

EMILY HARRIS:

Welcome to the Disability & Philanthropy Forum's Disability Equity Series. My name is Emily Harris. I use she/her pronouns and I'm proud to be part of the disability community. I'm executive director of the Disability & Philanthropy Forum and come to you from the Unceded Land of the Council of Three Fires, the Ottawa, 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 a purple jacket over a white turtleneck. Behind me is a white and tan screen. My access needs are met today because we have card captioning. A few housekeeping items, there are two ways to access our live captions today. Use the CC button at the bottom of your screen or to access the captions in a separate window. See the link to the external caption viewer in the chat.

Although 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 at any time during the session. We'll try to integrate them into the discussion as they come in and we will also make time for questions at the end. If the Q&A is not accessible to you, feel free to send your questions to communications at disabilityphilanthropy.org. We will be live posting on X, formerly known as Twitter, today and hope that you will join us on social media using the hashtag, DisabilityPhilanthropy. You can also follow along by connecting with us on X, @DisPhilanthropy.

Before we start today's conversation, just a short reminder that disability is a natural part of the human experience, one in four US adults, 61 million people have disabilities and our community continues to grow as the population ages and as people contract Long COVID, other chronic illnesses, mental health and other conditions where society creates barriers to full participation, yet philanthropy often overlooks disability. Our research demonstrates that funding for disability rights and justice, the systemic change that will equitably allow disabled people to fully participate in society is only 0.1% of US grantmaking. Let me say that another way. Disability rights and justice funding is only one penny for every \$10 of US foundation funding. We have a poll question to help set the context for our conversation today. Please answer it if you don't mind multitasking a bit while I talk. If the poll is not accessible to you, please feel free to email communications at disabilityphilanthropy.org or respond in the Q&A.

I'll read the question and choices now. What percent of disabled people experience barriers to participating in civic engagement? And the choices are 31, 57, 17, or 22%. If the poll is not accessible to you, feel free to email us at communications at disabilityphilanthropy.org. To moderate our panel, I'm delighted to introduce Satonya Fair, President and CEO of PEAK Grantmaking. Satonya is joined on the panel by two disability rights leaders and advocates who I'm thrilled to be with today. You can learn more about the panelists from their bios that are linked in the chat, but before we start, the correct poll answer is 57%. You guys did really well. You'll hear more from our panelists about the many barriers to achieving disability rights. Satonya, take it away from here.

SATONYA FAIR:

Thank you so much Emily and sincere appreciation to the Disability Philanthropy Forum who have this been amazing partners for PEAK Grantmaking and so thank you so much. I am excited to be here with you all. I am Satonya Fair, I use she/her pronouns. I am an African-American Black woman from Ohio who finds myself working and living just outside of Baltimore. We sit on Piscataway land in my particular area of the world and I'm wearing a black dress today with some silver and gold jewelry and I'm in my home office today, a blessing and a curse and in my home office, there's colorful things on the wall, lots of paintings.

It's a gray room so I can focus and super excited to be here. This conversation is something that I'm really excited to be moderating because I've already learned so much just in the preparation for this discussion with Dom and with Daphne, and as someone who considers myself an emergent learner always, I'm really excited for us to learn and grow together through this discussion, and with that, I'm pleased to welcome and instead of reading the bios, I'll refer you to our chat. We definitely have descriptions of both speakers, but Dom, if you can get us started with your introduction, I would appreciate that.

DOM KELLY:

Absolutely. Hi everyone, I'm so happy to be here. I'm Dom Kelly, I use he/him pronouns. I'm the co-founder, President and CEO of New Disabled South. I am a white man with brown curly hair wearing a dark gray button-down shirt sitting in front of a couch with some pictures on the wall and a bookshelf with a fake plant, a candle with Elliot Smith's face on it and in some books that I love. I am currently based in Atlanta, Georgia on stolen Muscogee Creek land and I am very happy to be here.

SATONYA FAIR:

Excellent, thank you Dom. Daphne.

DAPHNE FRIAS:

Hi everyone. My name is Daphne Frias. I use she/her pronouns as a proud Latina, I am coming to you all from Unceded Lenape territory otherwise known as New York City, particularly Harlem. I am wearing a dark red T-shirt. I have curly brown hair and pink glasses just with a blurred background here in my home, and thank you so much for having me.

