[Music by Molly Joyce]

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 Blumberg School of Public Health. On this episode of *Included*, we talk with Dr. Kimberly Phillips, Assistant Research Professor at the Institute on Disability at the University of New Hampshire. Dr. Phillips is a psychologist specializing in disability and currently serves as the principal investigator of the CDC-funded New Hampshire Disability and Public Health Project and the HRSA-funded New England Regional Genetics Network. She is co-principal investigator of the NIDILRR-funded Disability, Statistics, and Demographics RRTC, and she leads research related to the Kessler Foundation National Employment and Disability Surveys.
	Dr. Phillips has published a number of peer-reviewed publications, including *Disability and Health Journal*, *Review of General Psychology*, *Rehabilitation Counseling Bulletin*, *Journal of Intellectual Disability Research*, and *The Journal of Vocational Rehabilitation*. She received her Doctorate in Psychology in 2016 after completing her dissertation on employees with disabilities response to attitudinal barriers in the work place and perceived potential at work.

[Pause 01:54 - 02:02]

[Music Ends]

	Dr. Phillips, thank you so much for joining us today.
Dr. Phillips:	Thank you. I'm so happy to be here.
Nick:	You're working on a ton of projects at the moment. Could you give our audience a snippet of the broad area of work you're doing?

Dr. Phillips:	Absolutely. At the core, all of my projects are related to increasing equity and health equity for people with disabilities. For example, with the New Hampshire Disability and Health Program, the focus is on public health and access to preventive healthcare and healthy living opportunities. With the New England Regional Genetics Network, the focus is on access to genetics services, information, and resources, especially for medically-underserved areas and populations. Another segment of my work focuses on employment for people with disabilities. That's more about the social determinants of health angle and maximizing equity through community participation.
Bonnie:	Great. Thank you so much. Such important work. A lot of us in the field and community follow your work so closely. We wanted to talk to you about a paper that you published in October 2021 in an issue of *The Disability and Health Journal* titled "Disability Competence Training Influences Healthcare Providers' Conceptualizations of Disability and Evaluation Study". Before digging into the study details, health equity and disability is oft-covered topic on this podcast. We talk about it quite often. Can you first start off by sharing your motivation for pursuing this study?
Dr. Phillips:	Yes. In the earliest years of the New Hampshire Disability and Health Program, which started around 2012, our team created a training for healthcare providers to help improve their awareness of disability issues and thereby improve access to healthcare for people with disabilities in our state. I traveled around with my colleague, Kathy Bates, who is a trained educator and a powerful disability advocate. It was largely Kathy's personal stories of her lived experience as a woman with cerebral palsy in the healthcare system that brought our training to life.

Together, we gave the training in person to providers all over New Hampshire. We opened our sessions by asking, "What does disability mean to you," or "What do you think of when we say disability?" Many of our audience members answered with by naming specific diagnoses or by sharing activities of daily living like not being able to do certain things or requiring assistance to do certain things. Often, the conversation started with this very medical-model take on disability. Even though we were in front of medical providers, it still surprised me, and we wanted to change it. |
| *Nick:* | Thanks for sharing that. I wanna dig in a little bit because I think you're talking about a topic that I don't think people think of enough. There's this medical model and social model of disability. |

Your work sits on the social side, and I wanna get at could you tell our audience your own definition for how you think of medical model versus social model. Why is it so important to shift away from that medical model into a social model in the context of health equity?

Dr. Phillips: Yes, great question. With the medical model of disability, the emphasis is on individual deficits and deficiencies; underlying this view there's something wrong with a person that needs to be ameliorated or fixed or cured. Now, certain medical aspects of disability are not inherently bad. Thinking in terms of ADLs for physiological challenges are useful when it comes to making certain diagnoses. Diagnoses, in turn, can help people, sometimes, to get benefits or to access equipment that can assist them. Maximizing health is a great goal. The problem with the medical model is that disability is not a synonym for illness or injury. People with disabilities can be healthy. It's a health equity issue because it involves a shift in perception away from disability is bad to disability is, period.

In the social model of disability, the emphasis is not on individual deficit but on the interaction between a person on one hand like their being, their physiology, their mind, body and the environment in which they function on the other hand. Looking at things from a social model perspective, when the environment is set up to accommodate and include everyone, then people with disabilities have more equitable access and opportunities. The burden of change is not on the person; it's on all of us.

