

May 2018 *Solidarity Is This* Podcast Episode 11: Disability Solidarity

Guest: **Alice Wong**

Host: **Deepa Iyer**

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DEEPA: Hello, everyone! Welcome to *Solidarity Is This*. I'm your host, Deepa Iyer, and I'm so excited that you're joining me for the May episode of our podcast. This podcast explores solidarity practices and messages and talks to activists all around the country who are exploring what it means to be in transformative solidarity with each other. You can subscribe to the podcast via iTunes. You can also find past episodes there, and you can download the Solidarity Syllabus at www.solidarityis.org, which contains information and resources for each episode.

May is one of my favorite months, and it also happens to be Asian/Pacific Heritage Month. Did you know that Asian Americans are the fastest-growing race group in the United States? Now, while the myth of Asian Americans being the 'model minority' persists — you know, the one that says that we're all spelling bee champions or math whizzes or Silicon Valley entrepreneurs — still, we are an incredibly diverse community, socioeconomically, linguistically, and in so many other ways. The Asian American/Pacific Islander moniker is a constructed identity. It's a political identity that really enables our communities to come together with a united voice on issues of concern to all of us, from health to immigration to housing.

And it's from that vantage point that I am excited this month to welcome Alice Wong to *Solidarity Is This*. Alice is a disability activist. She's the founder and director of the Disability Visibility Project, a community partnership with StoryCorps and an online community dedicated to recording, amplifying, and sharing disability stories and culture. She created it in 2014. Alice is also a co-partner in two other projects: DisabledWriters.com, which is a resource to help editors connect with disabled writers and journalists, and #CripTheVote, a nonpartisan online movement encouraging the political participation of disabled people.

Alice, welcome to the podcast.

ALICE: Thank you so much for having me, Deepa.

DEEPA: So Alice, tell me a little bit about what got you into your work to promote disability rights.

ALICE: It took me a long time to think of myself as an activist. In a lot of ways, I couldn't help becoming one, because the society that I live in is hostile and inaccessible to me because of who I am. And at first it was just about advocating for myself, but as I grew up and became more

politicized, I realized systemic and institutional change is the only way to move all of us forward.

DEEPA: And Alice, if you don't mind, could you share a little bit about your own personal story?

ALICE: I'm a daughter of immigrants. My mom and dad moved from Hong Kong—of all places—to Indianapolis, Indiana in the 1970s, so I'm one of those rare Asian American Midwesterners. We do exist, we're everywhere, we're just not always – like, everybody thinks about East Coast and West Coast, but there are Hoosier Asian Americans.

I was always in the room as a kid as either the only Asian American kid or definitely the only disabled kid in a wheelchair. And very often I never saw anybody that looked like myself for years. And that really made me feel lonely. And if you want to know more details, I can also share that I have a neuromuscular disability, which means that all of my muscles are affected, so it's progressive. When I was younger, I could walk, but I started to need to use a walker as a child, and then I started using a wheelchair. This is just the way my body is and it's been a process of adaptation. A lot of people don't realize that disabled people are pretty savvy – they really do know how to adapt and innovate and hack their way into living.

DEEPA: I know I've been lucky and fortunate to have met you and become friends with you. You're just a force of nature, and I was not surprised at all when in, I think, 2014, you started this project called Disability Visibility, which, for folks who might be interested, you can learn more at www.disabilityvisibilityproject.com.

So Alice, can you tell us a little bit about why you started this project, and what have been some of the really great aspects of it that have been meaningful for you and for others as well?

ALICE: The Disability Visibility Project is made up of roughly two parts.

First, it's a community partnership with StoryCorps. Storycorps is a national oral history nonprofit, and as a community partner, we encourage people with disabilities across the country to record their stories at StoryCorps. They have two locations, Atlanta and Chicago. And there's also an app on the smartphone, so anyone can tell their story and it'll be uploaded into the Cloud and also archived at the Library of Congress. And that, to me, is a brilliant thing, that we all have the capacity to create our own history. We don't have to wait around for some historian to find us interesting to tell our stories. That's really empowering, and that's something I think that we – all of us – could really use.

