

UW Experience

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[Intro Music]

Kate Mulligan: Welcome to CLIMEcast, I'm Kate Mulligan and I am delighted to welcome you back to our series on anti-ableism and allyship, with our guest speakers Dr. Heather Feldner and Dr. Heather Evans, whom you'll remember like to be referred to as Team Heathers or as Evans and Feldner.

Thanks for joining us again, Drs. Evans and Feldner! In this episode, we want to take a deeper dive into what the climate is at University of Washington based on your CLIME funded research project on experiences on ableism and allyship. So, first up, congratulations on getting the funding and for undertaking the research study. Could we start with an overview of the project?

[00:38] Heather Feldner: Yeah, absolutely. So, the purpose of our study was really twofold. First to understand the lived experiences of ableism and allyship from faculty, staff, and students on University of Washington campuses, who do identify as deaf, uh, disabled or with a disability or as having a chronic health condition.

Um, and second to develop a disability allyship training curriculum based on these lived experiences. To really create customized training modules that could be used within health education in particular, as well as in other groups in units across the campuses. And so to do this, we, um, conducted a series of semi-structured interviews and focus groups, with these different cohorts. And we had 22 diverse participants, and I'm proud to say that a third of those participants were, people of color in addition to having a disability and these encounters were all audio recorded, transcribed and coded. Until we came up with themes that emerged from this data. Some of the themes we're going to be talking about with you with you today, you know, ubiquitous ableism, emerging allyship, as well as health care partnership building, and these experiences of ableism and allyship, we're really seeing are really lived by our participants at individual levels, as well as at group or unit levels and institutional or systemic levels. And not only did participants share their experiences, they also shared their ideas for solution building and ways to really help dismantle ableism and encourage a greater focus on allyship, across our campuses.

So, um, it was a really wonderful project to be involved in and we actually just got additional funding to conduct a more pilot testing of the curriculum modules that we developed as a result of the first part of our project. So, um, that's, it's been very exciting. Yeah.

[02:38] Kate Mulligan: Fantastic, congratulations!

So, let's hear about what you've found at UW in our local environment. I'm sure you have some sobering examples of what ableism looks like here. Perhaps we could start with how ableism is impacting the learning and practice environment within the school of medicine.

[02:55] Heather Feldner: Sure. Yeah, absolutely and I think, you know, the first thing to just acknowledge is that ableism is everywhere, right? So, it's absolutely bound to be within the medical school, as well as other places all across campus. Ableism can be subtle, or it can be really overt, and it can happen whether people are conscious of this or not. Right. So, we did hear from our research participants, in terms of the school of medicine specifically, and there we did have several participants that had worked or practiced in the school, and they talked about their experiences. This was pre pandemic one participant talked about their experience of remote work before remote work was widely accepted. And that was perceived as being cushy or slacking off. There was a sense of mistrust and some side comments that were happening about whether or not work was being done. The individual reported they were considered to be quote, "helping out" even though they were quote "just online." So that that's a great example and hopefully, something that has already changed significantly due to the pandemic. Thankfully, you know, other participants talked about physical spaces that were inaccessible break rooms, nursing rooms that were up a short flight of stairs that didn't have any alternate access. Many participants who experienced healthcare services talked about inaccessible equipment in terms of exam tables that didn't raise or lower, fixed room layouts that were hard to maneuver in a mobility device, harsh lighting that couldn't be adjusted that sort of thing.

We also heard about trainee experiences where there might have been side comments, such as well, we'll worry about accessibility if we have a person with a disability join our team. Um, and you know, that idea that accessibility is an afterthought or only needs to happen when there's a person there that has access to needs rather than more of a universal way of welcoming people with multiple needs and abilities into a particular space or setting.

One, physician participant spoke about their experience with clinical rounding in a hospital setting and talked about how the expectation was to move quickly from room to room and, navigate different floors using the stairs and this was brought up to an attending physician. Um, there, there was advocacy happening self-advocacy as well as allyship from the their training partners and it was dismissed and the solution from the attending physician became, while you can just meet us up at this next room, if you have to take the elevator. And then that, that trainee was missing crucial education and information and, and patient care information so that experience was also reflected in just this general sense of groups being unprepared when people with disabilities requested accommodations or came into a program, um, perhaps maybe not. You know, not having disclosed their disability. Um, but showing up for the first day of class, assuming that there would be, um, universal practices put in place and that, that wasn't the case. And so there was this sense of surprise or the sense of concern that people weren't aware of the situation and really even this idea of you know, whether or not even to disclose the need for access or accommodations for fear of being denied admission or, you know, being removed from the program, that sort of thing. So those are some of the things that we heard from, from our research participants, which were, which were really telling.

