

*[Music by Molly Joyce 00:00 - 00:14]*

**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 Bonnielin 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 talking with Sandy Ho from the Lurie Institute for Disability Policy at Brandeis University about her work advancing civic engagement of people with disabilities. Sandy Ho is a research project manager at the Community Living Policy Center as well as a community organizer in the Boston area. Her areas of work include civic engagement of people with disabilities, access to Medicaid HCBS for people of color with disabilities, and building research capacity among disability advocates. 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 01:39 - 01:47]*

**Nick:** Sandy, thank you so much for being our guest today.

**Sandy Ho:** Yeah. I'm glad to be here. Thank you both for having me.

**Nick:** Sandy, I want to start out, as an avid baseball fan, asking favorite Red Sox player of all time?

**Sandy Ho:** Oh my gosh. It's very hard to say, but I'd say Pedro Martinez. Also, very close second, Big Papi, of course.

**Nick:** Mm, good choices. Good choices. I have to admit, not the greatest player ever but great personality, love Kevin Millar.

**Sandy Ho:** Okay.

**Nick:** From the "cowboy up" there in Boston. Sandy, we want to take a deep dive today into your work in civic engagement. You wrote this report that—admittedly, Bonnie actually shared with me at one point, and Bonnie also talks a lot about sharing with many, many

people—this report was written with Susan Eaton and Monika Mitra, titled, “Civic Engagement and People with Disabilities – A Way Forward through Cross-Movement Building.” Can you share the key findings from this report?

*Sandy Ho:*

Sure. Absolutely. Think I’ll begin by talking a little bit about how we found our findings because, when it comes to civic engagement in people with disabilities, we think we know. Then I think what this report shows is that we have—not only more research needs to be done, but a lot more work needs to be done as well. For this report, we basically have three ways of gathering information. We conducted 18 interviews of both disability rights folks and then also the civic engagement professionals in the fields. Then we also had a cofacilitated Twitter chat. As many of you in the audience probably are aware, that Twitter is a hoppin’ place for the disability community. That’s where a lot of information and opinions are shared. We had a cofacilitated Twitter chat with Disability Visibility Project that involved 272 people.

Then, finally, we also developed an original online survey that had 360 respondents to it who self-identified as person with a disability living in the US and at least 18. That’s the context in the background for these findings. What we learned from both the interviews and the survey and the Twitter response is that what we understand as a broad and general society to be civic engagement is perhaps not what the disability community interprets as civic engagement. What I heard over and over and over again from these interviews, with disability rights folks in particular, is that civic engagement, just that term, kind of implies an option to engage, right? You have a choice to engage or not, and for many disabled people in this report, it really wasn’t an option. It was a matter of access to education, to employment, to housing, to really some basic civil rights. I think many characterize it as just way of life, like nobody signed up to be civically engaged. You had to, to live in society. That was one of the really prominent—difficult to measure and quantify, but I think, nevertheless, really important to bring up.

Then, 57 percent of the respondents in the survey said that they experienced barriers to civic engagement, so that could include stigma and attitudes, specifically, physical barriers. Another finding was that 20 percent of people who were surveyed talked about doing disability rights work with other members of the disability community rather than civic engagement entities and organizations. Then, finally, getting back to that finding around ableist attitudes was really prominent from the responses and was a

shared theme across both the Twitter conversations and the interviews as well.

*Bonnie:* Thank you, Sandy. These findings always are striking to me. I'm gonna ask a bit of an off-the-cuff question here, just listening to your responses. Your comments about this idea of civic engagement being an act of survival, I think, was your first comment, and about not having access to. Do you think that Twitter, social media, this change maybe in the pandemic is starting to shift that? Do you think that there is better options and opportunity now than before for the disability community and getting involved in civic engagement?

*Sandy Ho:* Yeah. I think the key term—word in your question is probably “better option” now 'cause I think what we are all—and when I say we, I mean many of us in the disability community—are on the edge of our seats and waiting to see how this unravels and unfolds. What is the direction society and civic engagement will take, quote/unquote, “whenever this pandemic ever is to end?” Because disabled people have always been gathering in alternative and more accessible ways like Twitter, like online forums, have always been asking for remote employment, and so it's a matter of, yeah, I see a shift happening. The question is will that continue and sustain?

*Bonnie:* Yeah. In this report, you talk about—and your coauthors—this need for cross-movement strategies. What does that mean, and why is that so important for the disability community?

