

Yvette Cozier:

Hello everyone. My name is Yvette Cozier, associate dean for Diversity, Equity, Inclusion and Justice at Boston University School of Public Health. Thank you for joining our latest Public Health Conversation Starter. Today's conversation is part of our SPH Reads series. SPH Reads is a schoolwide reading program, hosted by the Office of Diversity, Equity, Inclusion and Justice.

It aims to encourage critical thought and discussion among all members of the BUSPH community, and is centered on a carefully chosen thought-provoking book. The selection for the 2023/24 academic year is, *Disability Visibility: First-Person Stories from the Twenty-first Century*, edited by Alice Wong. In conjunction with this year's book selection, I'm having discussions with leaders who are working to advance the health of disabled populations.

Today, I have the privilege of speaking with Rebecca Cokley who contributed to *Disability Visibility*. Rebecca serves as program officer for the US disability rights for the Ford Foundation. Rebecca is a three-time presidential appointee. She has worked on education, employment, youth development, leadership, and healthcare. I'm delighted that Rebecca has joined us today. Welcome, Rebecca.

Rebecca Cokley:

Thank you so much for having me.

Yvette Cozier:

Great. Just to start, can you give us an introduction about your journey, and how it's led to a commitment in disability rights?

Rebecca Cokley:

Definitely. Well, unlike 80% of people with disabilities, I grew up in a household where both my parents have the same disability I have, which is achondroplastic dwarfism. In many ways, this was the family business. My mom was a disabled students' coordinator at a community college, and my dad ran a Center for Independent Living, which is a community-based organization that helps people with disabilities have what they need to live and thrive in the community. And so, from as far as I can remember, I grew up around a glorious abundance of diversely disabled people. I knew lawyers with cerebral palsy, teachers that were deaf.

My guidance counselor for my junior high school was a Vietnam veteran and an amputee. And so, growing up, for me, I never found that the expectations for whether it be my academic achievement, my social achievement were hindered by being

disabled. If anything, I found that the expectations were actually higher for me in my community.

And so, I think for me ending up on this path, when I think back to key moments in my ... Alice Wong would call it my hero origin timeline, or my villain origin timeline. When I was in high school, a good friend of mine who was in middle school had been beaten. What happened was he didn't show up in class after lunch. Nobody called his parents, nobody checked on him. He was supposed to have Boy Scouts after school. There were multiple hours where no one knew where he was.

Around seven o'clock, his parents got concerned because he wasn't home from scouts. They ended up sending his siblings to go look for him, and they ended up going to the school where he attended, and finding him beaten in a dumpster. And he was also a little person. The dumpster lid had been slammed down, and he was too short to get the lid open. And so, the next day when he went to school, he brought one of those little T bats that you might get at a baseball game that they give away, and he was expelled. He brought it to protect himself, and he was expelled for harboring a weapon.

I remember just feeling this massive rage well up in me. That the fact that I was blessed to go to a school district where even today I'm still friends with my elementary school principal on Facebook. Very supportive environment, high expectations, bullying was dealt with immediately, and there was no tolerance for it. And that, that wasn't the case for all kids with disabilities. And so, I knew really from that point on that I really wanted to do something in this space. Where I could find my own path in making the world a more just and a more fair place for people with different types of disabilities.

Yvette Cozier:

Thank you for sharing that. Can you tell us a bit more about your role as program officer for US disability rights for the Ford Foundation?

Rebecca Cokley:

Definitely. I've been at the Ford Foundation for a little over two years now. I joined in the beginning of 2021. I came to Ford because Ford had been on its own disability inclusion path. And so, in 2015 when our CEO, Darren Walker, came on board, he committed all of Ford's funding to the cause of social justice.

And when he talked about social justice, he talked about gender justice, racial justice, immigrant justice, LGBT justice. And we like to say it was the other ABD. The non-academic ABD. It's the all but disability, instead of all but dissertation. And so, many of us, Alice Wong, myself and several others included, really weighed in with a significant level of public frustration. That Ford was missing the boat on disability. And pointed

out things like, we'll never be able to close the Black/white wealth gap as long as the Fair Labor Standards Act allows a sub-minimum wage for disabled workers.

