

Getting Curious with Jonathan Van Ness & Professor Sami Schalk

JVN [00:00:00] Welcome to Getting Curious. I'm Jonathan Van Ness and every week I get to sit down for a gorgeous conversation with a brilliant expert to learn all about something that makes me curious. On today's episode, we have a fantastic guest – I love her so much. We are joined by Sami Schalk, where I ask her: what's at the heart of Black disability politics? Welcome to Getting Curious is Jonathan Van Ness. I'm so excited to welcome our guest today. We have an incredible episode coming up for you. We're going to dive in, honey. So we know the issues of disability are central to any discussion around labor protections, reproductive justice, mutual aid, and beyond. We've also talked on the show about anti-Black violence, scientific and medical racism, and environmental racism. This week's guest is bringing these threads together. She researches how issues of disability have been and continue to be central to Black activism from the 1970s to the present. Sami Schalk is an Associate Professor of Gender and Women's Studies at the University of Wisconsin-Madison. Go Badgers! In her new book, *Black Disability Politics*, she explores how Black cultural workers have approached disability as a social and political issue. And we're asking today, what's the heart of Black disability politics. And Sami, how are you?

SAMI SCHALK [00:01:15] Oh, I'm doing so well. I'm so excited to do this. Thank you so much for having me.

JVN [00:01:21] Thank you for coming on. It goes without saying, you're amaze. Also, I was telling you before we started recording, I'm just gonna tell everybody now, but I'm pretty sure I've already told them, like, 80 times because I am obsessed with the story. The first same-sex kiss that I witnessed in public was in none other than Madison, Wisconsin, in 2003, maybe 2002. Going to see my sister when she went to school there or worked there or something. And I saw these really cute lesbians kissing outside of this, like, noodle restaurant. And I was, like, "Ah! Lesbians!" And I just loved it and I really wanted to go to college there. But alas, I wasn't quite clever enough to get into the University of Madison in Wisconsin, but it's fine. [SAMI LAUGHS] Everything ended up fine and is totally good. And we're all here now. I mean, I'm not talking about me and we're not centering that fucking story, but I do just think that there's, like, a gorgeous lesbian, like, enclave in Madison that deserves a shout-out.

SAMI SCHALK [00:02:19] Oh, yeah. Madison is a very queer city. It's a very queer city. It's one of the ways that I can stay here.

JVN [00:02:26] And, like, I feel like people don't know which, like, on a wider issue, this has nothing to do with what we're talking about. But that is, like, an interesting thing when we think about, like, progressive people in places that we would label as conservative spaces.

SAMI SCHALK [00:02:40] Absolutely.

JVN [00:02:41] And how we feel when we, like, don't incorporate those people and their, like, voices and visions because, like, actually that's, like, such a resource to have progressive people in conservative spaces because it can, like, talk to more undecided people and it can, like, get more people in the fight. And that's fierce. Congratulations on your new book.

SAMI SCHALK [00:02:58] Thank you. I can't wait for it to come out. I'm so, so excited.

JVN [00:03:03] *Black Disability Politics*. What number of book is this for you?

SAMI SCHALK [00:03:07] This is my second book.

JVN [00:03:08] Ah! Second book, sophomore album, honey. Following up. We live! So you open the book—which is incredible, B.T. Dubs—you open your book by describing a 1977 cover story from *Black Panther*, the weekly newspaper of the Black Panther Party. Also, sidebar newspapers are so important, but who's featured in the story and what are the accompanying images? Like, give us a Sophia Petrillo. Picture it.

SAMI SCHALK [00:03:33] It's May 7, 1977. On the cover of *The Black Panther*, which is, again, the weekly newspaper for the Black Panther Party. The main headline reads, "Handicap Win Demands End H.E.W Occupation." And then there's three pictures there. And the first one is a picture of two Black men. So one is Brad Lomax and he's a wheelchair user. So he's sitting in his chair. And behind him is Chuck Jackson. And they are both Black Panthers. So they were the two Panthers that were in at this protest. Then there's another picture of a Black man named Dennis Phillips. And he's holding up a sign that says, "You don't have to see to know." And Dennis Phillips is a blind man. And then there's a third picture that just kind of shows the crowd. It's on the cover of this Black activists' organization's newspaper. But the main story is this huge disability rights protest that really just changed the face of disability rights for the entire country.

JVN [00:04:29] This was a, like, earth-shaking, like, momentous occasion. Everybody was talking about it.

SAMI SCHALK [00:04:35] So the H.E.W Occupation, it's called the 504 Sit In. And it happened in San Francisco in 1977 to force the U.S. government to approve and provide the explanations for this part of the Rehabilitation Act. Section 504 is part of the 1973 Rehabilitation Act that was passed. But Section 504 specifically banned any kind of discrimination based on disability in any kind of section of the public that has federal funds. So that's your public schools, your public universities, hospitals, things like that. So the act was passed in 1973, but in 1977 we still didn't have any regulations that basically defined what is discrimination and who is disabled. So because there was nothing explaining it, it couldn't actually go into effect. And disability rights activists had been fighting back, saying, "We need

these regulations, we need this to go to an effect." And the federal government, especially with changes in leadership, kept pushing off making this go into effect.

And so a bunch of disabled activists came together in a national coalition and said, "We're going to have these protests at different cities across the country." And they did. So a bunch of different cities had different protests: New York, D.C., L.A., Atlanta, Chicago. There were a bunch of protests, but the one in San Francisco lasted 25 days. 25 days of over 100 disabled activists taking over this federal building. It's the longest nonviolent occupation of a federal building in U.S. history in order to make this happen. And that's ultimately what forced the government to pass these regulations was because people were saying, "We are not going to leave." And so it was huge. And the Panthers, being based in the Oakland area, were really actively involved. So they covered this protest from start to finish more than any other newspaper except for the local San Francisco Chronicle. So they were the only ones. But the Black Panther Party had a national reach, so their paper was going all across the country to Black activists and organizers. And so it's so important because they are not a disability rights group. Right? The Panthers aren't. But they understood that disability rights was so interconnected to the work that they were doing for anti-Black racism. They also did anti-capitalist work, anti-imperialist work. So they saw this as lining up with their own work, supported it, and then let other people know this matters and this is connected to our own liberation.

JVN [00:07:21] Fuck yes, intersectionality! And then when you said that, like, the federal government was going through leadership changes, like, if y'all are too young to know, Nixon got, like, reelected in, like, '72, then he resigns, like, halfway through. Then you had Ford take over. But he, you know, doesn't get reelected because he had pardoned what's his face and was, like, not a good look. And then you have Carter come in. So the '77 is happening, like, in Carter's first year.

SAMI SCHALK [00:07:49] Yeah. And I think that was the, the problem for these activists and organizers that they had been working with the federal government to come up with these regulations. And then Carter came in and his administration, his head of H.E.W—H-E-W, it stands for Health, Education and Welfare—that, that person came in and said, "I want to reevaluate all of this." And so they had been working and working and trying to reach an agreement. And this person came in and said, "Eh, maybe not. Let me look over this." And so disabled activists said, "Absolutely not. We are not going back to years of negotiation over this. And so we've gotta move this forward now and we will take it to public protests, if that's what it takes."

JVN [00:08:27] Oh, my God. And God fucking love them. Like, so important. So in your work, how do you define Black disability politics?

SAMI SCHALK [00:08:34] Disability politics, generally, I understand as an approach to disability that understands it as a political and social issue, more than a medical and personal

issue. And so then Black disability politics are the way that Black cultural workers, which for me I use that term to mean activists, but also writers, intellectuals, organizers, artists, you know, people that are influencing culture. So Black cultural workers and how they do disability politics, how do Black folks in particular approach disability as a political and social concern outside of just a medical issue? And what I hope to do with the book, what I hope to offer, is that we can think about how Black folks might approach disability differently than the mainstream white disability rights movement because of the way that racist violence produces disability in very different ways inside of Black communities.

