Holly J. Humphrey (HJH): Welcome back to Vital Voices, a podcast from the Josiah Macy Jr. Foundation. I am Dr. Holly Humphrey, the President of the Macy Foundation. And on today's episode, we will discuss an area of bias and discrimination within the healthcare system that remains a significant challenge, namely the ableism and the healthcare disparities that Americans with disabilities experience. To help us explore this important issue and how health professions education can help address those with disabilities, I am joined by Dr. Lisa Meeks.

Dr. Meeks is an expert in disabilities in medical education. As an administrative leader and researcher, she is helping to inform policy and best practices in the area of disability inclusion for medical education training and practice. Her research interests include improving access to medical education for learners with disabilities, medical student and resident wellbeing, reducing healthcare disparities in patients with disabilities, and the performance and trajectory of learners and physicians with disabilities.

Dr. Meeks has published extensively in the literature, including in The New England Journal of Medicine, the Lancet, JAMA and Academic Medicine. She is the lead author of the Association of American Medical College's special report on accessibility, inclusion, and action in medical education, lived experiences of learners and physicians with disabilities. Importantly, she is also the host of the Docs with Disabilities podcast and director of the Docs with Disabilities Initiative. I can tell you that I for one have very much enjoyed her Docs with Disabilities podcast and have had the chance to learn from the lived experience of those who share their stories on that podcast.

As always, this conversation is a follow-up to our webinar series discussing the Macy Conference recommendations on taking action against harmful bias and discrimination in clinical learning environments. This will be our last podcast in this Vital Voices season. You can find this podcast as well as all of our webinars, the conference *recommendations and other resources on our website at macyfoundation.org. And now, here is my conversation with Dr. Lisa Meeks.*

HJH: Lisa, thank you so much for being here. Several years ago, you co-authored an important paper in the New England Journal of Medicine on some of the best practices for disability inclusion in the biomedical workforce. And at that time, you identified the challenge as simultaneously increasing the number of students with disabilities entering scientific and medical fields and sealing the leaks in the scientific training and career pipeline for people with disabilities. I loved that description in that paper, and I'm hoping that you might be able to share some concrete recommendations for how institutions might achieve these two goals.

Lisa Meeks (LM): Thank you. Thank you for the question. My team's research and the research of many of our partners and colleagues show specific pinch points in this pipeline, including into admissions, so into programs, transition to the clinical year for those programs with the clinical component, and support in the transition to employment and remaining employed. And I think to be honest, the biggest barrier to this is attitudinal and educational. And I choose to believe that none of this is intentional. I think it's attitudinal in that ableism, or the discrimination of and social prejudice against people with disabilities is so deeply embedded in our society. It's what we're taught. So we have to actively unlearn this, and that takes time and it takes practice. It’s educational in that someone has to decide that this is a priority, and then choose to act on it and to actively say that people with disabilities are important to our field. And then take steps to identify the barriers and remove them, while also providing this education about why the population is so valuable.

And this requires educational tools and trainings. And while many schools will opt to do this privately, we are hoping and seeking to create tools that are free and accessible to all biomedical training sites that can be used to educate faculty and staff about creating these more accessible and inclusive environments. And I think that training must include what I call myth-busting. Getting rid of those assumptions, getting rid of that kind of ableist mindset, and then stories about current researchers and clinicians that disrupt prevailing constructs of disability, which as you know, are often so reductionist. But I think as far as systems of entry, that this includes actively recruiting people into the profession, making a statement that we want you here, that is important. And then sharing the stories of successful physicians, and nurses and researchers who are already working and thriving in these spaces.

And I think this requires institutions and employers to review and update their messaging to develop strong policies and procedures aimed at making disability disclosure and request for accommodation a seamless, informed, and nonburdensome process, and then for leaders to set the tone for cultivating an accessible and inclusive environment.

That brings me to my next point, which is that this is an issue at all points on the continuum, from entry to training, progression and employment, and that is equal access through accommodation and universal design. And I think the reality of the situation is that most accommodations and accommodation solutions are easy and they're inexpensive. The largest issue is the lack of knowledge and experience in adjudicating these decisions and implementing the accommodations. Many of these programs lack that institutional representative who holds an expertise in disability, in law, medicine and technology such that they can work with a student or an employee who is entering the biomedical workforce and that they can properly identify assistive, adaptive technology, software, equipment, or other accommodations that are reasonable and appropriate to the program of study or the position.

