

Anti-Ableism and Disability Allyship in Medical Education Series

Episode 1: Definitions, Language, Conceptual Framework

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[00:00:00] **Kate Mulligan**: Welcome to CLIMEcasts! I'm Kate Mulligan, and I'm delighted to welcome you to our series on anti-ableism and allyship with our fantastic guest speakers, Dr. Heather Feldner and Dr. Heather Evans. Findings from the innovative CLIME funded research project here at UW sparked the idea for these podcasts. In this first episode, we'll explore what ableism is and how it manifests in our learning and work environments.

[00:00:24] So welcome Dr. Heather Evans and Dr. Heather Evans I want to invite you to introduce yourselves, um, as you both named Heather, how about we go alphabetically by last name.

[00:00:35] **Heather Evans**: Great. Thanks, Kate. My name is Heather Evans. I am a middle-aged white cisgendered woman. I use she, her pronouns. I have greying brown hair and wear eye glasses. Uh, I identify as disabled. I'm a sociologist by training, and I'm currently an acting assistant professor in the Department of Rehabilitation Medicine at the University of Washington. I am also a core faculty member of the disability studies program and currently the director of research at the Northwest ADA center. So glad to be here!

[00:01:07] **Heather Feldner**: I like to call myself the other Heather or Feldner. My name is Heather Feldner. I am a cisgendered white woman in my mid-forties with short brown hair streaked with silver and I wear dark rimmed glasses. I use she her pronouns and I do not identify as disabled at this time. Um, although I am a caregiver of family members with disabilities and that both shapes and limits my perspectives that I bring to the topic today, I am an assistant professor in the Department of Rehabilitation Medicine, and also a core faculty member in disability studies program, as well as an associate director of a new accessibility center on campus it's called the center for research and education, um, accessible technology and experiences and with that long name we use the acronym CREATE.

[00:01:54] **Kate Mulligan**: Wonderful, great examples. Thank you for modeling. I feel like I need to practice. So let me give this a go. My name is Kate Mulligan I'm a cisgendered older white woman with curly fair hair, and I wear glasses. I use she, her pronouns, and I do not

currently identify as disabled. I'm a teaching professor in the UW School of Medicine and an Associate Director of CLIME. It takes practice. Doesn't it. Okay. Before we launch into the topic, I think our listeners would love to know a bit more about both of you and how your partnership came about. I know you come from quite different academic backgrounds.

[00:02:33] **Heather Feldner:** Yeah. So Evans comes from a sociology background and I Feldner, come from rehabilitation medicine and disability studies. And we met and joined forces as a result of both being on the disability studies program faculty. And it's just been a really fun opportunity to get to know each other, get to know each other's work. And what we eventually kind of turned that into was a collaborative relationship, um, in applying to a CLIME small grant with a really diverse group of folks from our disability studies faculty, as well as rehabilitation medicine and the D-Center, um, that evolved not only in the project we just completed, but in, in ongoing, uh, work as well. So the team Heather's is continuing on, uh, in UW to stir up some trouble.

[00:03:25] **Kate Mulligan:** I love team Heathers, but I also think Evans and Feldner that has a really great ring to it, how did that come about.

[00:03:31] **Heather Evans:** Oh, um, yeah. So, you know, we were just talking about how many girls were named Heather and our generation. Uh, it seems like every time Feldner and I speak with each other, uh, I learned about some new parallel in our lives. It's a, it's a, it feels like destiny. Uh, but I honestly, I suggested we go by our last names in part, because I am enamored of mystery novels and I get to feel like a detective when my colleagues call me by my last name. So I shared this infatuation with Dr. Feldner and she was game to go along with it. So I love like in our meetings being able to go, all right, Felder, what have you found?

[00:04:08] **Heather Feldner:** Yep. Well, agent Evans. This is what I think. Yeah, it works well, love it.

[00:04:15] **Kate Mulligan:** We'll spend some time in the next podcast, in the series, taking a close look at what you found in your study at UW, but set the stage for that. Um, I'd like to ask you to help us understand what ableism is and how it manifests in our lives.

[00:04:28] **Heather Feldner:** Yeah. So I think I'm going to actually take it back a step further, even because in order to talk about ableism, it's really important to start by even considering the ways that we define disability and the language that goes, that goes along with that. Um, and you know, we know that there are a lot of different definitions of disability floating around, right. For example, there are. Um, a couple of different definitions of disability even used in federal laws, for example, that in some cases directly contradict each other. So it's a complex issue. We need to acknowledge that there are as many definitions as there are, you know, stakeholders and an individual perspective. Right? So, uh, this, I think it's important to recognize that going in. Um, I also think it's important to recognize that some definitions are more dominant than others. Right. You know, much of society tends to operate off of, what's known as a medical model of disability and this model situates disability as an individual health or medical problem or deficit, hence the

goal to provide cures, provide rehabilitation, provide fixes so that an individual with the medical problem can more closely approximate what has been deemed to be quote unquote, normal functioning. So we see that very broadly in our society. And, um, as a, kind of a counterpoint to that from a disability rights or justice framework, there's also a growing awareness and recognition of disability, not as something that's inherently medical or individual, but that's really just a natural and intersectional part of human diversity.

