Emily Ladau: Hello, everyone, and welcome to another episode of Disability Inclusion: Required. I'm your host, Emily Ladau, but today I am so excited not only about our guest, but to be passing the microphone off to my incredible colleague, Olivia Williams.

Olivia Williams: Thank you so much, Emily. And hello again to our listeners. I am also extremely excited to be back on the pod, this time on the interviewer side of the table. I am the senior program and communications associate at the Disability and Philanthropy Forum, and I am thrilled to be joined today by a black disabled writer, educator, and pleasure activist, Dr. Sami Schalk, who is doing groundbreaking work to bring black disabled activism to the forefront of disability studies.

Dr. Schalk is an assistant professor of gender and women's studies at the University of Wisconsin Madison, and her 2022 book, Black Disability Politics, features interviews with some spectacular black disabled activists who we've had the pleasure to have as guest speakers and advisors here at the Forum, including Candace Coleman, Patrick Coley, and Heather Watkins. And as I've already mentioned, but I have to say again, Dr. Schalk, as a black neurodivergent and chronically ill woman, your work holds deep personal significance for me, and I just really enjoyed following your work for the past couple of years. And before we dive in, I'd love for you to share a bit more about yourself and what you do with our audience.

Dr. Sami Schalk: Hi. Yeah, thanks, Olivia. So I'm actually an associate professor now, and yeah, I work at the Gender and Women's Studies Department, and my research really focuses on race, disability, and gender in contemporary American literature and culture. So my first book looked at disability in black women, speculative fiction, and then this book looks more at history, archival, and then it also involves some contemporary interviews. And yeah, I identify as disabled, fat, black, queer, femme, glitter femme in particular. And I am happy to be here, excited to talk to you about the work.

Olivia Williams: Excellent. Well, there's so much I want to dive into, but I'd love to start with grounding ourselves. And one of the key takeaways from Black Disability Politics. In your book, you address some of the narratives about disability and ableism that are often thrust onto black communities, and specifically the assumption that black people "don't talk about disability." So based on your research, can you elaborate on why this assumption is so often made and, connected to that, why might black people choose not to disclose a disability?

Dr. Sami Schalk: Absolutely. So when I talk about that assumption that black folks don't talk about disability, I mean it both in the community sense, in our broader social world, and then also specifically within disability studies, the way that sometimes black communities are talked about. And there are lots of reasons why black folks don't "talk" about disability in the way that we expect disability to be talked about within certain disability rights communities and within disability studies. So some of that is literally just the word disability. So there's an association for a lot of folks that if you are not literally on disability, right, you're not receiving benefits or support of some sort that you are not actually disabled.

So that's one of those assumptions that can be made by folks that then makes them not really use the word disability to talk about themselves. But also in my research, a lot of the work that black folks were doing, black activists were doing that connected to disability, were coming through things like health activism or reproductive justice, or even through housing access and housing rights, trying to fight back against the really dangerous and unhealthy disabling conditions of public housing.

So they were talking about health, they were talking about the ways that anti-blackness and racism were structurally and interpersonally disabling people, but they weren't necessarily using that word because of its strong association with diagnosis and with the state that that wasn't used. And part of that not using it as well is that because for black folks being associated with disability as being disabled adds an additional layer of oppression. So there's kind of this sense of if you can avoid having a diagnosis, having that label on you to hopefully avoid a little bit more of the systemic oppression bias that you might face. Now, we know as folks who have non-visible disabilities that you can avoid ableism just because you don't call yourself disabled. But there are ways, structurally, if we think about within the school system or within hiring, that avoiding that term might actually avoid some aspects of ableism for black folks.

And when you're already dealing with racism with the assumption that you are lesser in various ways, when we're thinking about different points in history, why add that additional thing. On top of that, if folks are, when we're talking about psychiatric disabilities, institutionalization is very different if you are a person in poverty, if you are a person of color, than if you are a person who is white or a person who is wealthy, you get a very different kind of standard of care in institutions and hospital settings. So for a lot of reasons, black folks have obviously experienced disability and have had ways that they've responded to the relationship between ableism and anti-blackness. But the term disability, that word doesn't necessarily show up. So in doing my research, I often had to look at things around specific health conditions. For example, talking about sickle cell anemia, talking about diabetes, or using other kind of words around health that were not necessarily the word disability.

