Down to the Struts

Season 8, Episode 4: Disability Data Justice with Bonnie Swenor

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Guest: Bonnie Swenor

Transcript by Sean Collins

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“To Recognize that we need to invest in our scientific workforce means we need to invest in our disabled scientific workforce, and that simply has not happened.”

[music: jazzy piano and horn chords, bass and drums playing smooth R&B]

**Qudsiya Naqui:**

Welcome to another episode of Down to the Struts—the podcast about disability, design, and intersectionality, where we uncover the building blocks for a more just inclusive and accessible world. I'm your host, Qudsiya Naqui.

Today we'll be pivoting from our deep dive into disability, history, and culture to talk about another one of my favorite topics: Advancing data and research on the disability experience across disciplines from public health to the medical and social sciences, and uplifting the disabled scientists and researchers who contribute in the fields of science, technology, engineering, and math.

We'll listen in on my conversation with Bonnie Swenor. Bonnie is the founder and director of the Johns Hopkins Disability Health Research Center. We talked about the early experiences that spurred Bonnie's love of science; how her disability journey impacted her pursuit of a career in public health; and how she leveraged data and research to push for greater inclusion for disabled scientists—and for the centering of disabled people as a demographic in scientific research.

Okay, let's get down to it.

**Qudsiya Naqui:**

Bonnie, thank you so much for joining me today on the podcast. I'm so excited to speak with you.

**Bonnie Swenor:**

Thank you so much for having me. I'm really honored.

**Qudsiya Naqui:**

To get started, I'd love it if you could share a little bit about what led you to your interest in the sciences and in health sciences in particular.

**Bonnie Swenor:**

I'm Bonnie Swenor. I am the founder and director of the Johns Hopkins University Disability Health Research Center. I use she/her pronouns. My visual description is that I am a middle-aged white woman with shoulder length blonde hair.

My interest in science started pretty young. As a young kid, I was always curious and interested in how—and why—things were the way they were. I always had an affinity towards math, admittedly. And so as I, grew up and went on to college, I wanted to keep moving forward with that and wasn't exactly sure, admittedly, what I was going to do in the sciences, but I think I always knew I wanted to be a scientist or a researcher.

I started out actually working in more of a basic science space in a lab, and then pivoted towards working in public health and data science, later on. So I've been in a few places in science across my career, but have loved all aspects.

**Qudsiya Naqui:**

Are there early research projects that you worked on that particularly excited you or sort of propelled your career in some way that you can share?

**Bonnie Swenor:**

Yeah, When I was an undergrad, I actually worked in a population genetics lab and we worked with fruit flies, or drosophila, and that was really what got me so excited about science. There were interesting questions about identifying genes that led to differences in, not just in drosophila, but in people.

And, it was really exciting and interesting work, and it's where I learned to really embrace, understand, and love research. So fast forward many years after that, I started working more in, in public health and what really sparked my shift towards public health was really a very specific moment when I was, at the time, working at the National Institutes of Health in a basic science lab, and the then director of the CDC, the Centers for Disease Control Prevention, came and gave a talk.

I attended and I thought, that's what I wanna do. I wanna do that. I want to be more applied in the research I'm doing. I wanna be able to use math and to more directly impact people's lives. And honestly, it was after that I started to make a switch.

**Qudsiya Naqui:**

One of the things that's so exciting about you and your work is that you have a disability journey. I wondered if you would be willing to share a little bit about that disability journey and how that, shaped your perspective as a scientist and a public health professional.

**Bonnie Swenor:**

So I was already at a place where I was pivoting towards a more public health career when my disability journey began, I had gotten to a point where I knew I needed further education to really make that shift. I was applying to masters of public health programs. And about a month after I sent out my applications, I had a very sudden loss of vision one day on my way to work.

And it was unexpected, and I didn't really understand what was going on. I was subsequently diagnosed with a degenerative retinal disease and have been losing my vision ever since. But it was also at a really pivotal moment and I didn't really know anything about disability at that time. I didn't know any other disabled researchers or public health professionals.

