



Raymond A. Mason School of Business

WILLIAM & MARY

DIVERSITY GOES TO WORK PODCAST

EPISODE 10: KATHLEEN BOGART – DIS/ABILITY PART 1

Kathleen Bogart

Disability actually is probably the most common minority in America. 25% of American adults have a disability. And so that's why it's especially surprising that it doesn't come up in these conversations more.

Phil Wagner

Hello from the halls of the Mason School of Business here at William & Mary. I'm Phil, and this is Diversity Goes to Work. Buckle up because we're getting ready to take a deep dive into the real human lived experiences that shape and guide our diversity work in the world of work. Should be fun. Welcome listeners to another episode of Diversity Goes to Work. We're so excited for all the engagement we're getting on this podcast. Thank you for continuously tuning in. And thanks for tuning in today. As we shift our conversation to a topic, we have not discussed just yet on the podcast, which is disability. And when we sat down to think about who we wanted to have on to talk about this topic, it was really clear that today's guest would be a great fit for all of her impressive work and engagement in this area. Our guest today is Dr. Kathleen Bogart, who's an associate professor of psychology and the director of the Disability and Social Interaction Lab at Oregon State University. She's a social health psychologist, and she specializes in disability and in ableism, particularly in the context of rare disorders such as facial paralysis. She's been awarded so many different awards, including the first annual Social Personality and Health Network Diversity and Research Award. She's been named professor of the Term at OSU, but she's a true advocate, an ally for people with disabilities and rare disorders specifically. She's the co-founder of the Disability Advocacy and Research Network, or DARN for short. And she's extensively involved in disability advocacy both at Oregon State and abroad. I love her bio because it says in her free time, you can find her walking her cat or developing pescatarian recipes for her food blog. Clearly a multidimensional guest today. We are so excited to welcome Dr. Kathleen Bogart. Kathleen, could you first begin just by telling our listeners a little bit about who you are and the work that you do?

Kathleen Bogart

Yeah, sure. Well, thanks so much for having me today. I'm really looking forward to this conversation. So my background is that I am an associate professor of psychology at Oregon State University currently, but backing it up. I was born with a disability called Moebius syndrome, and that's important because it really shaped the way I moved through the world and how I came to do the career that I do. So Moebius syndrome is a condition that's

characterized by facial paralysis and impaired lateral eye movement. So it's a very visible disability. And so, when I was going through my early life, I started to notice just that other people got a bit confused by what I was trying to communicate because they were looking for a facial expression that often wasn't there. And it just made me fascinated about communication. We do so much with facial expression, but we also do so much with all those other communication channels, words and body language and gesture and all that stuff. And so that really made me just fascinated with basic psychology. So I pursued undergrad and then grad work in those areas. My Ph.D. is in experimental psychology from Tufts, and I had just great mentors going through grad school who, honestly, I really appreciated as allies because they recognized that they didn't know a lot about Moebius syndrome. Honestly, some of them didn't know a lot about disability in particular, but they were happy to support me and learn. And that's exactly what I needed. I got this great position at Oregon State, and I've been just doing research on Moebius syndrome and then broadening out, right. So facial paralysis in general, rare disorders in general, and disabilities in general. And in this kind of like series of concentric circles, I've been really interested in the commonalities that all of these groups experience. So we really focus a lot on stigma and discrimination experienced by these groups and the way that we can change the way the outside world views and treats these groups.

Phil Wagner

That's so good. This is a little bit of an aside question, but one of the things. So I'm a communication researcher, and I love how you speak to those elements of gestures and nonverbals and all of the elements of communication that drive perception. The other side is the language piece. And we know one thing that we found in this podcast that there's so many different ways of labeling, for lack of a better term, the concepts that we're dealing with as we guide the conversation today. You use the term disabled. You say differently-abled. Like, what's the language that you would recommend that we use as we talk about these concepts?

