

Adulting on the Spectrum: The difference between speaking & communicating and advocating for non-speaking autistics

Andrew M. Komarow

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

Eileen Lamb

Hey, Andrew. Hey everyone. In this podcast, we want to highlight real voices of autistic adults, not just inspirational stories, but people like us talking about their day to day life and what autism means for them, basically want to give a voice to a variety of autistic people. And our guest today is Peri.

Andrew M. Komarow

Peri is a 24 year old autistic woman. After many years of her family wanting answers, she was finally diagnosed with moderate to severe autism at age 11, which was pretty late despite the obvious sign she was showing. She didn't say her first word until the age of six, and didn't say much else after that until she was 10. She wants to raise awareness about being nonverbal in such a strong verbal world.

Eileen Lamb

Hi, Peri, thank you so much for joining us today. I've been following you for a while and I love what, what you post and your stories, and I'm excited to have you here. We want to ask our guest how's it like to identify? And by that I mean, you know, do you like to say I have autism? Or I'm autistic? I'm on the spectrum. What's your preference?

Peri Savidge

Um, I like to say I have autism. Yeah, because I like, I like being Peri first, then or autism. I prefer that. But either way, I don't really mind. But I have a preference towards that a bit more.

Eileen Lamb

I like that. I like to be Peri first. Yeah, that's a great reason to use person with autism. Yeah, I want to be Eileen first.

Andrew M. Komarow

So when you were diagnosed with autism sounds like a difficult process. It also sounds like it took a lot longer than it should have. What can you tell us about that?

Peri Savidge

Um, okay. Yeah, it took a very long time. family went to like different doctors, different teachers. And they, they, I know, some of the doctors said that I was too severe to have girl autism back then it was very, like, people thought, boy autism, girl autism existed, which, obviously it doesn't. Autism doesn't have a gender functioning labels don't have a gender, you know, all that. But that was probably the main thing back then. Yeah, I was too severe to be a girl on the spectrum. Because to them, girls on the spectrum should have acted a certain way. And I didn't so, so yeah.

Eileen Lamb

And you say you didn't speak until you were? You didn't say your first, your first word until you were six. And then you didn't speak until you were 10. So if not autism, what did the doctors think was going on?

Peri Savidge

They thought it was laziness. They thought it was I was just really, mentally slow. But yeah, between laziness or just being slow. That's what they just pull it down to.

Eileen Lamb

Wow, thats really sad.

Peri Savidge

Yeah.

Eileen Lamb

It looks like you have a great relationship with your family, and that they really fought for you and for you to get the help you needed when you were younger. Is that right? Can you tell us more about them?

Peri Savidge

Yeah, so I'm from a big family. Five sisters, five brothers. And yeah, they were all pretty...Yeah, they were all pretty supportive. I was raised by my grandma, on my dad side, and my dad, my siblings. And yeah, they all fought really hard to try and get the right help and fought for answers even when they were unsure themselves. And that definitely helped.

Eileen Lamb

I mean, you don't even have supportive doctors and professionals. So I can't even imagine what your life would have been like, if your family wasn't supportive. It's, it's important even to these days, there are a lot of people who are autistic and who don't have the support of their, their family, and that can make things really hard for them. And yeah, I'm glad you had that, that support at least even though it was difficult for you, and I'm sorry, you have to go through through all of that.

Andrew M. Komarow

So we'd like to talk about adulthood on the spectrum here. Obviously. It looks like you've had quite a wild ride when it comes to college education. Can you tell us more about that?

