Emily Harris:

Welcome to the Disability and Philanthropy Forum's 2022 webinar series. My name is Emily Harris and I'm executive director of the Disability and Philanthropy Forum. I use she/her pronouns and am proud to be part of the disability community. I come to you from the unseated land of the Council of Three Fires, the Odawa, Ojibwe, and Potawatomi Nations, now known as Chicago. As part of our commitment to accessibility, our panelists and I will each provide an audio description of ourselves. I'm a white woman with dark, curly hair wearing rectangular glasses and a dark blue shirt. Behind me is a white and tan screen. My access needs are met today because we have card captioning.

A few housekeeping items for today's webinar. There are two ways to access our live captions. Use the CC button at the bottom of your screen and choose subtitles or full transcript, which will pop up as a box on your screen within Zoom. Or to access the captions in a separate window, see the link to the external caption viewer in the chat.

Today, only our moderators and panelists will be on camera. You will be muted throughout the event. The webinar is being recorded and you will receive a link to the recording in the next few weeks. Although we will be using the chat to share links with you, it will not be available for you to communicate out. Instead, please use the Q&A button at the bottom of your screen to share your questions any time during the session and we will have some time to share them with the panelists at the end. If the Q&A is not accessible to you, feel free to send your questions to communications@disabilityphilanthropy.org. And please note that even if we run out of time to answer your questions, they will inform the resources we create on DisabilityPhilanthropy.org. Check the forum early and often.

We will be live tweeting today and hope you will join us on social media using the hashtag #disabilityphilanthropy. You can also follow along by connecting with us on Twitter @disphilanthropy.

We're delighted to continue our conversations about how disability connects with all dimensions of social justice. Disability is a natural part of the human experience. According to the CDC, one in four US adults, 61 million people, have a disability that impacts major life activities. Disabilities can be apparent, such as a mobility disability, but many disabilities are non-apparent, including chronic illness and mental health disabilities. Disabilities can be lifelong or acquired, and we often say that we are the only minority group that anyone can join at any time. The COVID-19 pandemic has laid bare the systemic oppression of people with disabilities and is increasing the size of the disability community. Today, we will dive in to explore the timely topic of ableism, the systemic oppression of disabled people.

To moderate our panel, I'm delighted to introduce Sam Gill, president and CEO of the Doris Duke Charitable Foundation, a national philanthropic organization that supports the performing arts, medical research, the environment, and child wellbeing. He is one of the 17 CEOs who serves on the President's Council on Disability Inclusion and Philanthropy and is joined by three disability thought leaders and advocates. You'll find the link to all of their bios in the chat. And I'll turn it over to Sam now. Thank you.

Sam Gill:

Excellent, thank you so much, Emily, and thanks everyone for joining us today. As Emily mentioned, my name is Sam. I am a South Asian American male. I'm wearing glasses and a blue shirt and a blazer, and I'm in a fairly typical office. My pronouns are he/him. I am on the lands of the Lenape people today, and all of my access needs have been met. And I am absolutely thrilled about the opportunity to help facilitate today's discussion with three really amazing experts and advocates and leaders.

And I, just as a couple personal reflection, one of the reasons I'm really excited is I have one sibling, I have an older brother, and he has Down Syndrome, and my mother was a disability advocate. And even growing up in a household in the '80s and '90s where we were really passionately committed to ideas of inclusion and saw ourselves probably at the vanguard of what a lot of the thinking was around what civil rights could mean for people with disabilities and should mean, I am struck in retrospect by how many of the ways that we approached supporting my brother and his thriving really reflected what you would call an ableist paradigm, of course, unintentionally. And so I think today is really not about educating people that don't want to support equity and inclusion for people with disabilities. It's about widening our toolkit for all of those of us that want to and want to have a richer sense of the way in which we do our work does or doesn't help support the equity and inclusion of people with disabilities.

So with that, I am incredibly pleased to welcome our three panelists. Lydia XZ Brown, whose policy council for privacy and data at the Center for Democracy and Technology. Rebecca Cokley, who's program officer for US Disability Rights at the Ford Foundation, and Ryan Easterly, executive director of the WITH Foundation, and also a fellow member of the President's Council on Disability Inclusion and Philanthropy. And as Emily mentioned, bios are in the chat, so we won't get into those here. But I do want to just go around and ask each our panelists to introduce themselves, their pronouns, a description of themselves. So Rebecca, maybe if you could kick us off?

Rebecca Cokley:

Thank you so much, Sam. Hi, my name is Rebecca Cokley. My pronouns are she/hers. I am here from Lenape territory in the state of New Jersey. I have achondroplasia, which is the most common form of dwarfism, shoulder-length or chin-length red hair, a glorious abundance of freckles. I'm wearing a white shirt and a black blazer. I am migraining today, so I will say that my access needs are being met by my handy-dandy ice pack. And I would say that I wanted to pay particular attention to welcoming the disabled and chronic illness folks that have joined us today, wherever they are in their disclosure journey. Welcome, and our community is ever better for your presence.

