Emily Ladau:

Hello, and welcome to another episode of Disability Inclusion Required. Today, we're going to dive into an absolutely essential topic, health and disability. We're, of course, going to narrow our focus so that we connect it back to philanthropy, but this is a conversation that's without a doubt going to be relevant to everyone, because if you have a body, you need access to healthcare. But all too often, proper healthcare is out of reach for the disability community. And to talk about that, we've got an incredible guest who I can't wait to welcome, Dr. Bonnie Swenor, the director of the Johns Hopkins Disability Health Research Center. So to get us started, Bonnie, I would love for you to share a little bit more about yourself, and what you do, with our audience.

Bonnie Swenor:

Well, first, thank you, Emily, for having me on the show. I am so thrilled to be here with you, and just so grateful for all the great work that you and this forum are doing. My work and that of my center is focused on using data to advance equity for people with disabilities. Our tagline is that we're shifting the paradigm from living with a disability to thriving with a disability. And our area of work is pretty broad, so we span areas from healthcare to public health, transportation, food access, education, workforce issues, and even now doing some work in AI or artificial intelligence. We're really focused on improving the ways that we collect and use data to support and advance equity for disabled people, and are ensuring that all of our efforts are centered on, and are led by, disabled people. We also are prioritizing the inclusion of diverse perspectives and intersectionality in all of these efforts. That includes collecting and using data to address and elevate the exponential inequities that disabled people from intersecting marginalized groups face.

Emily Ladau:

I think what is standing out to me already is the fact that when you're thinking about healthcare and data, you're not just thinking about one area. You mentioned transportation, for example. And I'm always trying to remind people that every system is interconnected, and that if we are going to address ableism and inaccessibility in our systems, we need to acknowledge those interconnections. And for transportation, if you don't have access to transportation, you don't have access to healthcare other than telehealth, but then do you have access to the internet? It's a cycle for sure, so I'm really glad to know that you're taking a holistic approach to this work and this research, and I hope that we can ground ourselves with a little bit more context, and that you might be able to share some of the insight that you have on major healthcare inequities that disabled people are all too often experiencing. And also, if you could shed some light on the compounding factors such as race and class, I think that would really help us better understand this conversation, too.

Bonnie Swenor:

Yeah, sure. And first, what you just elevated is that interconnected web of inequities that disabled people face. That absolutely matters for healthcare, and we need to change the systems and structures to address that. And so, when we are talking about the healthcare inequities that disabled people face, it's really about that. These inequities are profound, and they're almost entirely unaddressed, which is also concerning. The way that we think about this are we think about tackling these inequities as they show up in forms of inaccessibility, and that crosses the entire healthcare journey. As we were just discussing, the process of making healthcare appointments is inaccessible. Getting to those appointments can be inaccessible. Even the healthcare interaction itself is far too often inaccessible, as well as the follow-up process and procedures. And so all of that, all of those aspects of the healthcare journey really have to be thought about through a lens of universal design and improving access for disabled people.

But it's not just about that. It's also about the ableism, the view that non-disabled people are the ideal that we also have to address and consider in healthcare settings. It really is a view that's so entrenched in healthcare, and healthcare providers are really taught still today that health is the opposite of disability, that you can't be healthy and disabled. That makes addressing ableism in these settings really challenging. And there's been great work by disabled scholars like Lisa Iezzoni from Harvard, whose research has shown how pervasive ableism is among healthcare providers. And so when we think about those two concepts, ableism and inaccessibility, our approach is focused on tackling both of those things at once. What can be challenging? So we really do believe that data, or a lack of data at times, is the root of some of these issues.