*Sandy Ho:* Yeah. Cross-movement strategy, very succinctly, is about moving beyond inclusion and, I think, getting us closer to equity. It isn't to say there is an *us-versus-them* position in context, which I think some of the folks that we interviewed in the civic engagement world talked about access from a compliant perspective, from a, “Well, we need to because the ADA says.” While that is true and that is fact and that is the law of the land and has been for over 30 years, it isn't enough, really. Cross-movement strategies is about let's recognize that there is no disability rights without civic engagement and that there's no civic engagement without disability rights. One example, which has always been true but I think is abundantly and most unavoidably true today, is just within the pandemic, we've seen the way people can, at any time and at any point, become a person with a disability.

That's been rehashed and hashed over and over again by many others who have also been on this podcast and others in the

community, but—I don't know—no matter how many times we say it, we're still waiting for that to actually become an understood reality and practice within civic engagement. Cross-movement strategy isn't to say, "Well, we'll have all the disability rights and issues over here and, also, we only have it over here because, usually, somebody with a disability brought it up to begin with. Then, we'll have a separate convening for"—all of the other social justice conversations will happen elsewhere.

That divide, I think, is something the civic engagement disability rights communities and leaders and work have been trying to bridge that gap more and more over the course of the last presidential election. We've seen greater visibility of disabled people being involved in national and also local campaigns, but it's still an area that, like all movement work, is messy and needs to just continue to be worked on. It's about building relationships. It's about also people being comfortable being vulnerable, I think, with what they don't know because cross-movement strategies involve just recognizing, okay, so this is how your community has been doing something. Let's see if we can also borrow or learn from you. What are some other successes and lessons?

*Nick:*

Thank you for that. In reading the report and building off of the cross-movement strategies that you're discussing, allyship is a key aspect brought up in the report. I won't speak for Bonnie, but I think both of us—and Bonnie, if you disagree, always chime in with me—but I think both of us think about how this is a complicated and misunderstood topic for so many. I was wondering if you could comment a little on allyship and what real allyship looks like.

*Sandy Ho:*

Yeah. When I was thinking about this question—and I might be wading into some contentious waters here, but I will own it—I think allyship is a term that you have to be given. It's something that comes with actions, and it is something that you have to earn to deserve rather than somebody calling themselves an ally and then patting themselves on the back for a job well done, when the community that you were, quote/unquote, "being an ally for" may be seeing it as more of your action might be a checked box thing or more performative. Because in some pockets of both public health or civic engagement and disability rights, there are moments of allyship that have become, quote/unquote, "trendy" rather than allyship that is sustained and meaningful.

When I say meaningful, I mean we all have power and privilege in various ways, and I think being an ally is about not just sharing

power and privilege with others who may not have the same access to resources or connections or networks, but it's also about prioritizing somebody else's agenda, somebody else's—recognizing, “Hey, you're not given a chance to speak at this meeting. Let me just give up my time on the agenda for you.” I think it's also about being all right to our own gaps and areas that we all need to work on and to improve. For instance, just last night, I was in a conversation with somebody who was talking about how donations to Black-owned businesses and organizations since last summer to now have significantly dropped. Allyship, getting back to that sense of—a kneejerk reaction to something I wouldn't say is allyship, but it's a first step. Then there needs to be follow-up and continued follow-up and relationship-building.

*Bonnie:* Yeah. I agree with what Nick said at the top, which is this is a complicated discussion. Thank you, Sandy. I think of this, allyship, as something you gain in drops and lose in buckets, right?

*Sandy Ho:* Yeah.

*Bonnie:* Like trust. Yeah. It's a deep issue that surfaces often actually, on this podcast, so thank you so much for sharing that. I think that is so important in this space, and I'm so glad that it was a part of this report. Thank you. This report also concludes with action, so talking about some action, so actions for civic engagement organizers and philanthropic organizations. Could you share a little bit about what those action items are?

*Sandy Ho:* Sure. Yeah. One of them will be, for example, in—being an ally, getting back to this earlier topic, isn't just about going back to the community that's most impacted to say, “Okay. What is the work that we need to do?” but rather, like, “How can we build and support a relationship and a system and a structure in a way that we are collaborators and partners rather than”—what often happens is disability community and disabled people are add-ons at the last minute, like, “Oh, whoops. We messed up.” Then we come in, and it's not allyship. It's more like being a fire extinguisher. When it's 2021 and we still get asked the questions—I'm sure you do all the time, Bonnie—like, “Where do I find people with disabilities who are doing work in X, Y, Z field?” I'm so, so tired of that question. It's so frustrating.

