

Transcript

Public Health Conversation Starter: Dielle Lundberg

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 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 2023-spring 2024 academic year is *Disability Visibility: First Person Stories From the 21st Century*, edited by Alice Wong.

In conjunction with this year's book selection, I'm having conversations with leaders who are working to advance the health of disabled populations. Today I have the privilege of speaking with Dielle Lundberg. Dielle received her MPH from Boston University School of Public Health and is currently a PhD student at the University of Washington School of Public Health. She is also completing a graduate certificate through the disability studies program at University of Washington. Dielle is in collaboration with two labs at Boston University School of Public Health, including the Uncounted Lab and the Aftermath Learning Lab. Dielle's mission is to dismantle structural ableism in public health and healthcare. Welcome, Dielle.

Dielle Lundberg:

Thank you for having me.

Yvette Cozier:

Sure. So to start, can you give us an introduction about your journey and how it's led to a commitment in dismantling structural ableism in public health and healthcare?

Dielle Lundberg:

Definitely. Thank you for creating space for this conversation. My name is Dielle, my pronouns are she/her or ze/hir. And just to offer a visual description, I am a white transfeminine person with wavy light brown hair and I'm wearing a white and black floral dress. So I think what really motivates me to research and attempt to dismantle structural ableism in health systems is my strong belief that many public health and healthcare professionals just really misunderstand how disabled people experience our bodies and minds. And that's a belief I developed through my own lived and community experiences, but I think it is also demonstrated in recent scholarship. Two really important studies were published recently that show that most healthcare and

Transcript

Public Health Conversation Starter: Dielle Lundberg

disability professionals have explicit and/or implicit preferences for non-disabled people compared to disabled people.

So I just want to start today by emphasizing that ableism is a topic that I think everyone in public health and healthcare needs to engage in dismantling. It's something that I think we all collectively need to unlearn and divest from. And it is something that I as a disabled person also continue to unlearn in the context of my own life. But regarding my own journey, I'm physically disabled and I move through the world slowly and with my walking sticks. So I have a visible disability in that sense. But a major lens through which I think about ableism is my lifelong journey with what I describe currently as madness and neurodivergence. But to put it in terms that healthcare professionals currently tend to use, that would be my experience with bipolar disorder, PTSD, ADHD, and ASD.

And I'm not going to share my whole personal story, but what I would emphasize overall is just that, like many disabled advocates before me, I've really come to challenge this idea of disorder. In all of those diagnoses I just gave, the word disorder is present. And I think that is essentially really the individual or biomedical model of disability. And what this model says is that it is a health condition that is disabling, like I have a disorder or there's something wrong with me that needs to be fixed or cured so that I can function. And I think what theories of neurodiversity and madness and the social model of disability really invite us all to think about is the idea that ableism is disabling, and that disability is created to a large degree by the fact that a lot of environments in society are very much not designed by or for disabled, mad, and neurodivergent people.

So as a researcher, what I'm really interested in is trying to reframe health disparities for disabled people from this perspective of ableism and structural ableism, and to really examine how policies and health system actors and other structures in society really uphold these systems that create disability, prevent disabled people from accessing opportunities, make existing as a disabled person very costly and stressful, and ultimately through all of those things really shape the health of disabled people across the entire life course. So focusing on those factors in addition to a health condition, and at times entirely focused on the environmental factors.

Yvette Cozier:

Thank you. And just for those who may not be familiar with the term, how would you best define structural ableism?

Dielle Lundberg:

Transcript

Public Health Conversation Starter: Dielle Lundberg

Yeah, so my colleague Dr. Jess Chen at the University of Washington and I just published an article in the Lancet Regional Health Americas where we sought to really describe and provide a conceptual framework for thinking about structural ableism in the context of public health and healthcare. And this built on, there's been a couple of really great articles this year published about structural ableism over the last year. And in this article we really tried to review some key literature from disability studies and disability justice scholarship and research on structural determinants of health. And so we cited scholars like Subini Anama, Patty Burn, Nicole Brown, TL Lewis, Mia Mingus, Sins Invalid, and many others who have been really talking and thinking about ableism and structural ableism for a long time and whose scholarship is very important for health professionals and systems to engage with.

And I think it's important to recognize that the conversation about structural ableism is, I think, a bit more new to some in public health and healthcare, but it is one that disability advocates and scholars have been writing and examining for many decades now. So there is a lot of work that already exists. And so to answer your question, though, so some of the things we discuss in the paper are that structural ableism is really a system of historical and contemporary policies, institutions, and societal norms and practices that devalue and disadvantaged people who are disabled, neurodivergent, chronically ill, mad, or living with mental illness, and they privilege people who are positioned as able-bodied and able-minded.