Peri Savidge

Yes. Okay. So, um, from the age of 11 to 19 I was in a special needs school. So that really, really really helped. It was basically a school where you learned just the typical subjects. But on top of that, there was other classes like speech therapy and occupational therapy and physical therapy and different types of, you know, things like that. And I feel like those really helped, you know, lessons to help us with our communication and our relationships and friendships and just our behaviors. And it was, it was tough going, you know, some days, I really didn't like it. But looking back to it, I'm very glad that I went there. And I was able to be in a school like that, that taught me the skills that I needed. I feel like a lot of people look at those sort of places, and they see as places that they see as sort of not great, because they feel like, Oh, they're making you less autistic. No, they're just giving us the skills that everyone else has. But we haven't, like, why shouldn't we be taught those skills everyone else has. So that was really good. So then I left at 19, and I went to a mainstream college. So just to college, like just a typical college setting. And that was very, very difficult. I feel like one of the downsides of the school was that I was kind of sheltered, you know, I was used to having, you know, one to one staff and school classes. And so when I went into a major in college, it was like, a massive, massive change. And I didn't really get the support that I deserved three weeks into the course, they told me that I needed to drop out, and that I was going to fail. And that. Yeah, they basically made it their business to basically try and get me off the course. But I wouldn't, I wanted to see it to the end, I was like, you know, if I fail, I fail, I just want to finish. Because I just I like to finish things. And eventually, I finished. And I passed and I was the only person that got accepted into all my university offers and all that. So I definitely proved them wrong, because they kept saying that someone who went to a school like mine, someone who had a background like mine wouldn't have passed. So it kind of I kind of gave them the toolbox for other people like me, who would join it. Join the college in the future. So I like that.

Eileen Lamb

Amazing.

Peri Savidge

Thank you.

Eileen Lamb

Congratulations. Yeah, it's, I can believe that they said that, and I'm so glad you, you push through and you stay till the end to prove them wrong. It's a it's a great story. It's, it's, it's a great story.

Andrew M. Komarow

Now one of the things that you want to talk about is being non-verbal. Now, do you have a preference on non-verbal versus non-speaking? I know there seems to be a very similar amount of people who

said how we should identify also have an opinion on nonverbal did not speaking, do they mean something different to you? First off?

Peri Savidge

Not really. They mean the same thing. To me.

Andrew M. Komarow

Okay. Yeah.

Peri Savidge

No, they mean the same.

Andrew M. Komarow

I just want to make sure respectful of that preference as well. So I think with many people, and although, you know, I didn't speak until I was three or four. I know, you know, others on our podcast, even others, you know, didn't speak until later. But I think you're probably, you know, one of the first guests we have we've had, who didn't, you know, speak or and speak of significance for, you know, many, many years and now is, you know, well well spoken. Um, so you remember what it was like to not speak? Right. So, um, what can you share out there? And what would you like to share about what it was like not being able to speak because forget, you know, I don't remember it. You you do and what helped you if you could tell us more about that.

Peri Savidge

Yeah, okay. Um, so it was just I just remember being like, like, downright frustrating. It was like I was in this like, goldfish bowl just looking in, and I knew, I could see that everyone was doing this thing that I couldn't, you know, talking is, verbal communication is such a massive part of everyone's lives, you know, it's used, even in ways that we just don't think about, because it's just automatic in that. And it's so puzzling and mind boggling when you're around that, but you just can't do it, definitely. So I have a sister who is two years younger than me, and I remember just being like, perplex that she could talk. And I couldn't. And it was frustrating, because I knew, I knew that I was older, and I knew she was younger, and I just couldn't put it really together. And I feel like it got so frustrating that some days, I would just be more kind of, like, out of this world and into my world, where, and those are the days where, you know, people just thought that I didn't really know what was going on. And I kind of just went into my own world, and I didn't really even want to interact, and I didn't even feel the frustration. And you know, and that happened because I felt like, well, if I can communicate them, what's the point? In being here, like, in my world, at least, people, people know me, I can communicate without talking. Communication is just in an abstract sort of concept there. But yeah, frustrating is probably one of the main words and that I would describe it just knowing on the day that where I was a bit more with it, I would understand what I wanted to say. And what I wanted to do, like, if I was in pain, that was a big one. I knew I was in pain, and I couldn't tell anyone or if I was hungry, and I couldn't tell anyone. And I just thought, you know, like, I don't know, I just why. And I would get irritated and angry. And I think that's why I would be quite angry all the time. I know my family. We

joke that I was just furious. Like 24/7. I was angry all the time. And I think that's because I couldn't communicate. And I didn't really understand why. I couldn't communicate. And I think not understanding why it was like a big thing. Yeah.