I want to urge folks in this space to instead ask how can I help facilitate work that people with disabilities are already doing in this state? Because it is happening. You might not call it the same name that we call it, but it is happening. Another action would be

uplifting and prioritizing disabled voices and perspectives and narratives, and this gets back to that finding on ableism. Ableism, though, difficult to measure and quantify. It is such a significant barrier for not just civic engagement, but across multiple areas of our society where we see disabled people are experiencing ways in which they are discriminated against, are thought of as less than, as just being recipients of services rather than folks who have ideas, solutions, and leadership power.

Another action is building those cross-movement relationships between philanthropy, civic engagement, and civil rights. That is something that is fraught with power dynamics. Whenever we have and talk about funding and dollars, that always exists, and that also always exists when we're talking about relationship-building with organizations and a community that has historically been excluded. Those cross-movement relationships really need to be equitable. When I think of cross-movement strategies and one example of what that could meaningfully look like, it's to have disabled people not just in positions of, quote/unquote, "disability work" or the disability office, but recognizing, yeah, somebody could be doing development, could be doing environmental work, could be doing any number of things because, again, there's a disability perspective and policy in all of our priorities here.

Then, finally, also, just fostering the leadership of marginalized disabled people in particular, and I think that's an area that our own disability community can really work to improve upon 'cause we don't do a good job of that. That's just my own opinion recognizing the ways in which white disabled folks, white physically disabled folks who often have the biggest clout or influence or platforms. When we look at not just the statistics of who is most likely to be disabled, it's not just about that, but also recognizing there's a shift happening in our movement and in our communities where those disabled folks of color, Black disabled people, in particular, are not given the same access to relationship-building, to funders, to opportunities that those of us with other kinds of privilege are.

*Bonnie:* Yeah. I just want to say that, moving that back to allyship, I've often thought that we don't do a good job in the disability community with our own internal allyship, right?

*Sandy Ho:* Mm.

*Bonnie:* Much to your last point. I think it's something we should probably think a little more deeply about on this podcast and talk a little bit

about. I think in the community, we talk about our dirty little secret is we don't all get along, but it's deeper than that, right? It is being an ally to each other and recognizing the power differences within the community and in these ways and being an ally. Thank you for sharing that.

*Nick:*

I always want to point out, because this is a podcast that we don't have the video, that there's a lot of positive head nodding going on right now. Yeah. I thought that was a really, really thoughtful comment, and I think there's a lot of things that you said that we should do another podcast to unpack. I also, the whole time we were talking, I was thinking a lot about academia. This is something that Bonnie is a leader in, and academia's an important space for civic engagement. Do you think there are also actions along the same lines that universities should take to support including disability in democracy?

*Sandy Ho:*

Yeah. Being somebody within a research associate position at Lurie Institute, which is a research center, absolutely. I think that to be neutral, with all of the power and privilege and influence that academia has on anything these days, is irresponsible. It is sending a message to not just students and the future generations that we're educating to become leaders in these fields, but it's sidestepping and taking the comfortable and easy way out that is doing a disservice not just to society, but also to the research institute, to academic universities. I probably got myself into a world of trouble there, but you know what? It's fine. I understand that it's difficult to—for instance, I'm the research project manager at the Community Living Policy Center. We are a federal grantee.

Most of us are also aware that Home- and Community-Based Services is important, the disability policy issue in the reconciliation bill right now. For us as a center, I see us being that bridge between advocates and the policymakers. Academia doesn't need to come out and say, "We're Democrats." "We're conservatives." "We're"—whatever. It's not about partisanship here, but it's about using our tools and our resources and our skillset to really meaningfully inform what is happening. That's why having disability led and disability-informed data is important to all of this. I think, yeah, universities need to just stop being this comfortable. It's time that we take ownership of each of our roles that we have in this, and I think that is also a way to build up and foster the next generation of leaders too.

*Bonnie:* I couldn't agree more. Well said. Sandy, thank you so much for being our guest and for sharing these important comments. Thank you, Sandy.

*Sandy Ho:* Thank you.

*[Music by Molly Joyce]*

*Bonnie:* 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 Nishimoto, 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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