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Brown
Anti-Ableist Research in Public Health and Research
April 28, 2023
11:45 AM - 1:30 PM (ET)

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(Captions provided by a live Captioner.)
11:45 AM (ET)

CAPTIONER: Testing the captions. This is just a test of the captions testing.

ALEKSA KAYE: Does anyone have any questions? How is everyone feeling?

JEN SORIANO: Excited.

ALEKSA KAYE: We ended up having 430 people register all the way from Glasgow, Luxembourg. Like I don't even know. Like it spread like wildfire. I don't even know.

JEN SORIANO: Awesome.

ARENAL HAUT: Hi, everyone. We are excited you are here. Thank you, very much.

JEN SORIANO: Thank you for organizing it.

ARENAL HAUT: Thank you for being part of it. We are really excited. I came in the tail of the end of it. I think we are at over 440 as of now which is really exciting. It is the

first event that I know of at the School of Public Health. And definitely the first one like this at Brown in a long time. I know you were talking about what you did a while ago, Sarah, but we are excited to piggyback. And keep the conversation going.

So I guess the other thing I want to share is when I talk to a couple of you, there is a question of who we expected to be here. I originally said a lot of people who knew about research. and less about disability. And after looking at what people are saying, it turns out that is not at all who we have. So our predictions were not what we expected which is still super exciting. So we definitely have more people that know more about disability than we anticipated which is awesome. But there is typically a wide range of people. Like there is someone who is a disability consultant, but there is also people who are high school students that don't know very much about this and just want to learn.

There's a super broad range of — so just want to acknowledge that and say we have a super wide audience, but we are really excited that lots of people are interested in this.

ALEKSA KAYE: Welcome, Cyrena and Bonnie. Great to have you here as part of the team. How are you both doing?

DR. BONNIE SWENOR: Good. Thank you. Thank you for hosting us. And including me. I'm really grateful.

ARENAL HAUT: We are so grateful that all you guys are here.

DR. CYRENA GAWUGA: Thank you for inviting me. It is actually quite nice to finally do something for Brown after, you know, being there for so many years and then being away.

I am really happy to join you guys and talk about ableism. It is really an important topic, and I am so glad that you guys, you know, launched this important project.

ARENAL HAUT: Before we get started, can you I'll pronounce your names for me and let me know how you want to be addressed? Just like I don't know if people would prefer to go by "doctor" or just pronounce your first names. Making sure I don't pronounce your name wrong. Being on the receiving end of that, I don't want to do that to anybody.

JEN SORIANO: I am unmuted. I will go. Jen Soriano.

And you can just call me Jen.

DR. CYRENA GAWUGA: So I am Cyrena Gawuga, and you can call me Cyrena. "doctor" is really weird. Please just call me Cyrena.

DR. BONNIE SWENOR: Bonnie Swenor. Same. Please call me Bonnie.

ELI CLARE: I am Eli Clare. Please just call me Eli.

ARENAL HAUT: Thank you so much. Does anyone have any questions about logistics or anything else? Yes?

DR. BONNIE SWENOR: Okay, —

ARENAL HAUT: I was going to say we have a loose flow, but partially to see where the conversation goes. But yes, I am sorry I interrupted you.

DR. BONNIE SWENOR: No, no. My apologies. Will participants, and I apologize if you covered this when I was joining, will participants, people in the audience be putting questions in the chat? And if so, will be reading that? Or will it be curated by someone on your team and read aloud?

MEDIA SERVICES: Chat is disabled. Raise hand is also disabled. No raise hand or chat. But the cohost can chat. But not the attendees.

ALEKSA KAYE: The plan is for me — because I am moderating the chat — that we will just pull any questions out of there that we have time for, and I will send them to Arenal and Sarah so they can ask you directly and you don't have to worry about that.

ARENAL HAUT: We are anticipating, based on seeing all the amazing questions we got on the forum, we know that we're not going to be able to get to all of them. We will definitely curate from the Q&A and Aleksa will take care of that. So no worries on that for our amazing panelists.

SARAH SKEELS: Since this is a student driven event, I am supporting Arenal behind the scenes. I really feel strongly that the student should be engaged in moderating this. So you know I am behind the scenes helping with the flow, but I really want the power to be with the students and engaging with all of you. And we worked on the flow of questions and hopefully, it will go the way we want. But Arenal is always extremely capable, and I think this will be wonderful.

I just wanted to share that all with you and thank you so much for being here and this is such — it is going to be such a powerful experience for everyone, and we are just grateful for the space.

JEN SORIANO: Is it a webinar format or a Zoom room?

ARENAL HAUT: It is a webinar format. Yes. Say it one more time? Sorry?

JEN SORIANO: We will not see the participant settle?

MEDIA SERVICES: You will not

MEDIA SERVICES: You will not be able to see it at all. If you click the participants, you will see the recording right next to the panelists, you will see the attendees, the number will show there. And also I want to let you know and to tell you that I am going to, this event will be recorded, right? Okay, I will do, right before 12:00 I will start locally recording.

And then I will start the webinar. When we start the webinar, you may like to wait for 30 seconds scene we had several hundred attendees. You want to wait to see the attendees number kind of slowing down and then you can start your introduction. I know Arenal you know that introduction. I will put that slide first.

And then when the attendee joins the meeting they will see the first slide.

And then when you start to speak up, Arenal I will start a second one. If you finished your speaking, may be two minutes, a couple of minutes, I'll stop the slides. Then I will give the attendee review.

ARENAL HAUT: Amazing! So the plan in terms of slides just so you guys know is when the panelist, sorry, when attendees come, they will see the flyer and we will have a visual description right when we get started of the flyer.

And then we will switch and show our new logo for our organization there was actually designed by one of our students who is an artist. They are amazing. So you want to share that.

And then we will talk maximum two minutes about who we are and why we pulled this event together. And in the first question is having each of you introduce yourself and your work and with a visual description. I will go first with a visual description in case people haven't done those before. But it is a quick overview of what people are looking at on your screen.

Any other questions?

JEN SORIANO: I think when we had done this, you set along with the visual description we should say a word or two about how our work relates to disability justice. Do you still want us to do that or is that at a different point?