Olivia Williams: Wow. Yes, I resonate with a lot of the things that you found in your research, and having talked to people in the black community who identify with some disabilities but don't call themselves disabled, that idea that I already occupy so many marginalizations I don't want to add another one, is definitely one that I've come across. And so playing off of what you were mentioning about how just because you don't call yourself disabled, that won't save you or exclude you from experiencing ableism, one of the things that you reference in Black Disability Politics is TL Lewis's working definition of ableism, which includes the disclaimer that "one does not need to be disabled to experience ableism." And so I would love if you could share some examples of this particular aspect of ableism as it's experienced by both disabled and non-disabled black people.

Dr. Sami Schalk: Absolutely. For me, the common example that I like to use, because I think, especially for folks who have experienced this, it feels very clear, is the assumption of lack of able-mindedness, this assumption of being "crazy," or unstable, or unhinged in terms of your behavior and emotional reaction. Our understanding of sanity is based on a very white, middle-class masculine model. And so for black folks, certain kinds of behaviors in public settings, whether or not you are a person with a psychiatric disability, are perceived as being outside of able-mindedness, of being irrational. And then, because of our association of folks with psychiatric disabilities in particular as violent, it means that black folks are often responded to with more violence, particularly police and state violence, for behaviors that might be outside of the norm or not as understandable to a white population. So we have lots of examples in terms of police brutality of police saying, Well, this person was acting erratically, or I perceived them to be angry and dangerous to me.

And so that assumption of danger is often associated with a lack of able-mindedness, the inability to control oneself. And so when we have these associations, like the angry black woman, the sense that I can speak very calmly, but clearly and firmly, and people are like, why are you yelling at me? I'm like, well, I haven't raised my voice at all. I'm just speaking to you directly, and there's already this assumption that I'm ramping things up because of the way that I speak and the way that I'm perceived. So that's one way that ableism can impact black folks, whether or not you're disabled, because of the perception of disability, and in particular, in this case, psychiatric or mental disability.

Olivia Williams: I just particularly want to highlight what you said about the angry black woman and that intersection there because that overlap of the misogyny that black women face in anti-blackness and ableism, that one shows up so much for a lot of black women. And I previously had never thought about how ableism plays into that until you teased that out. So I just really wanted to underscore that because I thought that was really, really eyeopening for me. And you've kind of already touched on this a little bit, but if you have more insights about something that we've heard often in the philanthropy space, which is some form of, well, we're already doing anti-racism work, we're already doing racial equity or racial justice work, so we don't have the capacity for anti-ableism work or disability inclusion.

But from what you've just said and what you say further in your book, many of the black disabled activists that you've interviewed emphasize that racism and ableism are actually inextricable and that ableism is inherently anti-black. And so I would love to hear more about how ableism functions as inherently anti-black and why addressing the relationship between systems of oppression is necessary for liberation.

Dr. Sami Schalk: Absolutely. So I think that one way we can think about this is going back to this sense of the norms, right? I said that our sense of sanity is based on this very white masculine norm, but all of our norms in our culture are really strongly based on a very white upper to middle-class masculine norm. And so when you fall outside of that norm, you might be perceived as disabled in some way, right? At least falling outside the norm and potentially to the point of it being concerning. And we have a long history of the way that black folks in particular have been labeled as disabled. So we have this history of scientific racism, for example, that said, drapetomania is a disease that only black people have that makes them run away from enslavement because sane, rational, normative black folks should be and are happy to be, or better off in enslavement.

So we have this history of saying, well, black people in their minds, in their bodies, people of color in general are so different from us that we have to have this different standard. And the way that we treat people who are physically or mentally different is, in terms of ableism, is we try to cure, we try to treat, we try to change, or when that doesn't work, we put them away. We put them away from the rest of society. And some of those parallels then start to come out that we can see that a lot of anti-blackness relies on the assumptions and the understanding of ableism that is, of course, that's how we treat disabled people. And so then, when we start to position black folks, or in this contemporary moment, I think we see this very strongly with trans folks. If we represent them as outside of the norm in a way that is a disability is something that should be treated and cured.