DVP is also an online community that creates, shares, and amplifies disability media and culture. And I do this by doing Twitter chats and having a Facebook group and a podcast and also collaborations with other activists. And the reason why I did this is, you know, frankly, our stories are not told by mainstream media. When they are told, they often don't center disabled people. Deepa, you would not believe the number of times, you know, there'll be a story about a disabled person but they'll interview the family member or somebody else. It's very much one of those things, it's often told by not disabled people on behalf of not disabled people. There's

also the practice of stories where disability identities of people are erased. For example, Harriet Tubman had a disability, epilepsy, and Fannie Lou Hamer, incredibly important civil rights activist, had polio, but that's something that's usually not mentioned in the civil rights and Black history things you read about. Their disabilities are not part of who they are and their biography. That's something that's problematic.

DEEPA: And that's something that we hear a lot on *Solidarity Is This*, where people talk a lot about the fact that their identities and histories and stories and narratives are often erased or told *about* them, and the importance of actually creating your own stories and narratives. Can you share a little bit about some of the stories that you are collecting and archiving, perhaps through the podcast or other components of Disability Visibility that are really, as you said, creating the identities for disabled persons and the issues and needs that folks are dealing with?

ALICE: I really loved, recently, I got to interview two Asian American about mental health. I got to interview two really dynamic and active disabled women, their names are Emily Wu Truong and Jessica Gimeno. And they basically shared their story about their experiences with mental illness and also the relationship between Asian American culture, their culture, their families, their understanding of mental illness. And you really see these types of stories out there, I think we need more, like—when there are stories about, say, for example, mental illness or disability or any kind of chronic illness, most of the representation is very white. One of my friends, Vilissa K. Thompson, she actually started a hashtag called #DisabilityTooWhite, and that's something that really drives me as well in what I do, because our disability community is so diverse, and I really want to highlight the full range of our stories and of our community.

DEEPA: And that's one of the things that I also have found—that the disability rights community, first of all, is very active online, so it would be great to hear whom you follow and learn from that we all could—but also the real point that the community often makes about increasing awareness of intersectionality. Can you talk a little bit about what you've learned and why that's so important?

ALICE: Within the United States, there's 1 in 5 Americans with a disability. We are everywhere, and whether people realize it or not, whether people identify or not, we are always present in every person's community. And there are some issues, I think, that are really important, talking about intersectionality. Intersectionality is so important when it comes to building solidarity with various marginalized communities. For example, there's police violence and brutality, because disproportionate numbers of Black and brown disabled people are being killed or harmed or oftentimes incarcerated without medication, treatments, or even access to communication. And there are many people on death row with intellectual disabilities or other mental health disabilities who are often convicted. These are issues that a lot of people care about, in terms of mass incarceration and police brutality, that we can all try to be in solidarity with one another and really try to tackle these issues.

DEEPA: You talked a little bit about the enforcement state and mass incarceration, police brutality, detentions, deportations, how these affect people who are disabled, and then there

are, of course, other issues like getting paid fairly or utilizing public transit that also affect people's lives. What are some of the best practices you've seen when it comes to actually addressing this intersectionality and being in solidarity with each other?

ALICE: I think it starts with being honest with what you don't know, and being honest about wanting to reach out and being willing to be vulnerable about it. You know, I am constantly trying to learn as well. I've got my own work to do. I think it starts with that, and some humility as well. A lot of us get siloed into our different spaces that we're a part of, and I think part of it is just being willing to push each other to make these connections, and I think, being honest about our interest and also our willingness to listen and also to do the work. I think that's really an important part of building solidarity. It goes both ways. It's really a shared experience and also a shared responsibility.

DEEPA: And you've definitely given us some food for thought—being vulnerable, being clear about what you don't know, and also being open to work out of the siloes that we're always placed in—like, “these are issues that affect folks with disabilities, and these are issues that affect immigrants,” and so we're constantly siloed from each other, which is one of the reasons that solidarity is so important to build that line and that connection. So if you were to tell us, and there are a lot of activists that are listening to *Solidarity Is This*, what are some of the steps that you would suggest that activists take as they're designing a campaign on equity issues in their community, what are ways in which they can actually make sure that they're including and amplifying people who have disabilities, people who are working on these issues from that vantage point – what are some steps that you tell us to take?