ARENAL HAUT: That will be one of the first questions. I feel like — the thing we notice is a lot of questions overlap which makes a lot of sense. Darrell sort of connected. Whatever feels natural in sort of the intro of your work, how does it intersect?

MEDIA SERVICES: About questions, would you like to allow attendees to send me the questions anonymously?

ALEKSA KAYE: I think that should be an option, but they can also submit with their name.

MEDIA SERVICES: Okay. I will check that. Thank you.

ALEKSA KAYE: And I just want to give a student shout out who designed our logo because they also came up with the idea for this event.

So I was brainstormed in, I think, early February. There was a need for it. What about we fill this gap and have a panel and spread awareness on the subject? Thank you all for being up to the opportunity.

ARENAL HAUT: Anything else people are wondering about before we get started?

DR. BONNIE SWENOR: Will be able to share resources through the panelist if we are blanks or anything? What would be —

MEDIA SERVICES: You can. Just send a link to the attendees. If you need to share anything to the screen — okay. You can write to the attendees.

ALEKSA KAYE: If you want or anyone wants to send those to me now, just do that in the chat and I will include that. Because I was anyway going to send little messages that say like "learn about Eli Clare process work" and for everyone.

ARENAL HAUT: I do have one quick question for media services. I e-mailed but have not heard back. Will be CART captions be included in the recording?

MEDIA SERVICES: I believe so. Let me ask Kyle.

MEDIA SERVICES: They will be included in the recording. But usually also we try to make public that they are resubmitted for just another pass over to correct any errors.

ARENAL HAUT: Amazing! I just want to make sure that was part of the recording.

MEDIA SERVICES: Absolutely.

ARENAL HAUT: Okay. If people need a break, grab some water, take a minute before we get started, will probably get started probably a couple of minutes after 12:00 as people trickle in. As you know, we will properly start closer to 12:02, 12:03, but thank you so much for being her. We are really, really excited.

MEDIA SERVICES: But I am going to start the webinar exactly at 12:00. I will start recording before the webinar. I will start right at 12:00.

ARENAL HAUT: Absolutely.

MEDIA SERVICES: Good luck.

ARENAL HAUT: Thank you, guys so much.

MEDIA SERVICES: You are very welcome.

MEDIA SERVICES: Okay, I'm going to start at 12:00.

»: Recording in progress.

ARENAL HAUT: Hi, everyone! Thank you so much for being here today. My name is Arenal Haut.

I am an undergraduate student at Brown.

I am a junior study and Public Health on the pre-med tract.

I am so excited to be moderating today's panel. I'm also one of the in founders of Disability Justice As Public Health." We Have Our Logo On the Screen Right Now and I Will Provide a Quick Visual Description. There Is a Black Border In a Circle with the Words "disability Justice As Public Health" In White Letters. In the Center There Are Hands and Green and Blue and Black and Red Holding a Yellow Light Bulb with the Letters DJAPH in the middle.

And then it says Established 2022. We are really excited to have this be the first event we premiere this logo which is designed by one of our members who is amazing, Melanie Ortiz, Mel, a Ph.D. student at Brown and really amazing and we are so proud to be sharing this logo with you. So thank you so much for being here what we want to start with is a quick introduction of why we are doing this. So what's important to us is we founded this group, me and Aleksa Kaye who will be in the chat moderating the Q&A, sending some resources throughout the panel. We founded this group because we wanted to talk about themes of disability justice in Public Health and how these themes are really essential to health and well-being of communities. So what we mean by disability justice, our working definition is a really foundational concept and was

developed in part by one of our panelists, Eli Clare. You will hear from him later which is really exciting. We are so grateful to have him here. So disability justice to us is a cross-disability framework. All bodies are unique and essential, and all bodies have strengths and needs that must be met. We are powerful not despite the complexities of our body, but because of them. All bodies are combined by-ability, race, gender, sexuality, nation-state, religion, and more and we cannot separate these factors. And the framework really centers disable people of color, immigrants with disabilities, queer people with disabilities, trans and gender nonconforming people disabilities and other people who are at the intersection of multiple systems of oppression. In today's panel is focused on ableism in research in Public Health and the medical spheres. What we mean by ableism is I'm going to quote a definition from the late disability justice activist Stacey Milbern who defined activism as, "A system of oppression that favors being able-bodied and able minded at any cost frequently at the expense of people with disabilities."

We are really excited to talk about this topic that doesn't get a lot of time in the spotlight specifically in health settings and realizing that it is really central to that theme, and we want to make sure that it gets the attention that it deserves. So we want to recognize that this event is amazing, and we are so excited that you guys are here, but it is also just the beginning of a much longer conversation and that we cannot solve any of these problems in 90 minutes and saying that we want you to leave here thinking and still talking and continuing this work.

So with that, we are going to have each of our panelists introduce themselves and provide a visual description. So as I mentioned, I am Arenal Haut, an undergraduate at Brown.

I am a White woman with long Brown hair.

I am wearing purple glasses and a red and pink flowered dress and I'm in front of a White cream board. Eli, would you be okay going first?

ELI CLARE: Yes. So thank you all for organizing this and much gratitude for the labor that was made for all of this possible.

I am Eli Clare.

I am from the unceded territory also known as Vermont.

I am a White transmasculine person with red hair, wireframe glasses sitting in a sunflower yellow room with some art behind me and I am wearing a Black shirt with a wooden pendant around my neck. I come to this panel as an activist, writer, rabble-rouser, community member long time, trans disabled, rabble-rouser. And it is important to say that I don't come here as a researcher. I come here as someone who lives in a world of deliberation that includes disabled and deaf and chronically old people at every juncture. In the future that I want and that all of us wants is a future that ends disability. So that's what I come in with. Thanks so much for letting me be here.

ARENAL HAUT: Awesome! Next I will pass it over to Jen who is next on my screen.

JEN SORIANO: Thank you. Hi, everyone! I am Jen Soriano. My pronouns are she/they and I am zooming in from unceded territory otherwise known as Seattle, Washington.

I am a light-skinned Filipino female, young-ish looking, but middle-aged and I'm wearing a White T-shirt and rainbow-colored striped earrings. And in the background of my room, there is a plant named Fran and pieces of artwork including a piece of artwork that nobody can read from this distance, but it says, "Collective care is the future." And it is a piece of art by an artist named Foz. I come to this panel very excited and very honored to be here.