So we have to work with multiple systems to be able to say, actually, you can be disabled and not want treatment and not want a cure and not have to be put away and still work out these tensions of it is also anti-black or transphobic to say that these folks are disabled because of their differences, but because these systems are constantly working together, we have to pay attention to the way that ableism is showing up inside of these anti-black discourses. The way that we talk about intellect, the way that we talk about even morality sometimes is based on the sense of there's something wrong and broken with those people. And those people have to be either pushed out of society, not given any power, or fixed, cured, treated, et cetera, in order to into the fold. So essentially, we're talking about norms and normativity and the way that those norms are based on both disability and race as well as gender and sexuality, but they really come together.

So we can't actually address these systems without thinking about that. So on the big systemic level, of course, these things are all connected, but when we're thinking about organizations, I also think it's so important to remember that you have disabled people in your organization, unless your organization is you and you know don't have a disability, you probably have somebody with a disability in your organization. And one of the things in 2020 that really was apparent to me was the need for more black organizations specifically to be thinking about disability in terms of who they are organizing with. Who are you hiring? How are you supporting folks? How are you making sure that folks have not only healthcare, but mental healthcare when they are dealing with really difficult, challenging things in their work, right? I'm thinking about folks I know that work for a rape crisis center, folks who work in advocacy for folks who are incarcerated, they're dealing with a lot, and they're not getting the support that they need, and there is an assumption that they are able-bodied.

There's an assumption that if you're involved in activist work, you're going to be out there in the streets marching or knocking on doors to campus, and that's not possible for all people. So really expanding our understanding of what can happen in terms of our organizing work and our philanthropy work. Any kind of organizational work is just so important. And I think 2020, in terms of the pandemic, really helped me, and I hope other organizations see that there are so many ways we can do our work. And actually, the disabled community has been doing really creative ways to do different kinds of political work from different kinds of spaces for a very long time.

And so now we know that we can do a protest that is a car protest, that we're all driving rather than marching, and that we can block off a street. We know that there are these other ways that we kind of developed in response to COVID, but actually expands accessibility as well. So I think that that's another thing that folks often forget is when they're thinking about disabled folks, so thinking about who they might be serving or advocating for, rather than thinking about who they're actually working alongside.

Olivia Williams: There are so many things that you said that I'm just like, I want to print out and put on my wall, and one of them that I really want to, it's so many things I'm just like, oh my God, it's just revelatory. But especially what you said about morality. That linkage between, oh, well, there's some sort of failing here when it comes to disability and ableism, and especially in organizing, and activism, and philanthropic spaces. If you are measuring success by productivity, and as you've mentioned already these norms that we set in society, productivity is what you can produce and it's measurable, then that's going to exclude so many people. And we can see how in philanthropic spaces that could lead people to be like, well, we can see more material, measurable, identifiable progress in our racial justice work, and if we're looking at something with disability, we're kind of afraid that we're not going to be able to maybe move as fast or we're not going to be able to measure our productivity in this way that seems as impressive in the impact report or something.

And I just think summing it up the way you did with measuring it as morality and end up failing if you are not moving through the world in a particular way is such a great reframe. I hope for our listeners to think about as they incorporate or reflect on incorporating the examples you mentioned of how organizing and philanthropic spaces have already progressed to be more accessible after 2020 and have lots of room to be more accessible. And especially what you said about black disabled people or disabled people in general who are leading the work and who are already working in organizations who are already coming up with creative ways to support and be advocates for progress, and how we can continue to listen to disabled people, putting them at the forefront. All of that is just like, it makes me excited.

It has me raring to go and thinking about ways to incorporate disability even further in some of the organizing I do in my free time. And one of the things I also wanted to highlight, and this will roll us into another question that I had, is what you said about how seeing these examples of how after 2020 folks made organizing more accessible, it shows us that this is possible. One of the things that you do in Black Disability Politics is demonstrate how disability has been central to black activism in the past. There's already a legacy of that in some ways. And so I would love if you could give our listeners a couple of examples. One from history and then one from contemporary activism, where disability has been central to a black activist movement.