And to be honest, I thought I couldn't do this. I didn't imagine that I would be able to be a scientist or a researcher because I didn't know anyone else who's blind or had a disability. And so I stopped. I did. I paused on, on all of those things, assuming that my career was really over before it began in many ways.

And that never sat very well with me. That can't be the end of, my love for science. And I started to ask questions and pay attention and, try and find other people who were doing this work with disabilities.

That wasn't many folks, it completely shaped and reorganized my approach to science and my focus. But it was, in the beginning, it felt like a formidable task because I didn't know anyone else doing the work that had a disability.

**Qudsiya Naqui:**

Were there particular resources or people or communities that, that helped you to make that transition?

**Bonnie Swenor:**

I think that the most profound shift, for me, came after I had decided to try and take, course by course, to get my way through a master's of public health program. And, where I was going, at Johns Hopkins, they allowed me to do that.

And I took a course out of pure curiosity for learning about what was going on with me in my life, called the Epidemiology of Eye Disease. I asked to meet with the instructor, whose name is Sheila West. And she was honestly one of the first people I disclosed my disability to in graduate school.

And I think probably one of the first people I really used those kinds of terms and words around; and her response, was amazing. And she basically said, without really missing a beat, “Oh, that's great. You've a lived experience. Have you ever thought about studying vision impairment and the impacts on people's lives?”

And I thought, *Wow, that's not what I thought she was going to say*. I thought she was gonna tell me all the ways I couldn't do this because she was knowledgeable and, she became my mentor and, really is fought for me and is the reason that I got through the master's program and then, subsequently, the doctoral program.

She also helped introduce me to blind researchers, which was really critical, so I really attribute a lot to her.

**Qudsiya Naqui:**

It's just incredible how meeting one person can completely transform the course of your life. I'm really happy that you were able to make that connection at that point in your career.

[warm, swelling orchestral string music, which continues under the next question]

**Qudsiya Naqui:**

What, from your perspective, are some of the greatest barriers that disabled scientists and researchers face?

**Bonnie Swenor:**

That’s such an important question.

It's ableism.

Science is the place where we are taught about our bodies. We are taught about disease, and, we are still taught through an ableist lens.

And so, to exist in those structures and in those places as a disabled person is hard and you are pushing back on ingrained notions that people are building careers on, quite honestly. All the barriers that exist, I believe are really linked to that. And I don't know that's necessarily different than in any other setting.

In research spaces, so much of how we are promoted and how our careers continue to expand and excel are based on, how others view us and score us and rank us, and those views still remain with unchecked ableism. There's profound inaccessibility in information on scientific publications in grant, portals to submit grants in laboratories in all the places and spaces that we are learning about and doing science and research.

And so, it is trying to combat at the same time the views and ideas that disabled people really don't belong in science and the lack of accessibility. And I know that is everywhere, but I do believe that changing those views in science is a critical lever or a critical place that we need to make that change because we are teaching the next generation how to frame our views of bodies and systems, and, all sorts of concepts that are undergirded by ableism right now.

**Qudsiya Naqui:**

What are some of the strategies and solutions to breaking down that ableism in research institutions and in this field?

**Bonnie Swenor:**

I acknowledge my bias towards data. I think data is really important. We don't have enough data in these settings about where and when disabled people are being excluded or what spaces and places and information is accessible or not.

Having that data, making it transparent, and using it for benchmarking doesn't answer every solution, but it helps. It helps to identify the barriers. It helps to identify the catalyst to inclusion. It helps to understand the impacts of policies and programs and strategies, but in addition, there has to be an investment.

This has to become a budget priority. To recognize that we need to invest in our scientific workforce means we need to invest in our disabled scientific workforce, and that simply has not happened. We don't have the same programs and support structures and initiatives to include disabled people and research and in science like we do for other groups that face barriers. That's something that needs to change.

There's too often in these places of research, in institutions and academia, a massive disconnect, or a lack of a flow of information, between people with disabilities doing the research, or in the educational programs, and leadership. And that is a problem.

We need to build bridges and connections to leaders making decisions and disabled people and value that feedback. And that also includes people, outside those institutions from the disability community. I think that far too often we don't have disabled people in leadership roles.