And so in the context of health, structural ableism functions to deny disabled communities equitable access to social resources and to disability competent and affirming health services, control over whether our experiences are listened to and believed, autonomy over how our needs are represented and responded to, and justice when we are exposed to harm, discrimination, and violence. And so we then zoom out a little bit in the paper and talk about how structural ableism is not a system that exists on its own. It is very much upheld by interlocking systems of power and oppression, including racism, sexism, transphobia, capitalism, and colonialism. And it really operates alongside other types of disability related bias and discrimination like audism, which is discrimination against people who are deaf, seenism, and internalized and interpersonal ableism. And structural ableism really I think particularly harms people who live at the intersection of multiple systems of oppression.

But that being said, structural ableism does not just impact disabled people, it can impact other populations as well. And it can function in very different ways for different communities. And that is one reason why there's a real need for a lot of new research. And so another big purpose of our article was to, that's a very conceptual and big picture, lofty description, but really what does structural ableism look like? What are examples of how structural ableism exists in our health system? And so some of the

Transcript

Public Health Conversation Starter: Dielle Lundberg

things we talk about in the paper are some examples, are things like social, economic, and health policies, things like subminimum wage laws for disabled people, rules in Medicaid and supplemental security income that can make it difficult for disabled people to accumulate assets. Whether a state or a workplace has paid leave.

Sociocultural attitudes about disability in media and health communications and health systems and how those all can really inform how people working in health systems understand disability and respond to disabled people.

There is a real exclusion of disabled people still from health system decision making and research. Less than 2% of NIH grant funding goes to researchers who self-report a disability, and only around 3% of physicians report a disability.

And then finally, something we talk about too is just the legacies of eugenics and institutionalization that are very present in the history of health systems in this country, that continue to show up in terms of policies and situations that deny disabled people autonomy. And I think there's a lot of different examples we could talk about, but I think the massive inequities in access to education, housing, basic income, and employment for disabled people, inaccessibility in the built environment. Disabled people are much more likely to have adverse childhood experiences, higher rates of assault, victimization, and harassment, and experience carceral and other types of state violence. So I think all of these issues can really be studied from this lens of structural ableism. So I think there's a lot more that can be said, but I will stop there.

Yvette Cozier:

No, that was very illuminating and very helpful, so thank you for that. In your article you talk about the need for public health to engage with disability studies and disability justice. What relevance do disability studies and disability justice scholarship and advocacy have for public health practice and research?

Dielle Lundberg:

Yeah, so I'll start with disability studies. So disability studies asks a number of questions, but a core one is, what is disability? And so a lot of prior disability studies literature has really examined the extent to which disability is a construct that exists in relationship to ableism and capitalism, because capitalism and other systems like settler colonialism have very specific notions of who is a productive person, who is a normal person, who is a person worthy of certain rights and dignity. And disability studies has frequently asked to what extent is disability a construct that represents deviance from some type of societal expectation. And I think just one example of how this is relevant to public health research and practice is just, thinking about how we

Transcript

Public Health Conversation Starter: Dielle Lundberg

define disability really impacts how we measure disability, and that really impacts how we inform policy based on the prevalence and experiences of disabled people.

And just over the last few weeks, there's been a big discussion about the census and the American Community Survey considering changing how it would define disability. And that can make a really huge difference to estimates, because we see the World Health Organization estimates that at least 16% of the world's population has a disability. The American Community Survey in the US estimates around a little over 25%. And then the Washington Group questions in the National Health Interview Survey count about less than half of that. And so how we define what disability is can really change how we think about disability and to what extent we might prioritize disability issues as being issues that impact a larger number of people.

And so I think that it is really critical that researchers and demographers and other scientists really engage with disability studies and have disability studies scholars on their teams in addition to representation of disabled people. I think the discipline just, there's a lot of perspective that it really offers. And two more examples in public health would be the quality adjusted life year and the disability adjusted life year, are two measures that have really attracted a lot of criticism and attention from disabled people. And I think both of those measures would really benefit from engagement with disability studies, theories, and ideas.

In terms of disability justice then, which is related to disability studies but is a movement that really specifically centers intersectionality and the experiences of multiply minoritized disabled people, such as disabled people of color and trans disabled people, I think disability justice advocacy and scholarship has so much that is important for public health to consider. It's, I think, scholarship that everyone working in health, whether it be mental health, public health should be reading and engaging with, books like *Disability Is Ability*.

And for me personally, I think disability justice really challenges and expands what a disability issue is. I think when people bring up disability issues, there is a tendency to think of inaccessibility in the environment or bias or interpersonal ableism, but incarceration and police brutality are very much disability issues. Because disabled people, especially disabled people of color, are very much more likely to be incarcerated, arrested, or impacted by police violence. And another example of disability justice would be just, a lot of disability justice advocates have been very clear, as I have, in speaking out on the public health crisis and genocide that is occurring in Gaza and calling for a ceasefire as a disability justice issue. Because I think people who have been impacted disproportionately by violence or who have been mentally or physically disabled by violence can understand very viscerally that bombings create a tremendous amount of physical and psychosocial disability.