Sam Gill:

Thank you, Rebecca. Oh, Lydia, how about you? Thanks, Rebecca.

Lydia XZ Brown:

Hello, this is Lydia, sign name L Brown, pronouns they/them. I am a youngish East Asian person with short black and teal hair and glasses, wearing a zip up, and behind me is a blurred room so that you don't all see my ADD mess. I am joining you from the traditional and ancestral lands of Piscataway-Conoy and Nacotchtank peoples.

Sam Gill:

Thank you very much, Lydia. I like youngish. I'm youngish from now on, until the end of my days. That's how I feel. Ryan, how about you?

Ryan Easterly:

Hi, everyone. My name is Ryan Easterly. My pronouns are he and him. I'm a Black-identifying man with black hair, wearing black glasses, with a black beard with some gray in it. I'm wearing a purple dress shirt with a black blazer and I'm sitting in front of a white wall with a diploma on it. I come to you today from the land of the Ohlone people in California. And as far as my access needs, due to my own disabilities, I may not always be in the center of the frame because my body posture may change. But other than that, my access needs are being met.

Sam Gill:

Excellent. Well, thank you all. So we'll get into it, and I think, as has been mentioned, I'll be guiding the conversation, but we really encourage people to provide their own questions and we'll weave them into the conversation as we go. I think it would be great to start just by helping, for all of us, I think, to understand how each of you thinks about the concept of ableism and what it means and what it comprises as a phenomenon and in its impacts. And so Rebecca, I'd like to go to you first, and to ask you, is our American society an ableist society? And if so, what do we mean by that? In what ways is this an ableist society?

Rebecca Cokley:

Thank you so much, Sam. I mean, I think ableism is grounded into the very structure of all parts of American culture and society. I wake up in a bed that is built for y'all, for average-height people. I pay twice as much for a wardrobe because I can't get clothing for myself because I'm a Little Person. I pay twice as much for the vehicle that I drive for the necessary modifications that I need. There is a series of systems and rules that were not developed for people with disabilities. And I think you can even look back to the founding of the country and even earlier than that to see ways that ableism is grounded in white supremacy, which I know some of our other colleagues will definitely probably delve into. But I think that you can't provide a thorough critique of American culture and American society, let alone philanthropy, without looking at the way that ableism is evident throughout.

Sam Gill:

Thanks very much. Lydia, I'd like to go to you next, and I'd like to ask you to reflect on two things. One, if there is anything you'd add to how Rebecca has set the terrain of ableism, that would be great. And then I would love to hear from you, you've worked in a number of different contexts in which you with others were helping people to see ableism where maybe they hadn't before, in a campus environment, now in a technology environment, and we'd love to hear about that process. Both how you see ableism, but also how, in your work, you've worked to make it visible to people who aren't necessarily looking for it or identifying it.

Lydia XZ Brown:

This is Lydia. Becca hinted a little bit at what I'm about to explain, that white supremacy and ableism are very deeply connected, but let's back up a little bit. At its most basic, ableism is a system of values and beliefs, a system of values and beliefs that teaches us who is valuable, worthy, and desirable, and who is expendable and disposable. Ableism teaches us, in other words, who gets to count as human or a person and who does not. It teaches us who is normal, but more than that, it teaches us who is ideal, what kind of person is idea. And as a system of values and beliefs, ableism is deeply wrapped up with every other system of violence, domination, and oppression. Ableism is deeply wrapped up with white supremacy and [inaudible] colonialism and it is also deeply wrapped up with patriarchy, with anti-queer and trans oppression, with classism, with any system of domination and oppression.

We can see that through the history and the founding of this country, its settlement, the justifications that white settlers used to justify forced removal, land theft, and genocide of Native and Indigenous peoples. We can see it in the ways in which white slaveholders literally used ableism to justify and perpetuate enslavement of enslaved Black Africans and their descendants. We can see it in the history of our immigration laws, in restricting immigration to those deemed fit, productive, intelligent, and healthy. We can see it through manifestations of centuries of anti-Asian racism and derision of Asian peoples' cultures, whether South, Southeast, or East Asian, as both exotic and uniquely dangerous and disgusting.

We can see the legacies of ableism, racism, and other forms of oppression and how ideas about our bodies and minds are always grounded in and connected to ableist values. The ways in which violence is enacted on fat people and trans people and immigrants and incarcerated people and homeless people are all deeply interconnected. It is impossible to understand ableism as a system of values and beliefs without also understanding it as a system that is both necessary for and dependent upon every other form of ableism that exists.