Kathleen Bogart

Yeah, I'm really glad you asked that question because so many people wonder about how they should talk about disability. And I think also that the worry of saying the wrong thing has stifled these conversations. I certainly don't want to speak for everyone, but I will say that I really like the term disability or disabled. And I call myself either a person with a disability or a disabled person. So those two are, in turn, are called person-first language and identity-first language. And they're a good argument for people choosing to use one or the other. I happen to just kind of use both as a way of honoring kind of flexibility there. But person-first language is all about ensuring that we understand that the disability is just the part of a person, whereas identity-first language is like, well, actually, my disability is a very important part of my identity, maybe like my race or gender or something like that. So we don't say people with blackness. We say, black people. Some people feel like we should disabled people and then to your question about differently-abled and words like that. I really like just saying the frank term disability. I feel like euphemisms, like differently-abled or even special needs, those kind of they're skirting around the reality of this identity, and it's nothing to be ashamed of saying and talking about. And I think when we skirt around using the word, it further stigmatizes it. And

this is also the word that's used in our civil rights legislation, right—the Americans with Disabilities Act. So let's say that word and mount that on to our civil rights.

Phil Wagner

Love it. Oh, my gosh. That's so clear and so helpful. So you've done a lot of research, and you've talked a little bit about what drove you to that research. We'd love to hear what that research has shown. What are some of the important insights that you've gleaned from your own research? Can you share those with us?

Kathleen Bogart

Yeah. There's so many different.

Phil Wagner

That's a big question. I know it's big.

Kathleen Bogart

Yeah. So kind of starting at the beginning, I did initially focus mostly on people with facial paralysis and speaking to the communication piece that we're both interested in. I became really interested in the way that people with facial paralysis may communicate in alternative ways. So if facial expression is limited, we find that a lot of really successful people with facial paralysis amp up their expression in other areas, and they call this alternative expression. We find that people who were born with their facial paralysis are more likely to use a great deal of alternative expression compared to those who acquired it at some point later in their lives. And jury is still out on exactly the mechanism there. But we think that it may have to do with going through one's initial development with one's disability may really put you at a teachable advantage for working out ways to engage with your world. So we also know that those are effective strategies improving other people's impressions of someone with facial paralysis. So we know that by default, people tend to view someone with dampened facial expression as kind of sad or bored or even intellectually disabled. But we find that our participants who use more of this alternative expression are actually viewed by strangers in more positive ways. So that's one angle. I like using that line of research as an example because it starts by focusing on the target, the person with the disability. But then here's how we turn it around so that people without disabilities also play a role in reducing ableism. So then what we do is we train or work to train people who are likely to interact with people with disabilities, people with disfigurement, stuff like that. We train them about alternative expression and about just comfort with using language and stuff like that. So we do that with a lot of different populations now.

Phil Wagner

You have just mapped out like 17 different pathways for questions that I have. So I'm trying to figure out where do I want to go next? Because I really want to talk about that allyship piece. I think that's so critical, but I also think it's so complicated. But I want to tuck that away because I really want to focus. Your work has this sort of meta-message, and the meta-message I take

away from your work really looks at disability as a broader entity. And you note that ableism is often like the forgotten ism. What do you mean by that exactly? And then I guess I'm specifically asking, what are the consequences for leaving this content domain out of our broader conversations on diversity and inclusion? Do you have any insight there?

Kathleen Bogart

Yeah, absolutely. I really do feel like disability is kind of this forgotten ism. When we talk about DEI, we have this really important list of identities. And I can't help but now every time I see a DEI statement. I look for disability because I'm just hyper-aware of the fact that my group has been erased over and over again, and many times it's not included. And so what happens here is that people do these DEI trainings, or they have these statements encouraging people to apply for positions, but it doesn't mention disability or disability is an afterthought. So I even think about who's training the trainers. Right. So when you think about the people who are running DEI initiatives, we often talk about how important it is to have people who have an identity that might fall into one of those categories as someone who is doing the teaching or designing the programs. And those people are rarely disabled. And, of course, we're not talking about these identities in separate boxes. We need to think about intersectionality, and disability is a totally great example because it absolutely can intersect with all of these other identities. And so, I'm always surprised when people don't acknowledge that.

Phil Wagner

Yeah. And that's so crucial, even in our podcast, for as much as we're trying to do this sort of deep dive into specific identity domains, we do so with that full acknowledgment that it's sloppy, so it's intentional, but it's misinformed because it's impossible to do effective DNI work when we do that in such a siloed fashion. So that's such a great point. To that point, thinking about the larger umbrella of disabilities, your work specifically focuses on disabilities and disorders that are rare. And I think in your work, the number was affecting 200,000 people or fewer every year. That's really where you sort of or have focused in on as a subset of your research. So does disability advocacy account for that? Is it inclusive in its own right? I mean, what steps can disability advocacy or DNI work sort of take to ensure that the wide spectrum of abilities are included in that conversation?