Eileen Lamb

But during that time, you were aware of everything that was going on around you.

Peri Savidge

Yes, like I said, some days, I will be completely unaware. Some days. And I think that's when the frustration got bad. And I would like invite into my own world. But most of the time, yeah, I did know. And I was completely aware of what was going on. But I just couldn't. Like, connect it. I felt like I was just one sort of piece away from connecting it all when I just couldn't find that piece.

Eileen Lamb

What do you think change from when you were 10 to to now that allowed you to be able to communicate verbally?

Peri Savidge

I'm not really sure. Like, I get this question. A lot. I don't really know. Like, it could be a numerous of things. It could be just time. Maybe I just needed time. And I think yeah.

Andrew M. Komarow

Do you? So question. So because you weren't diagnosed until later in life. Therefore, you did not really have obviously no PECS, obviously, you know, no ACC iPads didn't even exist, then, you know, how did we live before those? But, you know, do you think that if you had been given, you know, ACC device, and I know this is a you know, a little you know, hypothetical. Um, do you think that you'd still be non-speaking today? Was it the frustration of not being able to communicate and not be able to speak was that What eventually made you overcome that challenge and why you can speak? Now, if you had an alternative method of communication? Do you think you would be still non-speaking? And if you could go back in time, would you choose the path now? Or would you prefer to be non-speaking?

Peri Savidge

Um, that's a very interesting question. And I think it's like, I don't know, like, obviously, when I was like, very young, I was taught sign language and Makaton and that, but I just couldn't get on with it. You know, like, they tried and tried. And I just didn't get on with it with that sort of form of communication, because I was actually when I was very young, from like, I think it was like five to seven, I was put into a special needs school for another special needs school for two years, but I left because of numerous reasons. And I think. So I did have things like, you know, pecs and stuff. But I just although I just don't think I got on with it very well, I think PECS was useful. But it was just the continuous having to use them continuously. thing like, some days, I would be able to use them some days I didn't, because I seem to go in and out of regression quite a lot daily. So I feel like if I had an

AAC device, I don't know, I feel like it would have definitely made things easier. And I feel like I still would have spoken because even though I speak now I always say that I'm writing, like writing and hoping all that sort of stuff is my true voice. Like, my verbal voice helps me with basic demands, or what I need and stuff like that. But my true voice comes out in writing. So I feel like even with an AAC device, I probably would have talked I don't think it would have prevented it. Because I just yeah, I just don't think my verbal voice is truly. You know, the voice that I know that I have. So yeah.

Eileen Lamb

Yeah. And you know, it's been proven that using AAC doesn't delay language, if anything, it helps because you're practicing communication when you're using AAC. And on top of it every time a child or an adult makes demands on the AAC device. You can hear the words, you know, like for instance, my son surely will say I want eat cookie. And so you will hear it every time he presses the buttons on his AAC device, you will actually hear it. And you know, it's it helps with language for that reason, there is a lot of MIS information around that that using the device will delay language. And I don't think that's true.

Peri Savidge

No, yeah, I actually agree it kind of relates to when I was little, my brother had this, like train station thing and you could record it. And I became like obsessed with it, I would carry it around completely. And I would just walk around with it and play with it. My family noticed that I was recording conversations, what they were saying, and I was playing it back. And I was mimicking the conversations that I was had recorded. So I think just hearing something like that helped me. So I was actually kind of helping myself. And it took them a while to actually realize what I was doing. But yeah, I thought that was quite clever and quite similar in a way. Yeah.

Eileen Lamb

It's really interesting. I think a lot of parents and people are going to be intrigued by this conversation. Because you know, it's for so many autistic people who are non-verbal. We don't know exactly what's going on, because a lot of them can communicate to an extent that makes us understand what's going on when they're non-verbal. But you have that perspective, because you gained a voice if I can say now you have you can explain to us and it's just a perspective that we don't get to hear very often. At all. I'm really thankful for you sharing your story and talking about that stuff.

