

[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'm Bonnie Lin 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 inviting back Sandy Ho to discuss her efforts to expand intersectionality of disability identities. Sandy Ho is a research project manager at the Community Living Policy Center as well as a community organizer in the Boston area. In addition to her work on civic engagement, she focuses on intersectionality. She is the founder of the Disability and Intersectionality Summit, a biannual national conference that centers the multiple pressures that shape the lived experiences of disabled individuals as told by disabled people in a setting organized by disabled activists. In 2015, she was recognized as a White House Champion of Change for her work in mentorship of young women with disabilities in Massachusetts. Sandy identifies as a queer, disabled, Asian American woman and a Red Sox fan.

[Music by Molly Joyce 01:45 – 01:53]

Nick: Thanks so much for joining us again, Sandy.

Sandy Ho: Happy to be here.

Nick: I wanna start talking about your work advancing the inclusion of intersecting identities in disability research and advocacy. Let's start by discussing what intersectionality means. I know that this might be a new term to some in our audience.

Sandy Ho: Okay, yeah. I think over the years we have all seen and heard and read the word intersectionality more and more, and I think that use can sometimes have the unintended consequences of misuse, misinterpreting. Yeah, and I also encourage folks to do their own homework and to read into this a lot more, but when we talk about intersectionality, important to also acknowledge that this comes from Kimberlé Crenshaw, a black woman who is many things, but among them, critical race scholar, civil rights leader, and I think that when Crenshaw first was developing this framework of intersectionality it was based off of the court case *DeGraffenreid v. General Motors* where a judge had argued and decided that a black woman could not possibly be experiencing two forms of discrimination: racial and gender discrimination. Crenshaw, through this

case, developed this framework of intersectionality that I see and understand it to be a tool to better analyze the ways power can land differently for folks. When somebody has multiple marginalized identities, privilege and power are connected in various ways depending on what those multiple marginalized identities are. I think this is important because in the context of some of our, even like social justice circles, even in progressive circles, intersectionality is sometimes perceived as like a layering of identities, but then you need to take it to the next step of like, okay, this is why this is important in developing policy or framing other priorities, for instance, because we need to recognize that not everybody is affected in the same ways.

Bonnie: Yeah. What, from your viewpoint then, is the reason to focus on intersectionality in the disability community? Can you share with our audience, particularly again those who may new to this concept, sort of bringing that to disability and how we should be conceptualizing and utilizing that?

Sandy Ho: Right, so intersectionality is one of the principles in the Disability Justice Framework, which was developed and founded in 2004-2005, and I encourage folks to check out materials from Susan Ballard about that, but this Framework that was developed by disabled folks who are gender nonconforming, trans, LGBTQ, disabled people of color, was specifically to address ableism. In the sense that we have the Disability Rights And Independent Living movements, which are necessary, which have made progress in our society. This Framework points out that equality and access to laws is not enough, it doesn't beget and facilitate justice. What is important about this in terms of disability and intersectionality then is ableism, as a form of discrimination that disabled people experience, but also want to add that you don't need to be disabled to experience ableism, that it is intertwined with racial, sexual identity, class, with immigration status. These together, collectively, inform the ways that disabled people, who experience marginalization in other ways, do not have access to certain rights or power and privilege in the ways that disabled folks, who may be white or who are privileged in other ways, can.

Nick: That was well-said. It's got me thinking a little bit about academics. Building off of this point, could you talk about from your perspective why is it so important that academics include a lens of intersectionality in disability research?

Sandy Ho: Yeah, I mean, I'll use myself as an example. I've been at the Lurie Institute for a little over three years, and if you had told me like five years ago that I would be doing academic disability policy research, honestly, I would have rolled my eyes and laughed and been like, I don't know what you're talking about. As somebody who had a college degree and was

living on social security, The Disability And Intersectionality Summit was what I was working on. I mean, I had side hustles and side gigs, like many and most disabled people that I know, but I never perceived and thought that academic research had a place for somebody like me. I don't have all the fancy letters after my name, I don't have a million page CV, and I'm not published in all the right peer-reviewed journals. What we know about academia already is that it is not the most welcoming, not the most inclusive, not the most equitable place for disabled people, period. Then, on top of that, it is also not a place that is assessable for disabled marginalized folks. When we think about tuition, when we think about access to resources, to like be able to pursue an education.

When it comes to disability research then, the folks who have been in leadership positions that have really been seen as the pioneers or like the folks who have really started and led this area, are often not representative of the folks who are most impacted by the areas of disability research that is being done, including civic engagement or public health. What happens is we have this whole community and population of folks who are missing from that pipeline of professionals in disability police and research and access to places like the Lurie Institute, and so, when that happens, then you can continue that cycle and it doesn't really address systems of equity or ableism or justice. Being able to have folks who may not come from your usual [*unintelligible 09:42*] of PhDs and their research, and then NIH, NROI, and all of this is helpful because then I can be the person present to say, well, if we give participants an honoraria or a stipend, this may impact their Medicaid or food stamps or Social Security. Yes, it's great and we should, absolutely pay for people's time and labor to participate in our studies, but let's also recognize like what it means for this community that we want to involve and engage in to do this research with us.