I am a number of things but for the purposes of this panel I will share that I am a narrative strategist who cofounded social movement institutions like reframe and media justice. So for more than 20 years I have been working to influence public debates toward justice narratives. And I am also a writer and editor. I am, like Eli, not a researcher but an independent scholar that relies a lot on research for my writing. And I actually have an upcoming debut essay collection coming out in August, which is called "nervous," which draws a lot from scholarly and medical research, and it applies a disability justice framework as well as an eco-social Public Health framework to adaptive disabilities stemming from transgenerational oppression and trauma.

So I'm very honored to be here today.

ARENAL HAUT: Awesome! Thank you so much. Next I'm going to pass it to Cyrena.

DR. CYRENA GAWUGA: Hello, everyone. My name is Cyrena Gawuga. Just to describe myself I am a dark-skinned Black woman, and I am wearing green glasses. And in my background I have an array of plants and a panel of Ghanaian art. My parents are from Ghana, so it is very important for me to have this in my background. I'm a Brown graduate, both undergraduate and graduate school. I also spent some time in the Brown medical school, so I saw there were a number of questions about ableism and going through the educational process.

And so it is really important to me to address those issues just because that was something that I struggle with throughout my educational process. Currently I am the Director of research for the preparedness and treatment equity coalition which is an organization that actually is research adjacent, and we focus on funding research, particularly collaborative research between academic researchers and community researchers with regards to health equity. I also am a Fellow with the academy and OP-ED project, and I've been focusing on my OP-EDs during this project specifically on disability justice issues. I will say that I am not an expert in disability justice however I come here not only as someone who has a fair amount of research with ableism and in academia, but also as someone who has chronic illness, both physical and mental illness.

And so you know when Arenal reached out to me and asked me to be on this panel, I was really thrilled to not only bring my experience as a former Brown student, but also as someone who is still dealing with ableism in trying to build a career outside the Academy.

And so I and really thrilled to be here and hopefully, we will have a really excellent discussion.

ARENAL HAUT: Awesome! Last, but certainly not least I'm going to pass it over to Bonnie.

DR. BONNIE SWENOR: Thank you so much. I just want to first say how grateful I am for this discussion to be included among this amazing panel and for the organizers, the student groups of Brown University disability justice as a Public Health initiative. I'm so grateful as a Public Health professional to know about more and more groups like this and just how important conversations like this are. So my visual description is that I am a middle-aged White woman with shoulder length blonde hair. I use she/her pronouns. I meant my home office today and near Baltimore which is on the unceded lands of different tribal peoples. I'm wearing a dark shirt. I'm not great at visual descriptions because my disability is visual.

I am an epidemiologist by training, so this is a very important conversation to me as someone with a disability myself.

I am also an Associate Professor at the Johns Hopkins School of Nursing, medicine a Public Health, and I'm also the founder and Director of the disability Research Center at Johns Hopkins.

So I come today from different dimensions and different perspectives as a person with a disability, is a Public Health professional, as a researcher, as an advocate, as an activist, as someone who fights ableism every single day to stay in academia, try to change academia, to do the work I want to do, and to include the community in ways that I know as part of the community we want to be included. And I am just again so grateful for this discussion and this conversation.

ARENAL HAUT: Thank you all so much for being here. And one note we want to make is we were very intentional. We wanted to work with people that come to research from a variety of angles. People that are independent scholars, people that are at a university, people that are rabble-rousers, people that are working research adjacent that was very intentional we are so excited to have you share your perspectives both professionally and personally.

We will touch on the first question. We want to give you a chance to dive in. What are some ways that you notice ableism show up at Public Health and medical spaces or in research more broadly? And in particular how has ableism interacted with your work? And to the extent that you're comfortable sharing, how have your identities, both disability, but also intersecting identities you may hold impacted your career and your work? Does anyone — that was kind of a lot of questions we threw at you. Anyone feel confident to go first?

Okay, no volunteers. I will call on someone who looks eager. Jen, would you be willing to go first? Sorry.

JEN SORIANO: I try to stop smiling right when you said I will call on the person who looks eager. All right. I will take a swipe at it. So where to begin? I am sure that we all have hours and hours and days and days where we have stories about ableism has showed up for us. I will start by saying that this panel, preparing for this panel actually

reminded me about something that I had forgotten which is that right when I graduated from college, I had wanted to go into Public Health. I kind of swiped that from my mind because it didn't work out for me. I applied for a few jobs, and one of them in particular I remember I did not get. And they told me I didn't get it because I had to cancel on two of the interviews. And the reason I had to cancel on two of the interviews is because I could not get out of bed both of those days.

And at that time there was very little to no recognition I would say about accommodations and so even though I could've done a phone interview, that was never offered to me. I was expected to go across the river into Boston — this is the Harvard School of Public Health — and so you know that was definitely one example of the ways that ableism has affected my career path.

And you know the reason that — a lot of the reason that I am a writer today is because of my disabilities. It is a vehicle for me, to be able to start to change the narrative about ableism and disability. But it is also a lifestyle that unlike the academic world that I was in back then, and, again, this was in the Middle Ages, 20-plus years ago. So hopefully things have slightly shifted at least, if not significantly shifted, but it was pretty clear to me that in the ways that my disabilities got much worse when I was on college because of the ableism of the structures around me that I was not going to be able to continue in academia.

So I will leave it at that for now.

ARENAL HAUT: Awesome! Thank you so much. Cyrena, would you like to share a little bit? And we also recognize it is a huge question and don't expect you to talk about all of it. But just share a little bit.

DR. CYRENA GAWUGA: Yeah, sure.

So I will say because this is a Brown audience I think some of what I will say will be familiar to people.

But I started out at Brown as a student, the program in the medical education which is an eight-year bachelors, medical school continuum. And it is a difficult topic.

So I'm trying as much as possible to keep it together.

But I think that the first time that I really encountered significant ableism in my career was going through medical school. My chronic illnesses, you know, much like Jen, when you have a chronic illness, they ebb and flow. And I was diagnosed with Lupus while I was in medical school. And I very quickly realized that medicine was not a field that was open or willing to have patients who are also on, if you might say, the wrong side.