Sam Gill:

Thank you. Ryan, I want to come to you to respond to Lydia. To me, thinking about the intersections between systems of discrimination, oppression, is both a moral exhortation to recognize exactly what Lydia calls us to pay attention to, but it's also it's an analytical invitation to understand the way in which different systems of oppression, experiences of oppression, logics of oppression can come together. And so it would be great if you could help us in a contemporary context understand sort of what it means, concretely, for racism and ableism to come together.

Ryan Easterly:

I want to underline what Lydia said in general, and then mention that we know that identities are complex, and identities are experienced in parallel to one another. For example, one in four Black Americans experiences a disability, and we know that communities of color are disproportionately impacted by disability. We also know that BIPOC people often struggle with accessing resources to obtain a disability diagnosis, and diagnosis can be a key step in the acceptance of a disability identity. We also know that BIPOC disabled people experience additional issues when it comes to accessing high quality healthcare services. And we definitely know that there is room for growth when it comes to the leadership of BIPOC people with disabilities within disability organizations and beyond, as well as the representation of people of color with disabilities when discussing and when representing the experience of disability, in general.

Sam Gill:

Thanks a lot. Thanks a lot, Ryan. Thinking about the complexity of this tapestry, Rebecca, how would you help the people on this call think about the way in which ableism is a barrier to equity and inclusion? I assume people are on this webinar because they have some understanding of what was just explained, they want to know more, and then they want to translate that knowledge into some improvement in what they do or what their organizations do. And so, as someone who is having to take this rich and complex history and contemporary set of experiences and translate it into a grant making program, what's the framework that you use for thinking about how to organize either our understanding of barriers to equity and inclusion for people with disabilities or pathways to opportunity that can help us to overcome ableism as a limitation and an imposition on the dignity of everyone in our society?

Rebecca Cokley:

Thank you so much, Sam. I think about it very similar to how you just described it, but also with the lens of how can we use the mechanisms of philanthropy that we engage with to not just create a better future but address historic inequities? And I don't think that you can actually have the conversation around, frankly, the history of philanthropy in this country if you don't start talking about the fact that most of our major foundations, most of our legacy foundations, had a role in funding the eugenics movement and actively sought to see the eradication of disabled people. And just thinking about the way that that lens shaped the relationship that philanthropy went on to have with the disability community, from moving from trying to eradicate people to, frankly, acting like disabled people didn't exist for decades, to acting as though ... I mean, I know, for example, a foundation had only ever made one disability grant, and in their note to a disability organization said, "Go and beg the federal government for money or ask March of Dimes." And that the door really was closed, that there was a ... To use the actual technical term for the equipment used on a horse, there were actual physical blinders on philanthropy in a lot of ways, to even thinking about how to be inclusive of people with disabilities.

To a place now where any thinking about this work, it can't just be like, "We're going to do this." Something that our CEO talks about a lot is reflecting honesty and embracing risk. And so actually taking time within your institution to unpack what is your organization's disability history? What has the engagement been like with the community? Has there been any? Going through the archives and seeing what is there, what isn't there. What role did your institution play in perpetuating inequities? And how does that all inform the work that you want to do going forward, and who you bring on to really do that work?

Sam Gill:

Ryan, do you feel the same weight of history? You're in a relatively younger institution. How do you think about the issue of history in the context of how to conceptualize equity for people with disabilities?

Ryan Easterly:

I share a lot of Rebecca's feelings and thoughts in this work, and I'm also mindful that Becca and I are amongst a few, there are many folks with disabilities in philanthropy that aren't comfortable embracing their disability identity, don't feel safe at work, but Rebecca and I are amongst the few that are in leadership positions within philanthropy and the weight that that carries in the work that we do, and even in the ways that ... WITH Foundation has been very intentional in including people with lived experience of disability in all aspects of our operations. But there are ways in which through our self-advocate advisor committee that those advisor committee members challenge us and help us grow in our learning, in our journey, to better embrace the perspectives of the communities, the kind of daily lived experience of disability, and kind of keep us continuing to learn, continuing to evolve, and better address the experiences of all people with disabilities, including BIPOC people with disabilities. So I just echo everything we shared so far.

Sam Gill:

Lydia, just thinking sort of recognition of the different kinds of organizations that might be on this call, different kinds of issues people might work on, not really knowing for sure, I'm curious about an experience that you might bring distinctly, which is as someone who is thinking a lot about technology and the role of technology in either reinforcing ableism, exacerbating ableism, or helping to overcome it, I'm always struck, there's a saying in Silicon Valley that the best way to predict the future is to invent it. And you feel that from a lot of the corporate forces behind a lot of contemporary services. They are unburdened by history. They act as if they're just merely building a better future. Has it been part of your practice to find ways to talk to these organizations about both the history that I think you very eloquently detailed, but how to see themselves in relation to it? And can they hear that?