Kathleen Bogart

Yeah. So that's a great question. And let me step back for a minute because I want to contextualize actually how widespread disability is. And this really goes back to what we were just saying about how it's just forgotten ism. Disability actually is probably the most common minority in America. 25% of American adults have a disability. And so that's why it's especially surprising that it doesn't come up in these conversations more. Now there is so much diversity within that 25%. And here's how we get to all the different common and rare conditions that can result in a disability. Right. I have been especially interested in rare disorders. And so, in America, a disorder is defined as rare. As you said, when it affects fewer than 200,000 Americans, there are 7000 at least rare disorders. So when you collectively look at all of them in America, actually approximately one in ten to one in twelve Americans has a rare disorder.

So this is a common experience, even though the 7000 different underlying diagnoses vary. So we do need to be sure to include this in our advocacy work. Historically, any minority group needs to come together, put aside its smaller nuance differences sometimes, and just kind of become a large group for lobbying and organizing power. And that really is what is starting to happen in the disability community. Historically, it has been a bit more fractured. So you'll see, like most of disability advocacy started among people with mobility disabilities, which is, of course, a really important segment. I mean, if you go back and think about the history of it, the literal symbol of disability in this country is a wheelchair user. It's on our parking lots. It's on our bathroom doors. Right. So that group has been great about being visible, quite literally, but there are a lot of invisible conditions. And many of these rare disorders are invisible. Some of them are visible, like mine. The majority of disabilities are invisible, so they don't look like that symbol. So we really need to remember the diversity within that population. When I think about kind of how my work can align with the greater good of the disability community, I like to think about the social model of disability, which is in contrast to the way we think about disability by default in America. The way we think about it by default is the medical model, which is we really focused on the underlying conditions and so-called pathologies within an individual. And we place the onus on the individual and a few Esoteric specialist doctors to deal with the quote-unquote problem of disability. But the social model is the model that many disability activists and scholars adhere to. And this is very much like a social psychology view of disability. It says that disability is a social construct. So it matters less the individual diagnoses that people have and what's going on in their bodies or minds. It matters more the value that society attaches to those people and the way society includes or excludes them. So when I think about this work, whether I'm talking about one very rare condition like Moebius syndrome or whether I'm talking about the entire collective group of 25% of Americans. That is one thing that we all have in common. Right. It's the social exclusion. And to me, as a psychologist, that's the most exciting part is that it's much easier to act upon social behaviors than it is to act on more than 7000 different underlying euchologies. Right.

Phil Wagner

Yeah. It's so good because I think so often it's not that we try to make DNI work palatable, but we try to simplify it so that we can wrap our minds around it so that we can have action that sort of checks it off the to-do list. And I think one of the things our podcast is really showing us is that this work is sort of always moving forward because it's so deep, and it's so broad at the same time. To the point of actually getting involved in creating more inclusive spaces. I'm going to sort of take our conversation a bit of a different direction towards allyship. There's really two questions I have, and I'll start, I think, with the most simple, and that's in your lab. You do a lot of great work in your lab at Oregon State. You focus on disabilities. And that piece we just talked about, that social interaction piece, and we talked about communication earlier. We know that communication is sort of like a double-sided coin. It can certainly bring us together. It can be an effective agent for change, but it can also perpetuate distance and stigma. How has your work in your lab or in your research? How has it produced results that can help inform our approach to effective allyship, particularly as it relates to social interaction and communication?

Kathleen Bogart

Yeah. So this is a great point. I always want to start off when talking about allyship by saying allies are awesome, and we absolutely need them. And we also just need more disabled voices in our conversations. And what allies get to do is amplify those voices and spread it more.

Phil Wagner

So this is a good sort of segment you're getting right at my second question. This is perfect. We're totally on the same wavelength here. But I'm often reminded of that sort of ever-pervasive mantra. That not about us without us. Right. And there's been just decades of non-disabled people, perhaps sometimes well-intentioned, speaking up, speaking for, speaking over disabled voices. And so, I think allyship is particularly important, but it's also particularly complicated in this area, particularly because of just the history that's come before it. So as we talk about allies, where do you see their role in disability rights and advocacy if they don't have or hold a disability themselves?

