

OCALI | Podcast - Episode 1 Interview with Kelli

TERESA Welcome to From My Perspective. This is OCALI Family Center's weekly podcast. Each week, **KOLBELT:** you'll hear from people with disabilities, their families, friends, and others in their lives. You'll hear about everyday life, their passions, their interests and opinions. You'll be inspired. You might laugh or cry. But most importantly, we hope you'll better understand what life is like from our perspective.

On this week's podcast you'll hear from Kelli. An adult woman who received an autism diagnoses after college. She'll share that story as well as well as how she talks about herself and some encouragement and advice advice for families.

I wanted to do a with series of podcasts, because I feel like there are lots of places that you can go and read information about where you get a diagnosis, or what happens after the diagnosis, or, to some extent, where you can get services or support, but I have not heard as many things out there that are encouraging or even inspiring, or why the diagnosis of autism isn't a tragedy, or a death sentence. And so that's what I was really hoping with these podcasts help accomplish is give people different life perspectives that aren't tragic.

KELLI YEAGLEY: Right, yeah.

TERESA: So, with that said let's start with people with autism use all kinds of different words to talk about autism, to talk about themselves, to talk about their neurology. And so we start by just telling us how you talk about-- what words you use, how describe yourself, how you talk about autism.

KELLI: Sure, I was diagnosed later in life. And my experience with disability and autism was just informed basically by the media. We didn't have necessarily a lot of resources where I grew up. I grew up in a fairly underserved area. And so my exposure to any comprehensive or inclusive information about disability didn't come until I started doing research on my own. And I had begun just on my own working with mentally disabled people of all ages.

When I was in college, my husband's aunt actually owns a residential services provider. And so I started working there supporting folks with multiple disabilities who were adults who were living in the community. And one of the residents that I supported was autistic and also deaf, and so that really prompted me to further my own education, because I was so new to the whole thing. And once I started learning more about neurodevelopmental disability, I decided

this is an area of interest and passion for me. And so I pursued it more on a professional level with my education.

And then as I was going concurrently in college, I just started feeling very out of place and not able to kind of deal with everything that was going on. I assumed that it was just natural anxiety from being out in the world, and going to college, and doing all that. And it didn't get better. Nothing I tried, the standard approaches did not help. I began to have panic attacks and then very severe what I thought were just swings and not able to cope, so I sought out our university counseling center. And they then helped me with some supports, but I didn't have a diagnosis either.

Eventually I found myself going to a psychiatrist, and they had given me a diagnosis of bipolar II, which is very common for women on the spectrum, and put me on some very heavy medication which ended up being very bad for my health, and it didn't work because I'm not bipolar. And so after, I think it was, nine months to a year dealing with that, I had done enough research at that point and had graduated from undergrad going into mental health counseling for my graduate program that I felt comfortable enough to approach them and say hey, this isn't working. We need to re-evaluate. And I came in with in very me fashion with a binder full of information that I had researched, and we worked together, and I was assessed.

And that was really the point where I really dove deep into disability culture, and started learning more about autism and autistic culture, and really tried to just sit back and listen, because I was the new person and I didn't want to presume any of my experiences were somebody else's. And so that's how I developed my own language about talking about it, because I came from a perspective of I'm new, and I need to be able to be respectful. And so I really just got into to learning more about neurodiversity, learning more about disability culture as a whole, and then learning about how autistic culture fits into that. And so I learned to define myself more comfortably as an autistic person, as a disabled person, by understanding that disability is not a bad thing, and being able to say disabled, being able to say autistic is like a way of making sure that I'm solidifying myself and having more grounding in that culture.

TERESA:

I remember being at a conference-- it's probably been four or even five years ago now-- and there was a session, and the people leading the session kept referring to themselves as autistic, autistic. And it was really the first time for me that I had not heard people first, and so I finally just raised my hand and said, I just have to ask this. This is so different from what I'm used to that why aren't you say a person with autism? Why are you saying autistic person. And

so it was really great to hear a similar perspective from them, but if you want to say anything more about that like why you would--

KELLI: Well, the way it was explained to me and the way that I understand it from folks who also identify that way is that when you're discussing your neurology, it's very different than discussing something like cancer, or a disease, or something. Autism to me and that many people, it impacts every single thing that I do and has always been that way. I just didn't necessarily have a word to put on that experience. And so it's not as if you know I can, at the end of the day when I turned 5 o'clock, I can take off my autism hat and I can go home. It's not something that I can separate from myself.

And so linguistically, I think it just makes sense to be more simplified and identify as such. And also, I think it's a pride thing because I have learned and we all learn to be scared and ashamed of disability or difference. And so I think if you can just claim it and own it, then it's not so scary anymore, and you can project that and help support other people in their process.

