bit about it, but just because she's sharing your experience on our private Facebook page, and I feel like also other than that I haven't seen anything about it. I've seen it in that one movie in France, a long time ago. And you know, I'm I'm on social media a lot because I'm a blogger, and yeah, I don't see anything about it. And I wonder if it's something that, you know, the more people start talking about it, the more we will hear about it. So I'm really interested to hear more,

Jillian Nelson

We're definitely getting to a place where it is becoming more socially acceptable. Um, I'm a big fan of the show "Good Trouble," which is a spinoff from "The Fosters." And they just launched a polyamorous storyline, and like, I almost peed my pants. When I was just sitting there watching it completely unexpected. And then here, all of a sudden, there's like poly characters on a show that I've watched for years, it was amazing. But I think it's one of those things where we need more people to be open, we need to talk about it, we need to normalize it. And we need to break a lot of the stigmas. I think it's not that different than a lot of the things that the LGBT community has gone through, or even at the disability community has gotten to and gone through until we talk about things and are willing to expose ourselves in the world, like, we're gonna just keep facing a lot of stigma and stereotype.

Eileen Lamb

Yeah, that goes for so many things, you know, if it's secret, secret, secret secret, you only think about the stigma around it, the bad things around it. And then the more people talk about what it's really like, and the more it becomes like, normal, I don't like that word.

Jillian Nelson

But if you really break down the polyamory lifestyle, there, it's it's none of the sordid or like scandalous things people think it is. It's just this concept that love isn't finite, that it's not a pie that if I love more than one person, it doesn't mean that there's less love for everyone, it means that I get to love each person for exactly who they are, I don't have to try to find the one person that checks all the boxes on that mysterious list of the perfect person. And it means that I get to be authentically myself, because I don't have to be someone's everything either. So I can be the person who per separates on her career and like that you may not hear for three days during legislative session, because they have other my partners have other partners to support them. It means that I can like avoid social situations that make me anxious, because I'm not their only plus one, it means that I can be exactly who I am. Because I

don't have to be there everything and they can be exactly who they are. Because they don't have to be my everything. And then at the end of the day, when I do fall apart or when it is a rough week, I have a whole village of people that love me that rally around to make sure I'm okay and that I'm lifted up. Like I mean during session, it is not unusual for multiple partners to stop by just to make sure I ate because I'm sitting in a 15 hours senate session and they all know me well enough to know that I probably did not feed myself.

Andrew M. Komarow

Now why why is that was such an amazing explanation. I've never heard one that good or anything like that. Why do you think it's so hard for even you to speak openly about? Why do you think there still is that stigma?

Jillian Nelson

There's a lot of people that do I mean, let's be honest, I'm gonna, I'm allowed to say things like slut, right?

Andrew M. Komarow

Say anything you want. This is "Adulting on the Spectrum," we encourage it.

Jillian Nelson

We live in a world where there's a lot of slut shaming. So people assume that if you have multiple partners, it's all about sex, that it's oh, you must still have like this monogamous style relationship with your husband or your wife. And like, now you guys are just going out and sleeping with a whole bunch of people. And there's there's that stereotype about what it is. and society doesn't like things that are sexually taboo that they don't understand. I mean, in reality, though, that's that's not how it is like, I actually even have a partner in my polycule that I not even sexually active with. We're just, like, autistically love each other and support each other and snuggle and, like, people have this idea of like, what supposedly the sanctity of marriage and make this idea that it violates that when isn't like the whole purpose to just love and be supported? Isn't that better than following some stupid social norm? by mean talking to autistic people? So we all know that stupid social norms or stupid social norms? Yes, great. Well,

Eileen Lamb

I guess, I mean, there's got to be a lot of like, open talk and honesty. I mean, I'm thinking about it from my like, mono relationship is how you set point of view and I feel like you know, there's got to be some is there some jealousy involved? Like do you guys I mean, I assume that people you are with know that you're also with other people, right? Is there a lot of open communication and things and our the other people your ways, in poly relationships to or are some of them you are the only person for them? Does that make sense?