And so I found myself pushed out of the program. You know of course people might have other, you know, opinions about what happened.

But I was pushed out because of my illness is. Fortunately,, I at that time was living in a Brown program and I shifted to the Ph.D. at Brown while looking at pharmacology. I will say that the Ph.D. program was less ableist than the medical school was however I did still encounter problems with regards to accommodations in a research space.

I ended up researching something that was by far not my first choice because of difficulties, physical difficulties that I have an even in that space, I found that it was not necessarily welcoming of the many disruptions, I will say, in the career path during the Ph.D. program. And I realized toward the end of that that it would not be a welcoming space to me even though I really desperately wanted to continue on the academic track. It was just not a space. Actually bow my safe going into the social work school so now I am a Public Health social work academic adjacent researcher.

And you know I try. I found that I was really drawn to social work because it was a more open place for discussing how intersecting identities affect how we move through the world, how we move through a bio psychosocial space and more open to discussing how disability fits within that framework. And I also am a patient advocate and I do a lot of speaking with Fellow patients who are interested in going into medicine, Public Health, or academic research.

And I try as much as possible to make them aware of the ableism they might confront. And I will say again I'm very thankful for this group that has developed because I think that academia is being pushed towards addressing ableism and engaging in anti-ableist practices, but it is coming very much from the students and from people who identify as disabled who are researchers and not so much from people who do not identify as part of this community. I think really what we need to do is make things clear that everyone needs to have an anti-ableist approach to research and practice.

And I think that in all of the spaces in which I function, I really try to make sure I bring up ableism alongside of other forks of oppression and make sure people are aware that we are all temporarily abled and make sure that people know that.

ARENAL HAUT: Awesome! Thank you so much for sharing about your journey at Brown and all of your experiences. That was really, really amazing.

Next I am going to pass it on to Bonnie.

DR. BONNIE SWENOR: Yeah, this is definitely an important question, but as you indicated a big question. Ableism impacts everything I do all day, every day, it seems like most days. It certainly undergirds so much a Public Health and medicine, just a central idea. The idea of our societal views of health are constructed on ableist views. The idea that someone with a disability has less value in society is ableism.

And so much of the work in Public Health and in medicine and honestly in biomedical research is constructed around that idea.

So my center and the work I do is all about advancing equity and health equity for people disabilities, making our work extreme and challenging in the space where that is viewed as a radical idea. That how could we possibly imagine that people with disabilities have value? That we should be putting research funding into that kind of work? That we should be including the disability community and thinking of ways to do that? Quite honestly, it is upending a system that is deeply entrenched.

So I fight ableism in that way. As others alluded to as a person with a disability in the system, I fight it just to survive in academia.

As I indicated my disability is visual as a blind person. So much of academia is not accessible to me, from conferences to manuscripts to submitting grants, to getting reviews on grants.

Everything we need to do to be successful is not created to include people with disabilities. And that is just as a faculty member.

But I will add that so often we forget the fact that there are disabled faculty, and we need to be here to mentor and carry the torch to make change that the students are working at a grassroots level, and I think that it is something that is a sidebar these two change. Ableism, on the other hand, really feels the work we do. And I think not that I want to say it is a positive, but it really informs and constructs our efforts.

We are using data driven approach is to dismantle and so it is informing, honestly, our research from that perspective which may be is a slightly different take.

So I get to say I'm completely entrenched and surrounded by it which sounds a little depressing if you think about it. But we think it is all for a good cause. Where there is a lot of work to do.

ARENAL HAUT: Thank you so much! ELI, would you like to talk about your experiences and your work?

ELI CLARE: What to add? What to add? Jen is so right that we can talk for hours and hours and hours just by these questions. I want to name two really specific ways that ableism is embedded in the colonial medical system we are operating in right now. And in public health it is part of that colonial, and I will name very specifically the colonial medical system. One system among many systems of ableism. It is not the only one.

But I want to name two ways in which ableism shapes this colonial system of medicine really intensely. And the first one that needs to be named here is the ways in which ableism inside the system of medicine is killing disabled people, killing disabled people. And I'm not using that metaphorically.

I am not using hyperbole. I am thinking of people who died, who have died because of insurance denial. I'm thinking of people who have died because they are not allowed to have an organ transplant.

I am thinking of people who died because they were not worth having. I'm thinking of people who during the peak of COVID were medically triaged out of the emergency rooms. Like our resources, our medical resources are going to be used for other people whose lives are more worth saving.

And so ableism is embedded everywhere in this idea of disabled people living harder. And we could talk for a long time about how disabled people are being killed within the system.

That is the first thing. The second thing is more directly with the public and how over and over again Public Health uses disability and the scare tactics in terms of prevention, in terms of how Public Health campaigns are constructed. In prepping, I was thinking about certain dates of course, but I'm thinking about a campaign of 25 years ago, the antidrug campaign. It was a fried egg on a sidewalk and that tagline was on drugs, this is what your brain looks like. I want to name that as the vilest of ableism, right? Our

brains look a lot of different ways, they are really valuable all of those ways, and that campaign uses ableism as the blood test scare tactics.

I think of the drunk driving, the anti-drunk driving that again, and again, roll out teenagers in wheelchairs and how you have the tragic, tragic music playing, and we see the lonely, broken description in big air quotes as the scare tactic, as the reason not to drive drunk. And I am not against a prevention campaign.

I am criticizing how Public Health rolls out this intervention. And I want to acknowledge this in a world without gun violence and with clean-air and clean water and without rampant addictions that our body, our minds will be really different in incredible ways.

That does not mean that disability would be erased. And using our bodies, using disabled bodies and minds as a cautionary tale in prevention campaigns create so much damage on so many levels.

So those are two kind of micro-ways in which ableism is in the systems. And like other panel members said, I will get really personal for moment. Because ableism has shaped every single day, every single day. And as I was prepping and thinking about what story I wanted to tell about shaping specifically around medical assistance, I think about coming into undergrad. The student was interested in poetry, computer science, math, biology, and chemistry. And I became a poet.