ALICE: I really encourage everyone who's listening to learn about ableism. Ableism is something that is a term that still a lot of people don't know much about, even though we know all the many other forms of oppression. Ableism is very invisible, it's very sneaky, it's everywhere, but I really do encourage people to explore what ableism is and perhaps, if they have time, to really confront and reflect on their own implicit bias about disability. Disability, for a lot of people, is a scary thing. A lot of people are very uncomfortable about thinking about disability and talking to people with disabilities. I think part of it is, it reminds people of how fragile we all are. I think that's the thing that we all have to realize—that we're all interdependent on one another, and that somebody who moves a different way, somebody who sounds like me—because right now, for the listeners, I sound different because I'm using a ventilator to help me breathe, because I have a patch on my nose, so my voice sounds a little different. And I know that people, when they first see me, they have presumptions about me. And I would really encourage people to think about ableism and to think about disability as a cultural and political identity. Just as much as people have pride in being a Muslim, Asian American, LGBTQ, there are people like me who are very proud of being disabled, because I come from a community with a really long history of activism. We have a history. We have a culture. That would be my two suggestions.

DEEPA: I think those are really helpful ones. And you saying at the beginning about how ableism is another form of oppression is something that I want to think about more and learn about more, and I think that all of us need to, because I think that that's one of those biases that we don't necessarily acknowledge and that leads into or feeds into or informs not just the way we

treat each other but our movement work and our solidarity practices as well. So thank you for laying some of that out through that analysis.

So you talked already, a number of times, you've mentioned—and this podcast is going to be up in May, which is also Asian American Heritage Month—you mentioned your identity as an Asian American person. So I was curious to hear a little bit about, what are some of the ways in which you think that Asian Americans can amplify the concerns and increase the visibility of Asian Americans who are disabled like yourself and many others? Because I don't think that that oftentimes, at least from my vantage point, doesn't actually come into the conversations or the advocacy or the campaigns when we think about issues affecting Asian Americans today.

ALICE: It's on all of us to name it and identify it and say that we care about people with disabilities within our community. There are a lot of people who are Asian American who have a chronic illness, who have a disability, whether it's visible or invisible, but they don't identify because they're not comfortable, they're afraid of being seen as 'less than.' I think things like the model minority is a huge aspect of this, kind of intertwined and interrelated, because we always have to try to be strong or somehow uphold some sort of image. I think there's a lot of fear and stigma and silence that still exists within Asian American communities about disability, and I think the silence is the most harmful thing about that aspect. I really feel like, if you're not disabled and Asian American, I want you all to try to speak up and say, what about disabled people, to talk about it. If people are more open to talking about it, that gives permission to other people to feel like they can disclose. There are still a lot of people within the Asian American community that are hiding because they just don't know if they're going to be accepted. People just want to feel like they will be welcomed. And I think that's what it means to be an ally and accomplice is to really do that kind of work, that preemptive work, to say: you are welcomed, you are valued.

DEEPA: And I think you're so right to connect it to that sense of the model minority, because there's so much silence which leads to shame and this sense of taboo, that people are not living up to a particular standard. I think it's more of the reason that we need to really dismantle that myth altogether and, as you said, have the conversations within our own communities to make sure that we're not excluding people and making them feel ashamed about who they are, and instead making them feel proud and empowered about who they are. So thank you for making those links.

ALICE: One of the stories that I've heard from somebody is that—you know, I deal with Asian Americans with learning disabilities who, because of the model minority myth, they were so reluctant to say that they had a learning disability. Because it goes against all those horrible stereotypes that you have to be smart and a great test-taker and all that bullshit, and that really has led to people getting the right services, getting the right help, or even being able to tell their family members about it. There's a lot of people struggling silently. It drives me to do what I do, because it really feels so wrong.

