

[Music by Molly Joyce 00:00 - 00:15]

**Bonnie:** 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 season digs deep into topics, offering multiple perspectives, and will expand your view of disability. We are your hosts. I am 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 are talking with Dr. Lisa Meeks about her work to make medicine and healthcare more inclusive of physicians with disabilities. Dr. Meeks is focused on promoting equal access in health professions education for trainees with disabilities.

Dr. Meeks is an international expert in advancing disability inclusion in medical education whose work has informed policy and best practices. Her work has been published in *The New England Journal of Medicine*, *JAMA*, and *The Lancet* as well as featured on major media outlets including *NPR*, *The Washington Post*, *CNBC*, and *The Chicago Tribune*. She has authored multiple books, including *Disability as Diversity: A Guidebook for Inclusion in Medicine, Nursing, and the Health Professions* and *Equal Access for Students with Disabilities: The Guide for Health Science and Professional Education*.

Dr. Meeks is also the co-creator of the Twitter campaign #DocsWithDisabilities and co-host of the *Docs with Disabilities* podcast. She co-founded the Coalition for Disability Access in Health Science and Medical Education and served as the co-PI and lead author of the AAMC special report *Accessibility, Inclusion, and Action in Medical Education: Lived Experiences of Learners and Physicians with Disabilities*. She currently serves as a contributing author to the ACGME Equity Matters Initiative.

[Music by Molly Joyce 02:14 - 02:22]

**Nick:** Dr. Meeks, you are so impressive. [Laughter] Thank you so much for making time to be our guest today.

**Lisa Meeks:** Thank you both for having me. I'm excited to be here.

*Bonnie:*

I also wanna share my excitement for you being our guest. As a friend, a colleague, we're very excited for this conversation.

Thanks so much. I am so excited about inclusive practice in health professions education.

*Lisa Meeks:*

Our goals are to drive policy and practice changes through both qualitative and quantitative research. We wanna address inaccessibility on multiple levels and disseminate these research finding and policy recommendations.

As you know, accommodation really makes this an individually located and situated solution for individuals with disabilities. We wanna work towards system change that creates accessible environments for all learners while shifting the origin of inaccessibility to the institution and the responsibility to the institution. In doing so, we really hope to reshape how institutions view and embrace disabled learners, building a formative pathway for learners from pre-health profession experiences to and through health professions programs and then, of course, into practice.

I think it's incredibly important to highlight that these types of programs don't happen often, and they require leadership and space that's truly committed to change.

I point that out because I do think, without a top-down commitment to real systemic change, none of this is possible.

*Bonnie:* Thank you so much for sharing that. I think this work is—well, I know this work is important, groundbreaking, and really critical. I wanna just focus on something you said. I think it's important, and I wanna make sure the audience didn't miss it. The intention here is to really change the paradigm of how we're including learners and people in institutions, academic institutions, from a person-centric accommodation approach to creating more inclusive environments. Is that correct?

Absolutely.

*Lisa Meeks:* I think that's just—that really is state of the art. That's a shift from what, historically, has been. I just wanted to double down on that sentiment because I do not want that to be missed by our audience. That is so important, so innovative, and is the path forward. Thank you so much, Dr. Meeks, for this work.

*Bonnie:*

Absolutely. This work does not happen in a vacuum. There are lots of leaders in this area. The collective research works together to synergize and catalyze change. I always wanna pay tribute to people who start these conversations. This change, is really a result of the research that has been done by several people, but leading this focus is Dr. Neera Jain out of Auckland, New Zealand and Dr. Laura Bulk out of Canada. It didn't come out of the US necessarily, *[laughter]* but I do wanna pay tribute to the people that are really banging the drums in this area. It is because of their research and their findings and their work that we are able to shift the focus and see the possibilities.

*Lisa Meeks:*

I love it. I'll ditto what Bonnie said. I was about to make a comment as well underlining this importance. For our audience, I think Bonnie and Lisa were teasing me a little bit before the show that maybe I'm too positive, so I held back. No, I'm kidding. I think it's wonderful. What I actually was thinking about was not only is it so important that you're free-focusing, this has implications for so many other areas. We talk about healthcare accommodations, and we talk about workplace accommodations,

*Nick:*

and we talk about public polling and voting accommodations. The idea of shifting it from the person to the system, I think, is so, so important. I hope that your work and the work of the team lays the foundation for, maybe, some examples that other areas could learn from.