But I could have easily at that juncture in 1981, dating myself, could have gone into STEM. And I didn't because chemistry labs were not accessible to me. There is no way that I could walk into a lab and completed the first lab. There was no way for me, to handle the texture. There was no way for me, to handle the Bunsen burner. There was no way for me, to titrate anything, I mean anything in the lab. And this was the time before the ADA, right? But after 504.

So disability inclusion service offices, there was no mandate about accommodations, much less Universal Design and real access, not that that happened well now. And that totally shaped my trajectory. Like okay, I'm going to go be a poet. And I don't feel like being a community-based poet at all now. But an awareness of that being one moment of as I don't know — 10 million moments in my life of how my life and my choices have been shaped really radically by ableism.

And that is what is inherent in all of us. Ableism is a radical shaper for us. And the shaper, it is different depending on who we are as whole human beings. But it shapes the way ableism and racism and sexism and on and on interact with each other means the way that ableism shapes us is really differential from person-to-person.

ARENAL HAUT: Thank you so much. That was a really important point about talking about the macro, but also the personal and recognizing it is both. Next I am going to ask another question. So how do you imagine researchers can adopt a more anti-ableist approach to the research, especially when engaging with disabled communities and disabled populations? Can disability justice principles frame this approach? And what do you envision that might look like? I am going to start with Cyrena if that is okay. I'm sorry to throw someone under the bus to have to go first.

DR. CYRENA GAWUGA: Sure! So I think, especially now having — approaching Public Health research through a social work framework, one of the most important

things to me is a process called committee-based participatory research. I think it is very important when working with committee members in general, but particularly disabled people, you know whether they be people with chronic illnesses or physical disabilities, mental divergence. I think it is very important to center their voices into center their experiences. A lot of times the type of the research that is done with disabled populations treats them as objects, as things to be studied, and we are not things to be studied. We are people with our own opinions about research.

Our experience is our data. And I think a lot of times you think of data just as numbers or perhaps if you are a qualitative researcher, you know, that you know snippets of information from people and come up with your findings that way.

But I think it is really important to center the experiences of disabled people to understand how they approach their disability, how they approach their illness, and integrate that into research. I think it is really to — if we are thinking about making research blessed ableist, let's say that is our beginning point, to make research less ableist, I think it's important to start with think about disabled people as people and centering their experiences, centering how — one thing that, I think, is really important and when I do patient advocacy work interacting with researchers who are doing work on illnesses that I have is to make sure that they are aware that often the findings that they are interested in are not necessarily the things that we are interested in.

And I think it's very important to go to people and say, "What is important to you? What do you think we should be doing research on?" Because I will say for example I was participating in this advocacy day in DC. As we were having a discussion with, you know, some researchers from a pharmaceutical company, and they were talking about you know the results and they were talking about some of the symptoms that people were reporting versus the symptoms that they were interested in. And one of the things that was really critical for people was fatigue. And there's no, really good assessment for fatigue. And therefore, a lot of times is not included as, you know, a factor in pharmaceutical research, and I will say probably also in clinical research and Public Health research.

And so speaking to people and asking them what is important to be addressed makes them feel as if they are important. And it makes them more likely to want to engage with you as a researcher. You know if you look at other, people with other identities, I've done research with Black cancer patients, for example.

If you approach people on their Level, if you approach people, acknowledging the identities that they live in, it like different oppressive frameworks in which they engage with Public Health and with clinical medicine, it is easier to understand why they may not want to work with academic researchers and therefore, you can change the way that you engage with them, engage with them as equals, engage them as partners of.

And you are more likely to be able to get disabled people to want to be part of your research. And I think that is something that is really critical. And that is very difficult for a lot of researchers who are not familiar with disability as an identity, familiar with disability justice. You note disability is an identity. It is not just a condition. It is not just a state of being. Because we live and enable us to, that is a part of who we are.

And so when you are approaching your research, you have to recognize disability is not just a factor that you are trying to perhaps assess or eliminate even. You know it is just the way that people live, and you need to be able to meet people where they are, meet people where they live. And that is the beginning of making research blessed ableist. I hope I did not ramble too much and how I approach it.

ARENAL HAUT: Awesome! I will pass it over to Bonnie if you had anything to add. We are excited to hear from all of you, your own perspectives, but also recognizing that some of what you share might ring true to a lot of people.

DR. BONNIE SWENOR: Yeah. This is Bonnie. Thank you. And I support everything Cyrena said. It is ditto I would say. Thank you so much for sharing that. This is a question. Is so important. I'm lucky I get more and more of it. I think that is a good sign. My response in what we do and how I think about it is there is a few steps to think about. I think the first step is education, conversations like this. So many research spaces as we just described were still at disability 101. And it really will require hard work on the part of researchers who are new to the space, who are not familiar with the disability community to do some homework and to learn about disability history, to learn about the community. And that doesn't mean phone your disabled friends. That means to do some homework. It might mean that some cases to have discussions. The other is exactly what Cyrena said. It centers on the community. Form meaningful relationships. Don't just take from the community. It should be meaningful relationships. It is also important to prioritize accessibility. That will also take work. We are at accessibility 101. What does that mean? How do we do it? How do you fund it as a researcher? What do you do to include it in your budget? All important things to think about. And as was described by middle of the panelist and the principles of disability justice, do all of that work through an intersectional ends, recognizing the systems of power and forces of oppression are exponential for people who are disabled and have other oppressed intersecting identities, I'm sorry, intersecting identities that are oppressed. I think it is a component that is often ignored is understanding ownership. And I have a friend and colleague, we spoke with him yesterday at the Center talking about asking for permission is that a participation when first interacting with the community. She is quick to say not to mean you don't with the community to participate, but you should come to the community as they are, as Cyrena was saying, don't make the labor on the community. Go to where they are. Meet them where they are as Cyrena was describing. But also recognize the ownership of the data of what you are taken from the community and perhaps find ways to get back and get the data back for example.

And that should be part of the process of it, of anti-ableist research. And relatedly I think this is the stuff not thought about. It is creating structures of accountability. I hear so often for my colleagues in the disability community who do want to engage in research. But when things might go wrong or they feel like their time is being eroded, where they go? Who did they call? And thinking actually about working with the meaningful structures to allow for change and allow for the community to say hey, this isn't working. And to understand maybe going directly to the researcher might not be the best approach because there can be just conflicts of interest there.