Dr. Sami Schalk: I am going to pull for history one of the examples from the book and specifically this example because I think it connects to what you were just saying around philanthropy and grants and such, and impact reports because the National Black Women's Health Project is one of the organizations that I look at, and I only look at their work really up until about 2000, so early 80s to the 2000s. The organization still exists today as the National Black Women's Health Imperative, but it's a slightly different organization. And some of the work that they were doing in the early part of the organization was to do what they called self-help groups, which were small groups of black women formed within existing communities. So it might be folks who know each other from the community, from church, from whatever kind of social settings that we get together on a regular basis, meeting in community centers, in churches, or in women's homes once a week for one to two hours, something in that range.

And talking about what was going on in their lives around health, what are the health challenges they're facing, what are the things they're trying to improve on, work on, et cetera. So they had been doing these for a really long time. They would trained black women to lead and facilitate, and sometimes these leaders then would send back reports, but the groups were intending to be confidential, right? We're talking about our health needs, we're talking about our health concerns and challenges. And so the reports were pretty bare minimal. They were, these many people came this many times, et cetera, maybe a theme or something that came out, but not very much in terms of specifics. And eventually, by the 2000s, they really moved away from this model of what they called self-help groups, which were, again, these small collectives of women meeting together, often less than 10 women.

And one of the reasons that they stopped doing it was that it was really hard to fund because it was really hard to show the impact. It was small, it was slow. It was about convincing women that it was okay to talk about these things. It was okay to ask for what you needed. It was a really small community consciousness raising of a sort, and that's really hard to fund. So it was harder and harder for them to fund it as opposed to something like their Walk for Wellness program, that would say, oh, we had 100 women walk 10 miles. You could really get these numbers and show that kind of impact in that way. And so, I think, because of the type of podcast that this is and the audience, I want to note that that challenge of to get the money, we have to be able to show impact and change kind of quickly within the scheme of whatever the one, two, three-year grant.

And sometimes that change is not easily really calculated or demonstrable, but it's still so important. And so I'm not a person that is giving away grants or anything, but I would love for folks to really consider what these metrics are and how it is leaving out a certain kind of slow, deep, intimate work that needs to be supported and needs to be funded, but is often not, because again, it can't show that widespread impact in the same way. I've actually, in the course of doing this book tour, have talked to and met women who were part of some of these groups, and they've talked a lot about how important it was, even to the extent of if they were going into the hospital or going to see a doctor, one of the women from the group would come with them to support and ask questions.

And a lot of us, as disabled people, know it is useful to have a support person in the room sometimes. And so that's some work there that the National Black Women's Health Project, again, working in the 90s and into the 90s, shifting a little bit around the 2000s continuing their work today, was very inclusive of black disabled women while talking about health really broadly. They didn't say, you have to be disabled or you can't be disabled, or they didn't group people by health conditions. It was built on those existing networks. And for me, I really see them as a version of what we might consider a care pod or care community now in building those skill sets. So they would publish a newsletter where women would share stories about their experience with AIDS and with lupus with a variety of health conditions, including thinking about mental health and spiritual health, was a big part of their work.

So for me, disability is all over their work, but because it says health, I think sometimes in terms of disability spaces and disability organizing, we shy away from things that are considered health activism because we assume that they're about achieving health at all costs or that they're focused on cure and treatment. But that's not always the case. Sometimes it is about really providing holistic support for people with particular health conditions, whether or not they identify as disabled.

So I just thought I would use that example because of what you were just saying, that it really made me think about the fact of how they moved away from that early model of how they were doing their work in large part because they were moving towards getting more and more large funding like the Kellogg Foundation and things that it was much easier to fund things where they said, yeah, we did this walking program, or we did this training program, and we can say, this is exactly what people did, and we can take a survey after on what they got out of it in a way that you just can't do when women are sitting around together once a week talking about their health privately. So that's a historical example. Oh, yeah, go ahead.

Olivia Williams: Oh, no, I just want to respond really quickly. I mean, I definitely want to hear that next one as well, but I just want to say that is such a powerful one, and what you said about care communities, that's a discussion that we're having here at the Forum about how we can get philanthropy to think more critically about communities of care and how disabled people have created these informal, small, deep spaces that don't look as good on an impact report, but have a lot of deep impact on disabled people, and the isolation and the exclusion that a lot of disabled people feel is often eased by being in communities of care.