SATONYA FAIR:

Excellent, thank you both so much. We have a lot to get through, but we're going to start initially by just getting our conversation grounded in the story. We are really fortunate to have both of you here and it's important for us to kind of know how did you get here to this moment? So I'd love to open up Dom with you sharing your personal story and what has shaped you as you navigate this world we find ourselves in today.

DOM KELLY:

Sure, I'm happy to share. So this is Dom. I am one of a set of triplets. We were born three and a half months premature and were diagnosed with cerebral palsy when we were just about a year old. Cerebral palsy is a disability that is a result of brain damage at birth that affects mobility, and so my experience in this space is for one rooted in my personal lived experience as a disabled person, but I like to say that my mother forced us into advocacy when we were just four years old. She put my brothers and I in front of a room full of high school seniors and said, "You're going to tell your story, good luck." And really her intention was I want you to tell your story before someone tries to tell it for you, and that was a really important lesson that I learned at a young age that oftentimes people try to speak for disabled people and I felt and learned to be empowered at a young age to talk about my disability, to really share my story.

My fraternal triplet brother Paul died when we were six years old and his legacy really is the work that I do today. I do it because of my own experience as disabled person, but also in his memory and in his honor, and also it was my mom's field of work as well, and she passed in 2017, and so I feel like me being in this space is continuing this legacy that has been a part of my family. And so I've been organizing in the South since 2009 and have been organizing in different movement spaces, volunteer capacity, work capacity, and sort of found myself oftentimes as the disabled person or the out disabled person and saw that there was really a lack of a disability rights and disability justice education and lens in that work, and so found myself carving out those spaces and building out portfolios of work.

And it eventually led me to have this idea for a regional organization to do some organizing in the South or figure out how we can make some progress in this region where progress seems very slow, and so the New Disabled South is the first and only regional disability organization in the country, officially started building it in 2020, launched in 2022 and doing my life's work now full-time, have a 13 person staff and just incredible. We're doing really cool work. So all of my background has led me to really doing this thing that I kind of always dreamed about doing.

SATONYA FAIR:

That's fantastic. Thank you so much and shout out to your mom for that.

EMILY HARRIS:

Excuse me a minute Satonya and this is Emily. I just want to say our StreamText link is not working at the moment, however, the captioning is working in Zoom. If anybody is relying on StreamText only and cannot access Zoom, please either put something in Q&A or email communications at disabilityphilanthropy.org and we will pause the webinar, which is a little ironic for me to say that as I think about that. If you're not able to see it, you're not able to see it. We're going to see if we hear from anybody and we're working to get it fixed as fast as we can.

SATONYA FAIR:

Excellent. Shall we carry forward, Emily, or do a couple minutes pause?

EMILY HARRIS:

Let's carry forward and we will figure out how to communicate with everybody.

SATONYA FAIR:

Thank you so much and I'll stay abreast of the post as well of the chat if there's anything to share. So thank you so much, Dom, and I'm excited to get into key policy and advocacy issues around New Disabled South as we get going. Daphne, we want to hear your personal story. What is bringing you to this work right now and helping you navigate through this very interesting world we find ourselves in?

DAPHNE FRIAS:

Yeah, I resonate so much with Dom's story. I too am in the preemie club, born 27 weeks, have CP with spastic diplegia, use a wheelchair to emulate and have a lot of fun doing so, and my story begins similarly, my mom was a case manager for foster children when I was young and I saw how she helped to reunite families and find children their forever homes and I thought she was the coolest person ever and still think that, and saw how she used her voice and allowed her voice to amplify the voice of young people who didn't have one in really precarious circumstances, and she also sort of threw me in the deep end and put me into IEP and 504 meetings as soon as I can remember and said, "Okay, figure it out. Do what you got to do."

She made sure that I think by second grade, I was running my own meetings. I came in with my own goals and everyone was just like, "Okay, whatever you want to do Daph, we'll help and support you." And that was in the early 2000s in the New York City Public School, which is a very non-inclusive space and I was one of the first disabled young people in the New York City public school system to receive generalized education with special education services like physical therapy and occupational therapy. So navigating that was a really interesting time and I come to you all now working on the sections of the climate crisis disability justice and gun violence prevention with the public health focus, so I currently am awaiting my master's of public health approval. I did my dissertation a couple weeks ago and fingers crossed everything works out, but I feel really good about it, and really public health for me is the way that I saw my experience as a quote-unquote professional patient, really translate into real life.