[00:06:09] And so that, from this perspective, we think about disability more differently, you know, there's a social and political and cultural lens, um, and, and applied. Um, this, this way of thinking and, you know, individual experiences of body and mind are honored and cared for to be sure, but also, um, much greater attention is brought to the social constructs, like policy, the built environment and social attitudes that actually serve to marginalized people who identify as disabled or with a disability and viewing disability. You know, is really contextual from this perspective. It's something that arises between the interaction between someone's body and mind or way of being and their environment. So, um, that's, that's a perspective that Evans and I really, really take that. We don't necessarily see disability as a trait or an attribute of an individual themselves, but rather a disability experienced as a result of all of these levels of oppression and discrimination that are based on dominant perspectives, attitudes, and policies that support this notion of disability as an undesirable deficit of many people in the disability community actually attribute the external prejudice and the denigration and these social and cultural spheres, as one of the reasons that they experienced disability. So it's, it's really pushing against, it's a challenge to this idea, you know, of quote unquote, typical functioning of both the body and the mind as a measure of ability or inability. And so really the failure of society to recognize differences in functioning of the body and mind as both natural and neutral really becomes the root cause of disability from this perspective.

[00:07:55] **Heather Evans:** Yeah, and I would jump in and I would just add that when we talk about language, it is important to acknowledge that people have a variety of ways of experiencing and expressing their own identities in relation to disability. While many people have been socialized to use what is called a person first language, and this includes within healthcare professions, uh, where folks are trained to use person first language. Right? And so that is saying, for example, A person with a disability, others like myself, prefer to use identity first language. So you'll notice when I introduced myself, I describe myself as being disabled or as a disabled person. And as someone with primarily. Non apparent differences what are often referred to as invisible disabilities.

[00:08:44] You know, if I don't disclose to people that I am disabled, they will generally assume that I am non-disabled. So again, you, you notice when introducing ourselves Feldner and I included a disability disclosure statement, and that's really common in our work in part because, you know, we work with both disabled and non-disabled people, but it's also very common because in our collaborative circles, we began in many of our work groups or meetings with just general access check-ins, you know, just discussions of making sure all team members, uh, their access needs are being met and that they can fully participate in our meetings. So. Personally, I have a chronic illness that produces a whole

popery of symptoms and experiences that I manage, accommodate, and in some cases, frankly, I also celebrate.

[00:09:35] So using identity first language is a way of signaling that I see many of my most challenging experiences around disability as really stemming from moving through spaces both physical and social spaces that were not built for me and in many cases create significant barriers. So for me, I live with a degenerative disease, but I experienced disablement from stigma, attitudes and [00:10:00] inaccessible built environments. You know, like multi-story buildings that only have stairs and no elevators. So, the main point is that different people have different ways of describing themselves and their identity around disability. Some people refer to themselves as a person with a disability. Uh, it might be as being disabled. Some folks prefer saying that they have impairments or health conditions.

[00:10:22] Some individuals refer to specific medical diagnosis or see themselves as part of cultural groups, such as autistic, blind, uh, big D deaf or a linguistic minority. And you'll hear us intentionally use both person first and identity first language throughout this discussion, really to honor the preferences of our disability communities, but also the participants in the study that you mentioned in the opening who described themselves in their identities in a myriad of ways.

[00:10:54] **Kate Mulligan:** Great. Thanks for clarifying that terminology. Uh, now let's get back to ableism. What's the definition of ableism?

[00:11:00] **Heather Evans:** Yes. Yes. Getting back to ableism, uh, when you recognize that ability and disability are socially constructed categories, right? Then you begin to see the ways in which people labeled as disabled are exposed to systemic marginalization due to their social categorization. Rather than by their physiological status. So in the same way that racism refers to the institutionalized discrimination based on race, ableism refers to institutionalized a marginalization based on disability. So, the formal definition of ableism and the one that we shared with the participants of our study, just to make sure we were all on the same page is simply that ableism is a set of assumptions and practices promoting the differential or unequal treatment of people because of actual or presumed non-typical functioning that is disability and, you know, I'll just note that Ableism takes many forms, including non-disabled folks trying to take over or control disabled people's narratives, um, uninformed judgments on the reality, and even the quality of disabled people's lives and assumptions that disability is static or unchanging overtime

[00:12:20] **Kate Mulligan:** Thank you. I'm guessing that our CLIME listeners will be interested to hear more about ableism specifically in the field of healthcare. Uh, could you speak to.