And predominantly, in those working environments, it's Black disabled women. That as long as 80% of women with Down syndrome are sexually abused or assaulted by the age of 18, there will never be an end to gender-based violence. And to our CEO's credit, where most people would've just ignored being trolled or blocked all of us on social media, he actually invited many of us in to have a conversation. And said, "I've worked in social justice my entire life, why do I know nothing about disability?" And went on his own real serious learning journey. And allowed us to challenge him and push back on him.

The Ford Foundation was, at the time, had moved on to funding some work that I was doing at the Center for American Progress on building out a progressive disability rights public policy agenda. At the end of 2020, following the election, they reached out to see if I was going to go back into the White House and serve again. And at that point, I had no interest in doing so. And so they said, "We'd really like you to consider coming to Ford, and actually helming a pot of money, the first pot of its kind in any major foundation, dedicated to supporting the disability rights and justice movement." And so, I've been there now for ... At the end of this year, it'll be two full years, but we have moved a total of \$50 million over three grant cycles to disability led organizations, centering on disability rights and disability justice work.

Yvette Cozier:

Wow, that's amazing. I want to come back to ask you a little bit more about that. But I just want to follow up on something you said, and that is the ABD, all but disability. Why is it that, that's the case, even among those who are socially minded?

Rebecca Cokley:

I think you can even go back to the history of disability in the US. I mean, the first disability that was defined in, "The new world," was drapetomania, which was runaway slave syndrome. And the fact that our founding fathers created a mental illness out of the air to give credence and protection to slave catchers, and to give a justification for the going out and recapturing people that had been enslaved under the auspices that they were not rebelling, they were sick, and they needed to be taken care of. I mean, from that point, how is disability ever supposed to be something grounded in dignity? Grounded in rights and respect, if that's sort of the founding of disability in the new world, or in the western world?

And I think that coming from that, and seeing just a history of criminalization of disabled people from the beginning, let's be clear, unless they're veterans. If you're a

veteran and you're disabled, you're held oftentimes in a different level of respect and regard than just regular disabled people.

And so, I think we're seeing that change. I give a lot of credit to leaders of the Black Lives Matter movement, to Black women that are doing work around maternal mental health. To actually seeing that connection between disability and other social justice movements. I mean, the fact that we know that 50% of individuals that are killed by law enforcement are people of color with disabilities.

The fact that we know that something that my dear friend and mentor John Lewis, responsible for the good trouble sign behind me, used to always say is that we join movement work because of trauma. And we fail to recognize that movement work itself can be traumatizing. And so, I think as we've had a more nuanced learning and growth of understanding around mental health in particular, and trauma, I think we're starting to see that shift. I think COVID has also been responsible for a real shift.

I mean, we know that we're talking about at least 20 million newly disabled people because of long COVID, and we're actually no longer counting those numbers anymore, which is really scary to me from a public health standpoint. I also think the pandemic led to many people starting to talk about things that they were living with that they may not have been comfortable talking about before. And so, I think we're shifting. We're not where we need to be, but we're definitely on the path at this point.

Yvette Cozier:

Yeah, no, that's very ... Thank you for that response. So kind of going back to your role at Ford, what are some of the values and priorities in your position as program officer for US disability rights?

Rebecca Cokley:

So we did something kind of unusual for an old legacy, dyed in the wool, sort of foundation. We actually invited a community in to tell us what they thought we should fund. And I'm not going to lie, the first thing the community asked us to fund was healthcare. They said, fix the US healthcare system. And I said, I love all of you. I respect all of you. \$10 million a year is not going to fix our healthcare system. I wish it would. I said, but let's unpack that a little bit. What is it about healthcare? What are the things that maybe we can get at in another way?

It really came down to that connection between disability, poverty and healthcare. The fact that even today if you're on supplemental security income, you can't have more than \$2,000 in a bank account or you lose your health insurance. Up until January of this year, you couldn't live on your parents' couch and be on SSI without having that count against your income.

I mean, how many non-disabled adult children do we know live on their parents' couch, but they're not being told that they can't have a job or health insurance. And the fact that we have so many people in our community that can't get married. Because with marriage, it's implied the melding of economics, and they'll take away your health insurance. We know that the subminimum wage still exists.

There's a litany of programs and policies that frankly we're set up to keep people with disabilities poor. And it's all tied to healthcare. And for us, it really came down to, "Well, can we get at some of those broader healthcare shifts that we need by attacking that connection between disability and poverty?" And so, that's been our public policy focus or our advocacy focus in the work. And then, our broader focus in conjunction with that is how do we build the field of the next generation of disabled leaders, and what should that look like?