And Dom you said you're based in Atlanta and I was there a couple of weeks ago for some work and I realized how much Atlanta needs to do to increase accessibility. So it reminds me that although I faced tons of privileges here in New York City and access is radically different that across the nation and across the world, access means a lot of different things for a lot of different folks. I also do a lot of work as a recent cancer survivor. I was diagnosed with stage four Hodgkin's lymphoma in July of 2022 and recently came up on a year of survivorship in March, so I'm rocking my chemo curls as you might be able to see. I'm navigating that new space as someone who's in the healthcare field and the advocacy field. I'm really excited to be part of this conversation.

SATONYA FAIR:

Well, I am just so privileged to be part of your sharing and part of the moms are amazing, right? As activists and advocates, a kick-starter to all the things that happen sometimes for those of us

who have the privilege of having our moms and having that closeness, and so I am lifting up, you all will see me with a pen. I do that for my own notes, but also to track the conversation and so I am writing so many notes down and I feel like there's a part two that we should be having that's just about your stories and not so much about the work.

DAPHNE FRIAS:

Satonya, I just want to jump in quickly and say to Dom, I just want to hold space for your brother and your mother. We see them, we honor them as elders in this movement as wisdom leaders in this movement, and I know they're so proud of you.

SATONYA FAIR:

Absolutely. Yes, the angels on your shoulder is the blessing and congratulations in honoring you as you continue to fight Daphne, one of the hardest things in the world. There are so many things that seem to be against us at times, but congratulations on hitting your one-year milestone and may you have 99 if not more of those milestones to come. So we're going to get into some issues because in our discovery and preparation we realize there's so much intersectionality and a lot of these conversations. So Dom, I want to hear for New Disabled South and just in general, can you point us to some of the key policy and issues as well as advocacy goals that you're focusing on right now? We will have a call to action in general for everyone who is participating that really speaks about what do we do from here, but it is interesting to notice, you shared Dom, we'd love to hear what you're seeing philanthropy do or not do in support of these issues.

DOM KELLY:

Absolutely, so we really consider ourselves to be a cross-issue, cross-movement disability organization. So as disability justice is really rooted in cross-movement solidarity, we really try to have an eye and a lens toward those issues that may not be specifically disability or you may not think of as disability issues, but we know that they are and really focused on disability issues specifically. So we have three kind of buckets that we prioritize our work into. So the first is poverty and care. So really anything that is a determinant of poverty for disabled people that may be access to food, that may be the ability to have accessible, affordable housing, transportation, that may be climate and environmental disaster response. That is things like sub-minimum wage, and the fact that many people with disabilities are still legally able to be paid pennies per hour. The care piece is maybe one of the most critical pieces of our work.

We really are focused on improving the care economy in the South. We have 656,000 people with disabilities waiting for home and community-based services waivers in this country and 500,000 of them are in the South. So we really see that as a Southern issue. We are working to try to eliminate or significantly reduce some of these waiting lists, increase wages for care workers who are both non-disabled and disabled people, and really just help improve the entire infrastructure of the care economy in the South, which is so critical. Not just for disabled people but their families, their loved ones, and really everyone because care is an issue that affects all of us beyond poverty and care criminalization would be our other bucket and so we are really

heavily on the research side more so kind of trying to uncover some of that data to help us understand what it looks like for people with disabilities as they interact with the carceral system, with systems of policing.

We don't have a lot of data at a state level, even at a national level, but really we're trying to understand the regional picture of what mainly Black disabled folks in the South are facing when it comes to policing police violence. So that's our second bucket and then our third is democracy and voting rights, and that includes policy advocacy around anti-voting legislation. That includes talking to voters, reaching voters in places like congregate settings. Our organizing team works across issue, but on the voting and democracy side are really focused on how do we reach our community in places that are considered hard to reach. So maybe they're in rural settings, maybe they're in congregate settings, and then beyond those three policy areas, we do work around making sure that our community has the ability to understand the laws that govern us. So we created a tool called the Plain Language Policy Dashboard that translates bills and legislation into plain language that's easy to understand, not just for disabled people, for everybody.

