**Episode 9: Gender and autism**

**HOST:** This is Autism Points of View by Autism Speaks. I’m Felipe Maya. As our understanding of autism grows, researchers are finding that the way we diagnose autism may be biased. They’re also beginning to find that gender fluidity may be more prevalent in people with autism than the general population. In this episode, we’ll dive into both of these topics through the experience of three autistic advocates who have one thing in common, they were all diagnosed late.

A growing body of research is confirming what some in the autism community already know: that autism in girls manifests differently than in boys, and since diagnostic tools were developed to fit a pattern of autism that was predominantly based on boys, in some cases autism in girls may be missed.

**BRIGID:** I officially got an autism diagnosis when I was 16 years old.

**HOST**: Brigid Rankowski, autistic educator and circus performer.

**BRIGID**: I ended up seeing a provider who referred to me as a, “PDD NOS” which is Pervasive Diagnostic Disability Not Otherwise Specified, because he said that he had never seen a woman on the autism spectrum and I wasn't going to be the first autistic woman that he gave a label to.

**VALERIE**: I was in my early 40s when I received my diagnosis

**HOST**: Valerie Paradiz, Autism Speaks Vice President of Services and Supports.

**VALERIE**: and I had been wanting to pursue that for some time but was hesitant.

**KIRSTEN:** I was 19 when I got my diagnosis.

**HOST**: Kirsten Lindsmith, Autism Advocate.

**KIRSTEN**: Though I sometimes like to say 18 to 19 because it took a year to get through all the insurance hoops to get the official assessment. But I started seeking it at 18 and I got the paperwork around my 19th birthday.

**HOST**: A 2018 article from the Journal of Autism and Developmental Disorders points out that because some girls with autism may have little to no language delays, and can appear to have few challenges with social skills, they go undiagnosed. Valerie, Kirsten and Brigid told me finally getting their diagnosis was life-changing.

**VALERIE**: After getting my diagnosis things changed dramatically for me personally as well as professionally. And it did take several years for me to adjust as well as those around me. I can just state that sort of generally. Personally, I opened a door to looking at aspects of myself that needed my attention pretty desperately. It also opened a door to seeking more targeted support in therapy and sensory-related supports.

I was suddenly in a place where I could now advocate for my sensory differences instead of apologize or hide them or feel like I wasn't somehow living up to what was needed or expected in a number of environments and as a child that was really difficult.

**KIRSTEN**: So my autism diagnosis was by far the best thing that ever happened to me in my life. Like, hands down, that I, especially identity-wise, it meant that I had gone my whole life knowing that everywhere I went everyone hated me for no reason. I didn't know why. Everything I did was somehow wrong even when I tried my absolute best. And there were things that I couldn't do that people thought that I should be able to do. They didn't believe me that I couldn't do these things. I didn't believe myself I thought I wasn't trying hard enough that something was wrong. And so getting a diagnosis meant that I realized that nothing was wrong with me that I was a perfectly normal autistic person and there's a whole community and culture of people out there that are the same way, and maybe can't just open their mouths and say whatever comes to mind.

**BRIGID**: I think one of the things that helped me and I know that's helped others when they get the diagnosis is they finally understand that they're not wrong, that they're not broken. And especially when I was diagnosed about 15 years ago there still was not a lot of information about girls and women on the autism spectrum. So it was still a very new frontier for people.

**HOST**: Girls with autism may also “mask” or “camouflage” their autism. Broadly speaking, that means they research and mimic the behaviors of their neurotypical peers in order to blend in socially.

**BRIGID**: Yes, masking, camouflaging is a term that is sometimes used in this community where you quite literally mask as someone else or as I don't wanna say “not disabled”, but not as impacted by your disability. So it's the ability to maybe go and do paperwork, go to school, go to your job, look like you have everything going on everything handled, when behind the scenes it takes such extreme energy to put on that mask, and who you are inside you're sometimes afraid of the reaction you get from, whether it's coworkers, family, just the general public. So a lot of women as well as other individuals who may be non-binary, you have to try to resolve the masking and remove some of the internalized ableism which does impact us on a day-to-day basis.

**VALERIE**: So, yeah, the masking is something that as one ages can actually become a really difficult burden. And as a person on the spectrum you may not even know you're doing it, you may not be aware that you're doing it because you've been doing it for so long and not aware that other people aren't doing that. But I was I was doing all kinds of things that was requiring a lot of energy to just sort of maintain a face at school that wasn't humiliating and, and sort of ostracizing. I also spent a lot of time alone. And I would do this kind of what my friend Stephen Shore calls delayed echolalia, where I would review social interactions I had with people at school earlier in the day. And speak the words out loud that I said and try to remember what they said to me because I was extremely anxious about saying something wrong or something that would be perceived as weird.

**HOST**: Resources tailored for girls can be harder to find simply because, right now, boys are four times more likely to be diagnosed than girls.

**VALERIE**: Well the current statistics on ratio of boys and girls and women and men is something that many of us who are women, and many men on the spectrum too, feel will change with time.

Another concern that's emerging among researchers, and just in the community at large, is that the very tools we have to diagnose autism may indeed include some bias toward diagnosing males over females. And so, there's much greater attention right now in the research community at, looking at, you know, subject sample size in studies, numbers of men, numbers of women, numbers of boys, number of girls, who are recruited for studies, and also complete sort of re-evaluation of what kinds of questions do we ask, say if it’s a survey, or what kinds of things are we looking for when we're conducting a study. So, I think that people with autism can do a lot to help shape where that direction may take us in study design as well as in how we present the numbers in terms of male-to-female ratio.