It's hard to know where you need to go if you don't know where you're at. It's hard to know how strategies and programs are impacting accessibility and access, are changing views and addressing bias towards disabled people in healthcare, unless you have the data. But it's also critical, as you asked in your question, to consider that within the context of the world, and the fact that disabled people are diverse, and we face many barriers that are stemming from other factors of who we are. Racial injustice inequities across many dimensions of who we are as disabled people also have to be considered. I think far too often in this work in addressing inequities in general, we do take this myopic approach. And the challenge, I think the future, is expanding on that. And I certainly have a data bias. I think that data can help with that. We always say that if you're solving the equation for equity and you only have one variable, you're never going to get there. It's a complicated equation. But I think we can do that kind of complicated math.

Emily Ladau:

Look, I'll tell you, I am not a numbers person. I am a words person. But I think that when it comes to compiling the data, I often look at it in terms of how can we get not just the quantitative information, but the qualitative information, the stories, the anecdotes from people, and those are just free flowing and aplenty, unfortunately. When I think of all of the ableism and inaccessibility that I've encountered every time I try to go to the doctor or seek out medical care, and I am someone who exists at the nexus point of privilege and marginalization because I am a white woman, and I do have socioeconomic status that allows me access to healthcare.

But in spite of that, I still navigate the challenges of the healthcare system in the United States, and I know that I'm stating the obvious when I say that we have a deeply flawed healthcare system. And philanthropy, now we're bringing philanthropy into this conversation, for better or worse, has a key role to play in helping to provide funding to start to dismantle some of these inequities. I know you were talking about data, but can we get a little bit more specific? What should philanthropic organizations be paying attention to right now, in terms of where to direct their funds and their supports?

Bonnie Swenor:

Well, I'm so glad you shared that example, because what you just described is the arc of developing good community-grounded data. We start with the qualitative data to understand the community's perspectives, and then from that qualitative data, we develop the quantitative metrics. And so, both of those aspects of data go together. But what philanthropy can do is to support that development process, is to support the research, the work that goes into developing better data metrics and data infrastructure to address the systemic barriers that disabled people, and disabled people from intersecting groups that face additional barriers, to support equity for all disabled people. And so, we desperately need funding to do this work. The challenge as a researcher in this space that we often face is there's no great source for funding that type of research, of doing that really foundational work to develop the metrics that are the basis for the next steps, which are, then, identifying and enumerating the inequities, and then developing the strategies based on that evidence, without the support to develop those metrics to do that qualitative work. We're sort of stuck.

Emily Ladau:

I think this is the perfect opportunity for us to actually bring a few threads together. We've been talking about healthcare, and data, and philanthropy, and there's been quite a bit of advocacy lately, and action taken around an issue that, if I understand it, could have an immense impact on the disability community in the United States, so let's talk about it. The US Census Bureau recently proposed some changes to disability data collection, and there was quite a bit of reason to be worried, though now it seems the tides have somewhat turned, but there's still work to be done. And of particular concern to the Disability and Philanthropy Forum is what happens if we don't have accurate data, because philanthropic funding for disability inclusion rights and justice relies on accuracy of data.

And currently, the unfortunate statistic is that foundation funding for disability represents approximately 2 cents of every foundation dollar awarded. So it's urgent that we increase this, but if we don't have the accurate data and information to do so, that will help us understand just how broad the disability community truly is, then we're really worried that this already small amount of funding is going to drop even further. Could you talk us through what's going on, the current status of these proposed changes, what are the implications if we don't continue advocacy efforts? And then, loop us back to philanthropy. What can philanthropy do right now?

Bonnie Swenor:

Yeah, sure. The proposed changes from the Census Bureau were very concerning, because currently, the questions used to assess and measure disability, to develop the national estimates of disabled people in the United States, there are already many limitations. They're not ideal, let me be clear. But what was being proposed is a change to a set of questions that were even less ideal, and it would result in a shrinking of national estimates of disability by 40%. The alarm was elevated by the fact that the disability community was not engaged in this process. These changes were moved forward without meaningful engagement with disabled people. And when you're thinking about ways to measure to count us, to collect data about people with disabilities, absolutely have to work with disabled people and make sure those measures reflect us, reflect our perspectives, and are counting us accurately, as you described. And so, it was quite alarming.

