**Down to the Struts**

Season 4 Ep. 3: Disability Solidarity

Host: Qudsiya Naqui

Guest: Sandy Ho

Transcript by Qudsiya Naqui

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**Introduction**

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Hi, this is Qudsiya Naqui. Welcome to a new year and another episode of down to the struts, the podcast about disability designed and intersectionality. Today we're sharing the third and final interview from our series of interviews with contributors from Grace Bonney's book, Collective Wisdom. It's not too late to grab a copy of Collective Wisdom from your favorite bookseller. Today, we'll listen in on my conversation with Sandy Ho, Sandy is an activist and scholar and creator of the Disability and Intersectionality Summit. Sandy and I talked about how she established the Summit and the importance of creating space for disabled an intersectional voices in a disability justice framework within academia. Okay, let's get down to it.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Sandy, thank you so much for joining me on the podcast. I'm really delighted to speak with you and I'm so looking forward to our conversation. Could you start off by introducing yourself and telling us a bit about what led you to your disability justice, activism and scholarship?

Sandy Ho:

Yeah, absolutely. Thank you so much for having me. A lot of my friends and folks that I look up to in the disability community have been featured on this podcast. So I'm really thrilled to be in such great company. And so a bit about myself. My name is Sandy Ho, my pronouns are she hers, and I identify as a queer, disabled Asian American woman. I am short statured. And I'm a wheelchair user, as well as somebody who has hearing loss. So I wear two hearing aids, and my story, and what led me to disability justice activism as succinctly as I can put it, so I’m the child of refugees and immigrants. So my mom was born in 1960, in Hanoi, Vietnam, so in the midst of the war, and my father is from Hong Kong, and they came to the States in the early 80s. and settled in the Boston area, and I am their second child of three children. I have two brothers, and I'm also their only child who has a disability. And so my story, I guess, really starts there. Aside from being a child of the 80s, and growing up in the 90s with, you know, surrounded by all of the wonderful 90s Fashion sensibilities, I really benefited from the disability laws and civil rights that came about during this time, particularly, you know, I started kindergarten in 1990, so when the Americans with Disabilities Act, came into being and benefitted, of course, from previous civil rights and independent living movement, disability rights activists, including folks who enabled 504 to happen, IDEA, and you know, allowed me to be a kid and have access to great public school education and services, and, you know, had an IEP plan growing up. And so that was very much the start of my disability understanding was, you know, I have access to these “special accommodations.” It wasn't really until after I graduated from college, that I started to think about and wonder, Where is my place in the broader society just in general, but also kind of like, what is this part of my identity as a disabled person? And what is my role in this disability community? And so I started working at Easter Seals, Massachusetts, I was the program coordinator for a mentoring program called Thrive, which, at the time, it was the first mentoring program that focused on providing mentors for young women with disabilities between the ages of 14 to 26. And unlike many of the existing youth programs for youth with disabilities, this program partnered the young women with older disabled women. And so that was kind of my first foray into community organizing community bonding and exploring this identity of being a disabled woman. And at the time it was, like 2004/2005. And you know, myself trying to figure out my own disability identity as, as a disabled woman as well. And after, like four or five years in that position, I started to wonder what else? Like, what, what is the rest of the disability community like, and what are the other stories that I wasn't necessarily hearing about, and specifically, those who were disabled people of color. And I realized that a lot of the headlines at the time, including police violence, including climate justice, including incarceration, were not new to the disability community. And just, you know, from listening to elders who are disabled people of color, you know, talking about that this isn't new. And it's not something that disabled people of color, and also disabled people who are marginalized, and other ways, have had the space and platform to speak from from their lived experiences. And it was around this time that I came across this group called Sins Invalid, Patty Byrne and and the work of the disability justice framework, and, you know, learning more about why this framework was developed, and learning more about the ways that ableism is, and, you know, requires your understanding, not just intersectionality, but the ways that power and privilege inform disability experiences, in terms of racism in terms of, you know, gender, sexuality, race, ethnicity, in terms of immigration status. And I think that really kind of gave me a firmer footing, I guess, you can say, to develop and create a space, called the Disability and Intersectionality Summit with my friend at the time, Melanie Kumar . Also, you see more people of color, who are activists from across the country. And we saw that this was a space that was lacking in the sense that, unlike academic conferences, right, so where presenters are expected to have all the right letters, after their name, are expected to have all the right publications on their CV and abstracts and how incredibly inaccessible that world is for many disabled folks, particularly multiple marginalized disabled folks. So we created a space that's organized by disabled activists for disabled people of color. And they are the presenters, they are the experts of their own minds and their own issues. And we are very explicit in saying that, you know, this is not an academic conference, although it is welcoming to anybody. And that's kind of where my disability justice activism started. It was the first DIS conference started in 2016.