[00:12:28] **Heather Feldner:** Yes, absolutely. I think that, uh, you know, as a healthcare practitioner, myself, this is especially something that's near and dear to my heart. Um, and what we know from the literature right, is that there's a much broader issue across healthcare in general. We know statistics that tell us that, you know, the general us population of disabled people hovers around 25% and healthcare providers with disabilities

only represent 3% of healthcare professions, right? So there's a huge disparity there. We also know that over 80% of physicians believe that the stabled patients have a lower quality of life than their non-disabled patients.

[00:13:08] These statistics are really a direct result of that ableism that we see in society. And what the literature also tells us is that research with disabled folks themselves actually shows that self-reported quality of life and in many cases his is actually higher than folks without disabilities. There's actually an article that just came out last month. Actually, it was a perspectives article that was published by two medical school trainees, not at UW outside of UW. Um, but really calling for strategies to address some of these disparities right address, the low prevalence of, of healthcare professionals, students and practitioners who identify as disabled, and, um, really challenging the reproduction of harmful models and understandings of disability and healthcare education. So, it's being recognized more readily, which is, which is really great. Some of the other things that were, you know, specifically kind of called out in that perspectives article were things like more recently inaccessible website designs for people who are getting COVID-19 testing or vaccine information signing up for appointments.

[00:14:12] That was not an accessible process. In many cases, they pointed out the need for greater integration of lived experiences and disability related content in school, in clinical rotations that was actually led by disabled people themselves. Um, and also a greater focus on skill mastery. Right? You want your, you want your healthcare professional to have, have strong skills, but how those skills are mastered doesn't necessarily have to be uh, achieved in a certain way. So really kind of applying more universal design concepts to educational skills and how those are, how those are accomplished.

Kate Mulligan: How does your research intersect with these findings?

Heather Feldner: Yeah, so in our own research work, we've done some work on explicit and implicit bias among healthcare providers. What we know is that this type of bias, um, which really is a result of this year, conscious or unconscious ableism, um, not only significantly affects disabled people who want to enter healthcare professions, but also disproportionately affects disabled people accessing and receiving healthcare services.

[00:15:18] So, a number of studies, including ours have shown high rates of implicit bias among healthcare professionals even when explicit bias rates are lower. And this has been shown in turn to really directly impact the length and the content of clinical encounters. It can affect medications or services either prescribed or in a lot of cases left unprescribed.

[00:15:42] It also affects those direct provider attitudes as well as failure to provide accommodations during medical visits and um, what we've seen through this work is that these are all situations that contribute to health disparities and poor health outcomes for disabled people that really have nothing to do with any actual impairment or medical situation or condition or even wellness visit that a person might be seeking treatment for.

[00:16:09] So in this way, bias and ableism really become and are considered a social determinant of health. And the good news is that we're seeing increased research and advocacy work in, in the healthcare space, in this arena. Their attention is growing through, through the studies, um, that I just mentioned and even beyond.

[00:16:30] And I feel like I would be remiss if I didn't mention a few of the really powerful disabled women and pioneers in, in this field. People like Lisa Iezzoni is one who is a disabled physician and researcher at Harvard. And by the way, it was the first woman to be appointed professor in the department of medicine at Beth Israel hospital in 1998.

[00:16:55] Um, so you know, recent history. Yeah. Folks like Lisa she's really paved the way for a lot of this work, dedicating her career to health disparities research for disabled people. Dr. Michelle Nario Redmond is another contemporary who is a professor of psychology and biomedical humanities, and has published widely on ableism in particular why disability simulation, um, as is, and was often done in healthcare education is particularly problematic. Additionally, the keynote speakers for our 2022 crimes symposium doctors, Lisa Meeks, and Neera Jain they've done quite a bit of work here as well. Focusing on disability equity re-imagining what accommodations look like in medical and health science education. They have a, um, a really wonderful group called the coalition for disability access and health science education.

[00:17:50] And it's just a great resource for books, webinars. Um, there's an annual conference and it's all really aimed to reduce disparities and to support disabled [00:18:00] students and faculty in health sciences. So we're seeing the tide's turning a little bit, which is exciting.

Kate Mulligan: Great. Thank you. I think I should remind listeners that they can consult the show notes for the podcast to find links to some of those great resources. Um, I want to have us look at the broader context of your work now. At the moment, there is strong awareness and focus on DEI work, diversity, equity and inclusion work, um, especially at UW right. And I'm wondering how your work fits into that broader effort.