I sometimes have to read a bill 10, 15 times to properly understand what it's saying and sometimes that's intentional, it's written that way and I do this work for a living. So it makes it concise and much easier for people to understand. You can go through state by state, I can go on and on about all the work we're doing, but I think the big projects that we work on, the big overall goals and really our big goals I should say are policy change and narrative change around disability in the South and knowing that we have to both work within and outside of these systems that govern us because those systems are also oppressive and so we try to focus both on the policy and legislation and also the community side, the base building, the organizing, building power in people's communities locally and otherwise, and I'll say about the philanthropy piece that I think we really see a need for funders to think about how we can build movement infrastructure in the disability rights and justice spaces.

We don't have the movement infrastructure, we don't have the infrastructure to do the level of base-building that we need to do, right? There are so many people who may not even understand what it means to identify as a person with a disability as disabled. So right then and there, that's a barrier to entry, and so that takes time, that takes intentional conversations, that takes talking about the issues that impacts people's lives, and that is where the need for that infrastructure funding, the movement, base-building infrastructure funding is so critical for us to have the people capacity to be able to bring our community into these conversations, to give people resources that they need to help them, direct them to rental assistance, direct them to things like that while we have those conversations and bring them into that loop. So that I think is an immediate need and we also convene a coalition of advocates and organizations throughout the South who are working on disability justice and disability rights, and I think that support for coalition building and breaking people out of silos is also such so critical, especially in this moment.

SATONYA FAIR:

And for those who are taking in what you're dropping down, it's also such a clarion call for philanthropy to just understand that mission agnostic, the responsibility of supporting policy and advocacy, especially with whatever positional power that they have is really important, right? Because we are trying to both create and disable systems that are not serving us, but try to create new pathways. I think there's probably been about five New York Times, Washington Post stories just in the last week that point to your three areas that you're focusing on alone and what the need is across the globe, so let alone in the US and in the South. So thank you for lifting those up and again, for those who may not have noticed, we did post a link to the Plain Language Policy Dashboard for you all to take in and definitely we'll make those available as a resource following.

Not that we're changing subjects because I think all of this is overlapping, but Daphne, we were talking in the prep about how people can be a little bit confounded at times when you bring up certain topics as an activism right, a disability conversation and one of those things is climate justice. Didn't think we'd find ourselves in this conversation. Talk to us about how climate justice issues are impacting in particular people with disabilities both here in the states, but just why disabled people are also uniquely positioned to advocate for justice.

DAPHNE FRIAS:

Yeah, and Dom I have to say, I live on that plain policy reader. I'm constantly lobbying in DC and half the time I still don't know what's going on. I've been doing this work for almost eight years now and the words are still confusing, so I'm very grateful for that resource. Yeah, well, I like to start off by answering this by framing it through the simple fact that the climate crisis is a disabling event. We have to begin to understand that the health of our planet is intrinsically tied to the health of our bodies and that they are not two separate phenomena, and I say that the climate crisis is a disabling event because it exacerbates individuals with current disabilities and it is disabling new individuals. As we see the proliferation of climate migrants having to leave their homes due to adverse climate events, many of those individuals through the evacuation process are either becoming disabled or having to leave behind their support systems and mobility devices in order to evacuate in a rapid fashion.

Additionally, disability is inevitable. I think the way that we currently understand disability is that it is something that happens at birth or something that happens through a traumatic incident. Everyone will become disabled at some point in their life. It is a natural part of the human existence. It's the natural process of aging that we must accept as human beings, and I think that the reason of the fear around disability is not necessarily because of the way that your body changes, but because there's this subconscious understanding that you become a second-class citizen, that you then lose the structural governmental support that you are often afforded as an able-bodied person that disabled people don't have.

And that is the innate fear of invisibility and to bring it back to climate, you've also seen the ways that heat intolerance and extreme changes in weather patterns have greatly affected disabled individuals, especially those with neurological disorders who struggle to regulate their own body temperature and depend on external environments to do so, and a lot of the sort of narrow-minded feedback on that is like, "Well, just get a heater or just get an AC." Disabled people

systemically live in poverty. We don't have the ability to input these appliances into our homes, let alone pay for the increase in utilities by having these mechanisms within our homes.