JVN [00:09:32] Oh, my God. That was major. Can you say that last part again?

SAMI SCHALK [00:09:38] Yes. So I think about how Black folks might approach or understand disability differently because of the way that racist violence or racism neglect produces disability differently within Black communities.

JVN [00:09:53] Okay. Yes. The fuck yes. And also, you're a historian? Like you study history.

SAMI SCHALK [00:09:58] My degree is in Gender Studies. I'm an interdisciplinary scholar. So my research is archival. It's historical, but it's also very theory-based. To do this book, I went into the archives of the Black Panther Party, the National Black Women's Health Project, but I also interviewed contemporary Black disabled activists. So I'm trying to bring a lot of things in. I talk about how the book is kind of undisciplined. It kind of refuses to fit into one category because I want the book to be useful to a lot of different people. And so it's very historically based, but it's not, like, a history of Black disability politics. It doesn't cover everything I could cover, it really talks about two organizations, some contemporary people, and says, "Please, other people, come join me in this conversation." That's what I want. I want more folks doing this kind of work.

JVN [00:10:47] I'm obsessed. So we talked about, like, the 1977 story about the H.E.W occupation—is there any other, like, histories or stories that you covered in the book, not spoiler alert or anything else, that you think could kind of help us understand, like, how you approach Black disability politics in your work?

SAMI SCHALK [00:11:03] Yeah. So I talk about, again, these two organizations. So I'll tell a little bit about the National Black Women's Health Project. So the National Black Women's Health Project started in the 1980s, and they were focused on, again, specific health initiatives for Black folks, right? So focusing on Black folks with that, that includes Black disabled people. And one of the things that they did was they really worked with Black women with HIV. Right, so this is the eighties in the nineties, when most people thought that HIV was only something that happened to gay men. Right. So there was very little attention to women and to straight folks around this. And so they were actively doing some of the most important work to get proper information out there about how HIV worked because of the terrible representations in the media that gave people misinformation and made people think that it couldn't happen to

them. So they were actively doing this work in a way that focused on the Black community. And my favorite example that I made sure to write some notes to tell you about is that one of the things they did is that they worked with Black hairstylists and barbers and beauty shops and educated them about HIV and provided them materials about HIV and condoms so that they could take it into community spaces. Because a lot of Black folks were not going into the same spaces as the public health people were around HIV because they were focused on queer spaces. So the National Black Women's Health Project said, "Who are the people that are influential in our community? Where do people in our community go? And that's where we're going to start." So they focused on educating hairstylists and barbers about HIV so that the larger community could learn as well.

JVN [00:12:48] That's so genius. Like, going to a hair salon or going to the barbershops. It's like, so genius. When I think about the frustration around, like, having fucking Ronald Reagan and thinking about, like, ACT UP and all of the lives that were lost and, like, just how hard that was for queer people to navigate the HIV/AIDS crisis in the eighties. I cannot imagine how for Black women suffering from HIV, because, like, it was even more stigmatized.

SAMI SCHALK [00:13:19] Yeah. And largely that was because a lot of the Black women that had contracted HIV or AIDS were sex workers, you know, or they were needle users, intravenous needle users. And so there's that extra layer of stigma that allowed people to say, "Well, we don't care about those people." Right? There's so many layers to why Black women did not get the same amount of attention for this.

JVN [00:13:43] But there also had to be, like, lots of Black ladies who just, like, hooked up with some fucking guy and she got it. And even if she was a fucking drug user, like, who gives a fuck? Like, we shouldn't have been talking about it.

SAMI SCHALK [00:13:54] Yeah, absolutely.

JVN [00:13:57] So we know that language evolves as movements evolve, especially when it comes to how we speak about one another. As we get our bearings in talking about Black disability politics and your work around it, what's the history of language within disability politics?

SAMI SCHALK [00:14:11] Yeah, the language around disability has changed so much over time, and I think it's one of the things that my students in my classes are always worried about saying the right words. So the language has changed over time within the communities that we have now, within disability rights and disability justice communities, we use the term "disability," not "handicapped" or "handicapable" or these other kinds of words. There's a couple of reasons for that. Words like "special" and "handicapable," they're kind of considered these fake nice words, that they kind of try to move away from the stigma of disability without actually dealing with the stigma of disability. So those words don't get used. "Handicapped" is considered an outdated term, so the terms change over time. But one of

the reasons that words change over time is that a lot of words related to disability get picked up in our general social language and used as insults.

So more contemporarily, we might think about the "R word" and the way that folks moved away from using that as a term of insult. But it comes from a medical term to refer to people with disabilities that now we don't even medically use that term. We talk about "intellectual disabilities" and "developmental disabilities" because of the way that it became an insult. And you can go back in history and find more and more terms like this. So the one that I like to talk about is "idiot" and "imbecile." People think these are just things that we call people who aren't very smart, but they were actually medical labels for levels of IQ. So if your IQ was a certain level, you were considered an idiot, a certain level an imbecile. So those were, again, these psychological or medical labels that then move into our culture to become these insults. So language around disability is constantly changing because of the ableism in our culture that takes words for disabled people and turns them into these insults.

JVN [00:15:58] Mm. Yes. Hate. So what's the importance of examining words in a racialized context, like, in multitudes?

SAMI SCHALK [00:16:07] I think that it's important to understand how words are used within certain communities and to be aware that there might be a balance when we're talking about communities that have multiple marginalizations going on. Right. So Black disabled folks might be talking about disability in a different way. And just because they're using a different language than white disabled folks doesn't mean that they are self-hating or that they are trying to be insulting in some way. It's that language evolves within our communities, right? Our specific communities. So I think we saw that recently with the Lizzo and the Beyoncé lyric of using the word "spaz" that so many people within a disability community, particularly white disabled folks, said, you know, "This has been used against me as an insult. It's terrible, you know, you gotta take it out." And folks that were in Black communities were like, "We never thought this. That's what that meant. It didn't mean anything like that to us." And of course it does. We can trace it back to it comes from spastic and we understand how it got there, but folks aren't using it with this intentional connection to disability. And so for me, kind of watching that conversation unfold on social media, I felt like there wasn't nuance on either side. There wasn't attention to, like, how unintentional uses of language could still be harmful to someone. And there wasn't attention to racialized context for a word that, you know, these white disabled folks couldn't imagine that there was a world where a bunch of people were using this word and with no intentional connection to disability at all whatsoever, even if the word historically has that connection. So there was this interesting conversation that happened that felt like it was really leaving out a lot of Black disabled people in that moment.

JVN [00:17:47] When I first read that, my heart sank for her, especially Lizzo, but she literally was, like, "Wanna see, like, how you do class and grace like in spades and then still have, like, number one albums? Take a seat. I'll fucking show you how to do that." And I was just, like, [CLAPS]

SAMI SCHALK [00:18:01] Yes.

JVN [00:18:02] Can we stand how? But also there's probably, like, a larger conversation there too, about, like, how Black women have to be, like, fucking more graceful navigating because, like, I really feel like it came from her heart.

SAMI SCHALK [00:18:11] I think that yes, she was very genuine. And what she did, she did it quick. She made the change. She didn't fight back. Like, it was just, like, a masterclass in how to handle that sort of thing. Yeah, I think she did a great job. And also, did you know that I twerked with Lizzo one time?