I know that our research and commentaries, like another one that was in the New England Journal of Medicine from Dr. Rastogi, who's a current medical student, and our newest evaluation of over 2,500 medical students with disabilities in the second year of medical school consistently show that this lack of experience on the part of decision-makers within the institution is the largest frustration for students and one of the ongoing largest barriers to inclusion. And then, of course, training and awareness. It is essential that people decide that this is a priority, and again, just choose to act on it.

HJH: Lisa, thank you. That was a really inspiring vision in so many ways. And to some extent you have already touched on something that I have thought a lot about, and I feel like I must ask you about that. And that is -- given this inspiring vision that you just laid out, what do you foresee as the biggest obstacles to making that all a reality?

LM: That's such a thoughtful question. My research focuses on the barriers and mechanisms for inclusion, but rarely do I get a chance to think about or discuss what the obstacles are that could keep us from reaching these goals. And I think we can hope for, desire, and strive for equal access, but certain things do serve as obstacles. And first I want to recognize that we have experienced unprecedented challenges in the world the last few years and have witnessed the unfathomable acts of violence, and oppression and exclusion against people of color, those in the LGBTQ community, and people with disabilities. And all of this warrants action on our part.

However, I think that many people view these issues as competing priorities, and they don't necessarily understand the bigger connection between all of the “isms,” if you will, that systems of oppression work together to keep one another down. And I think that one of the obstacles would be if people do not consider the interrelatedness of these systems and to recognize how ableism, racism, heterosexism, ageism, all of the “isms” work together to deny people access. I think it is critical that our justice, equity, diversity, inclusion efforts include disability and that we address marginalization and harm of any category of person as a collective social justice issue. I would say that not seeing these systems as interrelated would serve as an obstacle.

I think the second obstacle that I have talked about a lot in the literature is lack of accountability. Following the double AAMC report that came out in 2018, we really asked schools to consider and reflect upon our findings that showed that having an informed person in medical education to make the decisions was important to make sure that the decision-makers were people who did not have a conflict of interest in this or people who did not have any experience. We asked that schools consider protections for students with disabilities. Those protections would be things like privacy, making sure that there aren't those conflicts of interest, making sure that they had access to an informed person, and that they could have their accommodations in place.

And if that included weekly appointments for mental health or physical health, that that would be recognized. That's already something that is in the LCME requirements, but it does not speak to disability accommodation. And so there are currently no protections for students with disabilities in medical education from the accrediting bodies. Similar protections exist for mental healthcare, the keeping of records, and include protections against that conflict of interest that I just discussed. But I think we need parallels for this for students with disabilities. Also, there are no mandates to employ best practice. The AAMC report was 2018, we're now in 2022, and there are several institutions that still don't embody or practice what we know to be the best practice for disability inclusion. There was a new report from the American Medical Association in 2021 that highlighted very specific needs and actionable steps. Again, many of those were a repeat of what we saw in 2018.

And so, I am hopeful that in this next few years, schools will start to embody these recommendations and align their practices with these recommendations. Because we know in our recent research that I was talking about with 2,500 second year students shows us that the experiences of students with disabilities, at least in medicine, are highly disparate across schools and that there is no continuity in the practice between schools.

Finally, I think one thing that would keep us from realizing these goals is if we don't do something about the transition to GME or to employment. These transitions are highly problematic. And where UME now has a ton of guidance available, GME stakeholders have not had access to resources up until now. There's an incredible increase in students as you know, disclosing disability in medical school, and the resulting impact on GME is inevitable.

And thankfully, the ACGME recently launched an initiative called Equity Matters, which includes two modules on disability inclusion. Our group was so lucky to be funded by the center for diverse healthcare workforce through HRSA to create toolkits for GME, and all of these resources will be released April 1st. It includes things like one-pagers, short animated films about discrete disability related topics, and two CME granting modules. But I think that in the absence of these educational tools, we risk not realizing all of the potential for disabled individuals in healthcare and our biomedical workforce.

HJH: I'm very glad that you brought up the point about medical students being now much more willing to disclose that they actually have a disability. In fact, you covered that in one of the papers that you published in JAMA. And I'm wondering if you have anything more to say about how we can create truly inclusive environments across the continuum. You mentioned the transitions, you mentioned this increase in students being willing to disclose a disability, but do you have any more concrete suggestions beyond what you've already mentioned about what we can do to create consistently inclusive environments?