And then the last thing I will say is to understand that this is a daily practice. And if you really want to, and I hope all of the audience do start to practice anti-ableist research, it is not just in the lane of your research. It is and everything you do all day. It is sort of a "see-something, say-something" approach. You need to embody this heart, soul, and mind of what you do all day, every day. And really be a critical thinker about how you're living your life. What language are you using outside of your research space and trying to change the world around you to be more into ableist. I think the message is that we all have a role to play, and we shouldn't wait to take action. And I think I can put this in the chat, but I want to say that recently the NIH, National Institutes of Health, I cochaired a committee and our committee was made up of largely disabled researchers. We put forward recommendations that may give some guidance on some anti-ableist approaches. I will share there is movement right now actually. Today and yesterday NIH hosted their first conference on addressing ableism and clinical research in medicine and hopefully, it will not be their last.

I sale of that to give a little bit of hope that maybe there is change and I think change for the funding agencies will also be critical for into ableist research.

ARENAL HAUT: Thank you so much! It was really exciting to see the NIH starting to be part of this. I want to specifically — I am going to ask if our next responded can be ELI.

But I want to specifically ask if you want to build on how researchers can build trust? Because I think that is an important theme and I want to hear both from Eli and from Jen about your experience as committee members in ways that feel valid and ways that feel manipulative and sort of exploitive and things you want to see that make the experience positive for everyone involved.

ELI CLARE: Right. I will get to that in the moment. There are two things more generally, I want to just kind of add more layers to the brilliance that has already happened here. The first is I want researchers to focus on ableism. So much of the research is focused on specific body/mind conditions with the intention of looking at the conditions either in the present or the future. I will research about ableism. I want research about how does ableism impact everyone and not just disabled people. How did ableism impact everyone inside the medical system? How does ableism become a factor in further disabling people? How does ableism get used in triage systems? How are differential diagnosis where one community is diagnosed more specifically and is not based on ableism and racism and sexism and Judah phobia and transphobia. I want research about ableism. And part of that is listening when disabled people are saying this is something that is said really strongly in another example of this. Listen to us when many of us are saying that ableism is as big of a problem as our body/mind conditions, if not bigger it is easy to overgeneralize that because for some that is our body/mind conditions are like the biggest source of trouble. But for many of us, it is a combination of the conditions of the body/mind with ableism. Research ableism, research ableism. And as you are learning ableism as a researcher, one of the things to unlearn is that here may not be the gold standard. Here is really complicated. I spent 12 years writing a book about the messy mental health care, grappling with care.

I am not being anti-cure. Care is messy, messy, messy. Care is everything from lifesaving to social control and all of that, all of the same time and ableism research, we need to let go of cure as the absolute pinnacle of achievement in Public Health and medical systems. So how to gain trust? It is long, hard work. It is long, long, long, hard work. I'm going to be really Frank. Medical assistance, colonial medical assistance, the medical industrial complex has been going on for hundreds of years. To really gain trust is a long, slow work that has to happen over time. No one action, no one thing is going to do it. And here are two really specific suggestions. Stop collecting data through public stripping. Normal public stripping. Never again, get to have a young disabled person and clinicians. Learn it off our bodies, no more public stripping ever. I would like to see every medical textbook in the universe destroyed tomorrow so that they will never use it as a teaching tool ever again. Stop with the bioethics policy that put disabled lives at risk over and over again. We don't trust you because we suspect you want to kill us. The lesson of the strappy, angry, rabble-rousing rant, but I'm not going to apologize for it.

But I am going to recognize it as a rant. Stop the practice of knowing, consensually bringing all sorts of people into exams.

I am done being a teaching tool.

I am done being a research officer.

I am done being the most interesting object of study in any particular day in a teaching hospital.

I am done. And if I am sounding blunt and angry and antagonistic it is because I feel exactly that. It is hard to live down.

ARENAL HAUT: Thank you so much. I think it is important, not the tone down version, the honest version so thank you for sharing. Jen, is there another point you want to touch on?

JEN SORIANO: Yes. This is a critical, necessary conversation. And the things I want to add our this. So Eli, thank you for being an example of agency and autonomy that needs to be centered in research around disabled communities. What you are talking about and the very direct way that you said, hey, let's have research on ableism and how it affects our bodies instead. It is an example of committee-based research questions that Cyrena was talking about that need to pay more attention to. I did a lot of community-based participatory research and the racial justice field when I was a community organizing and I think we can see an analogous thing has happened because of racial justice movement building where there is a quantifiable, it has been a quantifiable increase in the amount of research in the past 5 to 10 years about the effect of racism on people's bodies on chronic disease, chronic illness, the effects of microaggression, the effect of structural racism. And we need the same thing for disability and ableism. And I will add one other thing to everything, all the amazing things such so far around what we need to have that happen. And I think it begins about the research questions. All of the research questions and the way we frame research questions are shaped by the dominant narratives within which we operate.

And I think we can arguably say the colonial medical industrial complex is organized and still survival of the fittest.

And so we have social Darwinism still organizing the fundamental ways that are Public Health and medical system operate the research questions that come out of that dominant narrative current in which we are swimming are things like how can we get everybody to become fit? And if not, then well, sorry you just may not survive and maybe in the meantime, we can tweak some inequities in that process, right? but if we start to acknowledge that still the dominant framework and narrative that we operate under, we can start to change it to things like what Bonnie is operating under at her research department, driving with disability. Other things like disability is an opportunity for us to all restructure our spaces and environments toward accessibility and well-being for all.

And so we start to think about the frames, the research questions can become different. And also we can become more aware of checking ourselves around what is the purpose of this research. So Eli is saying everybody was saying like your note you may think that you know, but again, there is these underlying currents that may be pushing their research toward something that is ultimately going to be harmful for disability communities. But if you start out shaping the questions together with disability communities with an acknowledgment of power differentials, right? Even if you are a disabled researcher, there still a power differential between you as a researcher and the community members who have traditionally been treated as the subjects to be studied, poked, prodded, and eliminated.

And so acknowledging number 1, the harms. That is the point I wanted to make. It is deliberately acknowledging harm, ongoing and historical, is key to trust building.