Lydia XZ Brown:

This is Lydia. One problem that we address frequently in conversations that we have with partners and also with folks who are coming from industry or from research is the rush to technosolutionism as an answer to social problems. And what that means is a belief that if we can just create the correct technology, we can fix a problem and make it go away. Unfortunately, technological driven innovation still exists in the context of the world in which we live. Such innovations are often deeply informed by eugenicist ideas. Let's invent technologies that will disappear people with Rebecca's and my disabilities. Let's create technological innovations that try to fix disabled people. Gloves that will interpret sign language, wheelchairs that will climb stairs, robots that will teach social skills to autistic children. All of these ideas about far-fetched technologies that are aimed functionally at fixing disabled people, making us conform to abled peoples' expectations and norms, but that are not at all about actual access and that don't address the very real issues that disabled people, especially at the margins, are dealing with on a daily basis.

That many of us aren't thinking about whether a wheelchair can climb stairs or whether a robot can teach me to be better at a job interview. We're worried about being evicted, about being killed by our partners or the police. We're worried about being kicked out of a hospital, denied healthcare, or left for dead in a global pandemic that is happening right now and is not over. We are worried about life or death, and inventing a fancy technology that appeals to abled peoples' desire to become abled saviors by disappearing disability does nothing to address ableism and everything to reinforce it.

Now, when we're thinking about what we can do instead, how can technology then be leveraged to be actually about access, actually about justice, then the question really needs to be what are we making? Who is making it? For what purpose are we making it? Are the people who are designing and deploying new technologies from marginalized communities? Do they understand what is at stake for those who have the most to lose? Are they thinking about what future we are imagining?

Alison Kafer, in her introduction to the book Feminist, Queer, Crip, discusses the particular form of ableism that most of us have internalized that basically says that a better future, an ideal future, is one in which disability no longer exists. Or in other words, a future in which disabled people, Ryan, Rebecca, and I don't exist. And people like us don't exist. A future that for many disabled peoples' communities has already become more and more of a reality through development of prenatal testing, gene editing, and other selection procedures to prevent certain disabled people from coming into existence. But Kafer offers a challenge and an alternative to that vision by inviting us to consider instead what would a better future look like if we believe and assume that disabled people will be present, that disabled people are part of the future, that disabled people deserve to be part of the future, and that our future and our vision of that future is incomplete without disabled people? Disabled activist Annie Segarra put it a lot more simply. "The future will be accessible."

Sam Gill:

So I think a key axis for me in this part of the discussion as I've been listening to you is the difference between actual and apparent, and there have been a lot of different metaphors for perceiving either cognitively or sensing externally something that we are, in some cases, choosing not to look at, either intentionally or as part of a system that allows us not to look at it. So in now helping our audience to think about, well, what would it mean to begin to actually confront and then be part of overcoming ableism, what are we looking for? And Lydia, if one of the themes of these conversations ought to be actually giving voice to those who sometimes have less power in these situations, I think you working at an organization that is on the grantee side should really go first here. And I'd just love to hear what are just examples of ableism that you see in the way that philanthropy operates that come to mind for you?

Lydia XZ Brown:

This is Lydia. One of the most obvious ways that ableism shows up in philanthropy is in who is actually making decisions about where grant money goes. Rebecca and Ryan are the exception, not the norm. The vast majority of staff at foundations, at corporate giving organizations, or in any other grant making body, are not disabled people. And when disabled people are present, the vast majority of the few who are, are still coming from a place of privilege, from access to wealth, from whiteness, from heterosexuality, and from the global North, from countries like the United States and the United Kingdom. Globally, that still remains true, that philanthropy is still a force that often reinforces imperialism and modern day settler colonialism, in who gets money and how.

Secondarily, another major way that ableism shows up are in the application and reporting requirements in order to receive grants. Your organization has to demonstrate a five-year track record of success. Your organization has to demonstrate that you've already been able to manage a large multi-year grant. Your organization has to demonstrate that you've been able to do internal and external audits, that you've been able to balance your books, that you have access to mainstream banking services, that you've been able to keep people on payroll for certain amount of time, that you can show metrics and numbers quarter by quarter that show improvement and measurable outcomes.

And I'm literally word vomiting, because these are all the words that we are encountering, and the average disabled person of color, poor disabled person, disabled person in the queer and trans communities, we are literally just trying to take care of each other in our communities, and we don't have any fucking time for writing these 200 page long detailed grant reports to prove that we're really being honest. Because you know who doesn't have to prove that? Generationally wealthy people and extremely well-resourced organizations don't have to worry about where their money is coming from, that don't have to worry about who they're asking for money from. And so they have the privilege to be able to not care, whereas we have to be 100 times more scrupulous and still be concerned that we will be accused of inappropriate, questionable, or problematic financial practices, that we'll be accused of not showing stability.