LM: That's a great question. I definitely want people to know that there are resources available. One thing that I wanted to touch on quickly, because I just switched between disabled person and person with a disability. And I wanted to let the listeners know who may not know because we are all taught to use person-first language, is that I intentionally, in my work and in my speech, will switch between person-first (i.e., person with a disability) and identity-first language. This recognizes and respects the variation and preferred language among people with disabilities. Especially in this group, we are talking about - medical students and the increase in disclosure. This group is bringing a sense of disability pride with them to medicine and to research. I want the listeners to understand why I might move between those two ways of situating disability. But back to your question about concrete recommendations for schools, it is such a big question, and it's highly layered and highly nuanced.

This won't be an exhaustive list, because we do not have time to do that, but there are a few key things. And the first thing I want to say is, it's a behavior versus an action. I think programs need to bring an element of humility and space to their conversations about disability. And you can understand, we are all used to finding answers, right? Giving the right differential diagnosis, knowing the formula. We want to problem-solve, and we want to help people. Otherwise, we wouldn't be in this field, but disability isn't a problem to be solved. It's really a normative part of human development. I think for many people listening, many of the faculty and administrators of these programs, this may be one of the first times that they're not an expert in this space. And I encourage them as one of the main things they can do is to do more listening than talking. And if they want to know what their disabled learner or their employee needs, ask. Asking is the most respectful way to go about beginning the conversation, and then listen to what that person might need.

Next, I think institutions and schools and employers must commit, and this must come from the very top, time and resources. This includes disability positions. We have talked so much about one of the biggest barriers being lack of knowledge about what to do and when to do it. So consider getting an evaluation and having identified gaps be written up for you in your service or your policy, even attitudes, and then develop a strategic plan. To have a goal of disability inclusion is great, but until you have a plan in actionable steps, you are not likely to make a lot of progress. And make sure that you are coming at this and addressing the issues from every single angle. Not just, how do we get more people into our programs, but how do we sustain them? How do we make them feel truly included?

Because to simply rewrite a policy may make some level of change, and it might even impact a student at a particular time or an event, but in the absence of systems and attitudinal change, it is not going to change their experience. And that experience could be the difference between them wanting to stay in medicine or leaving medicine or research. I think in order to celebrate disability, we need to help people understand the value of this population. One of the ways to do this is listening to the podcast that we have, which is first-person stories about their experience, and making sure that we're highlighting people who are in the field and thriving in the field to be potential mentors for those that want to enter medicine or biomedical research.

Third, is to educate and encourage from one angle, but hold accountable from the other. I was giving a talk yesterday where I likened striving for disability inclusion to systems theory. And so many people are easily tackling the kind of outer system. If you think about a series of rings, it's easy to tackle the outer systems. And this gets back to our New England Journal paper. The forward-facing messages about disability inclusion, you can adjust your website, you can add the word disability to whatever current language exists, but once you start moving towards the center of the system, things often break down without that step by step plan. There's a lack of infrastructure to support inclusion. There's a lack of review of accessibility in the system. And I want people to think about the messages, the sends, when your website - that outer system - says, "We welcome people with disabilities and celebrate differences," but a student gets on your website and an admissions video isn't captioned, or your website is inaccessible. That speaks to the kind of inner rings, that automatic system, the infrastructure that you build to support what your goal is. Another example would be something like posting grand rounds about accessibility and about disability in a room that isn't accessible. Where a person using a wheelchair would have to enter the room through a complex labyrinth of systems in the basement to get through a quote, unquote backdoor of a lecture hall, which I witness all the time, and who also might be relegated to sitting in the first row where a seat has been removed to make space.

And I think we can all agree that in no other situation would we ask a member of another marginalized group to enter through the back door when everyone else is coming in through the front, this message that it sends, it's very covert, but it's part of a number of covert messages that we send to disabled folks that are much stronger than any overt messaging you might have on your program website. So, I think making sure that your intentions and your messaging to the outside world is backed up by the systems that you create and the accountability that you create for access stability within your system.

Finally, and this is a big one, funding must be centralized for accommodations and must not burden any one department. When you tether funding to a specific division or department, it automatically invites bias into decision-making and admissions processes. And the courts will view an entire institution and the collective budget as the threshold for meeting any sort of legal defense for rejecting an accommodation or not admitting a person which almost never prevails, but institutions can be proactive and reduce bias by setting up a centralized system and departments to actively recruit people with disabilities. And by the way, most accommodations don't cost anything, and those that do the majority of them are under $500. I think this goes back to the myth busting that I talked about. I think people's assumptions play into their decision making, but when those assumptions are wrong, it can obviously lead to the lack of inclusion for people with disabilities.

