

Adulthood on the Spectrum: Turning a special interest into a career

Andrew M. Komarow

Welcome to Adulthood on the Spectrum. I am Andrew Komarow, an autistic Certified Financial Planner. I co-host Adulthood on the Spectrum with 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 Dawn "Scully" Sikora. Scully, has Asperger Syndrome. She specializes in studying entomology, which is insects. She's been an autism advocacy since her brother was diagnosed with autism in the early '90s.

Eileen Lamb

Hey Dawn! Thanks so much for joining us today. So we start by asking our guests, because they like to identify and I'm talking about pronouns, you know, she hers they or any pronouns, and also your autism identity. So on the spectrum, autistic Asperger's, what are your preferences?

Dawn "Scully" Sikora

Oh, I'm female. So she her, you know, pretty standard. And I do identify as a person with Asperger's Syndrome. So, yeah.

Eileen Lamb

Nice.

Andrew M. Komarow

I think that's our first one who specified that is their preference. Would you agree, Eileen?

Eileen Lamb

Yeah, I think you're right.

Andrew M. Komarow

Yeah.

Eileen Lamb

Cool.

Andrew M. Komarow

Very cool. So can you tell us again, about your diagnosis, what led to it what it was, how your life changed since or didn't?

Dawn "Scully" Sikora

Well, um, back in, I don't know, when my brother was like, really little, about three or five. He started having some behavioral issues and needed support from the schools and the like. And he was diagnosed originally as PDD-NOS. And then, as time went on, they were like, okay, he's high functioning autism. And he had a lot of seizure disorders, a lot of challenging aspects to growing up with him. And it wasn't until I was about 28, when there was a study out of UIC, no, not UIUC, sorry, UIC University of Illinois, Chicago. And they were doing a sibling's brain scan study. So basically, to utilize MRI brain scans, to sort of identify, to see if they could use that as an identification tool for people on the spectrum. And so they were comparing siblings, that whom they thought would be, you know, neurotypical healthy representation, comparing them to their siblings, and also having a code control cohort of siblings that were basically non-ASD. And it really was the functional MRI that helped identify me as an individual with Asperger Syndrome, because basically, I do strongly present as mostly neurotypical passing. I am very quirky in my presentation. And it does cause interpersonal relationship issues. And that really came out in my mid to late 20s, especially as I got out of my undergraduate program, and moved into sort of very female centric, professional environments where a typical social profile of a female is more highlighted. I don't have those. So that that's kind of one of the things that I was like, okay, I'll participate into this research study, because one I really enjoy contributing to the scientific process, myself being involved in science and research. I also like to participate and help other researchers achieve their goals. And that sort of all wraps up with autism advocacy, because I grew up with that. Like, that was my community. Those were my peers, my brother has autism. And then, at that point, it was unknown if I had Asperger syndrome, or any ASD spectrum. They just thought, you know, neurotypical, let's see, and it was, it involves a look at family genetics as well. So they were looking for like, fragile X, just sort of like rule that out in blood, because that was one of the few things that was known to be a biological indicator for a possible Autism Spectrum profile at the time, and that was the early 2000s, roughly. So around 2006 2007 2008, I guess that's not like early 2000s. But it's 2000s.

Eileen Lamb

And so you use the term Asperger's, which, like we said, was, like, the first time I think someone prefers it. That's the term I was diagnosed with to and, you know, I like it. So do you indeed, identify with it more than any other seems like it and why?

Dawn "Scully" Sikora

I do. I strongly identify with Asperger Syndrome, because that is the diagnosis that was given. Um, it represents my position on the autism spectrum, as an individual with an ASD profile. And I think that's very important because it helps establish in communication, it's a communication vehicle, it

establishes to others what kind of supports and services I may need, in terms of like professional situations, employment. Just in general, the term Asperger's Syndrome has a well established, understood profile of how it is in the autism spectrum. Whereas like, for example, PDD NOS is a little bit more nebulous. And sometimes it sheds challenge for receiving services, which is part of the reason why my brother had to be multiple evaluated because he wasn't receiving the correct services for him. And then they established that he was high functioning autism, and that helped pinpoint better services and supports for him as we were growing up. So I believe each of those particular sub grouping sub headings and labels. While there's a lot of controversy here today online. With regards to those, I think they are extremely beneficial diagnostically, and for communicating an individual's personal needs and supports for themselves. For me, Asperger's is that and when I say I have Asperger Syndrome, I believe more people understand what that means for me, in terms of my peer groups, in terms of my family members, and in terms of the general public, I believe, I mean, both autism and Asperger's Syndrome are kind of recognized. And they recognize to gather, but each of them has their own understood profile, if that makes sense.