I mean, I think, as we said, if you can't have more than \$2,000 in your bank account, it's really hard to start a nonprofit. And up until this point, really, this whole thunder in the disability rights and justice space was the government. And so, when you're dependent on government dollars, you're restricted about what you can and can't do, what you can and can't say, what the priority is this year compared to the next administration. And the joy of being in philanthropy in this moment is to actually, in many ways, support the creation of organizations that the disability rights and justice community should have had 20, 30, 50 years ago.

So it's supporting disabled healthcare workers through the Docs With Disabilities Initiative. Creating an organization of disabled teachers inside of the NEA. Helping support the bringing together of indigenous disabled people through organizations like Crushing Colonialism. And these are sorts of things that have existed in other communities forever, and are part of why I think other social justice movements have been able to achieve more than we have. Or have been able to be more aggressive than we've been able to be in their advocacy efforts. Because we just simply haven't had the infrastructure.

Yvette Cozier:

Just to switch a little bit, I want to turn to your essay in Disability Visibility.

Rebecca Cokley:

I actually just realized, I have Disability Visibility right there on my bookshelf.

Yvette Cozier:

Awesome. I have my copy right here as well. And your essay in particular, The Anti-Abortion Bill You Aren't Hearing About. It was published in 2019, and it was based on

the Texas bill that eliminated the exception of the state's 20-week abortion ban for cases of severe fetal abnormality. Can you talk a little bit more about that, and your motivation for that article?

Rebecca Cokley:

Definitely. Abortion and disability have always had a very tenuous relationship. And in particular, I think that in the dwarfism community where both parents have the same type of dwarfism, roughly a quarter of the pregnancies are non-viable. And so, my parents lost two babies before me, and one after me. As a result of the fetus receiving the dwarfism gene from both parents. And that was before the genetic testing was available.

And so, my parents carried four pregnancies full term with me being the only one that made it. I watched many of my friends go through a similar situation before the genetic testing was available. I think in the disability rights space, and I think growing up with parents that were activists, my parents always really focused on the importance of bodily autonomy. We have a right to decide what's done to our bodies. We have a right to say yes, to say no, to elect to have some procedures, to decide not to have others.

And that, that right is probably one of the most important rights that we have as people with disabilities. Because historically, particularly people with dwarfism, didn't have that right. We were experimented on. We were stretched. We were bought and sold across carnivals. We still live in a day and age where non-disabled people paying us to beat each other up is forms of legal entertainment in some places. And so, my parents were very open in having those conversations, and talking about that issue.

And when we started watching these disability selective abortion bans come up in Ohio and Texas, there was rumors of a federal ban that would've been proposed. Obviously, this is all pre the Dobbs ruling. But a federal ban being proposed by Senator McConnell and others, I really felt like it was important to actually put down in words why abortion matters to the disability community. And that it is a hard conversation, and that the reality is that if we really hold firm to the belief, and our grounding, and bodily autonomy, it means that just as we have the right to make choices about our bodies, it means that non-disabled people have the right to make choices about their body.

And that might mean that ... Very likely means that ... I know know average height people who've aborted fetuses because they were carrying a dwarfism gene. And while that's really hard to reconcile, at the end of the day, that right to bodily autonomy is so sacred that it's part of the cognitive dissonance we just have to live with.

Yvette Cozier:

You also state in your essay about, again, similar to what you were just saying, "In an ableist society, it treats people who have disabilities as it's okay to be objectified." What steps do you think our society can do to improve that?

Rebecca Cokley:

I think that part of it is just doing its homework. I mean, the number of times I get asked questions is by folks, by random people in the public. But I'm like, "There's this thing, it's called Google, or Bing, or whatever search engine you like. You can look up what the disability community perspective is on an issue. You can look at how people with disabilities are impacted."

I think we live in a society where there's a desire for convenient disabled people, for inspiring disabled people, for disabled people that make us feel good about not being disabled. Or inspire us because we see the boy with Down syndrome who at the end of the game, his team's up by 40 points, and they pull everybody off so he can shoot a basket.

And doesn't that make us feel good that we live in a world where that's celebrated? And that's a hell of a lot more convenient than having disabled people tell you that your policy is bad and you're bad at it.

