

Yvette Cozier:

Hello, everyone. My name is Yvette Cozier. I'm the Associate Dean for Diversity, Equity, Inclusion, and Justice at Boston University School of Public Health. Thank you for joining us for our latest Public Health Conversation Starter.

Today's conversation is part of our SPH Reads series. SPH Reads is a school-wide 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 fall 2024/Spring 2025 academic year is *Strangers in Their Own Land: Anger and Mourning on the American Right* by Arlie Russell Hochschild. In conjunction with this year's book selection, I'm having discussions with leaders on themes of political divides, class, and race.

Today I have the privilege of speaking with Sarah Minkara. Ms. Minkara served as a special advisor on international disability rights in the U.S. Department of State during the Biden administration. She has led global initiatives to mainstream disability policy; has advocated for disability rights at many global forums representing the United States; and has connected government experts with international interlocutors, providing guidance in many areas, including labor rights and independent living. Ms. Minkara is the founder of the Dark Methodology, has delivered over 100 keynote speaker addresses at global forums, and led the inaugural G7 Inclusion and Disability ministerial. Thank you so much for being with us today, Ms. Minkara.

Sara Minkara:

Thank you, Yvette, for having me. I'm excited for this conversation.

Yvette Cozier:

Wonderful. To start, in your work during the Biden administration, what were the most vital strides taken towards improving disability policy and disability rights within the United States and internationally?

Sara Minkara:

That's a really good question. If I take a step back in terms of illustrating what are the gaps, and then we can talk about what are the strides we made. The disability community at large, the 1.3 billion individuals in this world with a disability, the 16% of the world population, we're very much either an invisible population, we're not even seen, but if we are seen and brought to the table, we're only brought to the table from a social protection lens. Let's take care of them, let's provide their social services, and it will stop there.

But most global spaces, most policies, foreign policies, we're not bringing in the disability community from a point of value, from a point of we are contributors to the economic conversation. We need to be at the security conversations, we need to be talking about disability and trade, we talk about disability and digital transformation. So very much, we're not part of most of those spaces.

So when I started in my role, we intentionally said, disability inclusion is not just a human rights issue. And it is a human rights issue. That is the baseline. But it is also an economic security and so much more. So we started looking and targeting at spaces where we're not being brought forward and how do we bring them forward. So we focus a lot on G7, on the Asia Pacific Economic Cooperation, on the U.S. ASEAN. We launched the first ever U.S. ASEAN high-level dialogue on disability, getting the Central Asian countries and the U.S. and the C5+1 to have disabilities as one of the priorities. So we were looking at spaces where disability is not really discussed or thought of, and bringing it forward. But we still need to make sure we're not just talking to each other as a disability community, we need to make sure we're not just looking at it from a social protection lens, and we need to make sure we're inserting ourselves in spaces that we're not thought of.

Yvette Cozier:

Great. Thank you. So disability is not a partisan issue, at least it shouldn't be. Why do disability rights and policy seem to split down partisan lines?

Sara Minkara:

It's not a partisan issue. And on all sides, people do care about disability to some degree. But again, I would go back to this point: we're a double-edged sword. If you come up to the person and say, "Hey, let's work on disability inclusion," no one will say no, right? They will be seen as a jerk if they say no, right? Everyone will agree on that. But on the other hand, society does not see the value in bringing us forward in a lot of these spaces. Society does not understand the barriers that we face in terms of being brought... that exists, preventing us from being brought forward to these spaces. Society still sees us as special needs or a different population or an add-on population. Society is still seeing us from very much a different lens. And I think that in itself, that narrative prevents individuals, prevents spaces and systems to bring us forward from an intentional lens.

Yvette Cozier:

So looking forward, or actually, looking in the present time, with the current political divides and the new administration, do you think this will bring setbacks to the work that has been done for disability policy and disability rights?

Sara Minkara:

It's a couple things. One, people keep saying eliminating DEI. Well, diversity, equity, and inclusion. Well, it's DEIA, right? Diversity, equity, inclusion, and accessibility. That itself illustrates that we're always dropped out of that conversation. A is not even in a lot of the discussion points. But on the other hand, we're still impacted by these policies that are being put forward. We're still being impacted either way. So we're not seen on either front, and I think that's the harmful thing. How do we really ensure that the disability community is at the table? And how do we make sure that we're bringing that voice forward?