Kathleen Bogart

Yeah. Thank you for adding that extra nuance to this conversation. Yeah. I agree that there is this long history of it's a generally well-meaning, people who do not have disabilities, who are designing and conducting the research about disability, writing the laws and policy and things like that. By sheer numbers, there are going to be 75% people who don't have disabilities and 25% or so who do. We absolutely need well-meaning allies, but those allies really need to listen to people with disabilities. So one concrete example from the research world is something called participatory action research, which means that you are including the people who have a stake in the matter, the participants, you might say, as actual participants. So they are designing the research. They're working as consultants. They're helping you understand and apply the results and get it out to the people that matter. And that's something really important to me as a researcher. I have a disability. That doesn't mean that I can imagine what everyone with a disability would want or need. So more and more, I'm including these methods. And I think especially non-disabled researchers need to do this more. It's still quite rare in the disability research world. So that model works at a much larger scale, too, when we're talking about making policy and making laws, listening to disabled people. That's done to some extent in the past. But often, it's not enough. Often you get kind of a token person to come into Congress and speak out about their testimony. But we need much more than that.

Phil Wagner

Is there a line, a definition line for what disability is or is not? A few weeks ago, we were talking about disability rights and advocacy in my diversity course. And this is not to belittle the student who mentioned, but she said, I have acid reflux disease. Do I have a disability? And I identified somebody. I have Tourette syndrome, which has not historically been classified as having a disability, though it certainly provides some awkward social interactions that lead others to perceive that I may in some context. Have you figured out that sort of space where this is or is not a disability?

Kathleen Bogart

Yeah, there are so many. It depends on who you ask. Basically, there are so many definitions of disability. I like to start with the Americans With Disabilities Act definition and kind of go from there. I think it's a pretty good one. So the Americans With Disabilities Act says that you can be classified as disabled if you have an impairment or a condition that significantly affects your ability to do one or more major life activities. Okay. So keywords there are significantly affecting, but the definition doesn't end there. There's two more clauses. So the next clause is having a history of such an impairment. So that means that if you had a disability at one time that has been remission or it's now recovered, like, say, you had cancer or significant depression, and now you're in remission, and employers still might find out that information and discriminate against you because they're worried about health insurance costs or people not coming into work or whatever. So that protects people. And then the final clause is or the person is regarded as such. So this means that the person does not even need to have an impairment that impairs their life. But if someone discriminates against them because they believe them to have it, then they are also covered against discrimination. And that's often like I teach about those issues, too. And that's often the one that my students have the hardest time wrapping their head around. So let me give you a concrete example that actually comes up a lot in my own community of people with Moebius syndrome. So because of our kind of relative lack of facial expression, sometimes we are erroneously thought to have intellectual disability. I've heard of many people in my community showing up to job interviews and being told explicitly or implicitly that they think that the person is not intelligent enough to be able to complete the job. It would be very uncommon for someone with Moebius syndrome to have an emotional disability. This is not even a real disability that they have that the employer is imagining one to be there.

Phil Wagner

Wow. That's such an effective vehicle to take that clause and really show the potential because even when you're explaining it, I was thinking it would be so easy for somebody to sort of co-opt disability status for those sort of malevolent reasons. Right. Like out of some misguided notion of convenience, like a parking pass being a prime example there. But I love that vehicle because it's so important. And I'm so sorry I'm going in so many different directions. But you bring up a really important notion of social support. And we know that to navigate all of just the tumultuous life circumstances that we face in any of those identity domains, social support is such a critical space for us to sort of get what we need to get through the day-to-day. You mentioned your community specifically. And to the extent that you're willing, I want to ask, what does that social support look like? Does it come from your sort of subset space of people who have the similar disorder that you mentioned that you carry with you? Does it come from like-minded people within the disability movement? Is it external? What does that sense of social support come from in situations like the one you mentioned?