Peri Savidge

Thank you. I think I think the breakthrough for me personally, was at my special needs school when they let me know that you can communicate without speaking for years I was in you know, I went to doctors and I went to other like therapies and that other special needs school that wasn't, wasn't nice wasn't good, because they all put the goal to speaking instead of communication. Speaking and communications, two different things you can communicate without speaking, and you could speak without communicating. And I think the breakthrough will be when I realized that I could communicate. Without speaking, I didn't need to speak like, it's great that I can, but I was told, I was taught that speaking isn't the goal, you know, my school used to, I had a really hard trouble at just if I was upset

or angry or feeling any sort of way, I couldn't communicate that, even when I could talk, I just couldn't communicate that. So they would draw, like, oh, like smiley face with a speech bubble. And they would write and they would encourage me to write, and we would have full on conversations with these, like comic strips. And I thought, you know, this is great, this is, this is me, communicating, you know, speaking shouldn't be the goal for autistic people, it should always be communicating. And you can communicate in so many different ways. I feel like when people make us feel like speaking is the end goal, it just, it feels like an impossible goal for most of us. And that can actually cause a lot of issues down the line. So yeah.

Andrew M. Komarow

So if I will, and I think this statement, and everything kind of helped clarify maybe an earlier what might be taken as an assumption. But essentially, the key to being able to speak was you being able to communicate, and the stress of just trying to speak before you could communicate, almost like, you know, trying to run if speaking is running, right and communicating as walking, you were trying to be taught how to run before you could walk is the way I'm looking at that. So it sounds like the best thing. And please correct me if I'm wrong, I know Eileen would love to, but I'm asking you, Perri for the moment. And that is the best thing parents can do to help their child speak, is to not help them speak, it's to help them communicate in the best way that they can. And then and then the verbal communication will follow if the individual is able to do so is that an accurate reflection of your words?

Peri Savidge

Yes, that is accurate. But yeah, just always communication is the goal. And if verbal communication does follow, then great, but if it doesn't, then that's, that's no biggie. I feel like everyone, even those not on the spectrum have a chosen way to communicate. And you know, for example, like, I prefer text, like overflowing like just don't, you know, no one should ever call me. And that's just the way that I prefer to communicate, and it shouldn't be looked down, like something bad in that. And that's the same with you know, autistic children and that they should just be, you know, let to communicate however way that they can.

Eileen Lamb

I want to go back to you talk about your, your personal life. And I know you were working in the food industry, is that right? Yeah. And you left that job pretty recently to work, you know, in a preschool right? How is that going for you?

Peri Savidge

Um, yeah, it's going really, really good. I'm really enjoying it. And I'm learning. I'm learning like so much. And I'm also able to give them some help as well, like they ask in regarding children, and that and I'm able to go well, obviously, I went to a special needs school. So this may help him that may help from my experience. This child may be feeling like this because and I'm able to bring mine site to the table. And it's just it's just really good because they they're so thankful and grateful for it. And they just, they, you know, they think my ideas are amazing, and that's great. They don't care that I don't they don't care that I might be quiet. They don't care that I don't look at them in the eyes, which I

know was a big issue with my other employer. And I'm like, if I've got good ideas and I'm doing the job, well, why should I look at your eyeballs, you know, that sort of thing. And they're just Yeah, it's great. And I feel like I've always wanted to work with children. And this is yeah, I'm definitely happier here. And it's just something. It's another thing that I family and I was told I would never be able to do what I'm doing, which is great, because I feel like it gives hope to other autistic families not to be on this level, but to just say that whatever their child can reach, they can like, whatever, whether it's, you know, something as big as this, or something that maybe people may consider smaller, but as big for them, you know, so yeah, it's great. It's going good.

Eileen Lamb

I'm so impressed with everything you've accomplished, despite what people were telling you. You couldn't do, and you didn't listen to any of that. And you did it again. And it's the best, the best way to be stubborn.

Andrew M. Komarow

Me and Eileen are both very stubborn. That's probably why we're seeing so stubbornness is the secret to success.