Qudsiya Naqui:

Thank you so much, Sandy, for sharing your story. And I want to dig back into the DIS event. And I have so much more to ask you about that. And I really appreciate the idea of breaking down the barriers even in an academic setting, which can be very exclusionary, for people with disabilities and also to people of color and people in those intersections. But first, I wanted to circle back to something you had said earlier about, you know, your first kind of foray into exploring your identity as a disabled woman. And that was through your mentorship experience. And part of the way we connected was through the promotion of Grace Bonney's book, Collective Wisdom. And you have a contribution in that collection of essays, in which you're in conversation with Alice Wong, who is wonderful and was also featured as a guest on this podcast. I wondered if you could talk a little bit about your relationship with Alice and how you met and kind of how that collaboration or relationship unfolded and, and how that has shaped your perspective of being mentored by someone. Having been a mentor yourself as well.

Sandy Ho:

Yeah, absolutely. So, Alice Wong is the big sister that I never had. But I am so incredibly honored and privileged and love that we do have the relationship that we do have. It's one that I treasure, that I, you know, I hold so dearly. And the way that Alice and I first met would have to take it back to I think it was may 2014 or 2015. So I was the program coordinator at the Thrive mentoring program working with disabled young women. And, you know, similarly to I think many of our experiences as young people who are kind of “encouraged” by whether it's our guidance counselor's at school, whether it's our parents, you know, to check out this like youth program for other kids with disabilities. For some of the young people it was, you know, they were ready, they were interested, they were eager to explore. And for many of the young people, and young women in this program, I guess, weren't quite there yet. And were a little bit hesitant to really connect and and get to know their mentors better. And so one activity that I had folks do to kind of get folks more comfortable with one another was to write letters to their younger selves. And it was really you know, about whatever they wanted. And so I had the mentors do that. And then I also encouraged them and the mentees to do it. And I asked that they share it with one another. And then with their permission, I posted it, I posted these letters on a Tumblr. So that probably dates me that too, in terms of social media, you said, but one thing that I didn't realize that would happen, because of the power of I think, not just social media, but this sense of community bonding and shared experiences, is that I started getting letters from disabled women from across the country. And then around the world was around this time, when I was just Googling for disabled women, I would literally just open a browser and type in w with disabilities, authors, painters, artists, athletes, politician, whatomenever have you. And in one of those Google searches, I came across this person named Alice Wong who, at the time, I believe was just starting the Disability Visibility Project. And I came across this piece that Alice had written that was submitted to a peer review journal, during her time in academia. And I started learning more about Alice and her story. And, you know, the fact that she's also an Asian American woman, and I cold emailed her. And this is I will preface this by saying, you know, this is not something that I actively encourage folks to do. I think we can all respect the boundaries of people in our community. But, you know, for whatever reason, Alice responded and was open to a Google Hangouts meeting. And that was when I first met Alice. And then she gave me permission to re-post a piece, an essay that she'd written onto the Tumblr. And really, since then, there's just been no looking back. In 2018, after the Disability and Intersectionality Summit ended, I flew from Boston to Chicago, and I got on the California Zephyr train that was headed towards the Bay Area in San Francisco. And I had known for a while that that was a trip I wanted to take by myself, because of the history of the disability rights movement, and, and also because by then, by 2018, so many of my friends in the disability community were in the Bay Area. And so it was in 2018, that fall that I first met Alice Wong in person. And then you know, Mia Mingus and Ellis and I, during that, in person meetup, we developed the plan for the Access Is Love Project, which is based off of Mia’s 2018 keynote speech for the DIS and yeah, you know, Alice keeps me in line, Alice encourages me, Alice is always my biggest champion and cheerleader and we kind of just keep each other in check. And in balance, you know, we do all the big sister things that she, you know, makes sure that I'm taking care of myself, but also she will send an entire cheesecake across the country. And then she'll also do things like, ask me what else she can do to help promote the things that I'm working on. And so, you know, having Alice as a mentor, as a friend, as a co schemer, in this work is, is such an incredible experience. And I hope that every young disabled person finds their person as well. They might be somebody who's older and might be somebody who's younger might be somebody who's the same age. And I think that's one of the misconceptions about mentorship is that it doesn't have to be somebody who's “more experienced.” But I think that's what gives our relationship and our friendship and our mentorship so much dynamic, fun time. And yeah, it doesn't really feel like work. It feels like I'm in community with an incredible friend.