Bonnie: Thank you for that. That, I think, is something we need the world to know and understand, quite honestly, right now. I know the scope of this paper really is in healthcare and healthcare providers, but I'm struck, at this moment, that it needs to even go beyond that. We need policy makers to understand this. We need higher education to understand this. This, what you just said so well, is the crux of the change that has to happen, so thank you. Thank you for the great work you do and for sharing that. Can we dig a little deeper now onto the training that you provided to these healthcare providers? Can you describe that a bit?

Dr. Phillips: Sure. It's a broad view. Our trainings, which, eventually, we made interactive—we made into interactive recorded versions so that they could be available on demand, both in our state and nationally. We explicitly explained the medical and social models of disability with their respective strengths and weaknesses. We asked people to reflect on their on perceptions and practices. We

also talked about health disparities, inequities in social determinants of health. We go into a number of different barriers and facilitators to healthcare, and we cover respectful communication.

Bonnie: Thank you. That's a great overview. I think something so important about your work here is that you're focusing on changing attitudes and perspectives of the healthcare providers. There's so much work that actually focus on the patients being their own advocates in a healthcare setting as the way to improve the experience in healthcare. Certainly, self-advocacy is so important. The question is why do you think equally, if not more important, that we shift the focus of this work to the healthcare system itself and not put it all on the back of the patients.

Dr. Phillips: Yes. Well, I do agree that patient activation and self-advocacy are really important. In one sense, the patients and the providers are two sides of this coin, and so it is important to address both sides. I believe that stigma, negative attitudes, and, frankly, outdated, old-fashioned medical model-type orientations toward disability and people with disabilities on the part of providers, that's a barrier to successful patient activation and advocacy. I think about it this way, and this is what I've seen as we've been offering this training over the years.

If you're a provider who sees one person in a wheelchair today or one person with a visible disability today, then it might seem like not such a big deal that this one person in your busy day has to wait for someone to open the door for them because it's not automatic or accessible or that this person has to wait while the exam room is reconfigured, and you move the extra chairs and take out the potted plant so that they can get in there and turn around or that there's no accessible scale for them to be weighed. There's no way to transfer them to the exam table, that you call them handicapped, that you didn't give them enough time to answer questions that they have or didn't, maybe, ask them or counsel them about health behaviors the same way that you would to non-disabled patients.

Possibly, it seems like, maybe, just this one person in your day. To the person with the disability, there is a cumulative effect. It's every time or almost every time. It's a huge deal when you have to wait to move the potted plant. I like that example for some reason. How could this repeated experience not wear someone down and make it hard to always have to be the self-advocate? No, I really

think it needs to be a two-way street, where there's give-and-take on the provider's side and the patient side.

I'll also mention that sometimes we get a lot of positive feedback from Kathy. As I mentioned, she's really an amazing person. She appears in our training video, so she's out there for people to witness. People would say, "Well, if everyone with a disability was like you, Kathy—" and I would gently say, "Well, people with disabilities are just like all of us." Some are great self-advocates and some are not. We have good days, and we have bad days. Maybe today, I'm feeling patient and happy, and I wanna educate you, my healthcare provider, about my disability. Maybe I've done that 15 times today, and I don't want to, and I'm cranky. That's okay too. It shouldn't be all on the patient. It has to be a two-way street.

Bonnie:	I wanna ask a bit of a non-scripted question if that's okay, Kim. I face this question a lot in the work we do, which is—and I'm guessing you do as well—which is how can we really do this? Disability is such a big group. How can we actually create inclusive, accessible spaces or healthcare for this huge group? Disability isn't a monolith. I am guessing there may be people that tune into this podcast that may come to this, that have that view and I think have that view because society has taught them that's the view to have. I'm curious how you combat that.
Dr. Phillips:	Well, for me, a couple of things come to mind. First of all, thinking about accessibility and inclusion in a universal design or a universal-learning way is one approach. The more accessible we make things, the better for everyone. The easy example to grab is if you put in a ramp, people who typically would use the stairs can use the ramp, but if you just put in stairs, then only a select part of the population can use that. There are examples of physical and structural disability. There are examples of negative attitudes and stereotypes that work with this. Plain language is another one. Talking and preparing written materials in plain language helps not only people with a cognitive disability but people who are maybe speakers of other languages, people with low literacy. I think universal design is one thought, and then you can go to a tiered approach after that.
	When certain aspects of the population, meaning maybe people with different disability types need more specific types of assistance or intervention, then that's the next level. Trying to design for as many as possible at the outset is what comes to mind for me.