HJH: There was a lot of rich information, and I loved the examples you point out in such a powerful way, some of the real ironies in how we do our work, but the specificity of some of those recommendations makes me think it really is possible for us to enact some of these straightforward things. And as you just point out, they're not even that expensive. So this is doable. And I hope that we can do this sooner rather than later.

I want to return to something that you mentioned a little bit earlier, and that is you were talking about the ways in which persons with a disability part of groups who have been historically discriminated against. And one of the recommendations that you have made and that you referenced earlier is a need to incorporate disability as part of institutional diversity initiatives. Can you say a little bit more about this? What are some of the specific ways that institutions should go about doing this?

LM: I think first and foremost, just make sure that everyone talks about diversity and all of the initiatives and forward-facing messages about diversity include disability, so that it becomes part and parcel of the greater JEDI or DEI mission. But more than that, having an awareness about inclusion for all of the events that our JEDI and DEI folks host. Making sure that accommodation requests are part of every event, making sure that the event space is accessible, making sure that there is representation of disability, and remember about 90% of the disabilities will be what we call nonapparent. Assuming someone is not disabled purely by looking at them is something that should be addressed and making sure that we understand that, even if we can't see it, it could be there, because 90% of the people could require accommodations and will also be part of that community.

Making sure that you are being mindful about including people with disabilities in the creation of all of these events and when you are striving for representation of all identities, that you also strive to have representation of disability, both in that DEI space, but also in leadership.

HJH: *That makes sense, and again, that sounds just very doable and something that institutions should ideally embrace and implement. I want to switch gears for a minute and talk a little bit about bias and discrimination against those persons with a disability. And one of our recent podcasts featured Dr. Lisa Iezzoni who published a seminal paper in Health Affairs in February of 2021, describing physicians' perceptions and attitudes regarding people with disability. I know from my conversations with you, that you have a paper coming out, which discusses physicians' mistreatment of those with disabilities. Can you say more about that?*

LM: Lisa is one of my mentors and one of the greats in this space. Her Health Affairs paper has been extraordinarily impactful. I think we've always known that medicine has this skewed vision of disability. And we actually talk about her paper in ours to say that it is even harder to think about inclusion and acceptance when physicians already have poor perceptions of people with disabilities, right? And they are not used to having their peers be part of that equation, but in our paper, partnered with the AAMC physician and research portion in our paper, we found something that is highly upsetting, and I think will be shocking to read, but again, not surprising given what we know about the climate, and that is that our physicians with disabilities when compared to their nondisabled peers were, in some cases, 17 times more likely to experience mistreatment. 64% of physicians with disabilities experienced mistreatment as just part of their everyday life, both from peers and from patients.

The thing about our paper that was so disheartening was we know that physicians, all physicians experienced mistreatment, they experienced sexual harassment. They might experience remarks about their gender identity, sexual identity, gender, religious views, things of that nature. And so that's a problem in healthcare already, but to add in an element of 17 times more mistreatment if you are a person with a disability was striking. In our paper, we talk about harm and physical harm. So many of our physicians were victims of physical harm by their peers, which was striking to us as a research team. We had a hard time in the final writings of this paper, because it was so heart-wrenching to know that this is the climate that physicians with disabilities are entering.

I think this also explains some of the other data that we have, which we've shown that about 10% of graduating medical students are saying that they are a person with a disability, so they are self-reporting disability. And when you go into training, working with intern physicians, that number is reduced to about 7.5. But then when you go into the physician workforce, the paper we recently published in JAMA Open, you get down to 3.1. There's a significant cliff, kind of a drop in the representation of physicians. And I think that our paper will explain at least part of the reason for this drop, and that is the way that people are treated when they enter medicine. Not to talk about this over and over and over again, but I do think that the education piece is extraordinarily important, and to myth bust and talk about physicians that are out there and practicing and doing great things to bring awareness to people. Because I think we just are raised in a society that does not appreciate disability, that “others” individuals with disabilities and sees them as being less than, or somehow broken.

We have to change that mindset, and that doesn't happen overnight. It's going to take a lot of intervention. We're currently creating an anti-ableist admissions module. I think we need, just as we need anti-racist education, anti-ableist education as well. Because it is just so deeply rooted.