Kathleen Bogart

Yeah. Well, I mean, ideally, it comes from all of those fears. Right. So personally, it was really meaningful for me when I connected with other people with Moebius syndrome, which I

didn't do until I was in my 20s. And like many rare disease groups, they will have, or the Moebius Syndrome Foundation will have a conference yearly or every other year where people can come together and meet each other. And so I went to this conference for the first time, and it was truly profound because it was the first time in my life I ever met not just one person who looked like me, but I was surrounded by a room of people who looked like me, and suddenly we were the majority group. So after that, I actually started conducting research on the experience of people who attend this conference. And my anecdote maps on really well to a lot of other people's experiences. They say, well, it's the one place where I feel normal. It's the one place where I don't have to explain myself. I know that people know exactly how I'm feeling. I think there's so much value in that, but it's got to come much more broadly as well. Kind of like I said, with my research, I found it to be really beneficial to kind of go broader than my own specific disorder. So I really enjoy connecting with disabled activists with all sorts of different types of disabilities and backgrounds. Allies, like we've been talking about, are super important as well. I have great family and friends who do not have disabilities but have always been really supportive. And I just have to give a shout-out to one of my best friends, who is another psychology professor. Her name's Amanda Hemmesch. She's a social support researcher, so it's definitely great to bring her up here. She's at St. Cloud State University, and she doesn't have Moebius syndrome, but because of her social support research interest, I brought her in to do this study on Moebius syndrome social support, and she just fell in love with the conference and the vibe there. And she's been going as my ally ever since. She knows a lot of people in the community, and I think she's just a great example of an ally and someone who exudes social support.

Phil Wagner

I love that. And I love that anecdote too because it's such a powerful charge to hiring managers, to leaders who can shape change. It echoes the reverberations of you can't be what you can't see. And within the world of work, I think the more that we check those unconscious biases, we work to move past direct, sometimes forms of discrimination. And we create a more inclusive space where people with varying life experiences, varying abilities, disabilities are represented in that space. It's better for everyone, right? That's not some charity act to people with disabilities. That's better for everyone. It's better for the clients that we work with. It's better for the quality of our social interactions. It's better for our bottom dollar. If we're thinking in a purely business case, it's such a clear charge and reminder of the potentials when we move past those barriers that may not even be barriers, to begin with, barriers that we've created so profound. I so appreciate you sharing that. One final question for you, and I think what we often wish is that we had some magic wand that we could just waive, particularly in the world of work, and fix it, make it more inclusive. If we handed you that magic wand with your perspective and your research and you're able to wave it and make the world of work a more inclusive place for people with disabilities. What would that look like?

Kathleen Bogart

My one-word answer to that would be flexibility. And I think the pandemic has really shown us what can be accomplished when we are more flexible. That's one little silver lining of a

really awful more than a year we've experienced at this time. So people with disabilities have been advocating for flexibility in the workplace in terms of the ability to work from home or the ability to work flexible hours for years and years to very little positive effect. Right. They're getting the messaging that, oh, it's not possible, you won't be productive that way. And then this is a great example of the social model at work. So as soon as the pandemic created barriers so that everyone was disabled essentially. Everyone could not go into work unless they were in a few certain essential fields. Everyone was disabled, and everyone had to start working flexibly from home. And we found that we can do it. And employers gave those accommodations. And I know I and many other disabled advocates are just really hoping that that does not go away, that we don't forget the adaptations that we've done through this time. So that flexibility can help so many people, as you were saying, not just disabled people, but anyone who, for variety of reason, has kids, even a kind of night owl schedule versus work schedule, and certainly people with all sorts of disabilities. Right. So maybe episodic conditions that you have good days and your bad days, and on a good day, you are ready to take on all of your work, and maybe you can be really productive and then get it in the bank. And then when you have an off day, maybe you're not going to work, but when you allow people to kind of use their own schedules and strengths and energy, then they're going to be productive.

Phil Wagner

That's so good. Those are all of my questions. I cannot thank you enough for your insight. I know that this is your research, and it comes from such a natural place, but it's so helpful, and it's such a great framing device as we really try to drive forward the conversation. So I really want to know that we appreciate your time so much. Thank you so much for being here. It's been a real pleasure.

Kathleen Bogart

Absolutely. This was a lot of fun. I really love your conversational style. And you've just got fabulous questions. I can really tell that you're in it for the right reasons.

Phil Wagner

Thank you so much. I appreciate it.

Phil Wagner

Thanks for taking a second to listen to Diversity Goes to Work. If you like what you heard, share the show with a friend, leave us a review on Apple podcast or wherever you listen to podcasts, and reach out, because we're always looking for new friends. And if you'd like to learn more about any of our programs or initiatives here in the business school at William & Mary, be sure to visit us at mason.wm.edu. Until next time in.