**BRIGID**: Well they used to discuss autism in terms of masculine and feminine brain. And again those are very gendered lines which as we all know the gender spectrum is not as binary as people thought, 300, 400 years ago, at least in Western civilization. So, I think there has been an ongoing conversation in trying to gender autism in specific ways, of how girls act, how boys act and again the conversations bends towards those gears. How society has framed autism in terms of gender, we are slowly opening the door of being like, “yes you are talking about this” and “let's discuss gender as a spectrum,” how like autism is a spectrum. Let's make sure that there is acknowledgement of all the people and all the places on the spectrum. So, I think that one of the dangers of basing things solely on scientific research, which my background is in psychology, is we only have so much data so far because people aren’t wanting to do these studies. There are very few studies about autistic women. There's even less studies on the trans-autistic population. As we start to get more data, get more information we can reach better ideas of what's going on, but I very much shy away from the causation/correlation method.

**HOST**: Brigid is referencing some early studies that suggest gender-fluidity may be more prevalent in people with autism compared to the general population.

**VALERIE**: The other piece in all this too is beyond male and female. There's the whole transgender element in this. And again, there are some studies out there that are very preliminary or smaller, that indicate that perhaps, people with autism may be more gender fluid in general, compared to other populations just you know in a broad sense, non-autistic populations. And, you know I can say anecdotally I think that's probably true. And so, I think that that's also really, really critical in how we go about the whole gender question regarding autism numbers.

I know many people with autism who have transitioned or who identify, identify fluidly and in a variety of ways. So I think that's really critical too. And it's also just a reflection of our culture in general. So why not for people with autism as well.

**BRIGID**: I tend to identify as gender fluid and that may mean something different to other people than what it means to me. But what that means for me is I don't fall squarely as female. I have masculine traits. I flux between them in clothing choices, in personality traits, I'm told, and I'm just kind of, I'm Brigid.

I prefer using “she” or “them/they.” I'm fine with either and I am very aware that I am a straight, able- bodied, most of the time, passing individual, so I do think that's important to be able to advocate for inclusive pronouns.

**HOST**: Valerie points out that success in the LGBTQ+ movement has been a model for autism self-advocacy.

**VALERIE**: Well I think our friends in the LGBTQ community have helped in many respects with their own movement in terms of safety issues and vulnerability issues. And I know even in the really early years when I was involved with some of the very first self-advocacy groups, this is in the mid-90s, we would actually invite people from the LGBT community--back then there wasn't a “Q” on there—to our early meetings to help us understand how to get our own movement off the ground as people with autism. And so that their models of ensuring safety, and also educating the broader culture around sexual vulnerability, gender vulnerability, we can borrow from that a lot. And so, riding on the coattails of those other movements is really critical.

**HOST**: Despite increased awareness of autism, Brigid, Valerie and Kirsten say they still have an uphill battle advocating for themselves and others on a daily basis.

**BRIGID**: There is a lot of still stigma attached to being autistic. There are headlines written about us. There are perceived behaviors which do impact people in our community. Young men of color are extremely targeted because of autistic traits and behaviors which are deemed “threatening” or “intimidating.” And it's something that we're kind of just viewed as separate and not necessarily, our strengths are embraced. We're not always viewed as the unique wonderful contribution to society that we are and I’m really lucky that I’ve kind of built a community not just in-person, but online of people that can, not just support me, but also reinforce the idea that it is okay to be your authentic self.

**KIRSTEN**: I need to be able to say to my friends like, “no I don't want to hug today. Can we do a high five?” I need to be able to understand when I need a break, if I'm at a party or bar and it's loud or there are bright lights or whatever. I have to be constantly thinking about the fact that I'm autistic because the world isn't designed for autistic people. So I mean maybe if I lived in a society where everything was built for me I wouldn't really think about it. But because of the way the world works I'm constantly forced to think about it so yeah I am an autistic person and it's a huge part of my everyday life.

**VALERIE**: Once I had the diagnosis I felt that I had permission really and an obligation to find out what my sensory differences were, but also how to navigate a variety of settings and social environments as an advocate for myself. To advocate for my sensory differences. So an example was walking into meetings where there might be 20 people sitting at a conference table and asking if we could turn off the overhead lights because there was plenty of natural light coming into the room and then also explaining to people why. And I felt an obligation not only to myself because I could participate more fully and also not be suffering later in the day for having no power through that or coped but also almost like an ambassador of autism to those who aren't on the spectrum for them to begin to understand our differences and the types of accommodations we need.

**HOST:** For Valerie, Brigid and Kirsten, it can seem like they’re living in two worlds. They’re able to mask their autism at times to better fit into what society expects of them, but their challenges are still very real.

**KIRSTEN**: A lot of autistic people especially like high-functioning people who can speak, like me, are effectively closeted because it is an invisible disability. So, you know you probably know more autistic people than you think if it's you know it's like one in 50 people or so is somewhere on the spectrum. Also that autistic people who are visibly autistic are more capable than everyone thinks. And people who are invisibly autistic are more disabled than people think.

**BRIGID**: The real Brigid is the person who will sometimes sit at home for three days and not have to be speaking, who doesn't always put her clean dishes away, who has difficulty caring for herself. Executive functioning disorder. So one of the things that I think everyone kind of battles on the autism spectrum is their public persona versus who they are intrinsically. And although I do pass as “higher functioning,” even though I reject functioning labels. Who I really am is an individual who struggles at time to adapt to a world that is not always accessible to me.

**HOST**: Thank you for listening to this episode of Autism Points of View. Make sure to subscribe wherever you listen to podcasts to get future episodes as soon as they’re released. This episode was produced by me, written by Elena Ferretti and edited by Dax Schaffer. If you have a topic you would like us to cover, we want to hear from you. Email us at connectwithusa@autismspeaks.org and write ‘podcast’ in the subject line. I’m Felipe Maya, thanks for listening.