Eileen Lamb

Totally, yeah.

Andrew M. Komarow

So no, and it does when you say autism, that can mean someone like Charlie, it could mean someone like Jude right. So you know, although there can be good as a scientist, quantitative ways of, you know, referring to someone that you can see the value in that. That makes sense. So you're finishing your PhD in Entomology? Can you tell us a little bit about how your interest in insects turned into a career?

Dawn "Scully" Sikora

Okay, yeah, how my interest in insects turned into a career. Well, um, so my undergraduate days, I did biochemistry. I love science, I love doing research. And then I sort of navigated adjacently to librarianship. And I was going to do like a career in bioinformatics and science librarianship. But I realized that my true passion has always been insects and studying insects. So I just decided to pursue both a Master's Degree and then go for a PhD in Entomology. Kind of one of those things of I guess, YOLO. "You only live once,". I really love insects. That's what I want to do. So that's what I chose to do kind of thing. I really wanted to do it. So I force of will chose to make it happen and communicated with various universities and didn't take no for an answer. When I got turned down, and I just kept looking for a university that could train me in Entomology.

Eileen Lamb

That seems like a very specific interest. Insects. Do you have any advice for someone who would want to pursue employment in their special interests?

Dawn "Scully" Sikora

Don't give up. You're going to face a lot of barriers, both personally, professionally, and developmentally, people aren't always going to understand why your special interest is of importance, or a value. Like for example, me just following bunch of ants who would ever think that's of any true importance. But if you find why it is important, and then you can work towards communicating that with someone who will then take value and see value in it, you can turn your special interest into a career goal. It really it's taking problem solving skills, and then just going forward. And like I said, don't, don't give up when someone is like, I don't understand why that's of any interest or value to you? I mean, let's say even your interest is in gaming, or you do like, like role playing. That's if that's your special interest, you could even turn that into something that would be career worthy. It's just establishing how to make that work. His response was, yeah, that's, that's definitely literal thinking there for you. Ah, his ability to interact with the social world is significantly more limited in what he's able to participate in, and I don't think that's the fault of him, or his autism, I believe that's a fault of society, being unable to integrate him, especially for the times period that we grew up in early 80s, late 80s, early 90s, people didn't even know what autism was. And I know, a lot of people get upset for some of the advertisements that were created, that reflected those time periods. But when I look at them, I do see an accurate reflection of my lived experience. And what happened to my brother, what happened to my family. It was a very isolating time. Peers in high school peers in grammar school, they didn't understand. I had peers in high school that really didn't want to interact with me until they heard a program on the radio that was describing autism. And only then did they change their social interactions with me to try and start including me, and coming over to my house and including me in social engagements. But for my brother. And since he was diagnosed first, it was a lot. It was a lot worse of an experience for him, because not only did he have a lot of seizure disorders, and communication difficulties and behavioral issues, but like people in stores would try and call the police on my family. Because he would have so much sensory overwhelm, being in the shopping center at age five, that he turned he just melt down. And there was no supports. Even in restaurants, you couldn't really go there because they would look at a person with autism, as though they're just disobedient, that behaviorally. They need more discipline. That it's the parents fault for being abusive or unresponsive to the child's needs. Just a overall lack of understanding lack of awareness of what autism is how it impacts a family. And yeah, It was definitely a very isolating time period to grow up in.

Eileen Lamb

Yeah, I feel like it's still true. Nowadays on a lot of the, I mean, it's gotten better because we have more awareness, but it's still not. Not great. So did that have an effect on your advocacy? When, when you say that you do autism advocacy, like what do you mean, what, what advocacy have you been involved with? And how do you decide which organization to support?

Dawn "Scully" Sikora

Okay. Yeah, um, it definitely had an impact on my personality development and what kind of advocacy I go towards predominantly grassroots. And I've been, I've been involved in advocacy, specific regards to autism for a long time. Basically, as soon as my brother was diagnosed, there wasn't so much as active advocacy back then. But I would explain to my peers that my brother has autism. And try to give them some brief understanding of what that would be like. And then as I got older, I got more and more involved. For example, I mean, I'm technically still Girl Scout now. I'm a lifelong Girl

Scout. But I was in Girl Scouting when I was younger, and one of their highest awards to achieve is the Girl Scout Gold Award. And for my project, I created a website called DPFDN. So DuPage Families Disability Network.org. And it's still in operation today. And what we do with that organization is we bring local local personnel like disability like PACT, or Ray Graham, these are local disability organizations within Illinois, specifically around the DuPage area. And we'd bring in speakers at our library and have them present. So topics such as transitioning, student needs, adult transitioning, and then general disability issues. For like, it doesn't even have to be autism, it could have been like something like cerebral palsy, or Down syndrome. But trying to connect our local committee community, which is basically my, my hometown is Lyle, and then all of the DuPage area with disability professionals. And another topic, we would bring up with the ABLE accounts. I don't know if you're familiar with those, they're for individuals with disabilities usually established before age 26 to help,