I am grateful that just last Tuesday, the Census Bureau director announced that that proposed change for the next cycle of the survey, that the changes were being considered to be included in the American Community Survey, that that is not going to move forward. And that is the result of amazing advocacy from the disability community. It really was fantastic to witness. More than 12,000 people wrote in comments to a Federal Register Notice regarding these changes. My colleagues and I initially sounded the alarm about this in mid-October, and I'll be honest, I don't think we even knew how deep this issue was, and I don't think we could have anticipated the fantastic response from disabled people. So this is great news, but it certainly doesn't mean this fight is over. The next steps for the Census Bureau, and to be honest, for the broader community, or the broader federal statistical community, is to now engage and to develop ways to engage with the disability community.

Sadly, there's no process or procedure. There's no relationships that exist, and that's problematic. They're starting from a very new place. We need to make sure that that engagement is happening, is accessible, is inclusive of diverse perspectives of disabled people. That's one aspect. The next is that we do need to keep pressure on for the development of better and more inclusive measures of disability. That's going to take work. That's going to take many perspectives, researchers, advocates, community members, as well as representation from the federal government to develop. The question here, and how this loops back to philanthropy, is how is that going to happen? Who is going to support that work? There's still a lot of questions about that. I am hopeful that there will be interest from philanthropy in response to the concern about the ways in which disability is being measured. I think this whole situation has elevated the limitations in how we are currently measuring, counting, estimating disabled people in the United States.

We're not doing it in near enough surveys. And when we are, we know we're under counting, even now. The lack of data on disability, or the limitations in the data, makes it seem as if the inequities we face don't exist. We call that disability data oppression, and that has to be changed. But the cycle also has to be changed, because the view is that money and support isn't needed, that the problem isn't big enough. And so, there needs to be a break in that chain, and a break in that cycle. And I think that's where philanthropy can have a role, is helping to break that cycle, and to get better data and evidence to know where and when and how we can best intervene to have the best outcomes in advancing equity for people with disabilities.

Emily Ladau:

I think that you are really highlighting two things that I want to focus on, the first being that disability is in no way a niche issue, and that we absolutely should be celebrating that really strong response of over 12,000 comments. But also, recognizing that that's just such a small sliver of how many people with disabilities actually exist in the United States. And so, when we're thinking about how to engage the disability community, that really means recognizing that it's not just a few people from the disability community, but that the disability community is big and broad and diverse.

And we mean to heed the concept, the rallying cry of the disability community, nothing about us without us, when we are working on this. And I think it's a great reminder for philanthropy as well that we shouldn't be relegating disability to the sidelines, that there are people showing up in force to have these important conversations, and that it's important for everybody. And as we're thinking about not only the data, but also about the experience of healthcare, I want to shift to that a little bit, because this is a big question, but we can have all of the numbers and stories in the world, and yet how do we actually make that applicable to the practice of healthcare? What does accessible, equitable healthcare actually look like from your perspective?

Bonnie Swenor:

Yeah, this is such an important question. To me, this is all about usability. And I don't know that we frame healthcare enough in this way. And so the point here, the idea, is developing healthcare so that it's easy to use, it's easy to interact with for a large number of people. It's easy to find a provider, to make an appointment, to get to that appointment, to interact with your provider, and to do all the things you need to do to support your own body and your own health. And I know that's far from specific, but that's sort of the point. We have to redesign healthcare so that there is flexibility in when, and where, and how, people can get healthcare. I do always have to take it back to data because that's just how my brain works. And so, to design a healthcare system and structure that is actually usable, we do need data to determine when and where new approaches are working, and for whom, and for whom they're not.