Then on top of it when you have a physician workforce that is used to only working with disability in the sense of a relationship that has a huge power differential, those negative perceptions can just be perpetuated in that model. Infusing the workforce with more physicians with disabilities who can actively, and with proximity, counter those stereotypes will be beneficial to improving health outcomes.

HJH: Like you, I find those mistreatment rates shocking. While we have made some progress, I feel like we have even further to go than I thought we had to go at the beginning of this conversation, Lisa. All the more reason for the importance of your work. But also, it makes me wonder, are there institutions that we might look to as exemplars who are doing some things that other institutions may want to emulate and learn from? Because obviously, as I said, we have a long way to go here.

LM: That's a great question. My running policy is to never put anyone up on a pedestal, because I think we are all learning in this space, and we all have so far to go that no one school is necessarily an exemplar. I can say that there are multiple schools who are doing good work in this space.

While no one person or institution is perfect, a lot of good work is being done and has been done at schools like the University of California, San Francisco, where I was so blessed to work for five years. One thing I will say about UCSF is that UCSF is truly committed to equity of all groups, and so the climate at UCSF is like something I have never experienced anywhere else, which is fully committed to inclusion in all forms.

That takes me back to that "we're all in this together, and all systems of oppression are linked." I think when you address it that way it's helpful to build a community. UCSF goes even further and employs multiple physicians with disabilities as not only part of the workforce for the hospital systems, but as educators in the system.

You have disabled faculty members who are there, disabled staff members who are there. That's a great place to start. There are other institutions who have longstanding commitments to disability rights and disability inclusion, including Rush University, who took a systems approach to, for example, changing their technical standards; where everyone from every program came together to decide who they wanted to be and to make a global commitment from Rush, the entire institution, making sure that learners who wanted to enter one of their programs would not be discriminated against in the process by unnecessary technical standards, or by having someone in charge of making accommodation decisions that were uninformed. They committed to hiring a disability resource professional for the institution. They made this commitment to evaluating their program, changing the technical standards.

We see lots of schools doing this now as well. Of course, Michigan has a long history of hiring people with disabilities and has multiple disability initiatives going on, and leaders in disability inclusion. Two of our chairs are people with disabilities. I can say that I think Michigan's admission system is probably the best for individuals with disabilities at this point in time. We actively address disability. I'm honored to be on the admissions executive committee. We actively discuss disability and actively talk about bias for all identities. We challenge one another and we ground ourselves in our commitment to the inclusion of people with disabilities especially.

There are multiple schools right now that are actively undergoing change. I know Stanford just rewrote their technical standards. UCLA is in the process of rewriting their technical standards. Lots of schools that are leading the way. University of Minnesota Medical School has done some incredible work both for mental health and for disability over the last 10 years. I think it's pockets of people who are doing great things. One of the things I love about crowdsourcing and being a team is that many of the representatives from these schools are coming together to work together, to create best practices, to learn from one another, and to make sure that we're not constantly reinventing the wheel. And then to write about these things and disseminate this information to other schools, so that they can witness the success stories and the processes that were in place at those institutions.

HJH: Those are wonderful examples, Lisa. As those schools are learning from one another, we have all learned from you today. I'm sad that our time is up. I want to thank you so much for sharing your incredible experience and expertise. This has been a very thought-provoking conversation. On some level I had a sense, I knew what we were going to talk about, but once again you have gone above and beyond and broadened and deepened my own understanding on this topic.

I am so grateful to you for sharing the hard-earned experience and expertise that you have brought to this field, and most importantly to the people and the patients who are impacted through the bias and discrimination and all the many ways in which we have excluded people rather than included them. Lisa, thank you so much.

LM: Thank you so much for having us, and we're so grateful to The Macy Foundation for letting me talk about our work. People can find more at docswithdisabilities.org, which is our initiative to increase the number of people with disabilities in the biomedical workforce. It's been an absolute pleasure.

HJH: Thank you, Lisa. For more on today's discussion, I encourage you to read the Macy Conference recommendations and related resources. You can find all of those on The Macy Foundation website at macyfoundation.org. Thank you for listening, and we hope you'll share this conversation with others.

This is the last episode in our inaugural season of the Vital Voices Podcast. We will be launching our second season later this year. Be sure to subscribe wherever you get your podcasts so you'll be notified when the next episode drops. Make sure you're signed up to receive email updates from The Macy Foundation.