JVN [00:18:25] I did hear that, but I wasn't trying to bring it up because I didn't want to be, like, this person who was, like, "Oh my God," because, like, I am like, yeah, I did hear that and I'm obsessed with her. I was just about to go into a tirade about, like, how obsessed I am with her. And I, like, one of my biggest fear is in life is that she's going to, like, unfollow me on Instagram, but I don't want to verbalize it because I don't want to, like, make it happen. Do you know what I'm saying? I'm just obsessed with her a little bit and that's probably, like, why we don't like text because she knows like that I'm a fucking weird super fan. I also think that was, like, an interesting example of even just, like, that little thing about, like, how really serious conversations can live next to humor. And that's okay. Which is also, like, a little like pleasure activism, like, sidebar that, like, you're allowed to experience, like, fun things even if you're talking about things that need to change, which I just think is cool, like, making space for that. But when we are bringing it back to, like, why we need to understand where words come from, what is the dangers around regarding disability as, like, a metaphor and what does that kind of mean?

SAMI SCHALK [00:19:22] Yeah. So there's this kind of long history of using representations of disability to be a symbol for bad things, right? So it's a symbol for war, a representation of the damage of war, a representation of harm that's been done. And that's not incorrect. Right? Disability comes out of war. It comes out of harm in all these kinds of ways. But it ends up making disability being this really negative symbol. And it relies on the negative associations that people have with disability in order for it to have the emotional effects. Right? The reason that you are emotionally affected by, you know, a story about a disabled child after war is in part because you think disability is bad, their life is over. So you have all these really negative ableist assumptions. So when we treat disability as a metaphor, it takes it outside of the real-lived, full life experiences of people with disabilities, especially people who have lived with their disabilities for a long time. Folks who are newly disabled, of course, are experiencing mourning for their bodies. Of course, they are experiencing the difficulty of that kind of transition, especially if the disability happened because of something particularly traumatic. But we get stuck in those moments and a lot of the representations of using disability as a metaphor.

So a lot of these metaphors rely on the assumption that disability is negative. So in disability studies, folks have really pushed back on that and said, "Disability shouldn't be used as a metaphor. That's a bad thing." And a lot of times it is. In my work, I try to also nuance that a little bit because sometimes in Black representations in particular, I look at a lot of Black literature. Disability is being used as a metaphor, but it's also being used to highlight the real harms of racial violence. So this comes up a lot in representations of slavery, for example, the ways that slaves were purposefully disabled by slave owners in order to prevent them from running away and prevent them from seeing their families. Right? So that's a real thing. It's not simply a metaphor in this context. It's not being constructed just to make you feel bad for this character and this representation, but in order to highlight real violence. And so one of the things I encourage in the book is when we're fighting back against particular kinds of oppression and harm that does produce disability, that is disabling, an example that might be police brutality, right?

That means that when we're talking about the disability, we can't just say, "This person was disabled, look how bad this is." Instead, we have to really focus on the violence. The violence is bad, the trauma is bad, the harm to someone's body is bad. But disability in and of itself is not bad. And one of the ways that I argue that activists can really push back on this is to, as you're critiquing the violence that's happening, to also really spend the time to materially support the people who have been disabled, to not just use them as symbols and discard them, but to really focus on "And now what do we do?" Now what do we do to support these folks who've been shot by police and are now disabled, people who have witnessed police violence and now have PTSD? How do we give them holistic, long term community support as disabled people in addition to still fighting that violence? And I think that that balance will allow us to really have a Black disability political approach that includes disabled people, rather than just using us as symbols and then discarding us from the actual work of making people's lives better.

JVN [00:23:05] Mm. Yeah. In the book, you make clear that Black civil rights and disability rights are not mutually exclusive from each other. Can you describe that connection for us?

SAMI SCHALK [00:23:16] Yeah, well, a lot of it just comes down to inspiration and history. So the civil rights movement happened much earlier than the disability rights movement in terms of actually getting legislation passed. And the Disability Rights Movement took inspiration from the early civil rights movement. So in terms of nonviolent protest, like, the occupation of the H.E.W. Building, right. Like that was inspired by the civil rights sit-ins. That taught folks, "Oh, you just go somewhere and you sit down and you refuse to move? That's going to get attention. That's going to do something." Right? It really helped inspire that kind of work. In the Black Panther newspaper they talk about that when the disabled activist learned that they had finally won and the regulations were going to be codified and passed, that they started singing "We Shall Overcome," which was this Black civil rights song. Right. So there was so much inspiration that was drawn from the Black civil rights movement that I think sometimes gets overlooked in the history of disability rights, especially, I think, more contemporarily. So

there's a lot of inspiration that was drawn and then there's also mutual support. So the Panthers sometimes partnered with disability rights organizations on certain issues, so they joined forces to try to stop this psychosurgery development center that was going to be at UCLA. And they partnered together to prevent it from being funded because the intention was to research the brain and to essentially practice psychosurgery, which is the most famous version of that is lobotomies.

JVN [00:24:44] Yeah!

SAMI SCHALK [00:24:45] That's the one that people know. But there are lots of versions of psychosurgery, but essentially that's, you know, physical surgery on the brain in order to change mental and behavioral effects. And this Center for the Study of Violence, that's what it was going to be called, intentionally wanted to test out psychosurgery for, for criminals, for folks who were in psych institutions, and also for women. So they worked together with psychiatric disability organizations and the Black Panthers, and they joined together in this coalition to essentially block the funding from ever happening. Because we know when they say violence, who they're talking about, when they say they want to test this out in prison populations, we know who that means. Even if they're not saying Black folks, that's primarily the target population, particularly Black men. And so historically, these Black civil rights and disability rights have partnered together in various moments where our concerns overlap. What I'm hoping I can do with this book is to show that Black civil rights and Black liberation work in general has also done this other work on disability that isn't always directly about disability rights or directly partnered with disability rights. Sometimes it's happening in these other kind of health spaces that they don't put the same label on it. So we haven't looked back, as Disability Studies scholars, in those areas and said, "Oh, that's disability," because they're not using the same words often.

JVN [00:26:13] Mm! That is so interesting. Okay. So how has white disabled people homogenized people's understandings of what counts as disability? Like, how does this exclude and deny the experiences of Black disabled people?

SAMI SCHALK [00:26:29] Yeah. A lot of Black people's experiences of disability are different than a lot of white people's experiences of disability. And this comes from the fact that a lot of folks who are Black have these chronic conditions that develop or worsen over time. So we're thinking like asthma, thinking diabetes, but also because of medical neglect and medical racism. Right. Don't get the same kind of health care experiences. So even if you are disabled from birth, your experience in the medical industrial complex is going to be very different than a white disabled person.

JVN [00:27:00] Which is the same reason, like, maternal mortality rates in Black women are, like, three times higher. Like, is it correct to say that, like, if in an able-bodied population, like, Black people have worse outcomes? So in a disabled population, it's going to be even worse-worse?

SAMI SCHALK [00:27:17] Absolutely. Yeah. Yeah, it's a lot worse. And so, our just, like, day-to-day experiences are very different. But then also our experiences within our communities are different because white populations generally tend to have wealthier communities that they're living in, which might mean that there are more resources, it means that it's more accessible. So for a lot of reasons, our experiences are super different. But the folks who have always been at the forefront of disability rights, have historically predominantly been white folks. So they're building and shaping the law based on their experiences. And so one of the ways we see this come out in terms of disability rights now, like, with the Americans with Disabilities Act, is that if you want to get accommodations, you often need to get a diagnosis and you need to have doctor's notes. You need to go through this really formal process. And we know that for some disabilities, Black folks are under-diagnosed in certain categories, overdiagnosed and others. And so it can be more difficult, especially getting access again to health care, to get these diagnoses, to get your accommodations.