But then words aren't enough, right? To change the approach, the rigor and is that you apply to research process must also be applied to research and the outcomes and the research questions are framed to elevate, uplift, center disability communities including around finding, around working with in an ethical manner and also obtaining disaggregated data for communities, within four communities within the disability communities who are further marginalized because of race, gender, sexual orientation, class, citizenship status. All of those types of intersectional identities and the last thing I will say I think a lot of times researchers are trained structurally to think that you don't have any control or necessarily in response ability around how your research is applied. But researchers can and must take responsibility for that. Even though you cannot necessarily control everything, there has to be your sense of agency in doing what Bonnie was saying around if you see-something, say-something. If your research is being applied in ways that harm disability communities, it is your response ability to make sure that that changes.

ARENAL HAUT: Awesome! Thank you so much. We are going to — sorry — we're going to go to you next, Bonnie. But will ship to audience questions. The accommodation is resubmitted questions, questions live in the Q&A. We have so many amazing questions. I want to recognize that we will not get to all of them, but we really appreciate you participating and asking these really important questions.

So one question we heard from a few audience members is some examples of what anti-ableist research looks like. And Bonnie, you are involved in that, but some people are little bit more specific about what that really looks like in practice as a model to follow. I will pass it on to Bonnie first.

DR. BONNIE SWENOR: Sure. Thanks. This is Bonnie. I want to quickly add to the wonderful comments made because I do think it is critical. But these points around study and ableism and change in our research questions, they can only happen with funding.

And so as researchers we need the money to do that kind of work and sometimes it is a bill it and it will come. I think that is how Jen was indicating. I want everyone to understand that dynamic of without the dollars of federal agencies or philanthropic organizations no matter how badly we want that research done, will never happen? So how do we do anti-ableist research? I will give my own just personal take on that. And I think the others certainly will have important takes on it.

So what we do is we always start with the community. Largely my center is disabled researchers. And we are part of the committee, but as Jen indicated there is privilege there. We are fighting to stay in academia.

And so we do that in a variety of ways depending on the research study. We are either using it in research approaches where we are working with community members disability activist and agencies to work with us as partners. We are drawing from qualitative work. We are primarily doing quantitative data science to understand the questions and the issues most important. We as individuals participate in ourselves, activism and policy work.

And so just understanding what the community really wants to know, what dated the community is looking for. So that is where we start.

And then we are trying to provide the data to support the advocacy to advance disability inclusive policies, to answer those kinds of questions. We believe that, as I indicated, we don't own the data. We work hard to give the data back as a center we create a lot of publicly available and accessible data dashboards and/or card to disseminate that to the community, the researchers, the policymakers, and it is downloadable. They can interact with the data, use it to however, they want. Contact us with questions and technical advice. And we have published it certainly in peer-reviewed papers, but that is not of importance or value to the disability community.

And so you know in a one-page summary or conversation calls to make sure that the top line hi points of what the data told us are disseminated well throughout the community.

And so that is just sort of an example. Break down the steps.

And you are starting with the community, as I said, understanding the questions that are most important and meaningful, doing the work with the community, understanding power dynamics, and making sure it is led by disabled people, and giving the data back, making sure it is truly getting back ended continuing to collect reflections. Is this working? Is this not? Is this working and what needs to happen next? And I will guess the last point I will add is really our data is working around dismantling those structures

that are enforcing ableism. We are not doing work that is about preventing, treating, or curing, as the group indicated. We view ourselves as working for the disability committee.

So that is very specific and admittedly our work is very focused in a certain area. I will turn it over to others to add their examples.

ARENAL HAUT: Awesome. Next I want to hear a little bit from Cyrena about your perspective in the research fields and then go to ELI engine and hear about your perspectives as a committee member.

DR. CYRENA GAWUGA: I primarily will speak from the role I currently have. And I have academic adjacent. And my organization funds research that is focused on advancing health equity in Public Health and medicine and most of the discussion with health equity is really focused on race and ethnicity and I find my role and again, we talk about the agitator and my role of having the constant refrain that disability is another source of health inequity we work with a lot of researchers who aren't aware of ableism as another form of oppression and disability is a valid identity and something they should be interested in researching alongside Public Health, clinical concerns as they are working with. And many people described here who are ever present oppressive structure in this were people it. I try as much as possible to walk the walk and talk the talk. To encourage people is another factor is a research team to center this in the work that they're doing. And it is hard I will say. It is very hard of how Public Health is structured, how medicine is structured. We are trying to cure things and prevent things. In a lot of ways disabled people are already there. You are not going to cure a lot of the things that we are dealing with. We want to live with them. We want to learn how to thrive with them.

And so it is turning people to think about conditions of the research, and when you do a people who deal with preventative research, I struggle with how to do this. I struggle with how to reorient people, to help them reframe the research that they are doing. To be more conducive, not just working with communities, but making sure disabled people are driving the work that they are doing. It is so hard. But even the concept of committee-based participatory research, it is hard for people to understand let alone bringing in ableism into the discussion.

I will be quite honest; it is hard to figure out what it looks like. But like Bonnie said, we are a disability 101. We are at ableism 101. How to get people to understand ableism and then build research frameworks that are anti-ableist is so challenging. And I don't necessarily have advice about how to do this because I am trying to do this every day. And I think especially the idea that you know accessibility, as someone who is outside academia, there is so much I cannot access in terms of the voluminous results that are produced every day. Journals are behind paywall. And I am a very privileged person.

I am a middle-class person. I know how to interact with academia, and I can't get that information. Thing about people who are in the disabled community who might find some of this research helpful and don't have that access, who don't have that understanding about how academia works who perhaps don't know people. May be like Bonnie says maybe you can send me a PDF of this thing. And even if you manage to work with the community, even if you have centered disabled people in the work or

created an anti-ableist research framework, and practice — if you are within academia, you are expected to publish in peer-reviewed journals. You are expected to publish in a very particular way.