So yes, what's happening is impacting our work. What's happening is impacting the disability community, both internationally and domestically. We need to really ensure that the voices are at the table. But I've also talked to advocates and activists on this issue, mainstream advocates and activists, and say, "Please make sure you are breaking down barriers so people with disabilities can be part of your coalitions and your movements, and being able to really bring their voices forward as well." It's not easy sometimes for us to even access basic tools for us to advocate and be part of these spaces, if that makes sense.

Yvette Cozier:

Can you just say a little bit more about that, what some of the barriers might be?

Sara Minkara:

Exactly. I'll give you a very simple example. Let's say me as a blind person, and a group of us are virtually meeting together and using one of the platforms... I'm not going to say which platform this is. Using one of the platforms that are not fully accessible for me to use with a screen or software. I'm not going to be able to access that meeting. I'm not going to be even able to really engage in that conversation. People don't think about those things. Or let's say there's a meeting at Congress. They're coming together, and one of the people that want to attend that meeting is deaf. If there's no sign language interpreters, they're not going to be able to engage in those conversations. So there's a lot of different ways that we don't think and truly, fully embrace the different barriers that the disability community might face on a daily basis just in living their daily lives, and that will translate in them being able to bring their voices forward.

Yvette Cozier:

Thank you for that. So just changing gears a little bit, can you please explain what the Dark Methodology is, and how you think these workshops can be particularly useful to organizations with our current political divides?

Sara Minkara:

So the In the Dark Methodology really stems from the space of, how do you create a space where people can bring their authentic self forward? And the way we do it has nothing to do with simulation of blindness. I'm against that. But what it is, is that we blindfold people before they enter the room. We tell them, "You cannot say your name, where you're from, what work and educational background," because those are four things that we tend to anchor ourselves in. We guide them into the room. We don't tell them anything about how the room looks like, who they're sitting with, how many people are in their groups. So there's that constraint of not seeing, there's a constraint of not knowing their surroundings, there's a constraint of not seeing those four things, there's a constraint of not seeing body language and facial expression. And then we facilitate an hour and a half long conversation.

Because of the setup, the structure, and those constraints, people become more open, more willing to share their perspective, their voices, and more willing to bring their authentic self forward. And on the other hand, they're not able to box and label and bring a lot of assumptions. A lot, not all. Again, a lot, because 85% of what you take in as visual. We do tend to box and label through hearing and through smell and that kind of stuff. But because we're limiting so many of those, the visual and the other constraints, that gives the freedom for people to really listen more intentionally, really get to know that person without a lot of assumptions. It's so powerful.

We've done it all over the world. We've done it for all kinds of sectors. It's so important for nowadays because we're not hearing each other, we're not really connecting. We're not giving a space to have those difficult conversations, which we do need to have the difficult conversations. Humans are humans, and there's one common thing that we all share as humans all over the world, is the desire to be seen, heard, and valued. And I think the In the Dark Methodology creates that space for those conversations.

Yvette Cozier:

That sounds incredible. The feedback from past participants has been, I'm imagining, just revelatory in terms of how they feel. What is some of the feedback that you've received?

Sara Minkara:

There's been feedback both on individual and organizational level, especially on the individual level. When they go through it, it's an experiential workshop, and it's a workshop where no one's pointing fingers. It's a workshop where we really understand how narratives impact us, and how much do we embrace ourselves and how much do we bring our authentic voice forward, and it's also about how we create narratives. But people leave the session learning more about themselves, learning more about what are parts of themselves that they're not really bringing forward, being able to connect with their group mates in a deeper way. We've done it for team members who've known each other for a very long time, but this workshop really takes it to another level. Sometimes people call it therapy. But it's very transformational. And 1 years later, people come up and say, "That was the most transformational workshop." And again, because it's not pointing fingers, it's experiential, and it levels out the playing field in so many ways.