JVN [00:28:22] And if you don't have access to public transportation, if you don't have insurance, how do you get the money? How does your family get the money to, like, get to the doctor to pay for it or to gain insurance? It's like, for me, navigating the HIV social safety net, like, with Internet, like, I almost threw a computer out the window, like, it was so difficult. And so I would imagine that navigating other social safety nets for disability access. It must be, like, one of the most frustrating things that you could possibly, like, want to endure.

SAMI SCHALK [00:28:54] Absolutely. You know, to get access to disability SSI, right, people have to hire lawyers. And so if you don't have access to these things to really push that process along, if you don't have the education and knowledge to read these forms and fill out these forms, you are not going to get access in the same way. And so that formal designation of disability to get formal support from the state, it's so much harder to access for Black folks, even as it is incredibly hard to access for people in general. And so because of that, because of the way the laws have been put in place and our expectations of what disability means, it's been really shaped by white folks and it has left a lot of Black people even not identifying as disabled because the state says they're not. So they're, like, "I'm not disabled, you know, I don't get this kind of thing or that kind of thing. I don't have handicapped parking, right? I don't have that. So I must not be disabled," even as they are very much living with conditions that we would consider disability as folks in Disability Studies.

And so a lot of the work of Black disability politics today is helping more Black folks realize, like, "Yes, you are disabled, that is not a bad thing. And there's a whole community of support." Even if the state is not supporting you in this way, there are ways that understanding that you're disabled and finding community, finding people who are sharing their experiences can help you realize, like, "Oh, this isn't a problem with me, this is not my fault. I'm not to blame here. There's these larger systems that are making this really difficult for me." And I think, you know, this kind of consciousness raising is important for any social group. Right, any marginalized group. It helps you to realize "I am not the only one who's experiencing this and

it's not my fault." But I think for Black disabled people, that is a big part of the work is now Black disabled activists are trying to get more Black folks to realize that it's okay to identify as disabled. And that's there's a whole community of folks that are ready to support you in having a better understanding of the systems that need to change to support your life.

JVN [00:30:52] What are some examples of, like, things that people would be having or that would be disabled but they wouldn't, like, like, what are some examples of that?

SAMI SCHALK [00:31:02] Yeah. So I'll just give you examples of things that students have told me. So I teach Disability Studies and I often have students at some point in the semester say, "I didn't think of myself as disabled until your class, but now I do." Crohn's disease. A student recently was, like, "I didn't realize that that counted as a disability." Having migraines. Even folks with diabetes, you know, there's lots of folks with diabetes in my family that wouldn't consider themselves disabled. A lot of these, the ones that are—, folks most struggle to identify as disabled, is when the disability is not super apparent on their body. I think because of things like accessible parking, right, that has the wheelchair symbol, we really often in our culture associate disability with very physical, visibly apparent things or things that are sensory, right, blind or deaf. But there's all kinds of ways that disability can be exhibited. So I also think that folks with psych and mental disabilities are also ones that tend to not identify. And sometimes I think people know they have a disability, but they still don't say, "I am disabled," because again of the stigma, of the ways that not identifying another thing that someone could use against you as a Black person, is a mode of protection. And so Black disability political work is really showing folks that there are ways that you can be out about your disability that is helpful. And it's not just all harmful once you get this label.

JVN [00:32:32] Cause you spotlight TL Lewis in the book and this is, like, this quote is major. "There is no racism without ableism. There is no ableism without racism. You quite literally can't have one without the other." Why is it not enough to simply say that racism and ableism are linked?

SAMI SCHALK [00:32:52] Yeah. TL Lewis is great for anybody that wants to follow TL, TL doesn't use pronouns. It's not just enough to say they're linked or they're connected because we need a way to say that they can't exist without each other. They're dependent on each other, and they help function for each other in certain ways. And so some, some ways that I try to explain this to folks is that when you think about racism as a whole was, like, this idea that certain races are inferior to others, right, inferior, bad, in whatever kind of way. Ableism is this idea that certain bodily or mental differences are, again, kind of inferior and should be treated, cured, fixed in some way. So they have this connection. But I think that racism, the idea that something is inferior, doesn't automatically, then, mean that it needs to be changed in some way or prevented from, like, mixing in other ways without ableism. So ableism is the thing that says "This is bad, like, inferior equals bad. Needs to be fixed. Needs to be controlled, regulated." But it has allowed for certain kinds of approaches to Black folks, but also other marginalized groups.

So historical examples of this would be, like, scientific racism, where there were certain kinds of diseases that were claimed to be "only Black people had them." The one that I talk about in my first book is drapetomania, which was this disease that supposedly only infected enslaved Black folks that made them run away. So the idea is that "healthy" Black folks would never run away, enslavement is the proper place for them, and so they must have something mentally wrong with them if they keep running away. And then ableism, right, that says, "We have to treat, fix, cure, anything like this." Says that the treatment, the fix, the cure is to do things like cutting people's Achilles tendon so they cannot run, right. It is doing these physical alterations to someone to say, "Something's wrong with you and we're going to fix it." There's these ways that ableism has helped extra justify racial violence. And so they really depend on each other to function in a lot of different ways that we can't really separate them. They're just so deeply linked. And so, you know, part of the work with this book is me saying, especially to Black activists who are not familiar with disability politics, is to say, "There is no way that we can dismantle white supremacy if we are not also dismantling ableism and talking about disability because they reinforce one another. And so if you're just paying attention to one, you're never actually going to address the other parts that are supporting it because you're not looking at the whole picture."

JVN [00:35:50] You know what that kept bringing up for me when you were talking about that? Eugenics.

SAMI SCHALK [00:36:50] Absolutely. I mean, I think eugenics historically in this country has been used against folks of color, queer folks, and disabled folks in a really interconnected way. That label of "feeble-minded"—

JVN [00:36:07] Yes!

SAMI SCHALK [00:36:07] —was this big umbrella term that could just include folks who, likes, people of the same gender and that made you feeble-minded, right? Not behaving in a typically expected way. One of the histories that I read for this mentioned that there was one woman who was sterilized for being feeble-minded, you know, under this eugenic lens. And one of the pieces of evidence that they gave was that she was "too friendly and familiar with the Black help." So basically she was a white lady that was just, like, nice and friendly with Black folks—

JVN [00:36:40] So they sterilized her. They're, like, "We don't want any other white babies that could possibly be nice to—?"

SAMI SCHALK [00:36:44] Exactly. Or potentially making babies with Black people, right. But just that, that familiarity and that friendliness was considered "feeble-minded" because they said, "A white woman in her right mind would not do this. So there's something wrong with your mind. And because there's something wrong with your mind that justifies us being able

to do these other things because we believe in eugenics and we believe in creating 'better' humans and better humans and not Black humans, and they're not disabled humans."

JVN [00:37:09] So we hate that story. So we love how much you are highlighting and spotlighting the Black Panther Party and the history of the Black Panther Party in your book. Can you remind listeners of some of the basics of the Black Panther Party and kind of, like, recontextualize that for us?

SAMI SCHALK [00:37:25] Absolutely. Yeah. So the Black Panther Party is this radical, revolutionary Black organization. And they were anti-racist, anti-capitalist, anti-imperialist, and they were started in 1966 and they were started in the Oakland area, which was like, you know, in the Bay Area of California. And they initially started with this image that most people know. Most people know a bunch of Black men with, like, leather jackets and berets and guns, and that started as basically community control of police. They said, "Okay, if you're going to harass us, if you're going to do this in our community, we're going to patrol around with guns following the gun laws." That was one thing that I think it's left out is that they were well-educated folks who were doing the reading on the wall so that they were not breaking the laws so much so that California changed their gun laws in response to the Black Panther Party because people were, like, "We can't have all these Black men driving around with all these guns."