And so just to hear that their organization was doing that in the 80s and 90s, and that idea still feels really unfamiliar to people today in 2024. It's exciting to me to know that they were doing that work then and to get our listeners to think about how they might be able to support such work today. But I want to also hear your contemporary example. I just wanted to jump in and say that I really loved that example that you shared.

Dr. Sami Schalk: Yeah, thank you. I mean, can you imagine an organization today funding and supporting organizers of small care pods across the country doing trainings for them and developments for them a couple times a year, and all they ask is for you to just say, these many women came and no questions asked about you just doing the work that needs to be done in your little community pod. It would be amazing. It would be amazing to really train folks on how to support care work in their communities and build these kind of pods. So a contemporary example, I interview a lot of folks from the Harriet Tubman Collective and the Harriet Tubman Collective has not been as active in the last couple years, but a lot of the folks involved have been doing all kinds of work individually, but I particularly like to highlight their work because the way that they push back on the movement for Black Lives, when the movement for Black Lives released a platform stating what are the goals of the kind of collective of organizations that formed the movement for Black Lives wanted and disability wasn't there.

And it is only black disabled folks that could come and say, Hey, we got to fix this. So they released a statement, the movement for Black Lives updated their platform, disability is now on there. It is on there more clearly, and they really put it on the national page. They put it on the forefront of folks' attention in a way that had not really been there for national black organizational work, in my understanding. And so the Harriet Tubman Collective, too. One of the reasons I like to highlight them in contemporaries because they're not a local group. They are black disabled folks across the country who organized digitally to make statements, to respond to things, but they were not in the streets. They were not raising grants to do something. They were pushing the black community and the disabled community on certain issues. And so I think that that work also, for me, is a great example of how there's lots of ways to be doing this work, and there are certain people that are more primed, more positioned to do certain kinds of work.

If a predominantly white disability organization had come out with a statement talking about the lack of disability in the movement for Black Lives platform, I don't think the response would've been the same, right? It was really important that it was coming from folks that were in the community, that were already activists. A lot of them were already in BLM chapters across the country, and were experiencing ableism in their organizing with those chapters. And then were able to say within the community, within the organization, Hey, this has to change. This is being left out, and it's a problem. So that's my contemporary example.

Olivia Williams: I am really moved by that one because I did read the Harriet Tubman Collective statement and seeing disability justice be incorporated into the movement for Black Lives' goals and demands is both a sign of progress and also a sign of what you said where it's only black disabled people could really move the needle in that way because with the experience of multiple marginalization, you can come into that space knowing black activists are working really hard to represent so many different types of black people, and also there are things that are missing and black disabled people deserve to have their lives protected and defended as well, and their work and their language and their framing and the way that they called in and encouraged accountability is something that I think could be a model for so many other types of activism and organizing spaces who are trying to be more disability inclusive and be guided by a disability justice framework.

So I really love that example because I think it can be such a blueprint for so many other types of activism and organizing spaces. So going off of particularly our discussions about legacies of disability in black activist spaces, one of the main goals that you listed for Black Disability Politics was to "ensure that the lessons of the past are directly connected to the work of the present," and something we've been reflecting on here at the Disability and Philanthropy Forum is the importance of disabled ancestors. So I'd like to know who are some black and brown disabled ancestors whose lessons you feel directly connect to your work?

Dr. Sami Schalk: I have several. I'm in my home office right now and looking around, so I have, on my altar space, I have an Octavia Butler Saint Candle because Butler is one of my favorite authors. I consider her a black disabled ancestor and have written a lot about disability both in her work and in her life based on my time in her papers at the Huntington Library. So even though she did not use that word to describe herself, based on my understanding of her papers, she had dyslexia. I also think that she had depression at various points in her life, more and less severe, and then later in life she had a heart condition. So she is one because I believe that her writing is so powerful, and as someone who primarily identifies as a writer, I'm an academic, but at the end of the day, writing is a thing that just lights me up and makes me feel good, and I want my writing to last and to have impact in the way that hers does.

I also think she was just so prescient in terms of seeing what's coming by paying attention to what's happening. I was really feeling that in the early stages of the pandemic, when I was finishing the book, watching what was going on and trying to think two, three, four steps ahead to be like, okay, what does this mean? What does this mean long-term for us? And trying to write about that and share that with folks so that we can prepare. I think that we are moving towards an increasingly disabled future where, if not the majority, then close to the majority of us will be disabled based on the way things are continuing with the pandemic and our healthcare system in particular, as well as climate change and war, just so many things that are disabling us around the world right now. So that is one person.