Transcript

Public Health Conversation Starter: Dielle Lundberg

And so I think it is imperative that disabled people speak out on issues of war and genocide, whether that be in Gaza or Sudan, the DRC, or any other locations where these sorts of events are happening. I think global solidarity of disabled people is really critical and powerful and is very key to disability justice, the idea that so many different issues are so connected to one another. And so I think if disability justice was really embedded into health systems, I think our health systems would look entirely different in terms of the issues we prioritize and who is given power to address and lead the solutions to those issues.

Yvette Cozier:

Yeah, thank you. Thank you. The COVID-19 pandemic has disproportionate impact on many populations in the US, including disabled people. Can you talk about how the COVID-19 pandemic has informed current conversations around structural ableism in public health?

Dielle Lundberg:

Definitely. So I think the ongoing COVID-19 pandemic has been really critical for illuminating a lot of inequities in health systems, whether that be racialized health inequities or disability health inequities. And just like I think these inequities contributed to increased consideration of structural racism in public health, I think the pandemic has really contributed to this moment of increased discussion of structural ableism. And I think we see that evidenced in the fact that in September the NIH declared disabled people as a health disparity population for the first time, which is a big action in terms of allocating resources and attention for research on the health of disabled people.

So a lot of disabled people have been very, very vocal about the pandemic, because I think it is a really glaring example of how policies were largely not designed to center or even consider the needs of disabled people. And I think closures and masking and physical distancing are all part of it. But more than that, the US and a lot of state governments really failed to provide people with basic income, universal healthcare, universal free masks, vaccinations that were accessible and easy to access. We did better with the initial vaccination, but didn't continue those efforts with boosters. And so I think the pandemic is just a really visceral example of public health policy in the US not adequately engaging and centering disabled people. And really failing disabled people in many ways.

And so here at Boston University School of Public Health, I have collaborated with Dr. Andrew Stokes in the Uncounted Lab, and we have really been examining and documenting the excess mortality of the pandemic since the very beginning. But a lot

Transcript

Public Health Conversation Starter: Dielle Lundberg

of our work currently focuses on examining unrecognized COVID-19 deaths. And in a study that we published just this month, we found up to 160,000 unrecognized COVID deaths in the first 30 months of the pandemic. And importantly, there was a lot of geographic variation. So there were some communities where the true impact of COVID-19 was essentially hidden or very undercounted and undermined.

And I think what we are starting to find and are continuing to look at now is that a lot of these unrecognized COVID-19 deaths were among people with multiple health conditions and who were chronically ill and were likely a lot of disabled people. And so I think unrecognized COVID-19 deaths could in many ways be viewed as an expression of structural ableism in the US death investigation system, because reporting that that many disabled and chronically ill people died from natural causes other than COVID-19 when it appears that many of these folks did die from COVID-19, has really functioned to absolve state and federal policy makers from some of their failures to really adequately protect some of these communities during the pandemic.

Yvette Cozier:

Thank you. So just changing gears a little bit, along with your work and passion in public health, you're also a multimedia artist. Can you tell me in what ways you've combined your work of public health with multimedia art, such as your work with the Aftermath Learning Lab?

Dielle Lundberg:

Yeah, so I guess first, just on a personal level ... Well, first, appreciate the question overall. And on a personal level, art has played a number of different roles at different times in my life. My creative writing has always been a place where I have learned a lot about myself and also unlearned a lot of the ways that health systems and other systems have taught me that I was abnormal, a problem, or broken. And when I have been in the psychiatric hospital before, it has helped me to just sit, and if there's markers available, to color and to focus on that when I'm dealing with something difficult. And I remember I went to visit my parents once over a break, and there was this coloring sheet my mom had put on the wall. And I saw it and I was like, "Wow, I really feel like I recognize that."

And it turned out, I guess at some point I gave it to her after I was hospitalized once, and she kept it and put it in a frame and put it on the wall. And I share that because there have been really hard times in my health journey, and it's often very difficult to talk about those, especially with people who maybe don't have the same experience or haven't experienced those things before. And I think art can be a very powerful way and a very helpful way to connect with people and to share difficult things with people

Transcript

Public Health Conversation Starter: Dielle Lundberg

in ways you might not be able to with words. And then in terms of my research and community work, I am currently really interested in collaborating on community art projects that either disseminate public health data, advocate for justice in some way, or build community. And I think art is a really powerful invitation to step outside of our own experiences and to really engage with someone else's.

