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Nick: Welcome to *Included*, the *Disability Equity Podcast*, brought to you by the Johns Hopkins University Disability Health Research Center. This podcast challenges stereotypes of disability by sharing stories, data, and news. Each episode digs deep into topics to offer diverse perspectives and expertise to expand your view of disability.

Bonnie: We're your hosts. I'm Bonnielin Swenor, Director of the Johns Hopkins Disability Health Research Center.

Nick: I'm Nick Reed, Assistant Professor at Johns Hopkins University Bloomberg School of Public Health. On this episode of *Included*, we talk with Dr. Kathleen Bogart, Associate Professor of Psychology and Director of the Disability and Social Interaction Lab at Oregon State University. Dr. Bogart is a Social Health Psychologist specializing in disability, ableism, and rare disorders such as facial paralysis. Much of her work focuses on the psychosocial implications of living with rare disorders or disabilities, such as Bell's palsy and Moebius syndrome. She is an Associate Editor of *Personality and Social Psychology Review* and *Orphanet Journal of Rare Diseases*, and an Editorial Board Member of *Rehabilitation Psychology*. Her work has been featured in multiple media outlets, including the *New York Times*, *Time*, and *Insider Higher Ed*. Dr. Bogart is also the co-founder of the Disability Advocacy and Research Network, or, for short, DARN, for social and personality psychologists who have and/or specialize in disability. She is the Faculty Advisor for Oregon State University's Disabled Student Union.

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Dr. Bogart, thank you so much for joining us today.

Dr. Bogart: It's really a pleasure to be here, and thank you so much for having me.

Nick: No, the pleasure's all ours. We wanna start, your team at the Disability and Social Interaction Lab has conducted a vast amount of research spanning perceptions, awareness, and attitudes towards disabilities. It's almost breathtaking, the scope of your work. We wanna start by asking you about your work related to examining what you refer to as Disability Self-Concept. Briefly, what do you mean by that?

Dr. Bogart:

Yeah. Well, thank you for commenting on the directive of my research because sometimes it feels very intentional and programmatic. Other times, it feels like overwhelming in a sort of exciting way. We'll pretend it's programmatic as intended. In general, my research focuses on the experiences of people with disabilities themselves, how they manage stigma, and then on the other end, the way other people and society at large form perceptions about people with disabilities, and engage enableism that harms people with disabilities. Your question about disabilities self-efficacy really gets to my interest in how people with disabilities can adapt. I got interested in this concept to really when I started thinking about the distinction between congenital and acquired disability, which is something that hasn't actually been focused on a lot in psychology. It's much more common to have an acquired condition, right?

There are many opportunities to acquire a disability throughout the lifespan through disorders, diseases, injuries, and things like that. It's also possible to be born with a disability. I was born with a disability, and kind of thinking about those of us who have congenital disabilities, we're minorities within minorities. There are fewer of us. Psychology has in the healthcare field at large, I think, is really focused on acquired conditions a bit more. Makes sense when you think about the size of the population. I also have been very interested in some of the different types of adaptations that people with congenital conditions engage in.

I have a hunch that disability, that disability self-concept might be one of the potential drivers. In general, self-concept in psychology is a multi-dimensional way of thinking about who we are, our identities, our ability to engage in the world, and enact our motivations. Specifically for disability, I conceptualize self-concept as including disability identity on the one hand, and disability self-efficacy on the other hand. Disability identity is a minority identity, like many others that we talk about, like similar to racial identity or sexual minority identity. There's a vast amount of research in those areas showing that having a positive in-group identity can be protective of your well being. There is kind of emerging research now showing that having positive disability identity or disability tribe is associated with positive outcomes as well.

Now, let's turn to the other aspect, disability self-advocacy. This is having confidence in one's ability to manage one's disability symptoms and navigate the world in a way that allows you to enact your goals. This is something that many people with disabilities

will develop over time, and especially through help from supports from the healthcare system. I have the notion that people who are born with their conditions would likely have stronger disability self-concept because they went through their initial development, their initial identity formation, their initial navigating of the world with their disability, alongside their disability. There's no sense of identity loss or having to relearn how to function, which is a very common experience for people with acquired conditions. People with acquired conditions often do eventually learn how to develop a positive disability self-concept, but it can take a while. It can involve a lot of relearning of potential internalized stigma that they have experienced before, developing a disability, and it can take a lot of supports.