Well, why don't we have stability? Because we're not getting multi-year general operations grant funding. Why are we unstable? Because our people are more likely to be in precarious employment, working multiple jobs, caregivers of other disabled people on top of being disabled ourselves, because we are less likely to be able to prove, according to racist, capitalist, ableist norms, that we deserve a handout. And that's how we're framed. We are both shamed and guilted for asking for handouts, and yet we're also expected to beg, and that is why the vast majority of philanthropical resources continue to go to the same well-resourced established organizations that are largely not accountable to directly impacted communities and to the people who have the most to lose, whereas organizations that are doing work on the front lines directly from community are infinitely less likely to be able to access even a fraction of the same funding pools.

And even in especially the space of disability philanthropy, if you're a smaller, community-based organization, you get really excited if a once in a decade opportunity comes up for you to compete for a single $100,000 grant. And our larger disability advocacy organizations, the ones that generally aren't led by disabled people or are led only by white disabled people, their operating costs yearly are in the multi-millions of dollars ranges. And they get grants of $100,000 like pudding. Just constantly. And when you ask how this ableism is showing up, it shows up in the expectation that all disabled people understand these complex fiscal responsibilities and requirements, that we understand these cognitively inaccessible forms, that we are capable of writing according to these secret methodologies for grant writing that people pay thousands of dollars to take classes on, and that we can just do that in all of our nonexistent spare time on top of having three jobs and multiple kids and volunteering because our organizations don't have money to pay us. This is ableism. The assumptions that everyone is on this equal, level playing field, when that couldn't be farther from the truth. Philanthropy so often claims to be addressing inequity and inequality while reinforcing, perpetuating, and exacerbating it.

Sam Gill:

That's really powerful. I want to go to you, Rebecca, because it seemed like you were reacting positively. You certainly were emoting something behind the veil of Zoom. But let me ask, I want to ask this question. You work at a place where I think people are certainly receptive to the ideas that Lydia has just articulated. And so I'd be interested in how open you think they are to the impact that she's articulating and how responsive are you and they actually, or what are you trying to do to be responsive to the kinds of ideas that Lydia has articulated?

Rebecca Cokley:

Any time I can speak after Lydia, it is all emoji and fireworks and snaps and claps and doing the robot and whatever else I am emoting over here in this moment. I learn from Lydia on a daily basis, and even during their most recent comments, my Slack was blowing up from board staff saying, "Oh my gosh, Lydia is amazing. We need to engage Lydia more often." So we will be in touch, friend.

I find myself actually thinking of a meeting that I had had before I joined Philanthropy at the National Council on Disability with automakers that were making driverless cars. And so we had Google and Mercedes Benz and Tesla and everybody in to talk to us about autonomous vehicles. And the Google people started out their presentation talking about their disabled engineering group, and they ended talking about their driverless vehicles. And so I asked the question that I assumed was a natural question which was, so, obviously, you have your disabled engineers working on your autonomous vehicles, thinking about the access issues, right? And they quite literally looked at me ... And I'm from the Bay Area, but I'm from the other side of the mountain. I went to Santa Cruz, so I went to the hippie school, so the Silicon Valley people typically look at me like I have two heads, and at that point, they actually really did. And I think one of the really key things that that instructed to me is just the eternal lesson in the disability community about the need to have us at the table.

And so when Ford started building out our US disability rights strategy, we pulled together a series of round tables with over 50 folks in the community to attend three different round tables. It included people with all different types of disabilities, legacy organizations, loose-knit volunteer coalitions that were doing really badass work but didn't have their C3 status yet, people that got fed up with the disability community and left and were working outside of the community. And then we had about 150 individual one-on-one conversations in the first year to help inform what we were thinking about. And I think one of the big takeaways, and this really echoes what Lydia said, is that as the community, we're told to be ... We ask for scraps and we're told to be thankful for crumbs. And it's beyond disheartening. It's an attitude that is really internalized in a lot of our spaces.

And so when I landed in my position and I started reaching out to people about providing grants to their organizations, I remember reaching out to an organization in the rural US, because we know that over 1/3 of people with disabilities live in the South, and it's an organization that has been doing phenomenal work around young people with disabilities for years, and I said to them, "Well, have you ever had the freedom to just stop and think about the work you're doing? Just think about it." And they're like, "You mean not be running to put out one fire over here, plugging out fingers in six holes in the boat, spackling everything just to keep things floating, but to think?" And I was like, "Yeah." And they're like, "Becca, we've never had time to think about why we do things or how we do things."

And so one of the first things that we did in our initial year of funding was a lot of planning grants just to give folks in the community, after five years, well, even more than five years of being constantly under attack but watching the programs that disabled people and their families depend on for survival to actually sit and think about the work. And we really communicated that with our folks across the foundation, saying, "The disability community has been in triage mode for forever, and this is the community's entry point to philanthropy, and so it's going to look different than a lot of other communities."