And I think making art together collaboratively can be extremely powerful in that way. And so I would say I'm still very much learning, as I imagine I will be for the rest of my life. But some examples of things that I've contributed to or am currently working on are, first, I collaborated with the Aftermath Learning Lab that you mentioned, which is led by a longtime colleague of mine, Dr. Julia Devoy, who is at Boston College actually, and then Matilda Larti, who is a fashion designer and environmental activist in Ghana. Along with a number of other folks, artist Mark Cooper, researcher Dr. Brian Smith, and a lot of other folks in that lab, which is a multi-institutional project. We created this aftermath sculpture, and it's a kind of large scale textile and multimedia sculpture and art advocacy collaboration about the global impacts of textile pollution and how textiles are getting shifted from the United States to primarily countries in the global south in creating a lot of environmental hazards.

And so this sculpture visited Boston University, including Boston University School of Public Health. It was in the Talbot Building in 2022 I think, fall 2022. And it's still on the road. It's currently at St. Mary's College of Maryland right now, and I think heading to Bridgewater University later this year. So that project has been an exciting way to really see how art can catalyze discussion and awareness. And here at Boston University I'm working on a project with Uncounted Lab that I mentioned earlier. We're working with a really important community advocacy group called Marked by COVID. And they are a justice and remembrance movement led by COVID grievors and people who have been impacted by the COVID-19 pandemic in various ways.

And what we are working on, we're still early in this project, but we're putting together some things to memorialize some of these uncounted COVID-19 deaths and to really advocate for a number of policy priorities related to the pandemic and to addressing some of these issues in the death investigation system as well. And so that project, I think, is an example of how art can really be used to bring people together, to be in community, and then also to hopefully advocate and advance justice in some way.

And then just the last thing I would mention is just, two of my neurodivergent friends and I have been inviting community together for a long time. We have a very, very lively group chat, if I'm ever on the phone I'm usually talking to them. And we are launching a little publication centering neurodivergence and some other topics where we're just going to publish some of our own fiction and invite some collaborators who are connected to some of these experiences just to build community. And so I share

Transcript

Public Health Conversation Starter: Dielle Lundberg

those examples just because I think art and public health are still not really viewed in the same sentence a lot of the time, unfortunately.

But I think each of those examples I gave represents really different ways that art can be used and has relevance in public health. And I think there are many more beyond that. And for me, I think art really helps me to stay connected to community and to keep imagining and dreaming. And when working on some of these heavy topics and thinking about all of the really very extreme challenges that our world is facing right now, it allows me to, I think, remain hopeful, at least occasionally, that we can create a healthier world if we come together to do that.

Yvette Cozier:

Thank you for sharing that. So my final question is, you're an alum of the School of Public Health, you're pursuing your PhD, you're involved in all these wonderful things. What piece of advice would you have for future generations or just even future MPH grads from our school?

Dielle Lundberg:

Yeah, so my advice is going to be directed to other disabled, neurodivergent, and mad students, trainees, and folks who are thinking of going into public health or healthcare professionally. I think what I would start by saying is that your voice is very needed and we really need you to help contribute to advancing health equity for not only disabled people, but for many other populations. But that being said, I think it is important that you know and understand that a lot of these systems and institutions and professions were not built by us or for us. And if you have a hard time, it's probably not about you. There is an incredible book called *Ableism and Academia: Theorizing Experiences of Disabilities and Chronic Illnesses in Higher Education*. And it really speaks to a lot of the challenges that disabled people encounter when they attempt to work in research and science and academia broadly.

And there's still a lot of change needed. And so I think it is very critical for disabled people to find one another for this reason, so we can support one another and build communities of care and take care of one another and just make sure that we can get through things together. And then the second piece of advice I wanted to give is related, but there is a concept in disabled communities and disability studies called *crip time*, which refers broadly to the ways that disabled people often experience time in non-normative ways. It takes time to navigate ableism. Some of us need to work from home, from our bed. Some of us experience mania, some of us experience hyper focus, some of us work in very nonlinear and oscillating ways.

Transcript

Public Health Conversation Starter: Dielle Lundberg

And Dr. Allison Kafer is one scholar who has written a lot of tremendous work about crip time, and she had a line in one of her pieces, which is, "Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds." And so I would just conclude to any disabled, mad, and neurodivergent folks watching that you are valid and whole as you are, and you deserve the resources and support that you want to live your life and make an impact in the world that affirms your full personhood and dignity. And I hope that all of us from all experiences can really join together to work to make that a reality for as many disabled people as possible. So thank you.

Yvette Cozier:

Oh, thank you, that was wonderful. And I really thank you for this conversation and for sharing your insights and your passions, and I think this is very helpful to the entire SPH community. So again, thank you very much.

Dielle Lundberg:

Yeah, thank you again for making space.

Yvette Cozier:

Absolutely. So thank you for joining us again this afternoon. And just as a clarification, both the Uncounted Lab and Aftermath Learning Lab are multi-institutional collaborations, including with Boston University. To get information on both labs, we will have links to them, the respective labs, on our website. Thank you.