Qudsiya Naqui:

That was such a beautiful story. And thank you for for sharing the the history of your relationship with Alice. And I also cold emailed her—poor Alice! That's how I first got in contact with her. But I found her to be incredibly generous. And I feel really lucky to know her also, and I am so glad I get to know you as well. I know I've seen her post your work, I was just listening to a piece you had both written in print and recorded for the Disability Visibility Blog about home and community based services. And I'm so glad that we're able to amplify each other's voices in this way. And so that leads me to talking a little bit about the Disability and Intersectionality Summit. I also was reading back in 20, I think it was 2018, Alice did an interview with you that she published about the experience of planning the summit. Can you tell us a little bit about what your vision was for that? And what went into executing it and what you hoped would come out of it?

Sandy Ho:

So in 2016, at that first gathering, my friend and I were organizing this, we just thought this would be a cool and fun and needed community space, where we wanted to explore what it would take and what it would be like to really implement the disability justice framework within our organizing practices. So in the way that you know, you have, I think, as much as possible. Now, I think that there are minimum events. You know, think about and consider best practices for disability rights, inclusion and accommodation. We were trying to center Access and Disability Justice framework and practices, for example, leadership by the most impacted. So centering presenters who didn't necessarily have a platform already, who are community didn't necessarily already hear from who may not have the education privilege or the employment privilege, that would have allowed them to travel to conferences to submit proposals to, you know, had even presented at conferences before. And we, as a team put out this initial call for proposals, it was just your quick and dirty Google Forms and asked for what folks wanted to present on, we didn't really have a structure or a theme to it. We kind of called it “TEDx Lite” in the sense that people would have a certain quick chunk of time to present on a topic of their specialty or their interest or passion, and then share that with the community. And, and that was different in the sense that I think for many marginalized disabled people of color, still, our broader disability community tends to reach out in ways that can be tokenizing that can be a little bit dismissive of the actual lived experience of disabled people of color. And, and rather than prioritizing and centering what our community has learned, as you know, us as our own strategy for survival, for advocacy, for movement-building work. This was about sharing the stories that mattered to our community because they wanted to share it not because it was in response to a congressional priority, not because it was in response to a breaking headline. And what we learned was, I mean, that first year, we were literally in just a tiny conference room that we had rented out for the day in this nonprofit building that had one elevator, and we were crammed into this space that No, I think, given the pandemic and what our reality is like now is just like, so cannot even perceive that in today's context, but it was just a full day of presentations. We had folks presenting, you know, resources that were available to undocumented disabled immigrants resources, experiences of disabled people of color who were formerly incarcerated and the topics that we knew were important, but weren't necessarily being heard from by us and from us. And so the vision, it really wasn't something that we thought would become such a community space and has grown in the way that it has. So in 2018, we had it at the MIT student center. And it grew in both number and days, we had it over the course of two days, folks from Canada, from California. It was just such a massive undertaking, but always we tried to center access at the core. So this included things like ensuring that we would always livestream the session, and that we were always, you know, have ASL in every session. And not just because somebody who's deaf requested it, that we would have captions available, that food would be accessible, that parking was available and ways of, you know, having attendees take breaks, whether it was through art therapy, or some other decompression way, we wanted this to be a community space, where we can really envision the alternatives to your typical standard conference setting, and what it looks like to value and we consider who gets to hold knowledge, who gets access to present that knowledge, and how that knowledge is shared within community. And so that has become kind of our way of imagining, and so each year, this is an every other year conference. And so because of the pandemic, instead of 2020, our our conference is ongoing in 2021. And it's completely remote. And we’ve also been thinking about sustainability of our movement, another one of the Disability Justice principles, will also recognize the privilege and power that exists between being a presenter versus being an organizer. And many folks in our community, particularly disabled people of color are often asked to conduct free labor, that organizing is not something that we do because we want to but it is for our survival for the ways that we take care of one another in our community. And so the way that we have tried to implement a sustainable structure for this, is to invite the presenters of the previous conference, to become the organizers of the Next Conference. And so that cycle allows not just new ideas and new perspectives and new ways of doing, but then, you know, it really becomes not just about Sandy Ho and, and and the original team of organizers, but it becomes a space for the community. And so that's something that we continually try to work on. Because with any organizing, I think hierarchy is difficult to navigate and, and you know, structures needed. But I also recognize that like being the public face of the Intersectionality Summit, people are really quick to to look to me for things, but I'm always kind of trying to remind folks that, you know, there, there's a whole team behind us. And there's a whole community of past and present organizers of the summit, who are also presenters. So I guess that's kind of my thinking. And, you know, I hope that it is a space that continues to exist. For folks,