Jillian Nelson

It kind of fluctuates. Um, I've dated some people that are monogamous, and I'm their only partner and I've dated a lot of people that are poly, um, there is so much communication, which actually I think is what I really like as an autistic person is because you're constantly talking about boundaries, you're constantly talking about needs, and there's so much communication and it takes all that guesswork out of a relationship. And it also takes out the expectations off the table. Um, but yes, there's also jealousy. Most of us try. Most people I know that are not ethically non monogamous, or poly, I'm sure try to manage the jealousy on their own. I really try to step back and figure out why am I jealous? Like, is it because I have a need? That's not been getting met? Is it? Is it jealousy? Or is it envy, because those are very different things. Um, and then also looking at, I'm really trying to embrace the concept of something we call compersion, which is finding joy in your partner, finding joy in someone else. So I'm, I am genuinely happy, like, one of my partners is an avid biker. And their other partner is also an avid biker. And I love hearing about their long bike rides and their bike adventures they go on. And I'm super happy that they have that support. And like I adore their other partner, I think they are one of the most amazing humans. And like I could sit and talk to them for hours, which is fantastic for our partner because he's an introvert and we are both chatty extroverts. So it works great, that we have that friendship, but like, I take so much joy in knowing that his needs are being met by someone because I there's no way in hell, I'm getting on a bike and biking for 25 miles with him all afternoon for fun, no way in hell. So I'm glad that he has someone that he can do that with and it makes me really happy. And you kind of find that that balance between the jealousy and the conversion. And when there is something that is jealousy, and if it is a need that's not being met. That's where you go back to that communication, communication, say, Hey, you know, I've been feeling this way. And this is a need I have or this is a boundary I had, and just having that open, healthy, honest communication and figuring out the why we're jealous.

Eileen Lamb

Yeah, that's eye opening. It's so great that you're speaking about it today with us. I think it's, yeah, it's a great first step for a lot of poly people. You is that an okay, thing to call?

Jillian Nelson

I think so. I mean,

Eileen Lamb

Is there any, like controversy, anything? Not to say any words not to use? I mean, again, I'm sure, you know,

Jillian Nelson

Um, you know, like, I mean, they're like, with any community, we have some controversy, like, there's a lot of stuff around unicorn hunting, which is like, when you have a heterosexual couple that's looking for a third, to join them and only date them and it's a package deal. You have to date the man and the woman or you're not welcome. And there's a lot of couple privilege and hierarchy, and it's gross. And it's not how a lot of them are just trying to save their marriage.

Andrew M. Komarow

And yeah, that sounds to me not like that sounds different. right then.

Jillian Nelson

Yeah, I pretty much I live my life under an umbrella called solo-poly. So I don't have a primary partner or something we would also call a nesting partner, I live by myself, I date by myself, and I just have a great network of people.

Eileen Lamb

That's awesome. That's great. Should we do the quickfire questions?

Andrew M. Komarow

Oh, I'm gonna talk about food maybe first, or do we want to do the quick fire? Oh,

Eileen Lamb

Do we want to talk? Yeah, actually, you were just talking about chicken delivery. Context. Do you want to tell our listener what we were talking about?

Jillian Nelson

So I was late hoping on our conversation because I got a box of food delivered that had a frozen chicken. And it's like 90 degrees here. So I had to like sort out getting my frozen chicken into its home before it became an unfrozen chicken and a biohazard. So we're talking about like food delivery on this box came from a program called Community Cooks, that really just dedicated to getting healthy food into the lives of people with maybe less cooking experience, or from lower income or marginalized groups. As a nonprofit employee and a person with a disability. I qualify. So, so yeah, and that brought up some interesting conversations about cooking and autism.

Eileen Lamb

Yeah, we're, I think all of us were saying that we're not very good cooks. Andrew, sorry. If you didn't say that.

Andrew M. Komarow

I can make I actually don't even think I can say I make make a mean mac and cheese. So I've been keto for five years now. So I just eat meat and cheese which absolves me of a lot of cooking.

Eileen Lamb

So I love meat and cheese. That's a very French thing to do actually Yeah,

Andrew M. Komarow

There you go. And baguettes, you know the the long bread.