And then we see sort of the inequalities in disaster preparedness procedures were oftentimes when evacuations are necessary before an extreme disaster event, it's great to have an evacuation center, but can disabled folks or people with disabilities access those evacuation centers and then once they arrive, how are they outfitted to help support them with keeping up their current healthcare and any other additional support systems that they might need? And then I think the most crucial point that doesn't necessarily get the attention is the villainization of disabled people within climate narratives. The way that we see particularly able-bodied folks harping on the use of single-use plastic.

A couple years ago we saw some turtles with straws and everyone lost their minds about plastic straws and decided that that was the way that we were going to save the planet. We're still here folks, and the climate crisis is still getting even worse, and I think that it erases a whole community and our needs by having really harmful conversations like these. I depend on straws to receive nutrients. I depend on straws to enjoy meals, and contrary to popular belief, disabled folks like to go out with their friends and go to restaurants and enjoy meals and have a drink and just live life, and the worst feeling is to ask a waiter for a straw and have them give you a dirty look because they think that you're part of this alt group that's still using plastic straws. I also think it's a distraction, right?

The real proponents of the climate crisis are the fossil fuel industry, right? Are the powers that be of the 1% that have created this crisis to exist in the first place, and by having narratives around single use plastic and about buying plastic straws, we are taking away the focus from the real perpetrators of this issue that depend on ableism and other systemic oppressions to continue this crisis to proliferate, and to sort of tying in your last point, I always have believed that disabled folks are some of the most astute climate solutionists. When we talk about climate preparedness and climate resilient solutions, the most common word thrown around is adaptation. I don't know any more adaptive community than disabled folks. We literally have to exist in a world that is not made for us to thrive or succeed. Every moment of our day is adapting to society. So if you want a group of people that are leaders and experts in adaptation, we're right here, the one billion of us that exist throughout the world, the 15% of the global population, we've been here the whole entire time.

We also lead with love and joy. I think that that is such a beautiful part of the disability community to take a saying from the Black Liberation and Black Lives Matter Movement, we keep us safe. We are a community that understands what it's like to not have the external support systems we need to thrive, and we share mobility devices, we share medications, we share doctors' recommendations. We allow ourselves to thrive together as a community and we also lead with love because we know what it's like to live in that darkness and we know what it's like to not be seen, and the more that I always say that in order to have equitable climate solutions and to have a climate positive future, we need to fall radically in love with their planet and we need to fall radically in love with ourselves and I wouldn't be doing this work if I didn't

absolutely love and am infatuated with our planet and who we are as people and believe in that better future.

And I think that disabled folks innately have that love within us because we've had to face so much adversity and darkness and we need your help, we need your funding, and we need your support. I also think to Dom's point, we are so critically lacking in research as to how the climate crisis affects disabled folks. As someone who has been two years or so working on their masters, I see data all the time. I see numbers all the time, but what I see beyond those numbers are people, are real stories, and I look at this data and various data sets and I think to myself, there must be disabled folks behind those numbers that we just are not seeing, and I like to push back against the idea of a lot of times I get called a voice for the voiceless, and I believe there are no such thing as voiceless people, just people who have not been given the appropriate platform to let their stories be heard, but just because you can't hear us doesn't mean that we aren't speaking.

We're still here and we're still being loud and so much of research defines policy. Policies are made because research shows the need for something to be created, but if we are not included in those research sets and we are not funded to conduct that research, we are being left out of policy and we are being left out of that conversation and that's what makes it really difficult and really hard because we can say 'til we're blue in the face that we need something, but if research does not back that, unfortunately, a lot of times policy and funding doesn't follow through.

SATONYA FAIR:

Thank you so much Daphne and Dom. I'm hearing so many things. If your first inclination is villainization, not helpful to the work at all, communities of care, the centering the love, definitely, in the work that we do, and also we can do hard things. Philanthropy can fund very hard and very complex issues. The better the data, the more segmentation we have, the better that we can advance some causes more effectively as leaders. I want to dig into and I'm just looking at time because we need 10 hours for all these conversations.