TERESA: Would you say little bit more maybe about what getting a diagnosis meant to you and maybe also to your family?

KELLI: Yeah. I had described my process earlier about how I got to that point. And being that it had been a traumatic journey, it was just gratifying. It was something that when everything finally clicked, it just made sense and I was able to not be so-- I didn't feel so alone. And I was able to immediately find people who understood, just inherently understood. And my family is-- they're very accepting, but they're still coming to terms with that, because I was raised my entire life not having any diagnosis or any supports. And then once I was able to find this community, and find the supports that I need, and get back on track, it's a learning process for them to. And so they're not interested in the idea of attending tons of seminars or doing anything like that, so primarily my focus with them is to just be more open and talk about it, so it's not so scary, and then any sort of support or resources that I have are a part of developing, I share with them and then it's their option to engage with it, and so.

TERESA: And you're married.

KELLI: Hm-hmm.

TERESA: Would you talk a little bit about what marriage as an autistic is like.

KELLI: Yeah.

TERESA: Or what marriage in general is like.

KELLI: Yeah. So my husband and I have been together since we were 15, which I'm learning is a very autistic thing to do. You find somebody, and then you go with it. So he's been with me through everything, and he's neurotypical. And so our perspectives-- it just helps to have somebody, I think, to bounce things off of and be in a space where I feel totally safe and totally open, which is not the case for everybody. And so for us to have gone through everything that we went through, through the misdiagnosis, through my health problems, through everything, I think having that diagnosis has really just helped solidify us even more, because now we both can access resources that help us.

If I'm having a difficult time communicating something, or if I'm not feeling very regulated, he's able to understand that from the outside. And then if I'm not able to bring those supports to myself, he will suggest it. Or he knows when I am completely overwhelmed and need to just have some space. We've just developed that rapport over time.

TERESA: So there is a myth that's pretty prevalent probably out there that people with autism do not want relationship, don't care about relationship. Would you want to say anything about that?

KELLI: For me, I don't think I ever didn't want to have a relationship. In terms of like romantic relationships, it never occurred to me that it was difficult for somebody to engage in a way that isn't also just difficult in my normal life. So if I have difficulty having a conversation with somebody who I'm not romantic with, I will also have that same difficulty. It's just, to me, the level of trust and safety and expectation and boundaries that shift. But I was never-- when I was younger, I didn't really pursue friendships as much. I wasn't very interested in it, and it wasn't that I wasn't-- it wasn't that I didn't want to have friends, it was just that the amount of effort that it took me to engage in that way was not as appealing as maybe spending four hours learning about dolphins or something.

And it wasn't in a mean way. It was just like, OK, this particular engagement, or task, or whatever is super hard and super taxing, and I always end up more depleted than I am renewed by hanging out with people. So I would just naturally gravitate towards whatever was more comfortable for me and often that was just hanging out in my room reading or doing something like that. I did have close friendships, but usually just with one person. I really thrived, I guess, on the idea that if I could just have one relationship or less variables to have

to worry about, I knew what to expect with that person, then it was much easier for me than having to navigate huge group settings, or try to go to parties, or do something like that.

TERESA: You mentioned dysregulation. Can you tell us a little bit what it feels like when you're dysregulation or what it looks like?

KELLI: I think the first thing that I always like this when I talk about emotional regulation is I'm 32, so my dysregulation and coping strategies are going to be very different from a four-year-old, and that's because I've had 32 years to develop all these strategies whether or not I've had a diagnosis or not. All of us go through emotional dysregulation of some sort, but I have had to maintain, and cope, and adapt these strategies over time. And so I think it's important to understand that whoever you are supporting is going to have their own strategy. And that will change over time, because they'll learn more and they'll have more experience.

My emotional regulation typically is most impacted by me taking in too much and then not knowing how to handle that. So I either shut down completely, or I get super anxious and just have a panic attack. And so that can be very difficult because I have a difficult time recognizing those signals before it gets overwhelming. And so it can appear as though I'm very quiet, very OK, and then all of this and I'll just have to leave or something, and I'll have a genuine panic attack. And so over time I've just tried to really focus on the idea of learning how to recognize those signals better. I'm not perfect at it, but it's gotten easier over time, because I've been able to put words to those things rather than just saying I don't feel well, and leaving, or going to sleep or something. So, yeah.

TERESA: You also mentioned earlier that growing up, most of your ideas or impressions about autism came from the media, what were those?