And, that includes people focusing on disability equity and inclusion issues, but also far beyond. That really is something that needs to change. Disabled people should be in all places decisions are being made, and that's absolutely not happening enough in science and research.

**Qudsiya Naqui:**

You've spearheaded some initiatives to further facilitate the, not just representation, but the meaningful contribution of disabled scientists. Could you share a little bit about some of those things you've done in your own institutions [and] in the spaces that you've been in?

**Bonnie Swenor:**

At the National Institutes of Health, that is something that I was pushing—as were many of us, for so many years—and it feels like we're at a moment where things are starting to change in a good way. And, I, at the beginning of my career, when I transitioned onto faculty, I faced so many barriers in having access to content that was accessible and facing ableism and discrimination.

I started really asking questions, including of our federal funding agencies, if there were resources, if I could at least be connected with other people at my level of, research experience to get advice, and no one seemed to know what I was talking about, really was just even surprised I was there.

And so I decided to do what I knew how to do. The only thing I know how to do, which is research and I, published data that I obtained through a Freedom of Information Act request on the percentage of, people with disabilities that have received grant funding from the NIH, the National Institutes of Health, to do research.

And it was over a decade of time and it was profoundly low. It was less than 2 percent, and declining over that 10 year period. I really, did that work with my colleagues out of frustration, out of anger. I did it, to try and make myself feel better admittedly. And, what it, to my surprise, led to is people then using it to help advocate towards the NIH to make change.

A committee was formed in 2021, and I co-chaired that along with Lisa Iezzoni from Harvard and Steve Barnett from Rochester. And it led to a set of recommendations to the NIH to address the ableism, and support the inclusion of people with disabilities in research studies and in research careers.

And that was unanimously endorsed by an advisory committee to NIH leadership. And things are moving forward still as a result of that. And that is not something I could have ever imagined would happen in my lifetime, and is been a really great outcome

**Qudsiya Naqui:**

That is so incredibly powerful and I love the fact that you took the thing that you are most passionate about, which is research, and leveraged it to do such tremendous advocacy. It wouldn't have happened if you hadn't had that fire of sort of righteous rage, which fuels so many of us.

So in addition to this problem of underrepresentation and the accessibility barriers that prevent disabled scientists and researchers from meaningfully contributing to the sciences, we also have the very much related concern of lack of research about the disabled experience and the lack of representation of disabled people in scientific research in general because of similar problems.

[quiet, echoing orchestral horn music, which continues under the next question]

**Qudsiya Naqui:**

You published a [really interesting piece in Health Affairs](https://www.healthaffairs.org/content/forefront/need-disability-data-justice) about a need for disability data justice. We talk a lot on this podcast about disability justice as an organizing framework, but what is disability data justice?

**Bonnie Swenor:**

Disability data justice really is all about using data to advance equity and justice for disabled people. That situation I just described with using the data I obtained through the Freedom of Information Act request, enhancing advocacy efforts, and then the recommendations to the NIH—to me that is an example of that right there.

We didn't have the data. We knew it existed, but we couldn't access it for a variety of reasons. Disability data justice is about eroding those barriers and those walls to data that are absolutely essential in, in getting us to a more just world and society for disabled people.

**Qudsiya Naqui:**

Something that I've been thinking about a lot [is something that’s] a significant issue of debate right now: This question of how do we even define disability to be able to disaggregate data based on disability status?

I know there's a debate around the [US]Census shifting from the American Community Survey six questions on disability to other types of models. And I wondered if have thoughts or advice about how we can better disaggregate data on people with disabilities?

**Bonnie Swenor:**

The principles of disability data justice that, we've put forward, I think are in support of that.

It's really about expanding the collection of disability data [and] including disability as a core demographic component. So when we are talking about, disability data in opportunities to advocate for this, we talk about a disability data in all places policy. So, what that means is every place for collecting data on race, ethnicity, gender identity, age, we should be collecting data on disability.

That will support the view and analyses of, examining the profound inequities that disabled people face and realizing that disability issues are not to the side are some subset of issues. All issues are disability issues.