JVN [00:38:23] Right, because, like, shotguns had been legal. But then they made shotguns illegal so that they couldn't have shotguns anymore.

SAMI SCHALK [00:38:30] Exactly. So reducing their, their ability to access, like, the most affordable things available to them.

JVN [00:38:35] Right.

SAMI SCHALK [00:38:36] That's how they started off. That's where most people's association with them went. But that's 1966. The organization actually was still an organization, doing various work in the community up until 1982, which I think a lot of people don't know. Most of the history that people have focused on goes from about 1966 to about 1974. And that's because that's when they were the largest. That's when they had the most cultural influence, and that's before they started to really get essentially shut down by the FBI. So there was a point at which the head of the FBI said that the Black Panther Party was the "greatest internal security threat to the United States." The greatest threat. Right. This group of mostly young teens, twenties, Black men and women. So most of our history that has talked about in the most way that people think about the Black Panther Party is up until that point. When the FBI did their COINTELPRO, so their counterintelligence program, with the Panthers, where they essentially, intentionally sent people to destroy the organization, to pin people against each other, to make accusations, and to straight up murder people, put folks in jail. Right. It really disrupted the organization, as you would expect. What then happened is that the organization

actually was predominantly run by women after that point because so many men had been killed and put in jail, more and more women were in prominence. And so they reorganized themselves to really focus on much more local, grassroots community work, especially in the Oakland area where they had their biggest chapter. And that happened around 1972. So their ten point platform made claims that they wanted full employment, land, bread, housing, education, clothing, justice, and peace. That was the original. 1972: They changed that to add completely free healthcare as well.

JVN [00:40:31] Fuck yeah!

SAMI SCHALK [00:40:33] Yeah! [LAUGHS] So around '72, then, the organization started doing much more what they call community survival programs. Community survival programs included food giveaway programs, food pantry programs, safe walk programs for senior citizens to walk them places safely. They started a school and a child care center for folks in the community, and they also started their own health clinics to get people free health care. So the organization really did all of this work for, like, a full decade after most people talk about what the Black Panther Party did. And this was mostly run, again, by Black women leadership. And so that's actually the period where they started doing a lot of disability political work was when they started doing these community survival programs where they weren't just thinking about the larger theoretical politics, but they were saying, "If we want people to be involved, if we want people to be able to do political organizing first, we have to meet their basic needs." You can't ask people to go to a protest when they don't have money, don't have food, don't have housing. Like what? People need to have had their needs met. And so they focus on meeting needs and then adding in some political education at these kind of events where they were helping meet community needs. So that's a little bit about the history of the organization. And yeah, I really hope that my work on this can help folks see that there's this longer history of the Panthers that is really quite radical, just radical in ways that are different from the armed patrol of police.

JVN [00:42:10] How did the disability aspect, like, get into, like, mainstream, Black Panther Party work?

SAMI SCHALK [00:42:15] Yeah, so kind of two influences. The first is Brad Lomax, who I mentioned was in the cover image in 1977. So Brad Lomax was a Black Panther who had MS (Multiple Sclerosis) and who became disabled while he was already a Panther. So, like often happens within our communities and organizations, there was just a person who was, like, "We need to be thinking about this," right? So he played a really, really critical role because he got connected with other disability activists like the Center for Independent Living and said, "Okay, we need to be working together." So in the Panthers' archives, there's evidence of Brad Lomax making meetings with major leaders in the disability rights movement. There's evidence of him connecting with people to make sure that ramps get added to every Panther building, which is something that they did. Once they kind of raised their awareness, they

made their buildings more accessible. So one is just literally a person, a person who became this bridge, as we often are, as multiply marginalized people between communities.

The other is that kind of coincidence of location. So the Panthers, again, based in Oakland, the disability rights movement really got its heart and its growth in the Bay Area, particularly around Berkeley. So Berkeley was one of the first state universities to accept disabled students. And so a bunch of disabled students went to Berkeley, created community, stayed there and started to build the disability rights movement. So because of that, there was much more collaboration and interaction than I feel there would have been at the Black Panthers or the disability rights movement were just based somewhere else, but it was literally just this coincidence of proximity that they were in similar areas. And so when certain issues came up, they started partnering for different kinds of things. So a person and a place just happened to line up. The Black Panthers, there's an interview where they say, like, "It wasn't hard to incorporate disability rights because it lined up with our politics and our values already. So it wasn't a difficult shift once we were made aware of it."

JVN [00:44:29] Because another thing that you addressed in the book is—which, like, I'm always, like, learning about a new industrial complex, but, like, the psychiatric industrial complex. So, like, what's the history? And we mentioned it a little bit earlier but what's the history of Black children and adults being mis- and/or, like, overdiagnosed and disabled?

SAMI SCHALK [00:44:46] Yeah. So I'll start with misdiagnosed, let's start there. So the misdiagnosis that the Black Panthers were really working on was inside of psych institutions, often ones that people were sent to from prisons. So a lot of Black Panthers were sent to prison for all kinds of reasons. And they witnessed the way that certain people, when they pushed back, when they talked back, right? When they were resistant inside of prison spaces, were labeled as having a psych disability. And that allowed, then, the prison to either send them off to a psych ward or heavily, heavily—

JVN [00:45:27] Medicate.

SAMI SCHALK [00:45:28] –Forced medicate, yeah. So the Panthers were fighting back against that. They were saying, "These are false labels. These are also being used to keep people incarcerated for longer periods of time." So one of the things that I talk about in the chapter on this is that there's a letter that came from a psych ward, from a man who had been incarcerated in this ward for months and never given a trial date because he was considered to not yet be competent to stand trial, but also was not being set free. And he explains that when people were put in the psych wards, even if they eventually did get a chance to go to trial, if they were then convicted, all of the time that they spent in the psych ward was not considered part of their sentencing time. So it wasn't, like, "You've been incarcerated in this space for two years and you get convicted and you're supposed to have three years and now you only have a year left." No, now you have another three years on top of that. So the

Panthers were noticing that these labels were being used to keep Black men in jail longer and to keep them there indefinitely, potentially, as well as severely overmedicated.

JVN [00:46:42] So then don't those types of institutions, like, those functioned through the eighties and then doesn't Reagan get rid of them?

SAMI SCHALK [00:46:48] They're not entirely gone. So you can still be put under an involuntary hold. And it's for 72 hours. And then there has to be a reassessment. One of the things that was not happening is that people were not being reassessed or if they were being reassessed, they were being reassessed while heavily medicated where they could no longer really fully communicate or represent themselves. So that was part of the problem was that people were being trapped because of the overmedication.

JVN [00:47:14] A lot of these stories about, like, forced sterilization or, like, disability, like, access rights, you would think that they were being debated in, like, just way longer ago. But in reality, a lot of these things were really recent. So a second group that you focus on is the National Black Women's Health Project. Cool! And you mentioned our recent guest Dorothy Roberts, who we already talked about but we're obsessed with her. She's a one time board member. How is this group an example of Black feminist health activism?

SAMI SCHALK [00:47:45] Yeah, the National Black Women's Health Project is this incredible organization that started in the eighties, and they were focused on health projects that focused on Black women. The founders of the organization noticed that there was very little research or information about Black women's health. And so it started off, which is that, like, "Where is this information? How can we get it? We're going to have to create it for ourselves." And what it became was this organization that did grassroots work to help create access for Black folks, particularly Black women, to different kinds of healthcare in a really holistic way. So they talked about your mental, physical, and spiritual well-being. So all of these were things that they wanted to address in this holistic way. And it came out of realizing that so many of the public health efforts that were directed towards Black women did not actually consider the reality of their lives. And I'll give you a couple of examples. One example is education around eating and health. So there was this focus group that one of the founders was working for an organization and was supposed to run for Black women, essentially to teach them about cooking healthy food and eating healthy food.