And so you are seeing people who are doing antiracist research, anti-ableist research, they can't get in the papers and stay in academia because they are not in those papers. When I was in social work I worked with a social work investor who struggled during the tenure process. Why? Because she was doing committee-based participatory research. We need to not only help researchers develop anti-ableist research framework, but help academia understand that ableism research, racism research. It works differently. And we need different ways of evaluating the work, academics, and also having people who are researchers who are scholars outside of academia be part of that work because we really de-centered those people, really those people who have that experience who are doing the work and engaging with the community are not valued as voices, not valued as speakers because they don't have affiliation with important institutions. They don't have the right labels. They don't have the shiny bubbles that make them important, quote-unquote.

And so it's a struggle because the most important voices are not as loud inside the wall. We are kept out in so many ways. We are kept out and we cannot really be part of this discussion. We will not make research-less ableist. I don't want to keep talking about this because we have two wonderful community-based voices who can speak more to this question.

ARENAL HAUT: Awesome! Thank you so much. I love to hear from Eli about if you see anti-ableist works done right and if not, what your dream of that is, if that is even a dream that you have?

ELI CLARE: That is such a big question that is so hard, right? We are in the middle class a Public Health. Wherein the middle of the medical industrial complex collapsing. We don't know how fast those are collapsing, but the collapses are happening. And it is so hard to imagine, and we can talk about what we are doing in the midst of these collapses. But part of this question is to think about what is on the other side. How to do anti-oppressive Public Health on the other side of these collapses. And that is such hard work. I just want to acknowledge how hard that work is. But unfortunately, I don't have examples of what it looks like.

But I do know two things. We haven't yet talked about profits. We been talking about research as if it is academia, somehow it is separate from the billions and billions of dollars of profit that are made inside the medical industrial complex every year.

I don't think we can do anti-ableism research that is driven in any way by profit. Because capitalism is so determined to make productivity the single bar of value. And that once disabled people no longer are productive, we are useless. And when we are useless we live in a culture that where someone is useless, they are of zero value. And that is so deeply built into every level of profit. And any research that is done to make money, it is hard to make anti-ableist down to its roots.

This is an anticapitalist call. In the meantime,, in the meantime before capitalism collapses and before the medical industrial complex is reshaped into some sort of

liberatory force which means the medical industrial complex will look entirely different than it is right now when it is a liberatory force. In the meantime, one of the things that, I think, is really important is that we train anti-ableist researchers. And all the places where researchers and healthcare providers are trained, we are doing serious, serious, serious anti-ableist education. How do we design accessible research? Like I am right now part of the community Advisory Board for the disability project on the Transgender Law Center. We have identified the need for broad-based survey of transgender and non-conforming disabled individuals, those who are chronically ill and deaf people. That is research designed to -and-a-half-years to get accessible on the way, to get it into Spanish, to get it into ASL, to get it into sign language, to get into plain language that might be more acceptable for intellectually disabled people. Learning how to do accessible research design is a real set of skills that need to be taught. We can't be anti-ableist at that level by saying we want to be ableist. There are specific skills to be learned. I think we need anti-ableism education at every level of training both health care providers and researchers. And that is both unlearning ableist attitudes that are working in both policy and practice. That is by listening to disabled people. It is about prioritizing accessibility. Everything stops until it is accessible. And I'm not talking about accessibility is a checklist or accessibility as meeting the ADA. Of course we meet the ADA. But really accessible research projects go well beyond the ADA. We need to be training that stuff at every level as soon as possible. How is that for a non-answer?

ARENAL HAUT: There are no easy answers. That is something we want to add. We recognize we are close to the end. We will have Jen respond. But also recognizing that this conversation is over does not mean the conversation is over. This one panel is just one panel and recognizing that we're going to keep doing this work.

So I'm going to send it over to Jen.

JEN SORIANO: Thanks. I will briefly add that I just want to underscore what you would said. Thank you. Thank you for the statement about how capitalism relies on ableism. And within the capitalist structure that we are working under, I also want to underscore what Bonnie was saying around funding. So what are more specifics around how you do anti-ableist research? So agitating for the funding to support the research we want to do, but also to support yourself. And here's where the call to action comes for all of you who are on this call, whatever your particular positionality might be. It is a call to action to organize amongst yourselves. Because this kind of discussion gives me hope. Seeing more than 400 people signed up for the discussion gives me hope. There is a body of people who care about this and who can be per supports for each other.

And so Affinity groups, right? Student groups like what Arenal and Aleksa have created, committee groups, grassroots groups, faculty affinity groups, funder affinity groups, organize yourself to be able to share the best practices, the frustrations, lessons learned. The questions that can start to answer this bigger question of how do we do this anti-ableist research. Because of like Bonnie and Cyrena has indicated, nobody has the answer. But that doesn't mean that there aren't actual good things to build off of anger practices.

And so let's share those with each other and let's build this anti-ableist world one block at a time, one research story at a time.

ARENAL HAUT: Thank you so much! We really appreciate all of our panelists. I want to do a special shout out to our behind-the-scenes team. So Aleksa has been reading all the questions coming in. So thank you, Aleksa and also thank you for cofounding this with me. This is not the kind of thing you could do alone. And thank you. And I also want to thank our faculty sponsors, Professor Sarah Skeels who has been an amazing mentor and an amazing support system in helping us build this and we are really grateful for that. We also want to shout out our other members of our club. You know who you are. Thank you for being part of this work. Thank you to the committed services for running all the technology. Thank you to our CART captioner, and we just want to say thank you for being part of this conversation. This is only the beginning, and we hope this will grow and become even bigger of a conversation even more present in the work that we are doing every day, whatever angle we approach it from. And as we have been saying it is not a checklist. It is not a one-and-done. It is a continual process and that the most important part is collaborating together. We will make this recording available, and we will also be sharing out the resources that the panelist have been sharing.

So if anyone has not submitted their email on our forum, please put that in the chat to one of our moderators we will collect this. You can always email us to ask more questions about the work that we're doing here at Brown. So our email is SPH-DJAPH@Brown.edu. We are so excited to do this work with you and we are learning from all of you. We are so happy to have your support. Thank you all so much for being here and we really appreciate starting a conversation here that has been going on a lot longer and recognizing a lot of Public Health is jumping into the middle of a conversation that is already going on and acknowledging people have been doing this for a long time and that we are just starting what will be a continual process. So thank you for being part of that with us.

1:27 PM (ET)