Then I also think a lot about Audre Lorde and Gloria Anzaldúa. Gloria Anzaldúa had diabetes. Audre Lorde had low vision, and then also later in life had breast cancer, which is what she's most known for. And both of them were just folks that I read very early on in my college career, in my women's studies classes, and they were just fierce, fierce writers, and they would say things so clearly and from these places of experience that really inspired me, really got me thinking, right, put words to things that I didn't have before. And with Audre Lorde in particular, thinking about self-care and thinking about pleasure have been major parts of my personal life and now increasingly my academic life as well. So her work has been really important to me. So those are the folks that I would say.

Olivia Williams: I need the Octavia Butler Saint Candle. I need to get that for my place. That sounds amazing. I read Parable of the Sower; I think I've read it four or five times now, and I read it so much as a text of disability and in a way that only a black woman living with conditions that could be qualified as disabilities could frame a world that is led and guided by a black disabled woman. I totally agree that she's such an ancestor in that regard. And then Audre Lorde is another person who I'm constantly trying to stock my home bookshelves with everything that she's written.

So those both are ancestors that I think of as well, and it's so special to see their work trickle into yours. And then, me learning from your work as a writer, I hope to someday also write something that maybe sticks with someone and has a lasting impact. So I love how you say that the final chapter of Black Disability Politics is not a conclusion, it's a pause. So as we pause our conversation here with the end of this episode and plan to continue the conversation throughout the sector, what call to action would you like to leave our listeners with?

Dr. Sami Schalk: Well, I think maybe two things. One, folks who are really in this philanthropy world and potentially folks who give away money, I think go back to that bit of our conversation of really thinking about what the expectations around impact reports. What are we valuing in that, and what are we missing in those things? I would love folks to really think about that and think about how some things might change in the way that grants work so that more creative, more grassroots things can be supported. So that's one. And then I would love for folks to read more from folks who are different from you. If you are a disabled person, read more disabled folks of color, read more disabled trans folks, whether that is fiction or nonfiction, poetry. I just think it's so important for us to have a deep understanding of the ways that our lives are all these Venn diagrams.

We can have the same disability and have very different experiences because of race or because of gender or because of sexuality. We can have very different disabilities, but have very similar experiences for whatever reasons. And so I want us to just be able to hold those stories because I think the more that we connect with stories and read about these histories, the better that we can come into situations with such a broader awareness and an ability to nuance what we're saying and hearing to be like, okay, well, this is the way this works for me, for us, for our organization, but how might it be different for you? And be really open to that rather than assuming that because we share this one aspect of ourselves that it's going to be experienced in a very similar way. It's just not necessarily always the case. And then share the book.

It's open-access. I want to make sure I say that. It is free open-access online. You can access it through Duke University Press. You can also go to any of my social media and go to my bio links, and there will be links to both of my books there. So both of my books are free open-access. You can download them and read them. You don't have to pay for them. It was a really important thing for me to do, particularly with Black Disability Politics, a book about activists. I wanted to make sure that it was available to activists, no matter their financial abilities. So I just wanted to emphasize that open-access aspect.

Olivia Williams: Absolutely. And can you share with us what those main social media handles or your website, just so folks know where to find you and make sure they can get access to that work?

Dr. Sami Schalk: Yeah, absolutely. My website is samischalk.com. There are links to the open-access from there, as well as descriptions of my work. On Twitter, which I will always call Twitter forever is @DrSamiSchalk, Dr. Sami Schalk. And then, my Instagram is a little less on the work aspect, although I do share politically-inflected things. It's a little more heavy on my cute outfit. So if you're interested in seeing all of my fashion, then you can find me on Instagram as FierceBlackFemme.

Olivia Williams: Wonderful. Dr. Schalk, thank you so much again for joining me today. For our listeners, if you want to keep your learning journey going, visit the Disability and Philanthropy Forum at disabilityphilanthropy.org. I am Olivia Williams, and this has been another episode of Disability Inclusion: Required. Thanks so much for tuning in and join us again next time.