

On the Pulse Podcast Transcript Episode 22

Dr. Tamar Rodney (00:00:00:21 - 00:00:39:03)

Hi, I'm Tamar Rodney, and you're listening to On the Pulse, a podcast from the Johns Hopkins School of Nursing. On this podcast, we take a deep dive into the experiences of frontline providers and researchers. We explore their insights and invaluable stories of how health care works in today's world. Today, we will speak with Bonnie Swenor, associate professor at the Johns Hopkins School of Nursing and founding director of the Johns Hopkins University Disability Health Research Center. Bonnie aims to shift the paradigm from living with a disability to thriving with a disability through research, education and policy. Welcome to the show, Bonnie.

Dr. Bonnie Swenor (00:00:39:03 - 00:00:43:07)

Thank you so much. I'm so pleased to be here.

Dr. Tamar Rodney (00:00:43:20 - 00:00:55:23)

Wonderful. So, as we said, today's show focuses on disability. Would you be willing to start by sharing your own story and experience with low vision, and how that has shaped your role as a researcher and a disability advocate?

Dr. Bonnie Swenor (00:00:56:16 - 00:03:04:11)

My perspective, my motivation for the work I do, is personal. I have a degenerative retinal disease that began when I was 25 years old, quite suddenly, very suddenly, that completely changed everything and everything about my life and shifted my career. I had very sudden, unexpected vision loss that happened just a short time after I had mailed out my applications to grad school, and I had a pretty rapid loss of vision in both eyes after that. And that continues today. I continue to lose vision every year. But at the time I was very much convinced that my career was over really before it even started. I didn't know anyone with a disability, anyone who was blind or had low vision, who's a researcher. I'm an epidemiologist by training, and that's what I wanted to go to school for. At the time I certainly didn't know anyone in public health who had a disability, or at least I didn't think I did, and I just didn't think it was possible. And so, for a while I quit and I didn't pursue it. Even though I had gotten accepted. And it was a really tough time, it was a time of learning and understanding about how my life was going to be. And to be honest, it was a period of grappling with ableism. My own ableism, which is the discrimination or the devaluing of people with disabilities lives. It is such a concept that is baked into so much of society, and at that time I bought into it. That's what I was taught. People with disabilities are lesser; that if you're blind, you can't. And I had to take time and do a hard look into myself and to change that view. Eventually I did and went to school. But through that process I realized the way that I was learning about disability was quite different than I was experiencing it. And so that really does shape and drive the work that I do.

Dr. Tamar Rodney (00:03:04:17 - 00:03:24:18)

Thank you for sharing that. And I think it's so important to hear that some of those feelings are shared by so many other persons with disabilities, but you can thrive, and one of the roles that you currently thrive in is, as we stated earlier, the director of the Disability Research Center at Johns Hopkins. Can you share your work with our listeners?

Dr. Bonnie Swenor (00:03:25:05 - 00:05:00:24)

So, we have a few core goals at the Disability Health Research Center. Primarily, our work is focused on data. And we use data-driven approaches to identify and address the inequities that impact people with disabilities, people with all types of disabilities. This ranges from inequities in health care to food access inequities. Inequities in transportation and education, and employment. Inequities across the board. We're also committed to training the next generation of disability equity researchers. This is an emerging area of research and there's not enough people doing the work. That's something we're committed to trying to change. We're also working to ensure more people with disabilities, more disabled people have opportunities to do the work and are part of diversity initiatives in higher ed and in public health and health care and medicine and nursing, and to make sure are included in part of our efforts. And we center all of our work on the disability community. We emphasize our partnerships with diverse communities within the disability community, including people with disabilities from intersecting marginalized groups that face exponential levels of injustice. And we are focused on giving our work back to the community. So, from a data perspective, we view it as we take data from them and we want to give the data back to them in accessible formats and ways.

Dr. Tamar Rodney (00:05:00:24 - 00:05:10:10)

You've introduced what I think might be a very new term for individuals—Disability equity. Could you expound on a little bit of what that might mean for individuals?

Dr. Bonnie Swenor (00:05:10:15 - 00:05:45:12)

Yeah, sure. It's all about getting to a place of equity for people with disability, as much like we think about equity for other groups that face inequities. Concept of equity is giving people what they need to be successful. And there's certainly a different lens or dimension when we're talking about the disability community. People with disabilities face different sources, or there's different reasons and sources, for the inequities that people with disabilities face. And so, disability equity is the point of which everyone has equal opportunity, equitable opportunity for success.