I was interested in idea that there might be something called a congenital advantage to being born with a disability in terms of adaptation. In the study that I think you're referring to, we sampled about 700 people with mobility disabilities, and the thing about mobility disabilities is that they can be congenital or acquired. They range in symptoms like severity and pain and things like that. We were able to control for those symptoms and compare people who had congenital versus acquired conditions. We were interested in looking at disability self-concept as a mediator, a potential mechanism, and so a potential mechanism in satisfaction with life, which was our outcome measure. As predicted, we actually did find that those with congenital conditions had a stronger disability self-concept, which was associated with higher satisfaction with life. This mediation relationship appears to hold. This is kind of an interesting first foray into kind of looking at these differences between congenital and acquired conditions. We're kind of following up with further research at this point.

Bonnie:

Well, thank you. That was a fantastic summary of a large amount of work, can we just say that, that you have done. You know what I think is so interesting about your work is these are concepts, I think, among the community we think about and talk about sort of through anecdote, but your work is really putting rigor behind it in studying these concepts. The other part that I find so interesting is from external views outside of the disability community, and I'm sure you do, but I often interact with views that disability really is a fixed perspective. You're sort of both, with your work, challenging that and encouraging sort of flexibility in that views change, and it's a healthy thing, right, to sort of get a stronger disability identity. That's okay, right? I find that so compelling and interesting as you think about disability across the life course, right, as you laid out so well. People born with disability,

congenital disability, and then you're comparing it even to people who have disabilities late in life. That's such a stark difference. We need to perhaps learn from these differences, and how to create an environment where both experiences, both groups of people can thrive across the life course, right?

Dr. Bogart: Absolutely.

Bonnie: Anyway, I just wanna say I think your work is just so compelling to me and interesting.

Dr. Bogart: Well, thank you. I think that the dynamics that you're talking about, how over the lifespan, things will change. It's so important, and I think under-recognized at this point. One little example I'll give is that in psychology, we used to talk about someone's response to their disability as adjustment. We used to use that word. To me, adjustment really implies something that's static, and you feel like you have to figure out how to adjust. Then you've adjusted, and you're done, right? It's a very dynamic process over the life course. People's circumstances and environment and functioning are always changing. I much prefer something like adaptation because it's a constant process, and that goes across all of human existence, right? It's not just people with disabilities who are adapting. Adaptation is universal.

Bonnie: Yeah. It's so interesting to me. I wanna shift gears a little bit, and now talk about another area of your work, which I also find so fascinating and interesting, which is looking at the attitudes towards people with disabilities among college students, and people attending universities. In one of your articles on this topic titled "Disability Models and Attitudes Among College Students With and Without Disabilities," you found that, and I quote, "Students with disabilities experience a cultural mismatch in higher education regarding disability models and attitudes." Can you talk a little bit about this area of your work and share some more details about what you found from this study?

Dr. Bogart: Absolutely. As a college professor, I'm very interested in how people with disabilities in universities are doing. We know from national data that there's already an under-representation of students with disabilities, so probably about 20 percent of our general population has a disability. Only 11 percent of our students in universities have disabilities. That is an under-representation, but 11 percent is still a sizable group, students in universities. The challenge is that even once they get to university, they're less likely to complete their degree, 16 percent less likely. One thing I

was interested in and kind of examining the very multi-factorial reasons why students are not completing was whether there is a sense of belonging, whether they felt a part of the culture. That's what inspired this research.

We conducted it all at my university, Oregon State. We capitalized on the fact that there is a class that all of our students, mostly freshmen, are required to take. We asked them to volunteer to do a survey. We ended up with more than 1,700 participants. They generally kind of reflected the demographics of our university. Of those participants, we had 215 who had a disability. We wanted to compare the students who had disabilities versus those who didn't on their attitudes towards disability in general, and also their underlying model. I know you've talked about models in your podcast before, but maybe I'll take a little refresher for people. We looked at social and medical models.

