

Episode 5 transcript

Welcome to That's Inclusive. Today I am here with Arielle Van De Water, who is a former New Hampshire DD Council member. I am Isadora Rodriguez-Legendre. On my good days I am the Executive Director of DD council. And we are going to talk to Arielle about her lived experience as a person with autism and mental health needs. Hi, Arielle.

Hi, how are you?

I'm good. Tell us a little bit about yourself and about your advocacy journey.

Well, I started out learning that I was atypical in towards the end of high school. It wasn't until later on that we learned that it actually had a name. It was around my 20s that we learned it was autism and a little earlier on we learned that I had some mental health issues.

So, that's pretty late to learn about yourself. Something that probably impacts a lot of the areas of your life. How did that feel?

Well, in the moment it was pretty scary. You didn't know what was going on. You knew something wasn't right, but you didn't know what. Once we finally had the name for it, that gave it, that gave me power. I had something I could research and look into. I knew what I was facing and how I could address it.

Yeah, that's great. I mean and that's a lot of people's story revolves around having the awareness to then be able to advocate for themselves. So how did you have to advocate for yourself?

Well, it's sometimes hard to get services as a person with autism but I was able to work with my parents and the people at Community Bridges and with a therapist and I was able to slowly amass people and supports in my corner until I was able to start taking steps forward in my life.

So, tell us, tell me a little bit about who those supporters were for you. Who those champions in your corner were.

Definitely, my mom and dad. Even when I was not sure and was unsteady on my feet, they were there in my corner making sure that I was the one making the choices on where I wanted my life to go. I also had supports through a couple of therapists, specifically Ken Potter from Warren Street Family Counseling, he was always in my corner. And I have had lots of help through Elliot Behavioral Health,

they were always trying to help me figure out what worked, what didn't work. And all in all, it has helped me get on an even keel.

Yeah, that's great. So, I had asked you before we started kind of what is a message that you would want people to take away as part of this podcast? So what is something you want people to know?

There is hope. You can achieve success as you define it. It's going to take some trial and error. You are going to fall down a few times, but it will be worth it in the end. I mean, it took into my 30s to really start getting in the groove of things, but I think I am finally living a life I can be proud of.

That's so fantastic. Tell us a little bit about what that life looks like today.

I am working full time with a company that understands, and not only understands what I am going through, but appreciates the contributions I make. They are willing to give me more or less work to balance out what I can give at any given time. And it's great.

That's fantastic. And, you also had another excellent thing happen recently. What was that?

I recently graduated from Southern NH University with a bachelor's degree in data analytics. I'm very proud of that. I've worked for a long time to get that one.

That's great. And so, what would your message be to people who need supports but who set goals for themselves? You've set a lot and accomplished a lot of goals in your life. I think people would want to know a little bit more, we can dig a little deeper, in how you did that and what were the tools and strategies that you used to be able to accomplish those things?

At the beginning it was trial and error. I had a lot of As and Fs in my classes. I was slowly through that able to figure out what worked for me and what did not work for me in studying. And I was able to build up that repertoire of skills and coping strategies. And, as I developed later mental health issues, I was able to use that slow learning and coping skill mechanisms and I was able to use those to build up my arsenal of tools I had to work against what I was facing. And using those, I was able to make my life easier. Like, sometimes I would deal with psychosis. I learned that using a digital camera, I could, even without a sim card, I could just take a photo and whatever I was seeing in my eyes and my brain, it would not show up on the lens, it would not show up in the digital photo. And using that, I was able to slowly get more control over my visual experience.

Yeah, I mean that seems like a very simple way.

I mean everyone has a phone now on themselves now a days, and every phone has a camera on it.

Yeah, I mean it is a cool way to check your surroundings, and to make sure that you are doing okay. Whatever that is. I think that is a great strategy. I wonder if there's more you can tell me about how your mental health needs impact your day-to-day life and how you found supports to help you with that.

Mental health is something you have to face every day. Depending on what you put in your corner, it can get easier and there are going to be times you're in remission and everything is going well. That means everything you have working for you is working. Don't get rid of it. Just because things are going well means your supports are well in place you are doing well. Don't get rid of the supports. Don't cut your legs from under you once you have it on even keel.

Yeah, I mean I've heard that so many times from people where they're doing great and so they may stop going to therapy or taking medication and then they end up kind of going backwards in their experiences and having consequences of changing, what you're saying, "Don't change what is working".

Exactly. If you find something that works, stick with it. It's not going to hurt you to keep it on for an extra month or two beyond what you think is necessary. And just because something is in remission does not mean it is gone forever. I hate to say this, but a lot of times mental health is a lifelong journey. But you've got this, honestly, and you can keep going. It may be tough. I don't remember who said this but, if you're going through hell, keep going. You've got this.

There's a light at the end of the tunnel.

Absolutely.

The great thing about things like developmental disabilities or mental health needs is that you don't have to do it alone. You can build a team of supporters around you, that get you, that understand what you need, and that really have your back, when you're not at your best, they can hold you up and help you walk through those fires. Right?

Absolutely.

Is there anything else that you want to talk about related as a person with lived experiences with autism? How that impacts your daily life and how you would want other people to understand either what your needs are or how they can improve their experiences with the world?

It is hard to separate autism and mental health-- it is all one person. The skills that helped me with autism also helped me with other things. Like, social learning does not come naturally to me. I wouldn't automatically know the person with the nice handbag and the candy does not want to come and say hi to me. So, you just learn. You take things from a basic level of 'I don't know this and what is there to learn' - there are times that I catch onto social cues nowadays faster than people who are defined as neurotypical. And that's practice.

Yah. That's great and that is a great message is that for anyone you can't automatically understand everything.