Dr. Tamar Rodney (00:05:45:22 - 00:05:55:05)

And another point that I'd love for you to share with our viewers is what were you learning about disability that was different from the way that you were experiencing it?

Dr. Bonnie Swenor (00:05:55:05 - 00:07:31:03)

Yeah, great question. You know, in and still so, the predominant view of disability and research in health care and public health is one that is under what's called a medical model of disability. And that is a view that disability is framed as the presence of an impairment or a condition. It's largely the focus on correcting someone. And disability, as a person living with a disability in this day and age, there's largely a perspective under what's called a social model of disability, where disability is part of someone's identity, like their race, ethnicity, gender identity. And the focus is instead on making the world around us more accessible and inclusive. And so, as a person with a disability, being only taught this medical model that disability is something to correct, prevent, to treat, and trying to get through life with a disability that is not correctable, treatable, and being proud of that and very okay with that is a tough juxtaposition and felt wrong. And it felt like there needed to be more space for so many of us with

disabilities, but honestly often are pushed to the margins or pushed to keep quiet when we have the option, our disability identity, because we are taught these ableist ideas that it's a horrible thing, that you should be ashamed of, and that in and of itself, perpetuates these inequities.

Dr. Tamar Rodney (00:07:31:10 - 00:07:46:11)

That's an excellent point of view, which is why your research becomes so much more important. Part of what you're touching on is that the way that we view disability or understand it. What is something that you wish more people understood about disability?

Dr. Bonnie Swenor (00:07:47:00 - 00:09:53:01)

I just want to start by saying it's hard to pick just one because we are, as a society, at a really important time point of unlearning and re learning about disability through the lens of the disability community. So, there's still a lot to learn. And for all of the audience out there who might be new to this, that's okay. That's where we are. That's where lots of folks are and you got to start somewhere. But what I would say is that I hope people will understand and begin more to understand that people's disabilities, visible and invisible disabilities, all types of disabilities are part of all of our communities, all of them. And we intersect with all groups, racial and ethnic and age and gender identity and wherever you're from, wherever place you're at, there's people with disabilities among you, among us. The disability community is one that everyone will join if you live long enough. And that's not to be a scary thought. That's reality. This is part of life, and we need to think about disability in a different way because of that. Such a large percentage of our population has a disability, so I want people to understand the way we include people with disabilities, the way we think about disabilities matters. Because of that, we're the largest minority group in the U.S. and around the world, but not often thought that way. And so, because it's not viewed that way, the biases that impact us really go unchecked. The last thing I would say that I hope people understand, that I think is so critical, is that disability is not a bad word. Language matters and not being able to say the word disability. People are afraid to say to me that I have a disability, I'm okay with it. I'm a disabled person. And I encourage people who are new to this space to take some time and to educate themselves from the framework of people with disabilities about the language of what the community wants, of what people with disabilities are hoping those without disabilities will start using to describe us. And there's been a huge shift, and I think there's a learning curve. But to jump on that curve and to learn from the community.

Dr. Tamar Rodney (00:09:53:10 - 00:10:21:00)

Thank you, Bonnie. I think I get more enlightened the more you speak because they're such important reminders, particularly highlighting that some of them you see and some you don't see. That's one of the biggest assumptions that we all know what individual disabilities are. And if I could push you just a little bit more to take it on a country basis, what kind of policies do you think we as a country could put in place to help end some of these inequities that exist and experienced by individuals in the disability community?

Dr. Bonnie Swenor (00:10:21:08 - 00:11:41:19)

Yeah, you know, from my perspective, what we actually need is not just any one specific policy. We need to instead apply what's often referred to as a disability lens to all policies. That's a shift that I hope happens. So, it's important, I guess another thing to understand, is that all issues are disability issues

truly from housing to health care, transit, climate change, bias in AI, all disability issues, meaning they all differentially impact people with disabilities. And unless that differential impact is considered in policy, we will continue to inadvertently deepen ableism, discrimination, and inequities for people with disabilities through these policies. That's institutionalizing ableism. So, this needs to change by making sure the disability community is involved in the process of policymaking, more involved in the democratic process, and in essence, it's making sure there's better inclusion of disabled people when policies are made. And I'll also just say, it's not just at a federal level or state level, it's at an institutional level like in universities, in all places, that there's policies being made. It's important to consider the ways in which you can take an anti-ablest approach.