Eileen Lamb

Oh, baguettes

Andrew M. Komarow

There we go, save the day

Eileen Lamb

I thought you said gates .I've seen a gate that opens and close they get the gate. Yeah. But yeah, yeah

Jillian Nelson

I'm pretty sure that if meat and cheese, like if there was to be a shortage I might starve to death.

Eileen Lamb

Oh, is that your favorite too?

Jillian Nelson

That is my like I have very low executive function in the kitchen. I have horrible fine motor skills. So my fridge is full of things I can grab and go. So it's a lot of cheese, a lot of deli meat, a lot of meat steaks because I can throw things in a bowl and be like, cool. Now I have a meal that's high in protein. You know?

Andrew M. Komarow

Yes, I could eat the same thing every day forever. And I do.

Jillian Nelson

I have been doing a lot of turkey bacon this week. It's been really exciting.

Eileen Lamb

That sounds a bit too healthy. Or too,

Andrew M. Komarow

It's like an oxymoron. Like healthy bacon.

Jillian Nelson

Texture. It's a texture food.

Andrew M. Komarow

Fair! Oh, yeah. You mentioned broccoli in the store. I can't stand the texture of broccoli. So

Jillian Nelson

Broccoli, carrot chips and turkey bacon have been my go to accompaniments to meat and cheese this week.

Andrew M. Komarow

You can have all of those, I will never take them from you. I'll save them in Connecticut for you.

Eileen Lamb

I have a few ideas for you. One of it is you take one of those square cheese that you find the at the store whether it's swiss cheese or cheddar. And you wrap it around ham, you don't even need bread, and I just eat it like that. I know it sounds gross.

Jillian Nelson

But I do that on a daily basis.

Eileen Lamb

And the Boursin on you know what Boursin is? It's like a cheese that you spread and you can spread it on ham and then you roll the ham. And you can just eat it like it like that.

Jillian Nelson

I did that over the weekend with ham and brie.

Eileen Lamb

Yeah, that's awesome. I love that too.

Jillian Nelson

Awful good.

Eileen Lamb

I have cooking tips.

Andrew M. Komarow

So what political party do you align, slash registered for if you feel comfortable answering that question?

Jillian Nelson

So outside of being a registered lobbyist where I am not supposed to be partisan, I vote and follow the very liberal democrat line.

Andrew M. Komarow

Okay, thank you. So I am one of 74 registered libertarians in my state. So

Eileen Lamb

Oh my God, cup twins!

Andrew M. Komarow

Oh my god. You guys didn't plan this, right.

Jillian Nelson

I didn't eat like I saw the ray done. But I didn't notice what it said till just now.

Andrew M. Komarow

That's awesome.

Jillian Nelson

Nice coffee mug. So mine is just dependent. Because I want it out all the time.

Eileen Lamb

That's funny. Mine was wine but

Jillian Nelson

Do I have to be a political party. Can I just be a registered feminist?

Andrew M. Komarow

I mean, I'm pretty sure you could register as any party you want. You get the write in the box. Why can't you just register as feminists being your political party?

Jillian Nelson

I mean, here in Minnesota, we don't actually register our political parties.

Andrew M. Komarow

There you go.

Eileen Lamb

That's crazy.

Jillian Nelson

I could vote half Republican, half democrat if I was on drugs.

Eileen Lamb

Yeah. Yeah. You don't want to do that.

Jillian Nelson

That's the only way I'm crossing that line.

Eileen Lamb

Alright, let's do this. Okay, so quickfire questions? We ask. I ask you some questions and you give me the first answer that comes to your mind. And yep, that's pretty much it. You're ready.

Jillian Nelson

I'm ready.

Eileen Lamb

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

Jillian Nelson

Love myself. Stop being my worst critic.

Eileen Lamb

It's so good. What do you like to do to relax?

Jillian Nelson

Not talk to people and not be on the internet. This COVID-19 living at home like working? No. Just done with the people on the internet. When I need to relax.

Eileen Lamb

What's your favorite food?

Jillian Nelson

Cheese.