So she goes into this and she's, like, "Okay, I'm ready. I'm going to teach them about calories and enjoy the stuff." And the women were essentially, like, "Oh, we already know all of this. The problem is we don't have the time. We don't have the money. Our kids won't eat that. My husband won't eat that. I'm not going to make multiple different meals." Right? They start listing all these other things in their lives that they're like, "It's not that I don't know or even want to do that. There's just too many barriers to doing that." So it made them realize, like, "Oh, actually we have to start addressing this much more holistically for us to get there."

JVN [00:49:30] Okay, so but really, what they realized was is that it's, like, it's not that Black women don't know. It's just, like, systemic stuff, like, food deserts. There was, like, literal financial or, like, physical barriers getting in the way of, like, bringing in different options into their homes.

SAMI SCHALK [00:49:44] Yeah, absolutely. And so it made them realize that there needed to be a different approach, more talking about Black women. The other example in their HIV work was that again, they were holding these focus groups, talking to Black women about condom use, about, "How do we get you to use condoms," you know?

JVN [00:50:01] Yes.

SAMI SCHALK [00:50:02] And most of the responses were not, like, "I can't afford them," or "I don't want to use them," or whatever it was that, "My partner will not use them," or "I'm afraid to even talk to my partner about this because of the assumptions, because of religious reasons around birth control not being accepted." Right. So they were learning that, also that people were just afraid to talk about safe sex in their communities or with their partners. And so they created programming—so like talk about safe sex—to sort of change some of these things because again, the public health approach is more generally, were just, like, "Wear a condom! The end." "Wear a condom," and not thinking about: what are the cultural contexts that might make "wear a condom," a more complicated thing than just, "Hand me a condom and now I'm going to use a condom."

JVN [00:50:48] Yeah, I mean, honey. [SAMI LAUGHS] How are Black activists and cultural workers enacting Black disability politics today? And, like, what are some of the differences between, like, contemporary Black disabled activists and cultural workers versus some of the groups you discussed in your book?

SAMI SCHALK [00:51:05] Yeah. So I interviewed 11 incredible Black disabled activists and cultural workers for the book. I started with folks from the group the Harriet Tubman Collective, so folks can look that group up. They released a response to the Movement for Black Lives when they released their platform and did not include disability originally in their platform. They've also released things in response to white disability organizations that have not properly addressed race in their work. So they're doing this work to push back and get more disability inclusion in terms of Black activism and then also pushing back inside the more white disability rights movement. So I interviewed these folks and then also some other people that got recommended in the process of talking to people. And I found that right now, the work is really a lot of consciousness raising. There's a lot of consciousness raising and there's a lot of just pushing back on the racism within one community and the ableism in another. It's a constant kind of going back and forth and back and forth. It's that bridge work, right? The bridge work that happens with multiply-marginalized people.

So folks have been doing all kinds of things that are just incredible. But a lot of the work is online, a lot of it is education and consciousness raising that's happening online. So folks can find some really exciting work happening, especially on Twitter, but definitely on TikTok as well. And the thing that I think is most different, because there's a lot of similarities. There's a lot of similarities in the approach to really, like, take racial and community contexts into concern and to really take an intersectional approach that doesn't leave people out. But the biggest difference is the use of disability identity. In the National Black Women's Health Project and the Black Panther Party, you don't see a lot of people claiming disability as an identity. And, you know, we talked earlier about some of the reasons why Black folks today might not identify as disabled, may not use that word. But the activists I interviewed are all claiming that term and claiming it in a way of, again, finding folks that we're connected to. And so all of them identify as disabled and all of them believe that there is value to this term. And so they're doing a lot of work to find some balance, because there's a lot of folks in white disability rights movements that are, like, you know, "Say the word disability!" and "Disability pride!" and they really want people to claim and use that language. Black disabled activists are, like, "It would be great if you could, but you don't have to. It's okay." You know, there's a, there's a gentle approach to it that recognizes that there's going to be some work and some intellectual work, some healing work, to get folks to feel okay and to feel safe identifying in a way because of the way that disability labels have been so harmful to Black folks historically.

JVN [00:53:52] It's also just, like, such a rigidity, that like, isn't conducive with strength. Flexibility is, I think, stronger and, like, yields a more, like, inclusive, like, desirable, like, you know, result.

SAMI SCHALK [00:54:02] Absolutely. Dustin Gibson is one of the activists that I interviewed and I really like what he said. He was, like, "I don't care if someone says they're disabled or not. I care that if they are diabetic and need insulin, they can get it, whether or not they call themselves disabled." So this emphasis on, "Identify as disabled and register as disabled so that the government can see how many of us there are," to just say, "Shouldn't we just try to fight for access no matter what? Shouldn't people have access to things that they need health care wise, whether or not they identify as disabled? Shouldn't we just be fighting for that more generally?" And I think Black disabled activists are really saying, like, "The identity is great, it is good, but it is not a requirement to come into this community or to come into this work because people are at different stages, and they need support. And the way they're going to get there is through community." There's a term that comes out of the work of Stacie Milburn and Leah Lakshmi Piepzna-Samarasinha and they talk about Disability Doula, which is the person that, like, helps support a person who is newly disabled, coming into their identity, coming into their life, what needs to change for their life and coming into just this, this world, right? That people need that support through these transitions. And the more that a mainstream community says, "If you don't behave in this and this way and use this in this language, we don't want you here," the harder it is to bring in folks who are more on the margins around their disabilities.

JVN [00:55:30] I remember when I talked to Wes in *Queer Eye*, I was, like, "What can I do outside of this to make sure that I'm, like, doing good work and being an ally?" He said, "One thing that's really important for me is, like, that able-bodied people think and ask business owners about access." Like, if you don't see a way for someone to get in, like, that's a thing that I think is important. And also when we think about, like, voting, like, who is talking about access. And when I've started, like, realizing that, like, I was like, no one's talking about it very much like, you know, anywhere, which is a huge issue. But what does it look like for news outlets and, like, cultural institutions and individuals to understand the importance of language and actively supporting people?

SAMI SCHALK [00:56:14] Yeah. So of course, I think that people should be aware of words that are particularly slurs, right? That we're changing our language. I think it also goes back to that being open to being corrected. Being, like, "Oh, I didn't know. Okay, I'm going to make some adjustments. I'm going to learn." I think that that's an important part. I think at the end of the day, language is... it's a reflection of, like, an attitude or an essence of being, right, that as we change our language, it just makes us become more aware internally. And then we start paying attention to other things, because at the end of the day, you know, I would rather folks, like, use the wrong language but actually provide access and provide care. Like, I want those material things. So thinking about access in a really broad way, not making assumptions about people's bodyminds, like, how someone might be able to function or not function is really important. We really assume that people are able-bodied and able-minded and create our, our meetings and our engagements based on that. So not making that assumption, just asking questions.