Eileen Lamb

It is. Yes.

Andrew M. Komarow

Now, one thing that I, you said that was very interesting is when people are asking you about your experience, you are talking about just your experience? Can you tell us why you don't feel the need to speak for every autistic individual there is? And that was a little bit of sarcasm right there. By the way, I should say, Eileen knows that. You know, anything I say usually is, but can you tell us why you only feel comfortable speaking about your your own autism? And how that's still helpful, a belief that Eileen and I both share, but it seems a lot of very loud advocates feel that their autism, they can speak for everyone?

Peri Savidge

Yeah, well, put simply, I'm Perri and they're not.

Andrew M. Komarow

Common sense, it sounds like,

Peri Savidge

Yeah, pretty much, right. I just don't understand why. Why anyone, like take autism out of the equation for a little bit? Why would you speak on behalf of anyone, they're not you and you're not them. Like, you can only talk about your experiences, like there's similarities, and there's lines, that means like, crossover with each other. But at the end of the day, it's is your story, and you can only talk about your story, I feel like you know, maybe others, they want to sort of say that their autism is autism, but

it's it's not because we're all very, very, very different people with very different personalities, which makes autism and you know, just very, very different, I don't understand why you would sort of speak about, you know, someone else that isn't your, your own. And that's why I'm making it so important on my page to let them know, like, this is my insight. This is my personal story that if you or you can relate your child to it then great, but like, I just don't want to speak for your child or the parents or because I don't know, I don't know them. I only know me. And yeah, it's that simple. Really.

Andrew M. Komarow

Yeah, I think the world would be a much better place if everyone autistic or not. You know what, ask those questions.

Eileen Lamb

Yeah. Agreed. And, I mean, you know, we all know that the autism online community can be cruel. And I mean, I can't imagine it's it's easy for you it's not easy for for anyone and I love what you said about Well simply put, I'm Perri they're not I mean, nothing else needs to be said like, it's just like, common sense and but, you know, even though it's common sense there are still going to be people who don't agree with that. And I'm wondering how that affects you when people you know, the backlash on the negativity in the autism community. How is that for you?

Peri Savidge

Yeah, it used to like it still does but it used to really really affected me because like, I was quite small page for a while and then I blew up literally overnight after I wrote a post about what it was like being non-verbal. And that so for a very long while, like, I just got, you know, positive comments all the time all the time all the time constantly, and that obviously felt really good. And then after all, While after that, the negative comments started, like coming in. I think because it was so abnormal for me to get them, it really bothered me to the point where I would, you know, really watch what I was saying I would delete whatever they didn't like and things like that. And I realized I shouldn't really be doing that, like, I shouldn't be censoring myself, like I never since I've never censored myself in real life. I haven't, I don't even know how to do that. Like, I'm Perri, this is what you get, like it or hate it. So I don't understand why I was doing it. Online, and I think it was because I was just used to such the positive attention for so long. And then, as years went on, I realized that I that the autistic online community that I should have fitted into, I really, really, really, really didn't. And that bothered me for a while. So couldn't really understand why I didn't that I didn't. Because, you know, autistic adult advocate, you know, I should have fitted in to very odd crowd. But I didn't and then that's when the hates sort of ramped up, because they felt like I was like, going against them. And I guess I was but like not intentionally. And I was just writing what I believed and was trying to. I didn't like the hate that I was getting them that I was seeing other bloggers was getting, like, in autistic community, we all want one thing is to spread awareness of autism. And I didn't really understand why there was so many different levels and different communities and well, and one very odd community that I would describe as cult, but I can't say that, but yeah, it's a cult. But yes. 100% cult that I just did not want to be a part of. I was here to spread about autism when I was here to spread about the awareness, all types of awareness, the good, the joy, the ugly the bad, you know, just so yeah. The hate did used to get to

me, and now I'm just like, you know, it's online, you know, I can just, I can just switch my phone off. Like, I've had my page hacked. I've had hate pages created about me. I've heard awful, awful threatening, like, pm messages. I've had, like so much. And I just, you know, I think it just describes them. It says more about them than it says about me. So, yeah, I have the odd day where it gets me down. And I'm still sort of going, should I write there through there, right, that are just yet to go ahead. And I just feel like you know, for all the hate comments, I get so many more positive comments. So that definitely helps.