When you think about yourself as an organizer, the type of support you need to have your advocacy really catapults, we know that there is a discussion around just straight up funding. You all have also mentioned some very specific bodies of work and ways of thinking, and so I'm going to combine a little bit from our grounding question to some of our other key points. You are going out into the world of philanthropy and every day with your story and with your goals and what type of support do you need from philanthropy in this moment? You've pointed out what's not so much working. Now I want to dig into a little bit more around perceptions and what is working and also maybe some glaring things that people just need to consider along the way. So Dom, I'll start with you.

DOM KELLY:

Yeah, I love this question because I think it's a good call in and moment to think beyond some of the barriers that I think have been put in the way in philanthropy. So I think often about just

the barriers to accessing funds are often quite difficult to move past really long grant applications, inaccessible grant applications and the back ends that you have to navigate that I have heard from many people who use screen readers who say that they're not screen reader accessible. The amount of physical labor it takes to type a really long grant application, the knowledge of some of the terminology that you might need in order to understand certain financial requirements, things like that, that I think can be laborious and can really I think contribute to that really alarming stat that Emily uplifted around that 0.1% of funding that goes to disability rights and justice.

I think that starts often with the barriers are in the way to actually accessing funding. I think oftentimes, reporting requirements can be very similar, especially with small movement organizations with very limited staff capacity, and I follow this LinkedIn account called crappy fundraising practice I think is what it's called, and it's so good they really uplift a lot of those things not through a disability lens, but so many I could point back to that lens and I've worked with funders before on how do we make your practices more accessible and inclusive of disability, not just a few funding disability, but also making the process to accessing funding more inclusive and accessible. So I think that is a big barrier in the way, and so I think improving that is a great opportunity. Trust-based philanthropy is I think the future and really critical, especially when we're talking about so many great ideas and so many great organizations in the disability rights and justice ecosystem that don't have access to these kinds of opportunities because of so much of the requirements that they would be required to adhere to.

And then I think really, it's making sure that when you are thinking about funding disability, talking to disabled people. In that stat of 0.1%, that is not including the typical organizations that do get funded that are not a part of this ecosystem, which are the charity model kind of medical model organizations that are looking for things like fixes or cures to disability, the sort of parent-led groups, right? They have their place, but they're not disability-led. Disabled people don't want to have seats at the table. So I think oftentimes they get a lot of the funding because there's nobody in that space when you're making funding decisions who's saying, "Hey, these are the groups that are doing really good work who are led by and for disabled people." So making sure we have seats at the table or you're coming to us and asking for recommendations.

And I think that's really critical and I think that's a way for philanthropy to kind of do better and would help support not just our activism, but the broader ecosystem and that's going back to that we need that infrastructure built for us or we need to build it and we need the funds to build it. That goes back to we don't get the kind of attention from the Mackenzie Scotts of the world that other issue areas might. So we need to be a part of those conversations, bring us in, have us at a seat at the table.

If you're bringing folks together to sort of think about who are going to be your new grantees, make sure you have a disabled person there to talk about that as well. So I think that will help strengthen our broader movement and philanthropy really, and this goes back to not just philanthropy, it's pretty much everywhere. We talk about the census, we talk about government, nothing about us without us, what I'm trying to say with this entire spiel is we need to be a part of that conversation, that's going to help us be able to do the work that we need to do.

SATONYA FAIR:

Thank you so much, Dom. Daphne, what would you add?

DAPHNE FRIAS:

I would say 100% agree with everything you said, Dom, but also it reminds me of especially during my cancer treatment, when I did have the energy, when I did have the spoons, there were so many times I didn't fill out grant applications because I was just like, "This is just too much. I don't have the capacity to do this." I'm going through treatment. I'm dealing with what my body can give me at the moment and I also think that there's not a lot of philanthropy infrastructure for rapid response in related to disability. I think what folks don't realize is disability can be dynamic. The way that my body shows up today is not the way that my body's going to show up tomorrow or next a year from now, etc. Disability changes even in many disabilities that were previously not seen as progressive.

And we need to be able to have the infrastructure through philanthropy to say, "Here is the current need of what's happening in a disabled community." To bring it back to where you're based Satonya, the Francis Key Scott Bridge collapsed a little under two weeks ago. I'm sure there are many disabled folks who can't access critical resources because that bridge is no longer available to them. That is a rapid response need, and are there avenues of grant making that account for that? There are very few and far between resources that I can think of. Additionally, I struggle to find resources that allow me to think beyond a western lens of disability. Like I said before in my introduction, I'm a proud Latina. I speak Spanish. A lot of my work is bilingual.