Andrew M. Komarow

They can, they can allow individuals to pay for certain expenses while still being exempt from government benefits. I'm a certified financial planner, I was an ABLE Ambassador with the ABLE National Resource Center and I speak around the country to other professionals and families on ABLE accounts all of the time. So So what can everyone do to, you know, be more kind to each other? What can people do to you know, advocate in a way that is, you know, as accepting as possible.

Dawn "Scully" Sikora

Stop targeting people for their diagnosis. Allow us to use the language we need to communicate our needs, the best, be that Asperger Syndrome or autism or functional labels. Yeah, it's very controversial online and it really needs to stop. It's it's not beneficial to families, it's not beneficial to individuals on the spectrum. It needs to change. You it's not gonna help any of us in the professional world if we keep doing these kinds of arguments that are semantic space.

Andrew M. Komarow

So what would you say to the person who says, well, it's not a diagnosis anymore? So you're the one distracting from the conversation? Why don't, what would you say to that?

Dawn "Scully" Sikora

It's definitely still a diagnosis. My paperwork didn't change any. I don't see them stepping up to the plate to offer to pay for a new diagnostic procedure. And it is how I get accommodations that work as a diagnosis. And they're not there in the office with me when I have to communicate with HR or communicate with a major medical professional. So they're just, you know, it's not distracting from the conversation. It's my life. It's my diagnosis. And they're going to have to start respecting that, especially if they want people to listen to autistic people. Individuals with Asperger's Syndrome are amongst that, and they need to hear us.

Eileen Lamb

That was a great answer. Perfect way to, to end this interview. Well, we do want to know where we can find you online. If you have a Instagram, Facebook, anything, now's a good time to tell us.

Dawn "Scully" Sikora

Well, ah, I'm on ResearchGate. Ah, I'm on LinkedIn. I am on Facebook. And I also have currently a GoFundMe setup for trying to get a service dog to help me with some of my other disability issues, both Asperger's syndrome, and then I do also have endometriosis. So those two kinds of things sort of tie together and creating a disability profile for me.

Eileen Lamb

Could have talked about that too. Well, we'll share in the when we go live. So hopefully you get some some help. I'm going to ask you some quickfire questions before we log off. So I'm first answer that comes to your mind. You're ready.

Dawn "Scully" Sikora

Okay, sure.

Eileen Lamb

What's your favorite animal or pet?

Dawn "Scully" Sikora

A bearded dragon and a praying mantis.

Eileen Lamb

Okay. Cool. What's your favorite drink?

Dawn "Scully" Sikora

Not water. Not water. Root Beer.

Eileen Lamb

What are you scared of?

Dawn "Scully" Sikora

I'm afraid of falling off the earth as in to explain that better I'm afraid of not being able to communicate my needs properly in a professional setting. And being misunderstood.

Eileen Lamb

What was your dream job as a child?

Dawn "Scully" Sikora

I'm doing it.

Eileen Lamb

Oh, that's an

Dawn "Scully" Sikora

An entomologist.

Eileen Lamb

That's great. Okay, so this question, we're actually started taking notes on it to see what people answer. Okay. So the question is, is glow in the dark, a color, a property, or both?

Dawn "Scully" Sikora

It's a property of a color.

Eileen Lamb

So both? Or property?

Andrew M. Komarow

Like so for example, the glow in the dark, we should have something glow in the dark, Eileen to holdup, to show someone. That's a good idea. We need to buy something so you can hold it up on the podcast as well.

Eileen Lamb

I guess,

Andrew M. Komarow

There are visual people right? So but like, like that yellow, like, like that glow in the dark when the lights are on like that color? Is that a property, a color or both?

Dawn "Scully" Sikora

It's definitely a property. It's usually fluorescence or incandescence. So, scientifically speaking, I have to say it's a property.

Andrew M. Komarow

Only a property. Okay, yes.

Eileen Lamb

Yep, sorry Andrew.

Andrew M. Komarow

Just kidding. No, no, I accept the scientific findings of the community. So

Eileen Lamb

Yeah, that was it. Thank you so much for for coming today. That was great. was great meeting you.

Andrew M. Komarow

Yeah. Great meeting you. Thank you.

Dawn "Scully" Sikora

I'll see you around in the community. Thank you for having me. Thank you.

Eileen Lamb

Thank you. Bye bye.