Dr. Tamar Rodney (00:11:41:19 - 00:12:04:13)

That's, again, a helpful reminder. And I stand in awe because it's so necessary to restate that because it seems so obvious. But thank you again for sharing that. And from a lived experience point of view as well, which makes it so much more authentic. Could you share with us some of what's your thoughts on the recent work you did on the White House Summit on STEM Equity and Excellence Program?

Dr. Bonnie Swenor (00:12:05:00 - 00:14:22:18)

Yeah, So I'm so grateful to have some really exciting opportunities to highlight really great change that's happening and change I didn't ever think I would see in my lifetime, to be honest with you. So, there's great traction for acknowledging and creating a roadmap to change the exclusion of people with disabilities from across STEM: science, technology, engineering, math. And there's another M for medicine, nursing included. And there's a recognition that people with disabilities just haven't had equitable opportunities to be included in or benefit from STEM. The Biden-Harris administration is doing really great things to change that for not just people with disabilities, but for all groups that have been excluded, particularly the Office of Science and Technology Policy, OSTP for short, has been working really hard to make a roadmap to change in bold ways the way that we do STEM from K through 12 and higher ed. So last month that office OSTP hosted a summit at the White House to unveil this roadmap. I'm grateful to have been a part of and spoke at that summit. Having the honor to represent disability inclusion perspective and at that summit was announced the formation of what's called the STEM Opportunity Alliance, which is a group of individuals who will be supporting and advising the roll out of that national agenda. STEM Opportunity Alliance is supported by AAAS and the American Association of the Advancement of Sciences and the Doris Duke Foundation. And I'm also really grateful to be an advisor to that. Such an important and exciting time. You know, when I started my career, I faced immense barriers. I still definitely do that I get frustrated about, admittedly, as a person with a disability, because I don't often see them being elevated, being addressed, being part of efforts to make STEM more equitable and to have it be a part of this national agenda is something I honestly am so grateful for. And I, like I said, I never thought I would see it in my lifetime.

Dr. Tamar Rodney (00:14:23:07 - 00:14:47:06)

I mean, we're grateful and grateful to hear that this thought that you're talking about, it's having the right persons at the table and that you get to be at that table, but also being an active voice at that table, that is wonderful. And we look forward to what that program might look like. You wear several

hats, obviously, Bonnie, and you're also a researcher. Can you share a little bit about your work? What is the latest thing that you have going on?

Dr. Bonnie Swenor (00:14:47:13 - 00:15:53:04)

Yeah, there's so much great work happening. It feels like we're really hitting the gas, I think, at this moment on disability equity research. And again, it's exciting. And I never thought I'd see this much interest. It's so hard for me to pick one. I think the most exciting and probably the most important thing that I get to do is honestly training the next generation. And that probably sounds a little cheesy to say, but it is so true. But also helping researchers who are new to this space get their feet wet in disability equity research or adding a disability lens to their work. That excites me enormously, and that includes some very seasoned researchers who are honestly really coming to this humbly and are deeply interested in making sure the disability community is now a part of things that maybe they wouldn't have considered being a part of, you know, just a few years ago. To me, that's changed. Like, that feels like a critical moment of change. But the amount of interest from the trainees and researchers coming to this table, that is the most exciting thing.

Dr. Tamar Rodney (00:15:53:17 - 00:16:08:16)

I can hear such passion in your voice and I'm sure this carries through in your work. We appreciate your part in helping people with disabilities not just live but thrive. So, it's been such a pleasure to speak with you and I look forward to hearing more about your work in the future.

Dr. Bonnie Swenor (00:16:08:16 - 00:16:25:00)

Thank you so much. And I'm so grateful for this opportunity and I'm so grateful to the Johns Hopkins School of Nursing. I just have to say that and just the unparalleled level of support from faculty and colleagues like you and staff and leadership, it's been amazing.

Dr. Tamar Rodney (00:16:25:06 - 00:16:59:20)

Thank you. And it does make a tremendous difference to have that support. So, thank you for saying that as well. And thank you to everyone for listening to this episode of On the Pulse. If you enjoyed this podcast, please share it with someone you know and subscribe through Apple, Stitcher and Spotify. You can also find us on the Health podcast network at healthpodcastnetwork.com/nurse. Be sure to also check out her On the Pulse blog. You can learn more about the Johns Hopkins School of Nursing at nursing.jhu.edu. Thank you again for listening.