Eileen Lamb

I am so sorry, you went through this, I don't know why, but I feel very protective of you maybe because you know, you were non-verbal, and you're younger, but it just really annoys me that they go after you too. And, you know, I feel exactly the same way you do, as in, it used to affect me so much, you know, literally I would lose sleep over it, I would cry, we get really angry and I would take it out on everyone around me when they would, you know, harass me. And, you know, I mean, I'm not saying that doesn't still happen when the harassment is really bad. But I've also reached a point where I know that it's not personal, I mean, a little bit, but at the same time they do it to everyone and what they're saying it's the same all the time, like you can guess what their next comment is going to be you know, and it's just a mob mentality. And, like,

Andrew M. Komarow

We should get an Actually Autistic Magic eight ball where we just shake it, and it gives like one of like, ableism it's your internalized ableism and that's the magic eight ball or we can make I bet you a digital magic eight ball exists. We need to do this. I am excited now. Okay.

Eileen Lamb

And here was the ideas. But you know, it's what you said Perri that it says more about them than about you and they get mean.

Peri Savidge

Yeah. Didn't have to, you know, agree with everything that they say and they just get angry when you don't. And that's just that's on them like not everyone. You know, it shouldn't have to be a fight to be an advocate. We're all you know, different and we all have very different, different perspectives, and we're speaking about our autism, you know, I don't understand how someone can be like, you should see your autism as a superpower. So excuse me this is my autism, you don't know what my autism is. This like, it's just very odd. I find it very odd. Like, I wouldn't be like going up to someone in a wheelchair and say "don't you know, don't see it as a disability". Like it's just odd. You know, it's very, if you, but yeah.

Eileen Lamb

You, You seem so, so much mature. Honestly. It's It's really impressive. To have that outlook I mean, at 24 I would have had your your views on things. It's, it's really impressive. I gotta say, we're going to ask you some quickfire questions. It's nothing crazy. We just ask you a question. And you know about

your what you like, and you tell us the first thing that comes to your mind. already? Yes. Okay. What is the best piece of advice you've ever been given?

Peri Savidge

Probably to forge a path away from the things that hold you back. Yeah, I think that was yeah, that was given to me at school. And I hope you're, there was a lot of things happening at home and yeah, and it was just yeah, basically just saying,

Eileen Lamb

I like it. Yeah, I need it. Well, you forge your own path. Would you like to do to relax?

Peri Savidge

I like to read or watch TV. Alright, so evil those vains are good.

Eileen Lamb

What's your favorite movie? Or TV show?

Peri Savidge

TV show is probably a toss up between Grey's Anatomy or New Amsterdam.

Eileen Lamb

Yeah. What's your favorite food?

Peri Savidge

My favorite food is probably probably strawberries. Yeah.

Eileen Lamb

I love them too. How was it to finally say, F**K OUT LOUD for the first time. (ALL LAUGH)

Eileen Lamb

Andrew just added that question, he is being silly.

Peri Savidge

Yeah, good. I don't I don't actually remember like,

Eileen Lamb

Probably good? Yeah. Okay, now is your time to shine tell people where they can find you on social media.

Peri Savidge

Yeah. You find me on Facebook. Not Raingirl, and you can find me on Instagram on Not Raingirl, as well.

Eileen Lamb

Oh, you're on Instagram. I don't even know. Yeah. Awesome. Well, thank you so much for joining us today. Honestly, it was really amazing. Like talking to you. Getting your your perspective on things. Right, Andrew?

Andrew M. Komarow

No, it was really interesting. I don't think I've had a guest, let alone read into somebody who is able to provide such a, you know, a unique perspective. And I'm sure others exist. I just haven't had the chance or opportunity to speak to anyone about a similar situation. So really, thank you for sure. Thank you.