As your listeners probably know, the medical model is kind of the default way that people in the west think about disability in general. It's thinking about disability as an individual problem, a pathology that is aimed to be cured and is the responsibility of the individual and a small group of healthcare experts to work on. In contrast, the social model views disability as kind of a universal human difference that is culturally created. Here, the responsibility for disability and for improving the lives of people with disability is at the societal level. We were interested in examining students' beliefs about these models, and whether they differed, if they had or did not have a disability. What we found was the students without disabilities had more negative attitudes towards with people with disabilities in general than those who did have disabilities. We found that that difference in attitudes was mediated or potentially explained by differences in models so that the people with disabilities had stronger social model beliefs and lower medical model beliefs than people without disabilities.

Now, this is something that hadn't been found before in psychology, and everyone had been theorizing that it would occur. It was interesting to see it actually play out. Really, what this suggests is people with the lived experience of disability are more likely to see the social barriers than the people who are looking at disability from the outside, right? This seems to be one thing that's driving more negative attitudes towards disabled people from the outer group. What this does suggest, to go back to that quote that you gave, Bonnie, is that students with disabilities are in an university system, where they're surrounded by other students who have some negative views about disability, and have kind of

different orientations about the meaning of disability, and how it should be addressed. I don't think that this is anything specific to OSU. I don't think it's probably anything specific to a university setting. What we can say is that this is one example of a cultural mismatch that can make it more difficult for people with disabilities to feel understood and valued.

Bonnie: I find this so striking, particularly I think at this time in society, right, where we are learning so many lessons from other groups that you need to take the cues and listen to the population on how they view themselves, for how then the rest of the world should view that group, right?

Dr. Bogart: Absolutely.

Bonnie: I am just constantly reminded that for the disability community, that still doesn't happen. What your work has done here, and what you just discussed, I think, illuminates that gap still. The other concept, I think, that is so critical for the work you've done here is that universities have a really important role in changing this, right? This is where we educate the future, future generations, and unless universities take a more active stance, position in changing this paradigm, listening to the disability community, and educating about disability in the ways in which the community views themselves, we're going to keep perpetuating these cycles.

Dr. Bogart: Absolutely.

Bonnie: I just think that's why, again, this area of your work is so compelling to me, too.

Dr. Bogart: Well, and I think it really feeds in nicely to the conversations you've already had on this podcast about improving education for healthcare providers. This is all happening at the university level, and we view universities as kind of that last training ground for people of other professional field. If we're failing to talk about disability in a way that represents lived experiences, then we're failing to prepare people to interact with a diverse world.

Actually, I've done some research on the way disability is represented in psychology programs. Kind of paralleling, to me, psychology is a healthcare field as well, right? It's a mental healthcare field. It's very important that we similarly prepare people to interact with a whole diverse group of people. A few years ago, we did a content analysis of all of the course catalog materials that the top undergrad psychology programs listed. We

wanted to see whether their undergrad classes that they listed online in their course catalog included mention of disability or synonyms of disability. We also kind of categorized the different types of disabilities that were mentioned, and we looked at the tenor of the description, so did it seem more medical model or more social model? Unsurprisingly, we saw that every single university talked about psychiatric conditions. We would absolutely expect that in the psychology realm. It's kind of our bread and butter. However, we should also be talking about the disabling conditions that are most prominent, that are most prevalent in our society, so that would actually be chronic health conditions and physical disabilities.

We've found that only about 40 percent of universities mentioned anything about those types of disabilities on their course catalogs in psychology. When it was mentioned, it was described in more of a medical versus social model. Of course, there is much more to a course than the course description, but I think that it is telling that when you look at course descriptions of classes that cover other types of diversity, things like ethnicity and race and sexual orientation are mentioned explicitly in their course descriptions, but disability often is not. I would really want to see change in our field such that disability is mentioned front and center at—let's set the bar low—at least, once in an undergrad's educational classes.