*Lisa Meeks:* I love that. I love the voting example. It's just a great example. It gets back to that equal access versus equal access and inclusion. It's "Oh, yes, you can vote, but you have to jump through these three or four hoops to be able to access the polling. We want you to be included, but it's not really inclusive." The experience isn't. It's very othering. That keeps people in an equal but separate situation, which is not okay. Just from a fundamental [laughter] social justice perspective, it's not okay.

*Nick:* Yeah, yeah, agreed. You've done some research focusing back to medical education. You've actually published some research in *JAMA* indicating that three percent of practicing physicians report a disability. Can you tell our audience a little bit about that work and what you think the impact of your findings are?

*Lisa Meeks:* Sure. Thank you. Well, first, thank you for calling it my research. I just always want to provide credit where credit is due. This was a project really led by an incredible team at the AAMC. Broadly, the AAMC has been working on this topic for quite a while in UME and GME. Now, with this iteration of the physician questionnaire, we were able to add disability and continuing that pathway to employment. It is a team led by Michael Dill, and Christopher Moreland is my partner, externally, from the AAMC.

As you know, we found that 3 percent of a sample of over 6,000 physicians reported disability. There was a lot of discussion on Twitter about that 3 percent versus what we've seen in the trainee pathway of 4.5 to 7 percent. I do wanna note that we have the same concerns about this three percent being an underreported number that we have in that trainee pathway and maybe even more so. We know that the numbers are likely underrepresented. The actual physician workforce may have good reason to be concerned about reporting a disability. Stigma is certainly the leading cause of this. Many physicians, even in an anonymous panel, may fear that reporting any disability could be tracked.

The other issue, I think, is how we define disability in the medical model. This cuts across all stakeholders, students, trainees, physicians. Many fail to identify as disabled even if they have a condition that results in some form of functional impairment

because the construct that we've created doesn't comport with their experience of disability. What we teach is not what they're living. Given that disclaimer, we did find three percent of physicians identified as disabled. They were overwhelmingly identified as white and male. Chronic health was the number one thing that we found.

There were a few interesting findings in there as well. I think one of the things that was so interesting to me was that there were a higher number of physicians with disabilities working in academic medical centers. Which, to me, provided an opportunity, if you will. If people were willing to disclose their disability and they're working in academic medical centers, that has implications for teaching disability in curricula, but it also has implications for providing mentorship, which is something we're sorely lacking.

This work that was published in *JAMA*, as you said, is the first of a couple of articles that will be coming out. The audience should look forward to reading some upcoming things that really looked at the experiences of these physicians. I will just say that it's not pretty, the experiences and the bias and harassment and stigma. Lots of work going on in this space that I hope will push us to think about how we protect people with disabilities and provide cultures and climates where they can disclose and be accepted as valuable members of the workforce.

*Nick:* Well, I'm looking forward to those pieces. It'll be a lot to stomach to read them, to be honest with you.

*Lisa Meeks:* It's a lot to stomach when you are writing the paper. It's quite disheartening, I will say.

*Nick:* Do you think there's been a shift in disability inclusion and representation in medicine over the course of your career?

*Lisa Meeks:* Yes, absolutely. I'd like to think that our team's work—and that includes, certainly, Dr. Swenor as well. That this work is contributing and contributed to elevating the conversation about disability in health professions. I think, partially, this has come as part of our educational campaigns, which includes the Docs with Disabilities campaign. There was actually the campaign on Twitter before the podcast. I think that there are two simultaneous truths that exist. One, we have more people entering the professions because of the education and change in practice. We certainly are seeing an increase of people matriculating into these programs.

I think we also have people that have always been there, and they're just now feeling more comfortable in disclosing, which is part of the increase that we're seeing in these numbers. The climate has been shifting. I've been doing this work for over a decade. Even five years ago, we couldn't have the conversations that we are having today. People wouldn't be disclosing their disabilities on Twitter and with a sense of pride in doing so. With that, I also think there has been this shift. I wanna give credit again to the healthcare providers and researchers that, in many cases, have bravely shared their stories and experiences, both as research participants and publicly through their stories and things like *Jama Piece of my Mind*, which Dr. Swenor has done as well, but also their stories on Twitter and their participation in panels.

By them sharing these experiences, we're learning so much that's helping inform practice, but it's also helping to reduce the stigma about having a disability. I think it's often the learners and the trainees in this space that have catalyzed the conversation. I will say, I'm especially grateful to my former students and trainees from UCSF who have just—UCSF is this microclimate of loveliness that has just allowed learners to go through at least UME—I'll claim UME—and other undergraduate health professions programs. They were so well supported that they're now leading the conversation and leading the scholarship in this space. It's created this group of leaders. I'm always really thankful for that and just seeing lots and lots of people get involved and jump into the work and conversation.