DEEPA: And that's why projects like yours are so important. As we close up, Alice, I want to ask you if you can tell us either something that we need to be aware of as solidarity activists, that is

either an advocacy goal or a campaign that we should be aware of, or if there's a resource that you think that we should be aware of to begin some of these important conversations around ableism and around intersectionality and visibility.

ALICE: So the ADA Education & Reform Act of 2017. It passed in the House recently, which is horrible and very sad. The ADA Education & Reform Act is basically a law that's going to weaken the Americans with Disabilities Act. The Americans with Disabilities Act that was passed almost 28 years ago is basically our civil rights bill. It basically says that we belong in society, we have protections if we're discriminated against, and that we have expectations to have access to public spaces. Right now, this bill totally puts the burden on disabled people to create access and change. It's really going to allow businesses to take their time and not even comply with this law that's been in effect for over 20 years. This is incredibly dangerous, because it sends a chilling message to a huge community. It just says, "you don't matter." Disability and disability rights, it affects all of us, because we're all interconnected and we all have a loved one or somebody that's going to be impacted by disability, whether it's through getting older, or just somebody that you know, that you date or your friend. So excluding one group hurts all of us, hurts all groups.

I would like everybody today who's listening to this podcast to email or call your senator and say 'vote NO' on the ADA Education & Reform act. Make sure that your elected officials hear from their constituents. Tell them that disability rights is civil rights is human rights. Disability justice is social justice.

DEEPA: And for those of us who work in civil rights spaces or racial justice spaces, we need to be aware of all that you talked about—the cultural interventions, the ways in which we recognize our own privileges, and the ways in which we are using intersectional language and lifting up voices like yours—we need to know all of that, incorporate all of that, but we also need to be able to identify these sorts of threats that are coming down the pike. And we'll have more information about the ADA Education & Reform Act of 2017 in the Solidarity Syllabus for this episode so people can learn a little bit more about what it is trying to do and how we can stop it.

So thank you so much, Alice, for being on *Solidarity Is This*. It was so wonderful to talk to you and to learn from you. I know that your podcast is something that all of us can learn from as well. Is that available at DisabilityVisibilityProject.com?

ALICE: It sure is. It's also available at iTunes, Stitcher, and Google Play.

DEEPA: Great. So hopefully people will download that podcast right away and learn more about the work that you're doing. Thank you so much for joining me on the podcast.

ALICE: Oh, thank you, Deepa. It's been a pleasure.

DEEPA: Please learn more about Alice's work at www.disabilityvisibilityproject.com.

As we end this podcast, I'm actually reflecting on an event I attended last month at the Japanese American Memorial in Washington, D.C. If you haven't visited this memorial, please go. It holds a really poignant and meaningful space in my own heart because I have visited that memorial many, many times, especially in the years after the 9/11 attacks. In fact, just about a week after the 9/11 attacks, many of us gathered at the Japanese American Memorial to send a message to the country that we must not repeat the same mistakes we made during World War II, when this government took over 120,000 people of Japanese descent and confined them in camps in the interior of this country—detained them because they were seen as threats to America's national security. If you visit this memorial, you'll find the names of people who were incarcerated as well as the names of some of the sites of incarceration, places like Manzanar in California, or Tule Lake, also in California, places like Topaz in Utah and Heart Mountain in Wyoming. Now these sites have always been preserved by the federal government, but they're often under threat for losing funding, as they were this year when Trump's budget called for the elimination of the Japanese American Confinement Sites Grants Program. Visit the sites. Advocate for their funding and preservation, because we cannot lose the stories and places that remind us of what discrimination and exclusion can do. I urge you to take a look at www.densho.org, which preserves the past for the generations of tomorrow. You'll learn about the Redress Movement, an effort that led to the passage of the Civil Liberties of 1988, a presidential apology, and payments to surviving former detainees. You'll learn about these sites of shame that I just talked about, and you'll learn about how people litigated the heinous governmental decision, people like Min Yasui, Gordon Hirabayashi, and Fred Korematsu, and you'll be able to read about the experiences of families who were incarcerated.

Thank you so much for joining me on this episode of *Solidarity Is This* during May, Asian/Pacific American Heritage Month. I look forward to talking with all of you next month on *Solidarity Is This*.