It's going to mean a different level of technical assistance and support. It's going to mean talking to our grantees about how do we make the application process easier? And I've done federal applications. I remember a 255-page application to the social security administration that then got audited, and I still have nightmares about it. But how do we look at our structures? How do we look at what data we collect? And how to make it as easy as possible on our grantees. And for our grantees that are not their own C3 yet and may have a fiscal sponsor or fiscal agent, how do you pick a good one? And how do you make those relationships work productively. I think there's a lot of knowledge around engaging with philanthropy that has been kept away from disabled people and disabled-led organizations. And so one of the things that we've really found really critical to do for the success of our grantees is to spend that extra time with them, is to help them think through how do we translate the black box that is philanthropy in such a way that helps or organization scale up the way that they want to with the information that they need to thrive in a way that's also accessible for them and meets them where they are.

Sam Gill:

Ryan, you're leading an organization that is, as a matter of mission, is focused on working with communities of people with disabilities, so do you, though, find that in spite of that, some of the dynamics that Lydia is pointing to are nonetheless present, nonetheless creep in to how you do your work? And what are the things that you do to try to combat that or overcome that?

Ryan Easterly:

The short answer is yes. Without a doubt, they still exist. I think it's important to acknowledge that WITH and many other foundations that are veterans in this journey, we're all still in the journey. There are things we're still learning every day. In the case of WITH, there are ways in which we're evolving our reporting mechanisms to allow for organizations to submit their reports via video and audio links, because some folks, typing takes a while.

So looking for multiple ways for us to hear that information from organizations when it comes to reporting. Looking for ways to have those intentional conversations around how can the money we're providing support you in providing accommodations? How can it support you in providing for access needs? How can it help you in succession planning? Because we also know for organizations that are disabled-led or led by people with disabilities that many of the leadership, as it stands now, come from places of privilege, so they often can accept lower wages because they have other means or other sources of revenue. So how can we support them in making sure, in their succession planning, that they're providing an equitable wage so that individuals from backgrounds with fewer resources can end up within leadership, can end up working for those organizations. So it's having those intentional conversations with the grantees while continuing to have conversations with our grantees and with the communities to say, "How can we do better?"

Sam Gill:

I'm looking at the questions that are coming in. A lot of it is effusive praise for you all, well deserved, although, hey, that's my job. But so this is clearly a valued conversation, which is fantastic to see. But there's a number of questions that are said either by those who might be seeking funding or on behalf of those who might seek funding from institutional philanthropy, and they're along the lines of, okay, how do I challenge a paradigm? To the extent that I see the funder having a different understanding of disability than I do or failing to see some of the issues that you all are pointing to about the way in which organizations that support, that advocate for people with disabilities, the ways that they're treated, how do I challenge the apparent paradigm that a funder might be in?

So maybe just staying with you, Ryan, for a moment, what advice would you give someone who you think maybe has a critique of the way that you're supporting organizations? That they may think, actually, it was ultimately pyrrhic and counterproductive, what would be the right way to deliver that critique to you? Because what's coming up in the chat is, I sort of fear that I can't say what I really think, that ultimately, that will jeopardize, to Rebecca's comment, whatever crumbs I may have to live with, but I nonetheless will take in the service of the important work we're doing. So what would be some advice that you would give someone who feels that they're in that situation?

Ryan Easterly:

Well, I would say, on behalf of WITH Foundation, if you do know us or have a critique, email me directly. I want honest, frank opinion at all times. So on behalf of WITH, just email me directly. If it's with an organization that you don't know where they are as far as their understanding of disability inclusion, disability justice, I do hope you would start by sending them links to the Disability and Philanthropy Forum to say, "Here's a resource that may be valuable to you." And that, in a way, is you're not addressing here exact issues, but saying, "Here's a resource." And hopefully they will take advantage of it and be a part of the conversations that are occurring in the forum regarding these issues, take advantage of the resources.

So that's often the first step that I suggest that organizations that are looking to support their funders in advancing their disability inclusion and disability justice journeys. Just start by saying, "Hey, here's a resource." Or introduce them to me, and I can also say, "Hey, let's have a peer-to-peer conversation." And I'm going to take Rebecca's nod for being voluntold, I'm sure she also volunteers to have those conversations, as well. So that's another way that you can help your funders in their journeys of disability inclusion and disability justice.

Sam Gill:

Rebecca, same question to you. What advice would you give to a grantee who wants to challenge the way they think they're being treated? Or generally speaking, who wants to challenge the way they think the foundation is addressing these issues and open up some of these pathways.