*Bonnie:*

Thank you, Dr. Meeks, for that. I'm so excited to see, as those trainees continue their careers and, hopefully, go on to become leaders, the continued shift that will happen. It is certainly long overdue and so grateful for all the work you've done for this space. It's so needed.

It strikes me that this conversation, this work is cast against an important backdrop right now around health equity. How are we going to advance health equity? Thinking about this effort to include people with disabilities in healthcare, can you talk about what maybe that connection would be to advancing health equity? Is there a connection to buy increasing representation and also inclusion of people with disabilities in medicine? How that could potentially shift health disparities we know exist for people with disabilities or advance health equity more broadly at a societal level. Do you think there's a connection?

*Lisa Meeks:*

Yeah. That's a big question. I do think there's a connection. I think there's a direct connection and an indirect connection. Certainly, we'll just start at the beginning where the people that are included at the table are involved intimately with quality improvement and selection of even medical equipment and policy. The thought process of even something as—which may seem as arm's length as building physical spaces. If you don't have people with disabilities at the table at those conversations, then you're not likely to have disability informed or disability understood changes or movements. There's certainly the proximity of having representation there. That's just at a baseline.

Also, I think there are unique opportunities when you have a biomedical workforce that is informed directly through people with disabilities. That's through several mechanisms. One of these, certainly, that we all capture in the writing is this increased empathy. Dr. Swenor, you're on the team right now where we've just gotten the data to be able to actually look at whether there are differences in measures of empathy from disabled and non-disabled physicians and trainees. That's going to be huge. Many physicians, nurses across the healthcare workforce report that they have an increased rapport with patients because of the time that they have spent being a patient themselves or having gone through the healthcare maze themselves and, certainly, informing about care for individuals with disabilities that may result in this enhanced responsiveness to clinical recommendations even.

I think our hypothesis certainly is that in no small part a person's lived experience as a person with a disability will positively inform patient care in, certainly, the healthcare system. They've been a consumer of this. I also think it provides a unique opportunity through this proximal relationship and through things like the theory of just contact, that contact theory, that it's not just people with disabilities that will directly impact patients. It will be the other providers and the other people in that space, the administrators, the staff, that then get to interact with people with disabilities that will work on reducing stereotypes, reducing assumptions, increasing the cultural humility of working with a person with a disability through these peer-to-peer relationships. That also provides a potential mechanism or pathway to impact patient care.

To answer your question, I think that there are a lot—that this is a multifactorial impact that would be had by the greater inclusion of people with disabilities. That's through multiple lenses, through reducing stereotypes, through direct information of patient care,

but also through things that you might not think about, like purchasing medical equipment that's accessible. Someone might not think about that unless they've interacted with a person with a disability or they, themselves, have a disability. We know that these disparities in health outcomes and disparities in access to healthcare are, many times, driven by a lack of education. I just think there are multiple pathways for improving healthcare through the inclusion of people with disabilities.

*Nick:* That was so well said and so well summarized. I just love the way that you brought up the entire healthcare system and team. I think, from an implementation science and quality initiative standpoint, sometimes we only focus on physicians as the leader of the team and the changemakers. In reality, the entire Allied Health professional team, our nursing team, all of our providers, all of our administrative and staff members, it's all a team. When you have a healthcare experience, you interact with everybody. It makes such a difference to have inclusion across the board. I love that point. What do you think are the important next steps to continue to advance disability inclusion in medicine and healthcare?

*Lisa Meeks:* Oh, gosh. I think we could probably talk about that all day, right?

*[Laughter]*

*Lisa Meeks:* Just the three of us, I know we're all equally committed to this charge and to change. Certainly, this podcast is a facilitator of change. The podcast itself is a change agent. From an education—

*Nick:* You don't have to be nice to us, Lisa.

*Lisa Meeks:* *[Laughter]*

*Nick:* It's okay. I'm kidding. I'm kidding. Thank you.

*[Laughter]*

*Lisa Meeks:* From an educational perspective, which is the area where I sit, my wheelhouse, if you will, I'm just gonna straight up say that there's too much variation in the system. A mechanism for having a little bit more control over that is, I think, at the top of my list. From school to school and, even within institutions, from program to program, the level of disability inclusion is too often directly related to the belief system of an administrator, a single or a group of administrators, faculty members. In GME, it could be a program director, or the knowledge of the disability resource professional



that is working at the institution to discern and appreciate the myriad of inclusive practices, including accommodations, that are available in the healthcare space.