Bonnie: Thank you.

Nick: I think that was super-well said. I can't highlight enough one of the points you're making is that universal design isn't just designing for everybody. It's also that there's these minimal touchpoints that—the stairs example is perfect. The stairs are exclusionary; the ramp, though, anyone can use. The same principle goes for almost every accommodation we make in healthcare settings for your specific work here. When we think about accommodations for—in my work with hearing loss, for example—the same communication patterns are good for everyone. This isn't about my work, but, interestingly, in our work, we've found people with quote unquote normal auditory perception say that they love our communication intervention. It's wonderful for them. It's because everyone benefits from it. Whereas, one side is exclusionary; the other side is inclusive of everyone. You're spot on.

Dr. Phillips: We speak the same language *[laughter]*.

Nick: As usual, all the guests we have on this podcast—Bonnie and I just start to geek out as we get further and further into the conversation. Speaking of geeking out a little bit, I wanna focus back to your science. I was really struck when I read this paper. You use mix methods. I personally live in a world of very quantitative methodology, so I'm very fascinated when people use qualitative methods. I find it incredibly insightful. I was wondering if you could tell our audience a little bit about the methods you used. Then, obviously, what everyone's waiting for, they wanna know what you found.

Dr. Phillips: Absolutely. As I mentioned, we created this training video. The evaluation study included two key questions: before the providers viewed the training video, and then the same two key questions were repeated after. The first was multiple choice, so quantitative. Before and after the training, we asked participants to select, from a list, the top three things that came to mind when they thought about disability. The list contained randomly-ordered items, some reflecting the medical model, which was words like illness, injury, physical limitations. Some reflected social-model ideas about disability such as social environment, communication challenges— which, to me, implies a two-way dynamic—and then a few we characterized as neutral like aging.

The second key question was open ended, so that's where the qualitative comes in. We asked training participants to share action

steps that they do or could take to facilitate disability-competent, accessible healthcare for their patients. After the training, we reminded people of their previous answers to this question, and we asked them if they would like to change. Then, two researchers analyzed the before-and-after responses using *[unintelligible 17:51]*, coding, and categories and such.

About the findings: for the first question, conceptualizations of disability, we found that after the training, participants were statistically, significantly more likely to choose responses that reflected the social model of disability and less likely to choose items that reflected the medical model perspective. The physical environment, the social environment, and communication challenges were all more frequently chosen after viewing the training video. For the second question about action steps, people were more likely after the training, first of all, to be able to name specific ways that they do or could improve disability-competent, accessible care at their facility; whereas, we had more blanks the first time around, people who had left a blank were then able to think of something to say, which was nice. About a third of the participants changed their original answers after viewing the training. Whereas, examples of pre-training responses included very generic ideas about planning or assistance such as quote emergency plans or have healthcare plans, provide assistance, use aids. Post-training responses included more specific items like speaking directly to the patient rather than their caregiver, be flexible and allow extra time when needed, treat the client like a competent, independent individual.

I'll also say, though, that among those who did not elect to change their answers, they had been more likely at time one with this item to provide responses that described patient-centered care, focused on the whole person, et cetera, so that was also encouraging.

Nick: That's really impressive. Thank you for sharing that. As I hear it—this is a commentary—that last tidbit's really interesting to me that those who already were focusing on patient-centered care didn't change. Something that always strikes me with this kinda work—we've spoken with other guests about this—there's always a survey-response bias. People usually know the right answer. In the context of disability, it doesn't seem like they even think about that same response bias that they might apply to other groups, where they might at least lie and tell you they do things correctly.

Your work is extremely important, but I think this little thing's always in the back a my mind that it's amazing to me that, for the

most part, our healthcare system doesn't even view disability as something that they should consider, should worry about. They don't think of it in that health-equity context or that social construct side at all. It's always on my mind. I'm not sure if you had any direct experience with that or thoughts on that as well.

Dr. Phillips: Absolutely. What you just said, it resonates with me a lot. When I started this work, I wasn't even sure that this training was needed because a lot of the things we cover seem like common sense. I quickly discovered that it really is needed, and people don't know what they don't know. I agree with you that disability is not prioritized as a health equity population, or I sometimes call a cultural competence with disability. There's so much talk about cultural competence, but it doesn't include disability most of the time. Without wanting to detract from any other groups who need us to be more culturally competent, disability should be in there, not even to mention the intersection of disability with these other groups.