I really struggle to be able to do disability justice work in Spanish because if you think that the need of disabled folks in English is very sparse, it's even more sparse in other languages. So not only am I learning how to translate complex terms, but then I have to convince people that we exist in other cultures and we exist across the spectrum of identities, and that's very difficult. I also think that for the disability philanthropy that does currently exist, it's definitely organization based and a lot of times I don't qualify for that funding because I'm not an organization or me as my organization, but that doesn't mean that I don't have impact, right? And I always say that I represent and allow my voice to be a human microphone for so many different individuals that don't get to occupy the spaces that I am privileged to occupy.

Late last year I got to meet the Secretary General of the United Nations, and I was the only disabled person in that room and I think about in moments like that, I have to carry the weight of one billion people on my shoulders, and when folks tell me that an individual person doesn't qualify or doesn't have impact, I was like, "Okay, but look at this. Clearly that is impact." So I guess broadening the horizons of who qualifies as we move into community care, mutual aid, individualized advocacy in community, we need to really broaden our horizons there.

And then just sort of I guess a housekeeping note, again, disabled people live in poverty. So when folks are wanting me to consult for their future philanthropy projects, pay for my transportation, make sure that things are accessible, please don't make me have to do all that

legwork. It is exhausting. I'm already using all my brain capacity to be the best consultant I can be for you and show up for my community. Having to think about all those extra steps is just entirely exhausting, and I've been doing that for 26 years. I would like to break now. So if you are wanting me to show up, don't just say you want me to show up without having the infrastructure ready for me to be there and for other folks to be there as well.

SATONYA FAIR:

Thank you so much. We have a question that's coming in, but I do want to do a moment of reflection that speaks to something that Dom shared in our prep, your last point. You all as folks who are both organizers who are also disabled leaders, you're spending so much time educating funders and community and there's really no funding for that piece of it. Even if you do call yourself a consultant, most people would say, "This is a consultant. I need to pay them for their thought leadership, their time, etc." Dom, you mentioned as well that there are some very simple things that more funders can do, changing accessibility holistically around the way they present grant and report applications, paying nonprofits, consultants and leaders like both of you for your time when educating and not trying to get you on a discount.

Because I do want to mention that the whole this is not the time for us to be trying to only pay \$500 when the entire cost of the trip can be easily shared, that it's going to cost \$7,500 for all the accessibility that Daphne is going to need to come to your event for the day, this is what is needed, and so please don't shortchange that. I also hear this kind of the representational that we have been saying that philanthropy internally just has so much more to do. How many program officers and or operation staff and grant staff and leaders are you identifying who share and have a disability who are not going to come tell people what you're going to do, but who can be part of that conversation and be part of that representation? I hear a million things. The question we have is there knowing that we are already kings and queens of adaptation, how are you shifting, especially in your particular landscapes, New York and in the South, between the state versus federal conversations? Is there an adaptation required to advance these different levels of policy advocacy or not?

DOM KELLY:

Sure. I quickly want to say to one point that you made, I had a meeting with a funder who we very quickly realized we did not qualify for their funding. They funded the Northwest, we are in the South, but they really wanted to spend the time to learn from me and I had no expectations about what that would look like, and they said at the end of the call, they wanted to send us a little bit of money as a thank you, and they gave us \$1,000 for an hour of my time, and I thought that was really a wonderful practice and something that I think really strengthens what you were talking about, which is there is a way to do that. So I just want to uplift that.

But to the question, I love this question because I think all advocacy tactics are probably useful and powerful no matter if you're talking to legislators at the federal level or at the state and local level, but I do think sometimes you have to sort of learn how to play the game so to speak, and so if you're in a state like where I live in Georgia, where to try to be very C3 and not partisan, you have a certain party majority in the legislature, I know that I'm going to approach the way I

talk about the issue in a different way than I would if I was going to Congress where we have a slight majority in Senate. If I'm talking to a senator, I may talk about the issue differently. The tactic I use might be slightly different, but really the most powerful thing, no matter if I'm talking to someone at the state level or the federal level is to tell my story. Personal story is always going to move the needle. They want to hear about big policy ideas, they want to hear about data, but you have limited time.