There's this big movement called precision medicine, which is using data and information to develop tailored healthcare treatment plans. But I actually think we have to use a similar approach to use data to design precision-based approaches to healthcare access, so that we're designing healthcare that meets people exactly where they are, whoever they are, and whatever environment that they're in. I think data can help us to get there. But to be sure, that's certainly not an easy task. However, I think this is a time and a moment where we're ready to take that on. There's advances in technology, in data analytics, in healthcare delivery options, and I think as we were just talking about a clear movement happening right now around this amazing interconnection between researchers, and disability advocates, and shifting perspectives on how critical including disabled people are. I think it's really a moment where we can pave such a path to take that kind of an approach. That's how I imagine it.

Emily Ladau:

How does philanthropy meet this moment? We've already talked about what potential role that philanthropy can play moving forward, but let's also think about the fact that philanthropy has some work to do internally to make sure that we are actually moving in the right direction towards disability inclusion. I like to ask everyone who joins me on the show to share their call to action for philanthropy. What is the call to action that you would want to leave our listeners with?

Bonnie Swenor:

Yeah, I love this. I love that you end with this. When I give a talk, I always like to end with a call to action, or some homework as I like to call it. As an academic researcher, I certainly admit I'm bringing that perspective. And I know in academics that comes with privilege, but I always appreciate and value the way, Emily, you describe that nexus of privilege, and at times discrimination and bias, as being a disabled scholar. And so again, as I was just alluding to, it's hard to ignore the power that we've seen in the past few achievements for the disability community in the working together of researchers and the disability advocacy community. But there needs to be more space for that. There needs to be more forums for that. And I think that there needs to be support to encourage that.

It's researchers with disabilities doing the work. It's researchers that aren't yet doing that work that are ready to do something and to take action and to support the disability advocates that have been doing this work for a long time. But also in academics, I think in academic settings, we need to support the people developing the evidence and the data. We need to support our students, the next generation of disability advocates, to include disabled people, and to make sure the tools are accessible for them and that they have the skills they need to continue this field and move it forward. Unfortunately, there's not many programs to support that kind of training, or disabled students in these fields. But we also need the academic researchers, and we need to support those doing the work right now. Those are our mentors. Those are the people generating the evidence at this moment.

Disabled scholars are far from well-supported. We are fighting in cultures that are ableist in academia. We are absolutely being squeezed out. It is hard to do what feels like everything all at once. And so, there needs to be better support for the work we do, and for our own career advancement. And last but certainly not least, we have to support the expansion and improvement of disability data and disability data infrastructure, making sure it is centered on the diverse perspectives of disabled people, and supporting innovation in using those data. As I mentioned before, there's just not good funding opportunities and mechanisms currently to do, really, this critical initial first step in getting to better measures of disability. I'm hopeful that there is a turning tide on these issues, and there is increasing recognition that all equity efforts have to include a focus on disability, and that data really is central to that.

Emily Ladau:

I really appreciate all of the insight that you have shared with us today, and I hope that what people take away from this is, ultimately, listen to disabled people, let disabled people lead, and the data matters, the data is crucial. And I hope that people will continue to follow along, not just with the census data collection, but with all of the important work that you are doing. I wonder if you could just let us know where we can find you on social media to continue following along?

Bonnie Swenor:

Yeah, sure. I admit I am not on Twitter or X as much as I used to anymore. I'm mostly on LinkedIn these days, but you can learn about the center, the Disability Health Research Center at Johns Hopkins, on our website, and get to all of our social media through there. Our website is disabilityhealth.jhu.edu. We also have access to a lot of resources, and I hope you'll check it out.

Emily Ladau:

I am so grateful that you joined us. I hope everybody will go follow along. Once again, thank you to Dr. Bonnie Swenor for joining me for conversation for this episode of Disability Inclusion Required. And if you want to keep your learning journey going, you can visit the disability and Philanthropy Forum at disabilityphilanthropy.org. Again, I'm Emily Ladau. This has been another episode of Disability Inclusion Required. Thanks so much for tuning in, and join us again next time.