Nick:

This is so fascinating to me. I mean, I think you're spot on with the healthcare analogies and this deeper dive into psychology in particular. I sort of wanna riff on this piece a little bit, just to dig a little bit deeper. It's a concept that we don't talk a lot about, but I'm wondering if any of your work has actually thought about almost like this psychological viewpoint from those who do see it from an allyship perspective. If we zero in on that group, is there anything in your work that comes out of that or from work in the field, or maybe that you'd hypothesize a little bit? I guess what I'm trying to dig deep on is what is it about disability that the allyship doesn't seem to be as strong sometimes? There's this inequity across these other sort of social constructs of minority that we have out there, right, when it comes to others recognizing and viewing them. I'm truly just sort of curious about this. Maybe you have some thoughts, or maybe not. I'm not sure.

Dr. Bogart:

Yeah. Yeah. I think that's a great question, and, Nick, I was listening to the episode where you were talking about allyship, and I thought it was really fascinating. Allyship is so important. We actually know from the broader discoloration research, this is not specific to disability, but we know that allies, when they speak up

against prejudice, they are more effective than if the in-group members, minoritized people speak up for themselves. That hurts me to say it is not a fair world, but it does speak to the power that allies can have.

There haven't been a whole lot of studies about allyship within disability in particular. There was a really interesting qualitative study that Joan Ostrove led. We did a special issue of the *Journal of Social Issues* on ableism, so that paper, I know a few people with disabilities who really centered them and asked them about what made a good ally. They were really some fascinating narratives in there. Kind of the high level answer really was allies respect us and listen to us. They amplify our voices, right, and don't make it about themselves.

Speaking to kind of how could allies make a difference in the field, talking about education, this is something I think about a lot because I have a lot of great colleagues who wanna be allies, who are not disabled. We know that people with disabilities are highly under-represented in universities in general, so this is an issue that we will have to deal with. We need to really support our allies and help them have the resources that they need to move the needle.

One thing that I'm very anxious for the end is simply giving allies the tools to teach about disability. This is also helpful because it takes some of the burden off of the, for example, three percent of disabled psychologists in the faculties here. What happens is when you teach a university class, especially if you teach an introductory psychology class, which is a class that most undergraduates teach, whether or not they're take, whether or not they're gonna be a psych major, it's just the most popular elective. We serve a lot of students that way. No professor is an expert in every sub-area of psychology, so they rely on the textbook and instructor manual and a little bit of extra information to teach those areas that are not part of their core expertise.

I think a lot of instructors would like to teach about disability, but wanna do it justice, and don't feel like they have the right resources to do that. We put out a few years ago an instructor resource manual for introductory psychology, where we basically saw this as a way to supplement the textbooks, which by and large contain no mention of disability. For each chapter in a typical textbook, we have supplemental material that represents disability and talks about disabled stories, videos, and things like that. We're definitely trying to engage more of these approaches where people get the resources that they need to start these conversations.

Bonnie: Yeah. Thank you for that work. I gotta say that's, I think, exactly what we need right now, right, because there is this gap, and I think to Nick's point, allies are what's needed now to move this movement forward. I think, and if I can reflect on, Kathleen, what you just said, there is sort of a gap in comfort or knowledge or understanding about disability community, about ableism, and people don't have the tools. The faculty teaching the courses don't have the tools, knowledge, or sometimes even comfort level in including disability, even though they want to. I know that's abhorrent in lots of ways because it's 2021, but it's the reality. I think we have to figure out a strategy to change that, and create a welcoming space for those that are willing now to be allies to make the change 'cause I do feel like that's actually—we have movement there for the first time in a long time, good movement. I just wanna say your work is, again, amazing because it is, I think, getting to the heart of where the change has to be. It's empowering the allies, empowering the faculty. We're educating the next generation to do this work.

Nick: Yeah. I mean, spot on. I sort of wonder, too, a little bit, as I listen to this, how many people think they teach disability because they view it through a medical model lens rather than a bio-social lens. If you asked faculty members across the board what would be the mismatch of your review of syllabi and programs versus how many just say, "Yeah, of course, I teach disability." I don't know. It's just very curious.