[06:44] Kate Mulligan: Yeah, I'll say, um, so it's great that you've generated so much rich data and it's helpful to hear about the school of medicine, but what about beyond, beyond the school of medicine? I'm sure you've had some other interesting data revealed.

[07:01] Heather Evans: Yeah, absolutely. Um, and again, you know, we interviewed both undergrad and graduate students, staff and faculty across campus, and so we heard about

experiences of ableism in a variety of contexts. We often, we heard about how physical environments, often were not only designed in inaccessible ways, but are sometimes arranged in inaccessible ways. Certainly ableism, pervades the language we use and so we heard lots of examples of people using language that diminished or felt very ableist. This is language that many of us use, even if we don't recognize or see the connection between disability in the words or phrases. So, some examples of that would be things like, language saying that someone quote, suffers from unquote a particular condition or diagnosis, uh, describing folks as being bound or confined to their assistive devices like confined to a wheelchair or being bedridden. Others are things, comments like, oh, I'm so OCD right now, or even uses of certain slang terms. Like that's really lame or that's crazy I can't believe it, or I felt like my, my talk was falling on deaf ears. It was like the blind leading the blind, et cetera. You know, these are kind of common tropes in our conversational toolkit, and you know this could often in some cases be used with positive intentions, so you know, hearing peers say things like, wow, you have really mad skills, you know, but these are all terms that again are, uh, have connotations of othering or making certain groups really fundamentally different from what is perceived as typical or normal. Um, some other examples that we heard about, whereas moments when accessibility supports such as American sign language interpretation, was not provided or captioning wasn't provided at events.

So people would show up to events and then realized that they were unable to participate because those supports were in place. Certainly, when the physical entrances for people with disabilities, is really separated oftentimes in the back of a building down by the dumpsters, you know through a maze to find your way there.

We heard examples of individuals talking about when their disability came up being called inspirational or amazing, for doing things that are just everyday things. Uh, but you know, it implied the assumption that a person with a disability really needs a lot of help or is viewed as generally incapable, uh, and viewed as, you know, having to have, uh, overcome their disability to achieve something typical.

Like just attending college, some participants mentioned examples of having someone report to them that the person understood, somebody's disability experience based on a simulation, or literally someone said, oh, I did that for a day so I completely understand what that is like. We heard stories of folks who use interpreters or captioners talk about interacting with individuals who would speak to the interpreter, for example, and not talk directly to the person with a disability in those situations.

[10:32] Kate Mulligan: Oh, yes. I had a learning moment when I invited a deaf professor from upper campus to address my medical students and he brought an interpreter and I naturally thought that we have to include the interpreter as part of the social interaction. The lecturer very clearly stated, nope, the interpreter is a device here and you are working with me and you deal with me directly. It was, it was really great to have that clear communication about how things should operate in those environments.

Heather Evans: And, you know, I just, I do want to be clear. That really all of us have engaged in some form of ableism. We've all been socialized into that kind of deficit perspective or the medical model that Feldner mentioned earlier. And some of the language I just talked about, you know, I'm guessing that many listeners are probably thinking to themselves like, oh wow, I've referred to my very hectic schedule is crazy.

Um, surely that's not that bad. Right. But, you know, I just want to emphasize, it's important to recognize that this isn't just a colorful phrase or in an innocuous reference or a joke that this language is genuinely harmful. So, laughing at an ableist joke or using that type of phrase reinforces the idea that people with disabilities, people with mental health diagnoses

are somehow fundamentally different, you know, are the quote unquote other and while neither of us have any desire to be the language police. Um, but still, you know, our point is just to encourage listeners to really be intentional about the language you use. So when you're, when you're laughing at a joke are you intentionally trying to signal to friends and colleagues that you believe, for example, that people with different levels of cognition are somehow worthless as human beings.

Are you intentionally trying to belittle folks who were different from you? You know, especially in the field of medicine, you want to use language that is descriptive, neutral, informative, rather than embellished or colorful. And so, when you say someone is confined to a wheelchair, are you trying to communicate that they are literally tied or chained to that chair and can never leave it, or are you talking about their assistive device that allows them to go further and faster the same way you might think of your car? You know, are you confined to your car, or does it allow you to get somewhere more easily? Right. And so instead you could use the term a wheelchair user or someone who uses a wheelchair. Right? Uh, so our participants talked about a lot of these kinds of little examples, but even the little examples really can take a toll when folks are constantly exposed to ableism in small and in some cases large ways.

[13:33] Heather Feldner: So, yeah. And I think just to elaborate a little bit from what Evans was just talking about, you know, one of the most powerful ways that we heard in our study, um, in terms of speaking about the extra cost of some of this ableism and discrimination, even some of these microaggressions really came from a participant who described the ever-present ableism on campus as a quote, "disability tax", and I wanted to share the quote directly as we were chatting here, and this was undergraduate. And we just, we just both think that this is such a powerful quote that kind of sums up, these experiences. The student said, quote, "I have really identified a disability tax it's all of the extra things we have to go through every quarter or weekly at times to have the same access that non-disabled students have that takes tremendous amounts of time and resources that is not going toward our schooling and education" end quote.