Rebecca Cokley:

The first thing, and I know this is something Ryan and I have talked about a lot over the years, is doing your homework on the front end, too, and researching what are the that the foundation is funding, and think through where is the disability angle on that? Are they funding police violence? Well, as we know, at least 50% of Black and Brown individuals who are killed or assaulted by law enforcement are people with disabilities. Are they working on poverty? A majority of low-wage workers are people with disabilities and disabilities are cause and consequence of poverty. Is it climate change? Really figuring out what is the lens by which disability would be a natural fit. And really having a sense of what the data is, having a sense of who's doing the work. If it's your organization, that's great. If it's other people, that's equally wonderful.

As Ryan said, I think peer pressure is really powerful in the philanthropic space. And I say this as somebody who works for someone who is often lauded as the cool kid that hosted the cool lunch table that people want to be at, the number of times that I've gotten phone calls from smaller foundations, from family foundations, who are like, "We saw Darren out there talking about X. How are you all doing it at Ford?" And being able to take the time to have that conversation and even in cases where other grantees have come to me and said, "Hey, we talked to this foundation. They seemed interested but they seemed frankly overwhelmed by thinking about how to do it. Would you be willing to have a call with them?" I'm always willing to have a call. I'm always willing to think about how do we expand the entourage of people that are doing this work. And I know it can feel overwhelming. But at the same time, it's only going to work if we're willing to take that call and to put in that labor.

And honestly, our grantees are so ... It's a privilege for us in philanthropy to do that labor. Because our grantees are doing so much and are trying to help so many people with the funding that they have and trying to save the world on a daily basis. And the last thing I would ever want to do is push back on my grantees and tell them that they needed to do it. That's the privilege that we have being in the spaces that we're in. And so really thinking about what are the tools and resources, as Ryan mentioned the forum, and other materials and information and folks to put them in touch with.

Sam Gill:

So that brings us to a question I want to ask you, Lydia, that's coming up in the chat. And so I think, Rebecca, you mentioned something, right, which is that I think in a lot of the sort of progressive institutional foundations, we're not combating malice, right? This is what it means to be a systemic problem. It's that what we're combating is, going back to the beginning of the conversation, the sort of inability to see and to change one's perception of what's going on. And so what someone asked in the chat, Lydia, is a dynamic that I have a feeling is familiar to a lot of people in this conversation, our panelists and our audience, which is a person says, "Look, I'm disabled and I'm much further along on my disability justice journey than my foundation colleagues, who are open to learning, but don't necessarily see it as a priority." And I might modify the question to maybe don't think to make it a priority or don't know how to make it a priority. And so the person asks, "What would be your suggestions for how to make this a priority?" So, Lydia, what are some suggestions you'd give to this person who themselves wants to be an advocate, who's got open-minded colleagues, and is just thinking practically, how do I keep this on the radar screen so that we really can learn together, or unlearn together, as it were?

Lydia XZ Brown:

This is Lydia. I think often about what my friend and colleague Eli McHale Lee says in describing access culture as a defining characteristic of disability justice. Access culture means that we build access into everything that we do. Not as an afterthought, not as something to do to appear to be progressive or inclusive, but because we believe that access is the work of justice, that access is a core component of and a necessary precondition for justice. So when I think how does that translate into a funding organization, I'm thinking what are your HR policies? Who do you hire and how do you hire those people? What are your grant making and application policies? What is the nature of your application process? How can you advocate for changes in each of these ways, in who you compensate, how much you compensate them, and how? What benefits you offer to employees? How you compensate community members providing advice on advisory boards or committees? What types of funding do you offer? What are your reporting requirements? How do you support grantees in meeting those requirements, understanding them? Can you simplify them? Can you make them functional and workable? At each stage of your process and each aspect of your organization's structure, you can think about what you could advocate for to center access in design.

Sam Gill:

Lydia, I just want to stay with you for a minute, though, Lydia, because I think ... And I'm speaking more for this person. I read the great question. But I feel like I've been this person or I know this person, and you're in this situation, and you're seeing everything you just said, but your fear is, if I don't ask, people won't act. I've got people who want to learn, but how do I light that spark so that they're taking on the action and they're asking that question as opposed to me bringing it up in every staff meeting or me catching them in the hall or me pointing out ... How do I get it so they're coming to me, for example, to say I'm working on a new hiring form and we really want to make sure that access is included in it. What have you found useful when you have encountered people who are interested but not as far along as you in their understanding, to help them to take responsibility for their own journey to make access an essential component of justice?

Lydia XZ Brown:

I'd tell them that. This is Lydia speaking. I tell people exactly what you just said. I can't be the one always speaking up. You need to start speaking up. You need to work to educate yourself and support our colleagues in educating themselves. You need to take this on. Because if I'm always the only person thinking about disability and talking about disability, then you don't actually care. If you want to care, if you want to do something about ableism, then you need to begin being proactive. That doesn't mean that you need to say, "Oh, I'm now an expert." And that doesn't mean that you need to say, "Oh, listen to me instead of a disabled person." But it means that you need to raise the issue. You need to ask the questions.