Anyway, I mean, this is so fascinating, but I wanna pivot slightly to another area of your research, your work on facial paralysis, and specifically related to communication. I think this is really fascinating work. You've noted that facial paralysis is a highly visible, but unrecognizable disability, and your NIH-funded work has explored the impact of education about facial paralysis. I was wondering if you could share a little about this work, and also clarify for our audience what you mean by unrecognizable disability.

Dr. Bogart: Yeah, absolutely. This is a topic that's very close to my heart because I was born with facial paralysis, so the specific condition that I have is called Moebius syndrome. There are lots of different ways that someone can be born with or develop facial paralysis. In the US, actually each kind of potential cause of facial paralysis is considered a rare condition, but collectively facial paralysis is not uncommon, so about 230,000 Americans every year develop it or are born with it. It is still, though, a very poorly recognized

condition, and that's why I say it's unrecognizable. It's so erotic because it is very obvious often when someone with facial paralysis walks into a room. You notice that their face looks unusual or is not moving in a typical way. Strangers will notice this difference, but not know how to attribute the cause, the nature, or the combinations needed for that condition, so meaning they may have no idea why the person's face looks different. You get some very strange interpretations of facial paralysis that I've heard from qualitative interviews I've done over the years. People are asked if they had just gone to the dentist and had a Novocain shot that made their faces temporarily paralyzed. People are asked if they were currently having a stroke, or children are actually asked if they had something serious, like were they going to die. In all of these cases, that was not an accurate interpretation of the condition at all.

Some people have just so little public awareness that they're kind of grasping wildly at trying to make an understanding, and simultaneously that means that the accommodations that they might make might be really off or counterproductive. It might be that someone interprets an unresponsive face as intellectual disability. In that case, the person might ignore the person with the difference or speak to them in a childlike way. A variety of things might happen that are counterproductive to interaction. Often, the only accommodation that's needed for someone with facial paralysis is to focus on other channels of communication. The face is one channel, but every human uses a whole collection of channels. That includes body language. It includes paucity or tone of voice. It includes the actual spoken language. All of these things are intact in people with facial paralysis. In fact, we find that those with congenital paralysis, especially do a great job in increasing their expression in those channels. We call it alternative expression. The challenges of having low public recognition of this condition can really result in some unfortunate misunderstandings.

Now, the research that I did around education was really based in the finding that in addition to the qualitative things that I mentioned, quantitatively, we found that when strangers view videos of people with facial paralysis, they make inaccurate and negatively biased impressions of them. They rate them as less happy and less friendly than they actually are because people are over-focused on the face as a communication channel. In order to try to stamp out some misconceptions and improve social interaction for people with facial paralysis ultimately, we were interested in seeing the effects of educating the population. We started with what I consider to be a small pilot study where we

simply gave some of our participants a couple of paragraphs' worth of simple information about facial paralysis, basically what I've talked about today, and then had the participants view videos of people with facial paralysis. There is another condition where people got no information as they would in their everyday life, and then viewed people with facial paralysis. We've found that people's biases were reduced with this additional information.

I've continued to kind of develop this educational strategy, and tweak it for different audiences. We've done it in England. I have done it for Allied Health professionals. We continue to kind of sort of riff on it, and really the goal is to develop a good protocol that would train people who are especially likely to interact with people with facial paralysis. That would be healthcare providers. That would be employers, perhaps teachers. Yeah, that's more to come on that, but it's something that we're really hoping to develop.

Bonnie: That's amazing. I love it. I love how you are taking your work and putting it to work, as they say. Relatedly, your group now has two awareness projects, a rare disease and a Moebius syndrome awareness project. Can you share some details in the goals of that work, and how that maybe relates to what you just shared?