Bonnie: Yeah. It is so important that you shared that, so I do hope that all the academics and academic leaders are paying attention particularly to this part of the conversation because you're right, this is a gap that has to be closed to address societal change, right? The change in academia has such broad impact and is, in my mind, the hold out in a lot of ways, right? We need to reexamine what an expert is and does a degree really confer expertise, right? Or just education? For the disability community in particular, I think it is beyond time to reexamine that, as you stated. We are experts of our experience and there's been structural barriers for us getting the education needed to gain entry, right? We still are the experts, but we've been denied access in all the ways for way too long. Thank you for sharing that. Can you talk more about the Disability and Intersectionality Summit? What is the mission of the Summit, and can you share with our audience when this occurs?

Sandy Ho: Sure. The mission is really to have a community space that is prioritizing, that is uplifting disabled people of color who are also marginalized in other ways. Whatever it is that they want to speak upon or present upon or share, and I want to underscore that piece of it because in my time in academia at least, I'm used to being at conferences that ask for certain like topics or a submission or conference proposals and things like that. Like you submit an abstract. Whereas, DIS, the Disability and Intersectionality Summit, is really a community space. We're pretty direct and explicit about like we don't care about the abstract. We are not interested in the findings and that, so much is like the way that it is traditionally presented, and so, for too long, and I think in some cases, this still happens today, disabled people of color in particular are often asked to participate when there's a need for, quote/unquote, some diversity. This is an area that we were talking about previously that our community needs to and should do better about. By having a community space that really just let's folk present and share about whatever it is that they want to, rather than responding to the latest breaking headline or policy agenda, it becomes more about remembering the fact that our community also is working on our projects, on our own passions, and our own areas of expertise, whether or not somebody is asking for it.

This space is designed and created by disabled activists from across the country, so it started in 2015-2016, and it was really something that was created because we saw that it was missing. That there wasn't really a place for my friends and myself to feel like we had a home in movement work or in our community. That phrasing of nothing about us without us is certainly present in this community space, but also, like the fact that it is designed with access in mind. That includes everything from access to food, paying our presenters, screening, online recordings, one thing that we have learned during this pandemic, as many conference organizers have as well, is the freedom, but also kind of the creativity that comes with designing a community space online. That's something that we have been learning to do and so, rather than being restricted to a certain date and space, our Summit this year has been going on since June and will end in December. It has covered a number of issues already, including we had a panel of disabled guest doulas. We had presenter Justice Shorter, who talked about the importance of building back blacker in terms of disaster strategies. We've had folks talk about experiences of climate and the environmental impact of somebody who is a disabled surfer from Puerto Rico. We are going to have, I think it's 11 more sessions, and it is open to everybody online. You don't need to pay a cost to attend. We do record all of our sessions, so we will be uploading them to our You Tube channel early next year. It's a place that I hope also can sustain on its own.

One thing that we've talked about as a group is the power and privilege that comes with being a presenter versus being an organizer. I think many

disabled folks are invited to be a presenter, whether it's in academia or in other places, but don't necessarily have a role or an opportunity to play in designing that conference or agenda. What we do is we cycle out, so there are some organizers who have been there since the beginning, but we have created a system that we willingly and enthusiastically invite the presenters of the conference to be the organizers for the following conference. That way we can continue to improve in our community, and activists can expand their own skills as well.

Nick: It's just amazingly innovative of you. I mean, what a wonderful concept. As an academic, it shouldn't sound radical to let people talk about what they want to talk about, but it sounds so radical, right, because it's just not the way conferences are put together. That's amazing. Sandy, where can people find more information about this? Are there any specific websites or any resources that you can share?

Sandy Ho: All right, so our website is DisabilityIntersectionalitySummit.com, and then our Twitter is @DISummit_ORG. That's usually where folks can find most recent, updated news and events that are happening, including like the next months sessions. Then, our website does have all of our YouTube videos that have already been recorded from previous conferences, so people can look for us on YouTube for our YouTube channel, or head to our website.

Bonnie: I strongly encourage all of our audience to check out the Summit, even if you're new to the disability space, curious, wanna learn more, it's amazing. Thank you so much, Sandy, for being our guest, for all of the incredible work that you do. I must personally share I've learned immense amounts from Sandy over quite some time, and I view her as a friend, colleague, and mentor, and I'm grateful for all that you've done for our community.

Sandy Ho: Thank you, Bonnie, and likewise.

Bonnie: Thank you. 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 Prateek Gajwani, Curtis Nichimoto, 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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