Yvette Cozier:

Thank you. So pushing towards public health, how can practitioners in public health make sure to keep the work that has been done in this space moving forward?

Sara Minkara:

So public health professionals, they play a huge, huge, huge role. And I think what's really important is that, how do we ensure that the disability voice, the disability community, are part of every single process within our spaces, especially when it comes to research and data? And I think we don't have enough data when it comes to disaggregate data on disability. There's so much more work to be done in the intersection of disability and public health, and we need to continue this work forward, and I think now more than ever. But again, bringing the disability community at the table. So not designing research, not designing thought leadership, without the disability community being at the table.

Yvette Cozier:

As public health practitioners, we often intersect with government and other structural organizations. How can we, again, keep this work moving forward in those fronts, certainly with the changes that we're seeing coming from this new administration?

Sara Minkara:

Are you talking about ministers of health and health practitioners, on that front?

Yvette Cozier:

I'd say both. Really, any of the larger places. So as public health practitioners, how do we engage here in Massachusetts with our legislators to make sure that the gains that have been achieved don't slip back? What is the role that we can have in that?

Sara Minkara:

It goes back to what I was saying. There's a phrase in the disability community, nothing about us without us, or nothing without us. So bringing disability civil society to any policy development, any legislation, drafting, and the feedback. But I don't have specific expertise on this. For me, what's really important is bringing the disability civil society who work in public health, and are brought to the table to make sure that their voices are heard.

Again, domestically, I'm not an expert. There is huge concern from the disability community in terms of the cuts of Medicaid, and also within the education that's more education related, Section 504. So there's a lot of different things that are being put forward that is going to hurt the disability community. For me, it's really important to understand the stories of the disability community and how these different policies might impact their lives. And how can public health practitioners really intentionally bring that voice forward? But I don't have more specific expertise on this.

Yvette Cozier:

These are good things for us to be thinking of. And certainly, each May, we graduate a new class of students. I know many of them would be very interested in this work, so your words are quite helpful. Thanks for providing that.

Sara Minkara:

For any student, I always say, "Whether you're a student of public health, whatever student it is, it's really important that you will always... You need to engage with a disability community." And I think this is something that we even told... We've really worked closely with our U.S. embassies all over the world, and sometimes these embassies have a health attaches. But our message for our U.S. embassies... And we developed a playbook. Our message was that every single division, every single section within an embassy needs to have a disability lens, needs to be integrated. And I'm not asking a specific disability project. Sure, there might be a need for a disability specific initiatives project. But anything that we do, there should be a disability lens to it.

Yvette Cozier:

Thank you. That actually rolls right into my final question, and that is, the more broad advice that you have for our current students and soon to be graduates as they embark on their public health career. So in addition to being inclusive and having the disability lens present, what general advice would you give them?

Sara Minkara:

My first advice is understand that we all have assumptions towards disability. I'll give you an example. I was in a country and we were meeting with this minister of health, and she was saying that their healthcare practitioners, their community, their hospitals, their doctors, their nurses, they're really great. There's no stigma. They're doing such amazing work. And I said, "That can't be true. Have you asked the disability community themselves what their experiences are?"

It's really important for us not to have assumptions towards what the disability community's experiences are. But instead, how do you bring their voices forward so you can hear their own experiences and their own barriers? It's really important for us to really understand, how do we keep breaking down barriers intentionally? And it's really important for us to really understand it will help our work in general when you bring the disability lens. It is a benefit for all. And I think that's a basic thing that people don't think about in the sense that when you make a system and policies accessible for the disability community needs, that will be a benefit for everyone. And let's be real. A lot of us, as we age, will gain more disability. We all have disability that touches us in different ways. It is part of our reality, but we always see it as something... We don't talk about it from a point of, how do we really make a system that's accessible for everyone?

Yvette Cozier:

Well, thank you so much for these great words. I think our students and our community will find them inspiring and great guidance as they move forward. I want to thank you for joining us this afternoon, for sharing your time and your experience. I wish you the best. I hope that you'll come by and visit us again.

Sara Minkara:

Thank you, Yvette. Thank you so much. It was great talking to you.

Yvette Cozier:

Yes, yes. Thank you.