Eileen Lamb

We touched on that. What's your favorite movie film?

Jillian Nelson

Empire Records. Nobody has ever heard of it. It's the greatest movie. It's basically a commentary on socialism.

Eileen Lamb

Yeah, I'll have to.

Andrew M. Komarow

I will have to check that out.

Eileen Lamb

Wow, even Andrew doesn't know it.

Andrew M. Komarow

Even I don't know it. Okay,

Jillian Nelson

It's like young Liv Tyler and like the greatest alternative soundtrack ever.

Andrew M. Komarow

I'm actually a little embarrassed, I haven't heard of it. So I'm gonna check that out. You should send me a message after you watch it. It's amazing. Will do

Eileen Lamb

So because you're autistic, you obviously are incapable of loving everyone. How do you handle so many emotions and relationships?

Jillian Nelson

Um, well, clearly I'm polyamorous, so I just compartmentalize it. There's like a person for this and a person for this. And if they all have other people, they don't know that I'm incapable of love and empathy.

Eileen Lamb

She nailed it Andrew.

Andrew M. Komarow

So good.

Eileen Lamb

A lot of the time we asked those sarcastic questions and our guests they're really confused. We have to cut them, edit them out at the end, because you're like, wait.

Jillian Nelson

I live in a very sarcastic autism world because at some point that I can't fix how the world is going to be ignorant. I can only make jokes about it. Like, my favorite one is the autism vaccine level up joke, like I would have be at level 64.

Eileen Lamb

We like that one too.

Andrew M. Komarow

Well, I think one of the reasons we're speaking today is because well, Bridget introduced us and I met Bridget at an Autism Speaks conference where we made fun of neurotypical researchers and shared autism memes back and forth for most of the conference. So this is appropriate. Speaking of which...

Jillian Nelson

The last conference I was at Bridget with we ended up having like the police come.

Andrew M. Komarow

I'm jealous now. Eileen, we got to go to a conference to get like the National Guard called we got a one up Jillian and Brigid.

Jillian Nelson

Fantastic, all four of us ended up at a conference. And my favorite thing is at the end of autism conference, like or at the end of the day, like after everything. I like to call it autism puddling we're all the actually autistic humans just gather and do like it's just adult parallel play. like someone's on like, everyone's on their phone, someone's coloring. Like there's fidget. Thinking on the floor. And it's like it's autistic puddling. And it's the best part of every conference.

Eileen Lamb

Yes, when you don't have to talk to people but you're still with people. Yeah, I do that too.

Andrew M. Komarow

And Brigid has a question for you. If you were to be any mythical creature, what would you be?

Jillian Nelson

Man, if I were to be any mythical creature what would I be? I think I would probably be a mermaid like Brigid, but not as good a mermaid. I'm just I love the water. The ocean is my happy place. I would live by the ocean if Minnesota didn't have such great waivers. The main reason I still live here is our disability services, because it's definitely not the weather.

Eileen Lamb

That was awesome. Well, thank you so much for joining us today. And if you want to tell people where they can find us where they can contact you anything. Now is your time.

Jillian Nelson

You can find me in a couple of different ways. I have a Facebook page on Autism on the Go, which is a very poorly managed YouTube channel. But I will randomly on that while I'm on the go get inspired to talk to people about different issues related to autism. Or you can reach out to me at the Autism Society in Minnesota. My contact information is on our website, which is ausm.org also pronounced awesome.

Andrew M. Komarow

That is awesome.

Eileen Lamb

So cool.

Jillian Nelson

And we are indeed awesome. I think we are an amazing organization with amazing leadership. That's really doing a lot to like center autistic voices and create artistic leadership within our community.

Eileen Lamb

Yeah, thank you for everything you do for our community.

Andrew M. Komarow

Thank you.

Jillian Nelson

Thank you guys for everything you're doing for our community if we don't have hard conversations, nothing's gonna change right.

Andrew M. Komarow

Yeah, I we agree. That's why we're here.

Eileen Lamb

So I love that we were able to different opinions tonight and still have a very nice and respectful conversations. So thank you, and bye bye.