You know, one of the things I do, if I, like, am going on a hang out or a date with somebody, I'll just ask in advance, like, "Do you have any access needs, like food restrictions I should think about before I make this plan?" Using a disability framework to say, like, "I don't actually know what an individual person needs when I'm doing these 1 to 1 interactions. So I need to consider that." And then pushing for access to be on the agenda all of the time. Any of the political issues that we can talk about have a particular impact on disabled people. Here in Wisconsin, there has been a battle over whether or not there can be dropboxes for absentee ballots or if you have to, like, mail it in or physically bring it in. And there's been this fight against drop boxes and absentee ballots here that really impacts disabled people. It really impacts disabled people if you have to go into a physical location that may or may not be accessible to you. And so drop boxes are a disability issue. But it wasn't always framed that way. It wasn't framed as, "This is disenfranchisement for disabled people." Republicans framed it as, like, a chance for—

JVN [00:58:22] Fraud.

SAMI SCHALK [00:58:23] Yeah, yeah, exactly. I think that the more that we raise awareness and think about disability, the more we're able to see how that might impact. So any time you're thinking about any issue, whether you're thinking about reproductive justice, you're

thinking about food access, like, how do you think about disabled people in part inside of this? And to remember that disability is not just physical disability, right? It goes beyond just thinking about physical bodies and, like, wheelchair ramps, although those are essential, but there are also these other ways that we can make more inclusive worlds.

JVN [00:58:54] So you wrote the conclusion to this book in June of 2020 amidst COVID lockdowns and the uprisings for racial justice. So what's it been like to reflect on the book from Fall 2022?

SAMI SCHALK [00:59:06] Mostly I just can't believe that we are still in this pandemic. Because I end with saying, like, "And I do hope this particular crisis ends soon." And I'm, like, "Well, not yet."

JVN [00:59:18] [SINGS] New endemic diseases everywhere. It's never going away. It's here to stay. [STOPS SINGING] Um, yeah, it feels like that song that goes on and on, but not fun. And when we were little and just, yeah. Fucked up. So that's bewildering. But also, like, there's still been more police brutality. There's still more systemic injustice as a result of COVID. Everything and nothing has changed.

SAMI SCHALK [00:59:42] Yeah, I do feel like that summer completely changed me. I write a little bit in the conclusion about being involved in on-the-ground protests here in Madison. I got death threats. I got all kinds of things sent my way because I'm a professor at a public university. And I was fundraising to buy supplies for protests, to buy supplies. I mean, literally snacks and water. I was handing out snacks and water to people and folks were very, very upset with me. It constantly felt surreal. And so when I read back on it, I was, like, "I can't believe that you were doing all of that at the same time." But it just felt like we had no choice. It felt like we had no choice in that moment. So looking back on it now, I feel like I learned a lot of lessons about disabled organizing, how to organize as a disabled person, but particularly during a pandemic of, like, one of the things we did was we did a car caravan where we shut down a highway here in Madison as a form of protest that kept us safer from each other, right? Instead of always just being in big crowds. There was a lot of folks making and handing out masks, like, we did all this care that now I want us to keep. I want us to keep having care in our protests.

And I do see that here in Madison with some of the Roe v Wade protests that came up. I was called up and people were like, "Can you bring food to this protest?" And I was like, "Absolutely. Like, let me get my resources gathered here. And I will be there handing out food and water to make sure that people are cared for in this space." And so these lessons I'm hoping that people can take into their work and continue to do it and understand it as a disability access issue. If you're going to have folks standing or walking outside for hours, there needs to be water and food in case someone needs that to keep going. In case someone doesn't understand how long a protest is going to go, you can let people know if it's going to be a stationary protest or a moving one so people can make the choices that are

right for their bodies, right. And they can be prepared for that. Not every protest has to be everything, right, but letting people know what's actually going to happen so they can prepare and know what will work for them is really critical and really key. Like, if you're going to do a march, tell people how far that march might be. Like, "How long are we going to be walking? I can walk for 30 minutes, but we're going to be out there for 3 hours, I need to reevaluate." [CROSSTALK]

JVN [01:02:02] Yeah, or maybe walk a couple blocks to get to, like, a car or something.

SAMI SCHALK [01:02:07] Exactly. Exactly. So, yeah, those are some of the things I like looking at that conclusion and going back, I feel like I can really take away from it and learn from that summer. But there are so many things, you're right, that have not changed. I mean, Black and communities of color in general are still more impacted by COVID. We are still experiencing higher rates of death by COVID. So we are still impacted in the same way. And it continues to be a concern. You know? It continues to be a concern.

JVN [01:02:37] We have seen really important changes. And I think that, like, the stakes for all the communities that we've talked about, especially as we approach midterms, like have really honestly never been higher. And and not that, you know, the left or the Democrats have done everything perfectly because obviously they haven't. And we've discussed that at length over, you know, very many episodes of this podcast. But they are closer and more aligned with, like, where we need to go. And so being able to keep that context and that duality in our mind as we, you know, go towards November, understanding that, like, people's lives, disabled people's lives and all of our lives, but really disabled people's lives and then more, you know, Black disabled people's lives will be more directly impacted, like, by who gets voted in in November. And that's, like, on state legislatures, that's on our federal legislature, you know, especially, like, with Dobbs. I mean, we just had Lindsey Graham, like, you know, introduce this 15-week national abortion ban, which really lays bare that this is, like, a federal mandate, like, this is not, "Let's let states choose," like, it's been made very clear that Republicans will dismantle—, and that, I mean, for disabled queer people, there is like marriage equality there, which has this whole other, like, list of, like, access resources tacked. Like it's this is really major what's happening and it's really important that we open our eyes to everything that's happening right now.

SAMI SCHALK [01:03:57] Absolutely.

JVN [01:03:58] What are your hopes for the Black Disability Justice Movement as it moves forward?

SAMI SCHALK [01:04:02] Well, I really hope that more Black liberation workers incorporate disability into the work. I mean, that's the goal. I say at the beginning of the book that, that this is a book for Black people, that that's my main audience for this book. And of course, I hope other people read it. But I say, like, "Consider it like you've entered a conversation

where I'm talking with my friends and, like, you're welcome to listen, maybe, maybe contribute every once in a while. But mostly this is an 'us' conversation." So I really hope that more Black folks can be involved in disability justice in a way that they really understand it as critically tied to Black liberation as a whole. And of course, I hope that the disability rights movement starts to pay more attention to the way that race has shaped the priorities of the movement, frankly, because of the history of who has been in leadership, who has decided which way, which way we move. So, yeah, that's, that's my hope is that we can just, like, get better at this. I hope we can get better at this. And that my book just, like, gives folks a little window to say, like, "Yeah, Black folks have been doing this kind of work for a while. We have a history of this that we can build on and understand so that we can use that framework to inform the work that we do now."

JVN [01:05:17] So in the book you tie pleasure activism, a topic we've had the pleasure of exploring with adrienne maree brown, into your work with Black Disability Politics. So as we start to wind down, what does pleasure mean to you?

SAMI SCHALK [01:05:29] Pleasure to me is, it is like adrienne maree brown says, like, a deep satisfaction. It is just being, like, "Yes!" That deep physical, enthusiastic yes to something. You know, I felt that when I got the invitation to do this podcast, I was like, "Ah! Yes!" an enthusiastic pleasurable, "Yes, absolutely." Yeah. It's that satisfaction of being, like, "This is good." And that can look a lot of ways. But it is really that, that satisfaction and that joy that I think is just so essential to sustaining ourselves in a moment that is really dark. It's really dark. And so to find these positive moments, to find the ways that we can recognize our joy and the little wins. TL Lewis that we talked about earlier, one of the quotes from TL in the book is that, "You have to, in a system that is so large and so complex,"—TL works in the prison industrial complex and access for deaf folks—TL says, you know, "How many families have you reconnected, are reunited? How many people have you given more access to?" Like, we have to really think about the small wins because in a system that is so oppressive, it wants to keep us hopeless. And so we have to really take the joy of every single little win and not discount that, not discount the win and not discount the way that it makes us feel, because that is what gives us the power and the hope to keep going for the bigger wins that sometimes feel impossible.