KELLI: Yeah, I think-- I mean unfortunately, we don't really have that many good media representations of disability except recently. And so my first exposure to autism or neurological differences was in Rain Man, which is very typical, and then also this movie, House of Cards. And I was so drawn to those movies that I don't-- when I was younger, I used to just ask to watch them all the time. And so I don't know if it's because I felt some kinship of it, even though it's dramatized, but I was so fascinated by psychology, and neurology, and trying to figure out why things are the way they are, why people feel the way that they are, so I think that was my initial understanding and a draw towards psychology and behavior, and all of that stuff. And I think a little bit of that was because I was trying to figure out what was going on

with me, and I didn't necessarily have the words for it.

And so yeah, I didn't have great-- I don't think many of us had great representation in media until recently where things like, Speechless came out, and people are starting to talk, and connect on social media, and things. But unfortunately, I think we still have a long way to go.

TERESA: What do you feel like your neurology has brought to your life? I mean there are things about it that are great. What are those things that you'd say--

KELLI: Yeah, I don't know. I think it's a balance. Like, I really enjoy that I can hyperfocus on something, and learn everything about it, and spend 10 hours a day doing whatever, but on the flip side, that can also be harmful, because I forget to eat, or go to the bathroom, or do like those basic things because I get so invested in whatever I'm doing that I just don't think about anything else. And so

My hyperfocus has been really useful in terms of learning new things and really diving deep into material, but it's always counterbalanced by a challenge. And so I like that I am able to often have a different perspective on things, but also it can be a challenge because if you're the only person in the room with that particular line of thought, then you have to be comfortable in talking about it or sometimes defending it. And so it's always that weighted experience of this is really useful, but also there is a challenge, and so what is that strategy that you can use to overcome that, or modify, or adapt, or I whatever.

TERESA: What are you passionate about? You mentioned this earlier, but--

KELLI: Yeah. In terms of like special interest or anything like that, I used to, when I was younger, it was super into marine biology, and dolphins, and whales, and stuff like that. And I spent summers reading encyclopedias, because I'm old and we didn't have the internet. And then once the internet happened, it was a whole different thing. But since then, I really just focused most of my energy on disability culture and autism, which is a fun interest to have, because it is constantly present in my life, and so it's just something that I get to engage in all the time. And it's so fulfilling, because I'm not only learning more about myself, but also helping other people. And so I really, really enjoy disability culture, autism, neurodiversity, and that community outreach perspective. And so anytime I get to do that, I will talk for hours.

TERESA: Along those lines, I guess, are there things that you would say to either people who have just gotten a diagnosis, families who have son, daughter, someone in their life who's just gotten a

diagnosis?

KELLI: Yeah, I think depends on where you're at. It's OK not to be OK. I think nobody ever told me. And I think nobody ever told my parents that. And I think it's important to say upfront, you don't have to be all sunshine and rainbows all the time. It can be difficult, but I think staying in that frame of mind is not helpful, not productive. And so what I would say to anybody who is having those feelings is to talk about it and then also seek out people who are at different parts of the process. So there are people who are right there with you, just starting. And then there are people who are a little bit further along, and they can kind of talk to you about what their experience was like transitioning. And then there are people, like myself who are a couple years out, who can give you that perspective as well, and then people who are many years out, and they give you their perspective.

I think for me, diagnosis was life changing because it gave me a language. It gave me access to a community. It gave me understanding of why certain strategies may work, why others don't and the ability to be flexible in that was really helpful. But I really stress that people should be OK with whatever feelings that they're feeling and understand that if they're not the autistic person in that situation, understand that the autistic person is also processing that new information. And we all process different ways and at different speeds, and so it's important to give everybody that processing time, and that leeway, and that ability to one day be super OK and the other days not be so OK, and be understanding that it's a process and it'll take time.

TERESA: You have a job?

KELLI: Mm-hmm.

TERESA: You are fortunate your job and your special interests align--

KELLI: Yes.

TERESA: But I think that's another-- people commonly hear that, and it is absolutely true, that the employment outcomes don't look great. And so would you talk a little bit about work and what that's like for you?

KELLI: Yeah, it took me a long time to get here. And I am certainly, having full-time employment, I am a rarity, particularly for people who are autistic or disabled. I think it's important to know that somebody's not going to walk up to your door and be like, here's your perfect job. It took me many years and many trials and errors to be able to find something that works for me. And

part of that was even learning about what works for me. I can't necessarily at this point in my life be doing 16-hour shifts on call anymore. Even though I really love direct support, that was not healthy for me in terms of regulating my sleep schedule and doing all that stuff.