Because we are sick and tired of always doing our own job and then also being the disability DEI person. We are sick and tired of doing our own job and also being the access consultant. We are sick and tired of also doing our own job and then also having to educate literally everybody all the time about disability and revisit and rehash our trauma every day, day in and day out. We need you, if you are not disabled, to practice saying something, even if it is, "I don't know what the best practice is, but I think something is off here and we need to go talk to our disabled community partners."

Sam Gill:

So I think we've just got a few minutes left, so maybe we could do this one very quick lightning round, maybe starting right there. I mean, I think this is a great way to end, which is, how do we help our would-be [inaudible] allies take responsibility for confronting and overcoming ableism? So if you could suggest to the people who are listening to this webinar one thing that they or a colleague could do today to get that ball rolling on taking responsibility for overcoming ableism, what would that one thing be? It's not the only thing, but just one takeaway practical thing. Maybe Ryan we could go to you, and then to Rebecca, and then close on Lydia.

Ryan Easterly:

I'm going to start by ... It's a multi-pronged answer, but if you are sitting in a boardroom of a foundation, if you're on a board of trustees of a foundation, I want you to look around that room. Do you have individuals that identify as having a disability at the table, on your board? If you are on staff, on leadership of a foundation, when you look at that staff, do you have folks with disabilities on staff, how are you engaging the community that you seek to benefit? How are you engaging the most impacted? How are you working with the community and not just for the community? If you are in procurement, when you look at your vendors, how are you engaging disabled led vendors and looking to them for their services and support? Because that also helps. So, ultimately, look and, in whatever way you can, as an ally, look for ways that you can work with the most impacted communities and not just for them. Because as Andre Lord says, "Remember, there is no such thing as a single issue struggle, because we don't live single issue lives."

Sam Gill:

I think multi-pronged is an abuse of one thing, but it was so compelling that we'll allow it, Ryan. That was fantastic, thank you. Rebecca, how about you? What's one practical piece of take home advice to take responsibility for confronting ableism?

Rebecca Cokley:

This is Rebecca. First, I want to add on to what Ryan said. The Ford Foundation now actively asks all of our grantees, "Are people with disabilities present on your board of directors and on your executive leadership team?" And this being the first year that we're doing it, it's really exciting to see the data coming in. I am actively doing data cartwheels on that.

I would also say there is power in being the first person to say the word ableism in a room. I remember the first time I was ever in a room and somebody brought up ableism before I did, and they weren't part of the disability community. And I remember actually having to check myself, because I was like, "Wait a minute, then what am I going to ..." My first response was I was like, "Well, what am I going to say since they said it first?" And it was this brilliant colleague and ally and member of the community now, [inaudible], from the Black Policy Lab and who runs Pink Cornrows, one of Ford's grantees. And I remember just being like, "Thank you for doing that. I have never been in a room in my 20, at this point, 30 years of doing this work where I wasn't the first person that had to say that."

And the last thing and I would just say, and I know because this is a three-pronged answer, but we're wrapping up, is take the disability inclusion pledge. You can find out information about it on the Disability Philanthropy website. And dip your toes in the water and know that you're not doing it by yourself. We have lifeguards. We have floaty devices. We have pool noodles. You're not jumping off the diving board. We're here to hold your hand and help walk you through this.

Sam Gill:

Thanks. And I know Lydia had to step away, but she still gets credit because she really sparked this line of discussion. Well, thank you all. This was absolutely fantastic and I think ... And everyone should leave this last segment of the conversation, I think, feeling empowered. I mean, I think what you heard really clearly from Ryan and Rebecca is looking around and just using the word ableism, that counts. That counts as taking action, as getting your organization going. So I learned a ton in this conversation. I hope you did, too. And with that, back to you, Emily.

Emily Harris:

Thank you so much, Sam, Rebecca, Lydia, and Ryan. Incredible conversation. And thank you to the audience for all of your questions and comments. We will be sending a short survey following the close of this question. Please help us learn from your experience by taking a few minutes to fill it out. A link is also available in the chat. And we hope you'll join us for the next sessions, in June on disability, arts, and culture, and September on economic justice. To receive future webinar announcements and continue your learning, as Ryan and Rebecca both noted, the Disability and Philanthropy Forum is here for you. If you work in philanthropy, you can sign up as a member. If you work in nonprofits, you can sign up to receive our newsletters, too. Come back early and often to explore the videos, curated resources that address the journey to inclusion, and if you are working in philanthropy, encourage your organization to sign the disability inclusion pledge. You will become part of a community with more than 65 other foundations and philanthropy serving organizations that are on this journey by taking concrete steps in the direction of confronting ableism.

Thank you so much, Sam and panelists, for joining us today. We've all learned an incredible amount. And lets go out and fight the good fight. Thank you.

Speaker 6:

Thank you so much, and this does conclude today's webinar. Have a fabulous day.