And so, I think that there is a real need and a desire to listen to people. I think there's a need to listen to people with, in this moment, complex immune systems, who it's still not safe for them to go out in society unmasked. If even masked or unmasked in some cases. It's important that we listen to people with significant support needs, and don't dismiss them as completely dependent on society because they might need someone who cuts up their food for them. Or helps them bathe, or helps them go to the bathroom.

That those people still have rights and a voice, and that we need to listen to them. I think if anything that people can take away from Alice Wong's own personal experience from her first book, to the Year of the Tiger now, it's that, that voice doesn't go away just because you might not speak. People with disabilities still have opinions, and thoughts, and a right to make decisions about their lives regardless of whether or not society thinks we're deserving of that. All people are deserving of it.

Yvette Cozier:

So at [inaudible] School of Public Health, our goal is to train the future generations of health advocates, public health practitioners and researchers. What piece of advice would you have for our future generations?

Rebecca Cokley:

I would actually start with what advice do I have for your faculty because it will impact your students. If you're a person with a disability, find a way to self-identify. Because so often ... I always quote Marian Wright Edelman who says, "You can't be what you can't see."

So many people with disabilities want to enter the public health field and [inaudible] field. I think that and the special education fields are the two fields I often hear from young people that they want to go into. And they have a right to see themselves in it. They have a right to see their experience reflected in it. And I think academia as an institution can be so harsh and unforgiving.

It can be really tumultuous. The tenure process is not a fun process for a lot of people I know. But to actually know that you've had a professor who might not have the same disability you have, but has a different disability, and has made it, makes you feel seen. Makes you feel empowered, makes you feel like you can do it.

I think so many of us often feel like we're the only one like us in the space, because society has taught us that we are the only one like us in the space, when that's actually not true. And so, to start, I would really encourage your faculty and staff who have a disability or a chronic illness to find a way to self-identify if it's safe to do so personally or professionally.

I think about the first time I met a lawyer with a disability, with my own disability, and I ended up not becoming a lawyer because I bombed the LSAT epically, numerous times. But he went on to work in the White House, and I went to work at the White House because Paul worked at the White House. I think that having those examples are really powerful.

What I would say to your students is, we've been waiting for you. Our community is infinitely strengthened by your presence. And we stand at the ready to salute you, to celebrate you. And to amplify you, who you are, the work that you do in every way imaginable. Our community is amazing and powerful because of its diversity, and don't let anyone ever tell you otherwise. And we can't wait to see what you're going to do next. And challenge the status quo. Challenge our own opinions on the status quo.

I think now is the time for such incredible innovation, just given where we're at in the public health space, in the technology space. And thinking about AI and its implications in public health. All of these different things. Now is the moment to ask the juicy third rail question. And so, when you find yourself pushing down on those questions, or being like, "Nobody's going to want to hear it from me, those are the questions that need to be asked."

Yvette Cozier:

And even if those questions, if I may, maybe aren't picked up or responded to, continue to ask those questions.

Rebecca Cokley:

They'll ask them, yes.

Yvette Cozier:

Wow, that's great advice, and I will be sharing that with our incoming group of students. We're getting close to time, but I really want to thank you for all the work that you've done, and just really showing that these things could be addressed in many different ways. Both in the foundation world and in the White House. And before we go, can you tell us a little bit even about your time at the White House? I think that's fascinating too.

Rebecca Cokley:

Absolutely. I had the pleasure of serving as the ... My title was Director of Priority Placement for Public Engagement, in the presidential personnel office at the White House. And in shorthand it was, I was the Chief Diversity Officer for the latter half of the first term. And so, I like to say that I had the best job. I mean, being in charge of diversity, equity, and inclusion in the Obama administration in the first term, every appointment we made was historic. Every phone call I would make.

I'll actually never forget actually how I met Alice Wong. It was Asian American Heritage Month, and one of my colleagues had done a video contest to the API community. Where he said, "Okay, folks, API citizens of the United States of America, send President Obama a video that talks about something about API experience that you don't think he knows about."