And so what helped me was understanding how my ideal setup would work every day, and then trying to figure out what I could do to earn a living that would help me stay regulated that would provide a consistent schedule, that would allow me to be able to take time off when I needed to, it provide insurance for all of the different various appointments. It is not an easy process, but it's possible. And I don't think that we have a lot of conversations about maybe the day-to-day accessibility, the day-to-day accommodations that each person might need in order to make that work for them, because I think once somebody is set up and in an environment that makes sense and is as supportive as possible, our abilities are endless to be able to engage that way.

TERESA: Can you say a little bit about those accommodations for you?

KELLI: Yeah. I think for me it's really the idea of predictability. Being able to-- as I said, when I first started in the field a long time ago, I was working in direct support, and so my schedule did not necessarily line up always. It was supporting other people. And so whatever their schedule was became my schedule, which was fine, but when emergencies happen, or people call off, especially as I got into more management position, it became my responsibility to cover those gaps, and it was much less predictable and much more difficult for my health.

And so 16-hour shifts unexpectedly, or having to go in the middle of the night because someone's sick or whatever, while I loved it, I love doing it, it just eventually-- people burn out. And I think that even people with typical neurology also burn out. And so understanding that, oh, OK, if I had a little bit more regularity, if I could call off if I needed to, if I could have reliable insurance, and all that stuff, those are just like the little things that weigh on you during the day that if I get sick, or if I get overwhelmed, or whatever, and you're replaying that through your head, you don't have to worry about that as much. Your anxiety goes down. And then you're able to focus on what you're doing. And so being able to have those conversations openly and say, there might be some times when I need to work from home, and I hope that that's OK. If that's

not OK, then what would be OK for me to do that while I'm in the office or whatever. But really having my flexibility in my openness conversation is really helpful.

TERESA: When you think about people that are getting a diagnosis now as opposed to five years ago, 10 years ago, 20 years ago, are there things that give you hope for the future or--

KELLI: Well, I think we're very lucky in the sense that the internet exists. I know that not everybody has access to the internet, but that was truly a game changer for me is to be able to reach out and find resources on my own. Particularly when I was in that questioning phase, before I even got a diagnosis, I wasn't ready to necessarily talk about it in a serious way. And so being able to access those resources on my own time just as a solitary process was really helpful, because then I was able to build up my own foundation, and then when I felt ready to actually talk about it, I had some information that I could rely on.

I don't know that that was available as much, the culture on disability, and the culture around ableism, and all that stuff was very different even when I was growing up. And so, it has changed so much to even be able to have a disability march, or a campaign, or anything that is-- or a small community that meets up every week or something like that. It seems like it's more available than it was even 10 years ago when I was trying to find the same supports for folks I was working with. So yeah, the internet was definitely helpful and remains helpful. But also even just going to the library and seeing books written by disabled authors, and seeing people give keynotes, and things like that, it just seems like slowly we're moving to a point where it's OK, and that people are not as weirded out, I guess, by talking about it in public. Yeah.

TERESA: Are there authors, speakers, people in particular that you enjoy, or inspire you, or have shaped your thinking in terms of your neurology or disability culture.

KELLI: Yeah. I would say the first person that comes to mind is Stella Young, who passed away a couple of years ago. But she gave this Ted Talk and it was about the concept of inspiration porn. And that was a milestone moment for me, because it was somebody who was visibly disabled, and who was irreverent, and funny, and she just got it and put it all out there. And so that was a moment for me. And I still go back sometimes and watch that video, just because it's like, you know, she just went out and lived her life, and talked openly about all of her strengths, and challenges, and everything. And it was fine. And the world didn't end, and that was great. And I think that anybody who emulates that openness is really helpful for me.

Zach Anner, he has a really funny YouTube channel. And Stella Young, and then there are lots of people who I'm going to forget, who you are wonderful writers and bloggers. Lydia

Brown is an autistic scholar. There is Rudy Reagan, who does the wonderful Twitter real social skills. And she just is so smart and just analyzes things in a way that make you shift your perspective or shift your way of thinking, and I think that there's so many people. But yeah, it's wonderful that there are so many people that I can't necessarily make them all.

TERESA: Anything we didn't talk about that you feel like you'd want to mention or share with folks.

KELLI: Oh, man. I think my biggest piece of advice for anybody who is just starting this process, whether or not you are a disabled person yourself, or you're a parent, or a professional is to take your time and really get comfortable within yourself, and reach out when you need it. And there are so many people who are willing to support you in wherever you are in the process that when you reach a point where something doesn't work, or something doesn't seem right, or something doesn't fit, go ahead and move onto the person who does or an informational or resource that is. Because, ultimately, it's your life and you need to do what works for you, and so there is no one right path, but there is good information and bad information. And so learning how to parse that information, and have conversations, and getting more comfortable is really helpful.

TERESA: That's great advice. Thank you.

KELLI: Yeah, no problem. Thanks for having me.