JVN [01:06:59] So what I hear you saying is, is that when we start to feel hopeless or, like, defeated, we need to imagine, like, a Destiny's Child from Hell made of, like, Marjorie Taylor Greene, Candace Owens, and, like, Lauren Boebert. And they start, like, singing and, like, doing like this, like weird, like, dance and almost, like, Cater 2 U, but with, like, fucking, like, like, just, like, weird fucking, like, relics of, like, racism and transphobia and homophobia, like, in the background, it's like, not like a pretty dessert with, like, blue dresses. It's, like, it is, like, all, like, fucked up and, like, super like, Twilight Zone-y. And, like, and they're, like, "Yeah, give up, go home." And then you're just, like, "No, no, no. I'm going to go do something nice for myself because you're a fucking liar, fake, fraud, and a phony."

SAMI SCHALK [01:07:45] Mhm.

JVN [01:07:46] "And your dress I know was not made by House of Dereon because Tina would have never let any of you into the fucking house to pick out those outfits."

SAMI SCHALK [01:07:54] That cheap spandex. She looks a mess.

JVN [01:07:57] Get out! 'Kay? Go fucking do something else everyone doesn't want to you here unless you fully apologize and recant. Anyway, so yeah, I love that. That's a really good visual for me. So, like, moving on: what role does pleasure have in your activism, in academic work?

SAMI SCHALK [01:08:14] I'm in the book *Pleasure Activism* with adrienne. She invited me to write for it back in 2019 and it really, it changed my world. It gave me this framework for bringing together so many aspects of my life. My teaching that brings me so much joy, my politics, my research. But also, you know, I'm a polyamorous person. I'm a queer person. I'm a kinky person. And so it brought all this stuff together for me in a way that I was, like, "Oh, this is all about seeking pleasure and joy in a way that sustains my life, in a way that rejects the shame." You know, I was raised Catholic so lots of shame, in my background.

JVN [01:08:51] Yes! No, I'm really interested in polyamory, but I have a really jealous pussy and I'm so like, no my pussy's, like, so jealous that I know that's, like, probably colonialism and, like, patriarchy and stuff, making my pussy jealous and I don't want it to do that but, like—

SAMI SCHALK [01:09:09] There's lots of ways to do non-monogamy. We can have a whole chat about that.

JVN [01:09:11] I know but seriously, like, no, like, Tan calls my pussy my growler and she gets so she has such a bark, you know what I'm saying? She has such a bark. But I'm curious, this is about getting curious, so we'll have to have you—, but, yes, I mean, I'm—, I didn't mean to interrupt you. You're getting me excited. But anyway, so tell me, how does pleasure activism show up in your work?

SAMI SCHALK [01:09:25] Yeah. So this pleasure activism for me, it's been a way of, like, asserting my right to be my full personhood. And that's been so important for me as a person who works for a public institution. I do get a lot of public pushback. I, you know, I've had state legislators call the chancellor of my university about me. They try to take away awards from me because of my political work. And so I have had to really push myself to be, like, "No, I am just going to be my full self. I'm not going to try to hide in the hopes that it will protect me because it has never worked." And so I embrace my pleasure and I embrace my joy because it is hard for Black disabled people and queer people to, like, find our place. So I do that through clothing, like, I wear a different outfit every day of teaching this semester. I don't know if my students noticed that I have a different outfit every day, but it really brings me joy

to do. And then I am very public about the things that I love. I love unicorns. I have a lot of unicorns in my world, and then I bring that into, to activist places.

So when I'm going somewhere and like giving food at a protest, I'm often dressed up in lots of sparkly. And I try to be, like, smiley and kind. And when people are, like, "Oh, can I have this? Is this free?" I'm like, "Take as much as you want, baby. Like, What do you want? We got it. It's yours. This is community space. You—, don't pay me money. Don't do anything. Like, we will, we got you." Right? And so I just try to bring that energy and that, like, love and joy to people and encourage them to do the same. Because, again, I think that it transforms the way that people feel about these spaces. It transforms how my students feel about the classroom space, but it also changes how people feel about protests. Like, if you know you're going to go to a protest where there's people who are smiling and dancing and, like, handing out food and treats to just, like, care for one another, it feels different. It feels like even in the midst of the hard, dark thing, right? There's community and there's care and there's potential there. And so bringing pleasure throughout my activist work, but also understanding, engaging and pleasure is activist work for me. It's been really transformative, you know, we talked about the twerking with Lizzo before, but, like, that was a real turning point for me because so many people, like, tried to get me fired for twerking with Lizzo because they said it was inappropriate behavior for a professor. And I was just, like, "I am having fun. Like, what do you mean?" And my students, I mean, my students loved it. I still get people that are, like, "I was at that concert, I saw that happen!" You know, they still love to come tell me. That was a moment for sure that I realized, like, no matter what I do, no matter how innocuous, people are going to find reasons to tear me down because they know these larger politics and they know what I do. And so there is no pleasing, there's no pleasing them. I can only please myself. And so that's, that's what I'm trying to do now.

JVN [01:12:12] I can't think of a better way to end this episode of Getting Curious than I thought was such a gorgeous mic drop.

SAMI SCHALK [01:12:21] Thank you.

JVN [01:12:21] I mean, I feel complete. Do you? How do you feel? Is there anything that we would be remiss if we didn't say that we need to add?

SAMI SCHALK [01:12:30] So the only thing that I would want to add is that this book is going to be open access. So I was able to use funds from a teaching award that I got from the university, and so I paid the press. And so this is going to be a completely open access book, meaning if you have \$0 at all, it's going to be online for free for anybody to read. I want activist groups and organizations to, like, use it as a book club. Use it however, works for you all. Teach it. If you're teaching it, it's going to be free to your students. So, you know, folks can buy the book. That's great. My press would love for people to buy the book, but if you truly cannot afford the book or you want to get it to a bunch of people, like, at of school or inside

of a nonprofit organization, it will be free, open access available to anyone for all of time. So please check out the book.

JVN [01:13:18] That is fucking major. Ah! Sami Schalk, literally. Honor and a pleasure. I loved getting to meet you. I've already followed you on Twitter. Are you on the 'gram? Do you like the 'gram?

SAMI SCHALK [01:13:28] Yes. I'm @fierceblackfemme on the 'gram.

JVN [01:13:32] Yes.

SAMI SCHALK [01:13:33] And also, I just-, you're coming to Madison in October.

JVN [01:13:36] Oh, and you're coming backstage and we're going to meet and it's going to be fun. Should you twerk with me on stage and we'll see if they try to fire you for that, too?

SAMI SCHALK [01:13:44] Oh, my God! Please, please. I would love that.

JVN [01:13:45] I do a whole thing. Yes, I do a whole thing. I love you so much. I can't stand it. Thank you so much for coming on Getting Curious.

SAMI SCHALK [01:13:54] Thank you!

JVN [01:13:57] I can't wait to meet you in real life. You've been listening to Getting Curious with me, Jonathan Van Ness. Our guest this week was Sami Schalk. You'll find links to her work in the episode description of whatever you're listening to the show on. Our theme music is "Freak" by Quiñ - thank you so much to her for letting us use it. If you enjoyed the show, introduce a friend, honey, and please show them how to subscribe. You can follow us on Instagram and Twitter @CuriousWithJVN. Our editor is Andrew Carson. Getting Curious is produced by me, Erica Getto, and Zahra Crim. And give it up for our producing team, honey - we do it without you! Thanks for listening and we'll see you next time.