And whenever we would do these video contests, hundreds of thousands of videos would come in. And I ran into this colleague in the hallway and he was like, "Cokley, I have a problem." And I said, "What?" And he goes, "I still have to watch 2,500 videos by next week to get 20 to give to the president. Can you help me out?" And I was like, "Yeah, let me look at my schedule." And so I moved some stuff around and I was like, "Okay, my Thursday is completely free. Give me however many videos you think I could watch in eight to 10 hours, and I'm happy to watch some videos."

And so, he just sent me a random stack. And in that stack was Alice Wong's video. Alice Wong's video talked about the challenges and the stigma of using home care services in a traditional Asian household.

I'll never forget it because it was incredibly powerful. She talked about her experience living in the Bay Area. I was from the Bay Area. I was actually kind of shocked that I had never met Alice. I was like, "How is there this awesome leader from the Bay that I don't know, I know everybody," but I didn't. And at the time, we were looking for appointments for the President's National Council on Disability, which is the Chief Advisory Board to Congress and the White House, on all issues of disability policy. And there was nobody on that board that used personal care services.

I remember being like, "Well, I need to find this person." So I started Googling Alice. I saw that at the time she was working with San Francisco State, so I called San Francisco State, but she didn't have a voicemail set up. I called every phone number. I tried every email address I could find for her. And when I finally reached out, it was almost like that movie, *The American President* with Michael Douglas and Annette Bening, where she thinks it's a prank call. Because when you call from the White House, all that shows up is 202 and nothing else.

And so, she thought I was prank calling her. And I was like, "No, my name's Rebecca Cokley, I'm calling from the Obama White House, and I'd like to talk to you about opportunities to serve in the administration." And at the time, she was very open about saying, she was like, "Well, I can't travel." And I was like, "Well, I don't care, we'll figure this out." I was like, "I have to still run it through the lawyers to figure out how we'll figure it out, but we will figure it out, because this video was incredibly powerful. We're going to recommend that the president watches it. And because your experience is not represented in this administration, and it really needs to be."

And so being able to make phone calls like that, Alice's is probably one of my favorite phone calls because it was sort of the origin story of our friendship. But to be able to make phone calls like that any number of times and say, "My name is Rebecca Cokley, I'm calling on behalf of the White House. President Obama would like to know if you're interested in serving the American people." And I still get chills when I say it. I think it was such a unique time. And actually this photo I have up here is of the five disabled women that worked in the Obama White House. It was myself, Maria Town, who is from Louisiana and has cerebral palsy.

Leah Katz-Hernandez, who now works for Microsoft, for the CEO of Microsoft, and is a longstanding deaf activist. Taryn Tyler Williams, who is now the assistant secretary of labor for the Office of Disability Employment Policy, is a Harvard Brown grad and from Inglewood. And then Claudia Gordon, who is the first Black, deaf woman attorney in US history, and is a senior leader over at T-Mobile.

And to be able to work in an administration with a group of people like that, all doing different roles, all committed to serving, there was nothing like that. I'm still very blessed to get to spend time and engage with many of the Obama alumni. Because I

think for a lot of us, especially in the first term, we didn't know if we'd get a second term. And we worked so hard to get the president elected, and to build an administration that looked like nothing before. And frankly, nothing since. That there was just an energy and a commitment that was different than anything I've ever experienced.

Yvette Cozier:

Wow. Wow, well thank you for sharing. That gives me goosebumps as well. Yeah, that'd be pretty awesome.

Rebecca Cokley:

It was pretty ... I like to say that ... And so it was funny, because when the White House reached out and were like, "Are you interested in coming back?" And I was like, "What job would you give me that is cooler than the job I had before?" And I was like, "It was amazing." And I consider myself so blessed to have been able to serve in that administration. And that's the other thing that I would tell your students, is this is achievable by you. You can work in the White House. You can work on a presidential campaign. You can work on Wall Street. You can work at the Ford Foundation. Any of these opportunities are open. And those of us that are in those spots are always looking for, "Who should come in and replace me?"

Yvette Cozier:

Great. Well, that is a wonderful note for them to hear, and for us to bring our time here to a close. This has been absolutely wonderful, hearing more about your journey, and your incredible work. And again, thank you so much for spending this time with us, and for contributing to such a great book. So we thank you [inaudible].

Rebecca Cokley:

Thank you so much. It was an honor to be asked to contribute to the book, and it was an honor to be asked to be here with you today. Thank you so much.

Yvette Cozier:

Yes, you're very welcome. Thank you.