Dr. Bogart: Yeah, absolutely. That comes directly from these same interests, and these early findings that education can really play an important role in improving the lives of people with disabilities. We started the Moebius Syndrome Awareness event first. That's supposed to be started pre-COVID. We had some really fun events in our university quad where we would set up a station and pass out information. We had fun games and activities. The main activity, though, was that we wanted people to consider the different ways that people express themselves as a way of raising awareness about what I call expressive diversity, right? We had people fill out signs, and the signs were a template that said, "I express myself with ...," and then people would fill in all these cool, creative things with art, with writing. Mine was with cooking. My department chair walked by one day, and she said that she expressed herself with data and then during a normal term, like I blurted out all that. *[Laughs]* These are really fun. We had a bunch of campus community members fill them out and take pictures and turn them into kind of a social media event. The idea was most members of our campus community do not have facial paralysis, had not heard about it before, but we were getting them to think about other ways that they expressed themselves besides the obvious, oh, with my face, my smile, whatever. We also posted

these things on social media. It was really interpreted as a way to show support for the community.

Then we did a similar set of activities for Rare Disease Day, which happens on the last day in February. Sometimes that's a leap year, so the rarest of all days. We hold that, again, in the quad pre-COVID. We did a similar sign event where we had signs that said, "I am rare because," and people would fill in what made them rare. Again, most people didn't have rare disorders, but actually we were surprised by the amount of students who came up and said, "Oh, I think I have a rare condition." We actually had information there so we could help them on the spot figure out if their condition was considered rare or not. It was just a fun way for people to think about what makes them unique.

Rare conditions are actually collectively pretty common, so it did make sense that we had lots of people showing up that had them. The definition of a rare disorder is a condition that affects fewer than 200,000 Americans, but there are more than 7,000 different of those disorders. Collectively, about 1 in 10 Americans has some sort of rare disorder. The point of a lot of my research is that there are collective challenges despite very different medical model issues and symptoms around a condition. The social ramifications are quite similar. Everyone is experiencing ableism, and those are things that we can act on together in solidarity.

Nick:

I love this. I'm gonna be honest with our audience. I'm sitting here sort of taking notes off screen on how I wanna apply some of these concepts. It's just so fascinating. Thank you so much for being with us today. This is super fascinating, and I just wanna ask are there other topics or issues that your team are working on that maybe you wanna give our audience a hint of while we've got you?

Dr. Bogart:

Yeah. Well, I think really tying into the action orientation of this podcast, and what we were saying about education. I have started this new organization, DARN, so Disability Advocacy and Research Network. As you said, it's really geared towards psychologists who are in the social or health areas, and those students who are helping to go in that direction. We fortunately got some funding from one of our parent organizations, the Society for Personality and Social Psychology, to build this network. It's really like an affinity group within our larger organization to support faculty, students, people who are interested in getting into the field, and who either have a disability or are allies. We have a

lot of great allies who are doing the work of studying disability and teaching about it, as we talked about before.

Currently, we're building a website. We already have a great active listserv with almost 200 people. The things that we're working towards are developing teaching resources, so that more people are empowered to teach about disability. Also in the future, we'd like to develop recommendations about psychological measures and scales to be used in disability research. For listeners who are interested in joining up, we are certainly open to people outside of the realm of psychology as well. We have lots of people in public health that are joining on, so we would love to hear from you. A way to get connected would be to connect with me on Twitter, so I'm on Twitter at Kathleen_Bogart, and I link to DARN through there.

Bonnie: We will make sure to include some of this information when we disseminate this podcast, so our audience can find it. Well, Dr. Bogart, I have to say I am so happy that you took time to talk to us today. I cannot hide my enthusiasm for your work and all the great things that you are doing. I'm just so happy to have gotten a chance to talk to you today.

Dr. Bogart: Likewise. I'm so impressed with your work, and all of the hard important efforts of communicating the world of disability and research out to the public. Thank you for your efforts.

Bonnie: Thank you so much.

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Nick: Thank you for joining us for this episode of *Included*, the *Disability Equity Podcast*, and thank you to our *Included* podcast team and everyone who made this podcast possible, especially Prateek Gajwani, Curtis Nishimoto, and our guests. The music is by Molly Joyce.

Bonnie: This podcast is brought to you by the Johns Hopkins Disability Health Research Center. You can learn more about our work at DisabilityHealth.jhu.edu.

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