Additionally, that expansion of disability data would allow us to, as you are indicating, disaggregate across intersectional identities so we can better understand the elevation of injustices and inequities that people, disabled people, from other marginalized and oppressed backgrounds face.

We also really do need better data on all of the wide web of inequities, impacting disabled people together, so we can make substantial policy change.

But part of disability data justice is about improving the ways in which we collect and capture disability data, like you alluded to. We need what we call a growth mindset on disability data collection.

Our current approaches and standards are inadequate. And there's evidence that shows that. The move in Census, or the proposed move from the ACS six questions to the Washington group questions, would be a move backwards. It would undermine the opportunity for us to use the currently available data, flawed as it may be, and that is a huge concern.

Additionally, part of this approach is that disability data collection use has to be informed by and centered on the disability community. That includes diverse perspectives of disabled people. And again, the Census issue is elevating when that doesn't happen, how things break down. Our data really needs to reflect the current views of disabled populations to really use data how it should be used—[which] is to understand the issues impacting people with disabilities.

Then it's critical that we consider transparency and accountability, and that means making data accessible. That means making our results accessible to disabled people. That means making data sets accessible to disabled researchers, and providing data and accessible formats using accessible tools to analyze that data.

Those all are really critical steps to disability data justice. We have miles to go, and we certainly do need more disabled researchers working on data issues. That just brings a really critical perspective.

**Qudsiya Naqui:**

That's a really helpful breakdown of all the elements of challenge, and also how disability data justice principles can help us get to better solutions that are more driven and centering of disabled people.

Bonnie, are there any projects that you're working on right now that are particularly exciting that you want to share?

**Bonnie Swenor:**

There's always so many fun things we're working on, and always excited for the opportunity to share. The project I've been so invested in for a number of years is developing a disability equity index and a related scorecard or dashboard.

So what this project is about is trying to assess or develop a way to understand how equitable a community or a space is, for disabled people. It's a complicated approach, but it's similar to the approaches we have used to look at equity indices for other groups, such as, indices of racial equity.

And we don't have such approaches for people with disabilities, which means we don't have that type of quantifiable information to help highlight the barriers that we as disabled people face all day every day. We have a little bit of funding and we have a fantastic disability community advisory panel, and we are starting the work with the community.

We're holding community convenings to inform the metrics that we will use to develop the index. And we are hoping to get more funding to grow and scale that project.

**Qudsiya Naqui:**

What would be your vision in terms of how the index could be used?

**Bonnie Swenor:**

The full vision is that we would end up with an accessible dashboard that would be publicly available and people could interact with the information.

You could imagine that maybe you would want to look at, what's the disability equity index for my community? What's the disability equity index for my state? And how does that score or index relate to things like, employment outcomes or, educational attainment within the area?

The idea here is that equity is not just one thing, it's this intricate web, and we are hoping to develop and a strategy to put some numbers behind the deep barriers that disabled people face and give that information back to the disability community.

I also hope that researchers would use it, and that policymakers could use it to develop better evidence-based strategies, programs, and policies.

**Qudsiya Naqui:**

Thank you for sharing that. Bonnie. Where can our listeners find you and your work?

**Bonnie Swenor:**

If anyone wants to learn more about Mm center, which is the Johns Hopkins Disability Health Research Center, they can go to [disabilityhealth.jhu.edu](https://disabilityhealth.jhu.edu/). And from there you can link to our recent projects, our news, our initiatives, and we sometimes have seminars, and we have a (recently on hiatus) podcast as well called Included, and you can get there from that website.

**Qudsiya Naqui:**

Thanks so much, Bonnie, for joining us. It was such a pleasure to learn more about you and your work.

**Bonnie Swenor:**

Thank you. I'm really truly honored to be on the show. Thank you for all you do.

[upbeat instrumental hip-hop music featuring a heavy drum beat with a spirited brass sample looping over it]

**Qudsiya Naqui:**

Thanks for listening to Down to the Struts. This episode was produced by Ilana Nevins and me. Our social media manager is Avery Anapol. With special thanks to Claire Shanley for designing our logo, and to Eiffel Gangsta Beats for our theme music.

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