And so either way, I'm going to tell them when I sit down with a legislator in the state of Georgia and I ask for them to come off of their 16 billion dollar budget surplus to give a little bit of money to our home and community-based services, care infrastructure, I always start by saying I am one of a set of triplets with cerebral palsy, and I am somebody who relied on Medicaid home and community-based services to receive the care I needed in my home when I was a kid, and telling that part of my story to then tie it to the policy issue, that's going to work no matter who you talk to. So I may need to tailor it a little bit to talk about the economic benefits of spending that money if I'm talking to someone here in Georgia versus going up and speaking to a legislator in DC, but really the approach of telling my story, the human connection, which is what Daphne talked about, there's humans behind the data, that human connection is so critical. So that I think is sustained and consistent no matter who you're speaking to.

SATONYA FAIR:

That's so perfect. So I heard know your data, I heard tell your story, which is part of the primer for all of us to do policy advocacy work, but also know the room, right? All of us are supposed to spend time preparing. We prepared for this conversation with you all along with the team, and all of us have to know who are you walking into, who is your audience? And even just that knowledge should apply some need for tailoring. Thank you so much for that. Daphne, a question for you that's coming from our audience, goes back to intersectionality again, what do you say to foundations working on racial equity who don't necessarily consider the race and environmental racism aspect of that work?

DAPHNE FRIAS:

Well, that question is speaking to my heart because I just be raging about environmental racism, especially living in Harlem, predominantly Black and Brown community, a community where for over 79% of folks, English is their second language. That hits very close to home. I think about the way that we sort of quantify ableism and the fact that ableism isn't just based on your disability, but it's the sort of the multiple layers of isms and discrimination that exists. So helping folks understand that the way that a BIPOC disabled person experiences their disability and the way that a white person experiences their disability is completely different.

And that on average, BIPOC disabled folks also deal with higher levels of comorbidities, right? So not only are we facing the realities of our disability, but we also exist in other multiple jeopardy situations as well, but then understanding that systemically, we also experience massive healthcare bias as well, especially when we bring in the race component. I think about something called the VBAC score, which is a vaginal birth after cesarean. It's a score that quantifies if you're able to have a natural birth after a cesarean and before 2022, race was a

part of that calculating model. So if you were a person of color, you automatically had a higher VBAC score because they just thought that individuals of color had less of an ability to have vaginal births, and we're still trying to untangle microaggressions, macro aggressions and just internal and external biases in so many different ways that are tied to our race.

We even think about the Black Lives Matter Movement, there was a sub movement called Black Disabled Lives Matter Too where even in massive social movements, we are excluded from that conversation because we don't fit sort of the model of what it looks like to be part of those movements. So sort of similarly to how I said the climate crisis is a disabling event. Your culture and your race defines your existence with your disability in many ways.

I think about screening for social services, one of the questions they always ask you is about your race and ethnicity, and a lot of that is for data points so they get more funding on the back end, but then it also creates this subconscious connotation that in my public health research, I found that a lot of those screener questions actually help to determine where you rank in hierarchy for social services. So by answering those questions, a lot of BIPOC folks get on the lower end of priority lists just because of societal external biases. So it does play a massive factor, and just like you can't take disability away from our identities, you can't take our race and our culture away from our identities either.

SATONYA FAIR:

Well, I think that's a nice drop mic moment. We have more questions. We're going to get some answers to folks who posted them, but I do want to just thank you all so much for what you shared so far. The closing question that we'll have you guys come back to if we get a chance to via typing is the call to action around what can philanthropy do to support more civic engagement of disabled folks? And so hold that, maybe start typing something that you're thinking, and then Emily, I will pass it back to you to really close this out. So thank you both so much for this engaging conversation. We needed three hours.

EMILY HARRIS:

This is like the worst part of my job, the part where I am the one who has to end this. We're sorry we couldn't finish. We couldn't address all the questions, but we look forward to hearing back from you. We will be giving a short survey, and when you close out, you'll see it. It will also be emailed to you, and we hope you'll join us for our next webinars in the series. May 9th coming up soon. Grant Making for Disability: LGBTQIA+ Funding. So thank you again. Don't forget to support disabled people and pay them for their services. I think that was one of the big takeaways for me. Satonya, Daphne, Dom, we can't thank you enough.