Qudsiya Naqui:

that is wonderful. And I appreciate the the detail that you described in terms of what it took to put this together kind of how it started and how it's evolved over time. I think a space like this is so important. And I hope that it continues for for many, many years to come. And I hope I can attend it one day and meet all of you in person and get to know the community. I feel like my activation and my connection with this community is really new. And I'm again, I'm so moved by everyone's generosity and openness. And I hope that I get a chance to meet everyone in person one day. So I wanted to wrap up by asking you, you know, we've talked about the summit, we talked about your views about mentorship and your relationship with Alice and then your relationships of mentorship with others. What advice would you want to impart to the disabled women of color, particularly young women of color, who are coming up now into the movement and into the community? What What advice do you have for them?

Sandy Ho:

Oh, my gosh, so much. But I think that the most important takeaway, if I could impart anything is you shouldn't feel obligated or the expectation Shouldn't be to do, “disability work,” please like, find ways to do what it is that you want to do. And I think that, you know, finding your community of folks that will support and guide and nurture your own passions and what you want to do with your future is the best way that we as a community and movement can continue to uphold both disability rights and Disability Justice work. I think that when we get to a point of, you know, expecting disabled people of color, in particular and disabled women of color to always be doing this work, it's, it is no wonder why we we are seeing so much burnout, it is no wonder why we are seeing so much frustration and kind of a feeling of being lost in the movement work. Because for some of us, who are up and coming, it might be because you're not in a place that is really, I guess, seeing you for who you are. And rather they want to see you for what they want you to be for them. And I think that's important to always keep in mind is the only person and the agenda that matters is your own. And I think finding people who will help develop that and give you the space to to explore that is probably the best thing to do. And so that's why it's folks like Alice Wong in my life, folks like Harilyn Rousso, who’s book, memoir, Don't Call Me Inspirational: A Disabled Feminist Talks Back was really such an influential book in my life that I read when I when I was working with the young women, but it's finding the other possibilities of being, whoever it is that you want to be.

Qudsiya Naqui:

Thank you so much, Sandy, for that wisdom. I appreciate that you were here and took some time out of your very busy schedule to talk to me and to share your story. So thank you so much, Sandy,

Sandy Ho:

Thank you for having me.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Thanks for joining us for this episode of down to the struts. This podcast would not be possible without the energy and creativity of audio producer Elana Nevins and our social media manager Avery Anapol. If you'd like to become a patron and support the awesome team that brings this podcast to life, you can visit www.patreon.com/downtothestruts. You can also join our Facebook group down to the struts podcast, and follow us on Twitter and Instagram at down to the struts. Finally, don't forget to subscribe, rate and review the podcast on Apple Podcasts, Spotify, Stitcher, or wherever you love to listen. Or you can do none of that and simply enjoy the conversations that you find here. Stay tuned for Episode 4, coming into your feeds on January 18. We'll hear from Erika Rickard of The Pew Charitable Trusts about the role that technology has played in our civil legal system, how it affects disabled people and what that means for family and financial stability for millions of people across this country. See you in a couple of weeks so we can get back down to it.