Sometimes, at trainings, I started to say to people, "Some of the things that you're gonna learn seem like common sense once you know them, but they really make a big difference to people with disabilities in practice. Don't dismiss this because—" I said, "Speaking to a person instead of their caregiver sounds like, 'Well, yeah, okay. That makes sense.' Being person centered, 'Yeah, that makes sense.'" It does, but if you're not doing it, it's a huge shift. I try to get people to leverage other work that they're doing. We'll ask providers, "Are you probably already working on cultural competence in some other areas? Have you perhaps not thought of disability in this way before, but now you can broaden your way of thinking in your approach?"

Bonnie: Thank you for that and this work. I also wanna add healthcare doesn't live in a vacuum. Again, I'm struck by the fact that we need this kind of training, not just for healthcare, but for public health and for policy makers. I think we all interact with all of those intersections of life and experience the same phenomenon that there is a lag in awareness and education around these ideas of cultural competency, cultural humility—however you wanna define it—of disability. To your point, Kim, it shocks me every time. You would think by now it wouldn't, but it still does. We've got lots of work to do. This is such powerful work. Can we now talk about what the next steps are for this and how you think this work can be integrated into our healthcare system?

Dr. Phillips:	Sure, I'll try. Also, Bonnie and Nick, I would be remiss not to mention that there are several limitations to the study that we published. Of course, I would refer people to our article in *Disability and Health Journal* for a fuller discussion of these. Certainly, there are things to follow up on. In this preliminary evaluation study, we learned that there does seem to be a benefit to discussing medical and social models of disability conceptualization in healthcare provider training. Future research could include creating a validated scale for measuring these conceptualizations. We based ours on our personal experience, conversations with disability experts and people with disabilities. A next step would be to create a validated measure, and I'd love to be involved in developing something psychometrically sound and robust that would help to replicate these findings in the future.

I'll also mention that since we started the efforts I've described here, the Nisonger Center at Ohio State University and others have done extensive work to develop, vet, and publish core competencies on disability for healthcare education. I'm a huge fan of Dr. Susan Havercamp and her work, which provides a strong foundation for next steps in this area and moves us closer to having common, measurable competencies that will bring uniformity to a lot of the pockets of trainings that are happening around the country.

There are also a number of projects and initiatives out there that look at upgrading and integrating healthcare provider disability training into medical schools and nursing school programs. I think that's a great area to focus. We need to target practicing physicians and providers, but getting the newly emerging providers and physicians is also a really good strategy. As for me, I'm currently working on a couple of projects related to accessible telehealth and carrying many of these disability-competent concepts into the virtual healthcare world because that's definitely where we have been lately.

I'd also like to share that the ten currently funded state disability and health programs, including the New Hampshire Disability and Health Program, are working together. We have a new funding cycle. It just began in August. Ten states are working together on an updated version of a training for healthcare providers. Once we've developed or adapted that, we'll be implementing it in all of our individual states. I'm pretty sure it will be available nationally as well because I imagine it will be—we're definitely going to have a remote version, at least. That's something to look forward to.

	Finally, I agree that while healthcare providers is a crucial audience, this does need to be broader. Our program, in the past, has focused on also training public health professionals and community organizations and whoever was willing to come to the table. We have versions of our training that are targeting people outside healthcare as well.
Nick:	This is all so amazing. You're doin' so much work. This is almost like one pillar of the seven or eight pillars I'm seeing in your bio. Thank you so much for joining us today. Where can our audience go, at the end here, to learn more about your work?
Dr. Phillips:	Thank you. The New Hampshire Disability and Health Program website is nhdisabilityhealth.org, and it's a great place to look for updates on our disability and health project work and trainings. For a broader look at my ongoing projects, I'm at the UNH Institute on Disability, online at iod.unh.edu. We have staff pages with summaries and contact information. My email address is kimberly.phillips—with two l's—@unh.edu. I would love to hear from anyone from your audience, so thank you. This has been so much fun.
Bonnie:	Thank you. Thanks so much for all your work.
[Music Playing]	
Nick:	Thank you for joining us for this episode of *Included: The Disability Equity Podcast*. Thank you to our Included Podcast team and everyone who made this podcast possible, especially Prateek Daswani, Curtis Nishimoto, and our guests. 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.
[Music ends]	
[End of Audio]	