Heather Feldner: So, this is a great question because when we think about addressing issues of diversity, equity and inclusion, that that's really become a central conversation for us, which is, which is fantastic. Right? And, and I think that extends to healthcare and it extends beyond, you know, in the, in the greater community. But when we really look at the, the crux of DEI initiatives, the constructs of disability and deaf identity and culture, as well as ableism and allyship tend to be overlooked there they might be tacked on as additions. They might be approached from outdated philosophical beliefs. That again, kind of medicalized disability and failed to really prioritize the lived experience and expertise and intersectionality of disabled folks. And so kind of understanding that climate that we're in, you know, both Evans and I feel pretty strongly that a critical disability studies framework really can provide the background for understanding and responding to these issues.

[00:19:37] And. You know, foregrounding disability as a central part of DEI. And when we think about this type of framework, this is critical disability studies is something that uses a

very intersectional lens to examine social and contextual processes. Right. Is something that's rooted in feminist and queer and critical race theory. And it really, again, recognizes disability as this complex relational construct, where, as we mentioned before, experiences of body and mind, experiences of environment and attitudes of others, all kinds come together and to, to matter contextually. And it really rejects this idea of conforming or approximating to normal or seeing disability as something that needs to be quote unquote fixed. Um, and rather it celebrates disability as diversity. It names the goal of access, representation, justice, and equity, as well as care for and about the body and, and as it is defined by disabled people themselves. Right? So, this is a framework that both Evans and I became familiar with during our work in disability studies and this is the approach that we really took with this project. And we feel this has a lot to offer to ongoing conversations about DEI, to inform actual practice and how that's carried out, how we actually carry out DEI in our day-to-day lives, in our work.

Kate Mulligan: So I've heard, um, some people discuss the possibility or wisdom of adding an, a for access to the DEI framework in order to explicitly include disability in DEI initiatives. What are your thoughts on this? Do you, do we need to have an a D E I a? I know my accent is messing things up there. So DEI is what we are thinking about.

Heather Evans: No Kate, I'd love your accent. Speaking of honoring diversity, it's such a pleasure to listen to you speak. Um, you know, we, we want to start by recognizing that there are really differing opinions on whether to include the term access or the a DEI in order to highlight disability access in particular, you know, however, in, in our opinion, um, honestly, Absolutely not.

[00:21:52] There is no need to tack on an, a, the word inclusion means the practice or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginal. Right. So, in other words, providing access is a key mechanism for achieving inclusion. And because we have a well-documented history of excluding and marginalizing disabled people in this country, you know, disability is and should be deeply embedded in the spirit of DEI, if not already existing, explicitly in diversity equity and inclusion initiatives. So, you know, just, just to repeat what Feldner said a moment ago, I think one of the reasons that people see disability as needing to be added on to the more familiar list of marginalized groups is because of this enduring conception of disability as a purely medical or psychological attribute, right.

[00:22:53] Largely viewed as a defect or a problem rather than really recognizing again, to be categorized as disabled, uh, is simply means that you have some way of functioning that is considered non typical. Right. And sometimes that non-typical way of functioning might be an impairment, like the kind of fluctuating muscle strength that I experienced due to my chronic illness. Um, but sometimes that way of non, of, of kind of difference in functioning is just that. Different. So, like being born deaf, you know, not being able to hear is only an impairment in an environment that is built around hearing and where everyone only communicates through spoken word, but in environments built again using universal design principles and among people who communicate, say with sign language, being deaf in and of itself is not impaired functioning.

[00:23:52] And it's certainly not a defect. And you know, this is where deaf culture really blossoms out of this recognition of deafness as an example, as a really unnatural and celebrated way of being. But, you know, despite this recognition from some communities, when it comes to access in a disability and deaf culture, existing intersectionality folks who identify as such are routinely excluded and they've had their rights violated on a daily basis.

[00:24:25] So in, in our thinking about, you know, whether disability is already baked into DEI, uh, we just, we can't think of this as anything, but essential to diversity, equity and inclusion. Um, so disability is essential to it's already happening rather than needing to be in addition to what's going on. Uh, and so we just want to emphasize that, you know, if, if you're working in DEI spaces, there's no need to add the, a access is part of achieving diversity, equity and inclusion. We're already there. [00:25:00]

[00:25:02] **Kate Mulligan:** Lots of food for thought here. Thanks so much for sharing the definitions and language and frameworks that we should be using. When we talk about ableism and disability. Again, thank you, Team Heathers for this episode, we look forward to hearing more about your research study in the next episode.

[00:25:18] **Heather Evans:** Thank you so much.

[00:25:21] **Kate Mulligan:** We hope you will all join us for episode two, where Evans and Feldner that we'll unpack some of the rich data that they've collected from across the University of Washington in their innovative CLIME funded research project, aimed at understanding the lived experiences of ableism and allyship for folks who identify as deaf, disabled living with a disability or as having a chronic health condition. Oh, and please don't forget to visit the CLIME website for more information and resources on these.