[14:33] Kate Mulligan: Wow. Thank you. So there's still clearly lot's to work, to be done to dismantle ableism. It's a never-ending task, I think, but perhaps you uncovered some rays of sunshine or bright spots where we got things, right. Uh, maybe there was some stories where ableism was challenged or maybe conspicuously absent at UW.

[14:50] Heather Evans: No, no, you're, you're absolutely right. Um, and, and we did, we did hear those stories. In fact, rather than absence, we heard about when folks kind of went one step further than just not being ableist. Uh, but instances of engaging in disability allyship. So, when discussing examples of allyship in the context of healthcare, several participants emphasized the difference between feeling like providers were working with them rather than on them as patients, you know, some, some examples included, um, when providers stopped and took the time to listen to a patient rather than as one participant described it as asked what they wanted to work on, instead of being told what to do. Another example was having a provider really recognize and acknowledge the expertise derived from lived experience.

In fact, a few participants noted that living with their condition and in their own body, uh, generates a considerable amount of knowledge about what works well for them what doesn't and having a provider really engaged them in the discussion of what to try out, felt like the health care provider, again, both recognized, but also valued the expertise of the patient.

A couple of folks pointed to instances when healthcare providers asked if there were any accommodations the patient needed at the beginning of the exam, which removed any

pressure from the patient, with the disability meaning, like they had to interrupt or go out of their way to bring up accommodation needs and also, you know, kind of relieve them of feeling like they had to ask for a favor in order to get an accommodation. One example of disability allyship was when a patient was invited to discuss the ways that other health concerns such as like a mental health issue, in one example, might intersect with or impact the treatment that was being talked about, you know, uh, for the issue at hand.

And so, participants really described examples of allyship, both in the healthcare setting, but also across campus, more broadly. Um, there were a number of folks who mentioned having taken courses in which instructors implemented a number of universal designs in learning techniques, such as automatically providing captioning on all videos, uh, scheduling regular breaks into those long lecture courses, or really making an intentional effort to present material in multiple modes and really providing opportunities for students to demonstrate content mastery in a variety of formats. So not just in one way that required everybody to learn and be evaluated in one.

[17:47] Kate Mulligan: Oh, I especially love the sort of preemptive nature of a lot of what you've been talking about. That seems like a really smart way to go. Yeah. You mentioned universal design in learning. Can you say a little bit more about universal design?

[18:00] Heather Evans: Yeah, absolutely. Uh, you know, when we think about universal design, often we think about designing a physical space, uh, an activity, or even an object or item so that the broadest variety of people can use or access it right without the need for additional modification. So universal design is often thought of as, as really most relevant to buildings or parking areas, et cetera, but there are lots of strategies for incorporating universal design principle into all of our spaces, whether they're physical or social spaces. And certainly, as an educator part of my pedagogical toolkit, if you will includes really intentionally incorporating universal design and learning or UDL practices into my own teaching.

[18:48] Kate Mulligan: So outside of the healthcare arena, you mainly heard students talk about disability, allyship in their classrooms. We're undergraduate students, the main group of research subjects?

[18:46] Heather Feldner: No, actually we, in addition to talking to, undergraduate students, we also talked to graduate students, faculty, and staff, and it really did go beyond the classroom and our participants recognized that allyship experiences of allyship and kind of this recognition of allyship really needed to grow much more outside of the, kind of more intimate friends and colleagues, circles, kind of into the broader picture of advocacy and community building on campus. For example, our participants really noted how much allyship is needed, especially given the pervasive nature of ableism, both in our society and in our campus. One participant noted, and this is a direct quote they said, quote, thinking about how much allyship that community needs and does not get is kind of heartbreaking. So, I think so I think thinking about the ways we can advocate for those communities is a really important part of the process, end quote, and that was a grad student. One of our other participants recognize that most of their allyship to date comes from other people with disabilities or close friends, without disabilities that have personal motivations or multiple reasons to be invested in disability, allyship. So that, that student, um, noted quote, most allies have been other disabled people like I've had a really hard time finding good allyship from non-disabled people. Um, and that was an undergrad um, student. So, we're seeing our participants thinking about this and thinking about ways that allyship is not only happening, but also where and how it can grow in our community.

[Outro Music]

[20:33] Kate Mulligan: Thank you Evans and Feldner. We've covered a lot of ground today thank you for sharing the data from your study about the lived experience of people who identify as Deaf, disabled, living with a disability, or as having a chronic health condition. And this seems like a good stopping point because our third episode will be talking about ways to actively dismantle ableism and foster allyship so stay tuned!