When you rely on the belief system or the exposure of an individual, there's way too much variation there. You're not going to have continuity in care or understanding. That's what I'm working towards. I laugh. My new thing after turning 50 was, okay, I've got a decade left to make an impact. What's it gonna be? What are my goals? I think my goal—success to me would be some standardization that is backed by accountability. Things like standardization across medical schools and accountability by the LCME for these changes. I want movements to be, certainly, as organic as possible—and it's helpful to have all of these different people at the table—but recognize that a bottom-up and top-down approach, simultaneously, is important, but it must be layered by a level of accountability.

Otherwise, you're going to have people—'cause remember, we're driven by belief systems of individuals. You're going to have people who don't think this is important. They're never gonna think this is important. No matter what I say, I could be blue in the face, it's just not in their value system. Their belief system is so hardwired by that medical model that they're not going to be change agents. They're not going to sign on to this unless they're held responsible for that.

Too often, in this space, all of the work is resting on the shoulders of individual trainees who have disabilities or on advocates and researchers, change agents, like all of us sitting here having these conversations. We have a lot on our plates day to day. I think about the medical students who have driven this and how much they are supposed to be doing, how much they have to do. They're taking on systems change. So many times, they'll go to administrators and raise an issue, and the answer from the administration will be, "That's great. Why don't you go out and find best practices and give us a report on what changes we can make?" Again, that's taking a system that is putting the onus on the individual to make change to also make the individual make change at a systems level for policy. *[Laughter]*

We really need the LCME to step up. The ACGME has done an incredible job stepping up and making regulations and then backing those with education. As you said in your introduction, we have been charged with creating a toolkit for program directors, people that are in charge, that are likely to be the first line of this

disclosure from trainee to administrator to help people understand how to navigate this space. We really need for these accrediting bodies and other organizations to step up and say, “You must do this.” We’re hoping for that.

*Bonnie:*

This is why I adore Lisa Meeks. This is the genius that she is. Our shared commitment to this work and *[laughter]* draw towards accountability and change. What you just shared and that vision for change is profound. I do hope our audience understands the power in that, the impact that will have. Also, I just wanna take it further. I hope it doesn’t just stop at medical schools. I hope that this moves to higher ed across the board, to funding agencies perhaps, and even beyond higher ed. That is, as we are recording this conversation right before the 31st anniversary of the Americans with Disabilities Act. The onus, as we started this conversation, is on the individual for change. Lisa, that’s just how you *[laughter]* discussed this. That is the shift that needs to change. Thank you for this work and for shifting that paradigm and working to shift that in this space. I’m just so excited for what’s to come and the byproducts and the spillover effects from that.

*Lisa Meeks:*

I’m just grateful to all of the people doing this work. I think we were talking the other day, and I had a learner this morning that I was on a call with. She’s very interested in getting into this space and research and advocacy for inclusion. She said, “Everyone I’ve met and worked with in this space, they’re just incredible people all committed to social justice. Just good humans.” When you roll out of bed and you’re getting ready for your day, it’s so invigorating to know that the people that you will work with and work alongside are there as a team. I’ve never worked in such a team-based, collaborative environment as when I started working on this topic and these issues. Certainly, I think both you and Nick have been fabulous collaborators. I really appreciate just the work that everyone’s doing.

*Nick:*

Thank you. Thank you for sharing all of that. I echo what Bonnie just said. It’s an amazing perspective, and I hope it catches fire. Your book *Equal Access for Students with Disabilities* and the AAMC report *Accessibility, Inclusion, and Action in Medical Education* are truly a roadmap to inclusion of medical trainees with disabilities. We encourage everyone in our audience to check out these resources. Dr. Meeks, Lisa, thank you so much for being our guest today. This was amazing.

*Lisa Meeks:*

Thank you both for having me. I’m loving listening to your podcast. Thank you for doing it.

*Bonnie:* Thank you so much, my friends.

You have been listening to *Included: The Disability Equity Podcast* brought to you by the Johns Hopkins Disability Health Research Center.

*Nick:* Thank you to our *Included Podcast* team and everyone that made this podcast possible, especially Sabrina Epstein, Prateek Gajwani, Curtis Nishimoto, and our guests. Music is by Molly Joyce. This podcast is supported by a Johns Hopkins Ten by Twenty Challenge Grant.

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