Just because it does not come naturally does not mean you won't get it eventually. You can learn anything. You just have to put your mind to it and use what strategies work for you. If flash cards are your thing, then make flash cards with social examples. If you learn best auditorily, there are lots of audiobooks.

Yeah, and I think something that you said that is so important is that it is a practice. I think about things like meditation or Tai Chi. Those are the things that I know that are talked about as a practice. It goes for anything else too, right, so how do you practice?

Well, I put myself out there in social situations. I play dungeons and dragons with my friends-- that puts me in a social tabletop role playing game. I use that to practice social engagement. I go out and I sit at a coffee shop and I'll listen to people and see how they're conversing. It's people watching.

Yup. I think that is a great tool, for people to understand I guess societal like expectations, or....

True. You can take those expectations and develop your own opinions on them, and you put that into practice. It is not all limitation you can put your own spin on it.

That's a great point. It is important to be yourself.

Always! Everyone else is taken.

That's right! You can't be anyone else.

So, I talked about in the beginning a little bit about how you used to be a DD Council member and we loved having you as a DD Council member. What was that experience like for you?

That was my first experience meeting a large group of people with issues different but facing similar challenges I had. Who mostly found success as they defined it and taking what they learned and paying it forward. They were actively trying to make the world better for people like them and people who aren't like them. People who are facing challenges that we have never even heard of yet but need support. We are trying to be there for them and were paving a path for those who haven't seen one yet.

Yah, that's great. I like to think that we are making the world a better place for the future generations of people with lived experience with a disability. That really speaks to me, the way you talked about your service on the DD council and what were some of the highlights, if you will, of serving on the DD Council?

I definitely liked helping out at events. Being there, being one of the faces of the DD council, communicating with the public is something I wouldn't have dreamed about doing back when I was in high school. I was so shy! Now I can face people and I can talk to them freely and educate them on things they are facing and let them know about resources. If you were wondering where to get started but don't have to resources, reach out to the DD Council. They can definitely get you in the right direction.

Yeah, I have to say you were one of our favorite tablerers at different events because you are just an engaging person. And I know that you typically help us out at PRIDE events and those are so fun. And even when you left the DD Council, you continued to help us out at PRIDE events. What do you like about tabling at PRIDE events?

I think one of the nice things is that when you go to a PRIDE event everyone is being themselves there. Most often when you're dealing with people who are LGBTQ+ they have hidden long enough. So, these are events where they can find people who are like themselves and just be who they are in public. I wish I had as much courage someday. 15:54

Yah. I think it's important when talking a lot about intersectionality, it's important to embrace all of the parts of yourself of who you are, and each part is as important as the next, right?

It is not mental health, physical health, eye health-- it is one whole person, and you have to treat it as such at all times. Otherwise, you're really losing sight of the end goal.

Yeah, which is to have a robust community-based life, right, and you've done that. You're doing it, you're living it on daily basis.

One day at a time.

So, you also mentioned some policy. Policy is a big part of what we do at the DD Council. We follow legislation, and we look at certain bills that might impact a person's life with a disability and then we also look at adjacent bills. So, things like housing, transportation, LGBTQ rights. All of the things that support people who have a disability to be able to be their true authentic selves, and to engage with their community and get to work and go to school and have all of the supports that they need to be able to do those things. Are there any policy initiatives or topics that are of particular interest to you?

Well, I know there is currently a vendetta against trans rights, but other than that, I haven't been following politics as much as I like.

Yeah, trans rights is a very important topic area for us. A lot of the folks in the ID/DD community also identify as LGBTQ + and so like I said earlier, it is really important for us to support all of the parts of a person's identity. We work really hard to make people not just comfortable, but welcomed and I think that there is a difference of what that is, and I think you understand that difference as someone who has worked really hard to become part of a work community, a school community, a community-based life, and an advocacy community, that you've really tried hard to build in what it means to have a full life. Like I can tell from your accomplishments that it's not been easy. But that you've worked really hard to do that.

I just have a goal to be so authentically myself that it gives everyone around me default permission to do the same.

That's great. That's the best way to make people feel comfortable, right, is to be yourself. Yah. Is there anything else that you want to talk about or that you want to use this podcast platform to message to different communities or to help people build their interest in or comfort with advocacy in general? There's is no right answer.

Even if you feel like it is a small step, it is always worth taking a moment celebrating each step that you take. It does not matter if it is three stairs and one step or if it's one toe in front of the other, you're still making progress-- you're still moving forward. And be kind to yourself. You'll get there. I have faith in you.

That's great. Thank you. I really want to thank you for coming on the show and for getting vulnerable and talking about your experience. One of the most powerful

mechanisms that we have to create the change that we want to see in the world is by sharing our stories. And so, thank you for sharing your story with us today. I really appreciate it. I think our listeners can really learn a lot about from just finding what works for you from your story. And that's like kind of what I got. You just have to figure it out as you go along. It's not going to be perfect; it's not going to be a one size fits all. In fact, it is a very person-centered approach to finding what works for you but even when you have challenges that you face, you can rely on supports to help you through those challenges and then you can come out the other end having some more tools and strategies to really help you engage with your community. Have you found that?

Yah. Even if you found something that does work, you've still found something that doesn't work-- you know not try it again.

Exactly, that's a great point. So, you heard Ariel here. If you are interested in learning more about advocacy, learning more about the DD Council or learning more about how we support individuals with co-occurring disabilities or multiple experiences or multiple identities, give us a call and come check us out or find us at a PRIDE event and you can have a really good time while you learn something about what we do. And with that I just want to thank everyone for joining us today, and I hope that you tune into our future podcasts.