Emily Ladau:

Hello everyone, and welcome to another episode of Disability Inclusion Required. I'm your host, Emily Ladau, and I am so thrilled to be kicking off 2024 with a topic that I think is absolutely essential for philanthropy to consider, and that's funding direct action and organizing efforts. I am such a big believer in the power of supporting grassroots work as a really effective pathway towards change.

Today we have two guests who are going to be able to speak directly to the power of providing funding for these efforts. I'm really, really excited to be welcoming Jen Matheson, who's the director of programs in Northwest Health Foundation, and Julie Farrar, who's a disability rights activist. And I wanted to be sure to have both a funder perspective and an activist perspective for this discussion, so I'm feeling particularly glad that we have both of you joining us today. And I'd love to have you introduce yourselves. Jen, let's start with you, and then Julie, we'll have you jump in. If you could just share with us a little bit about who you are, a brief overview of the work you do, that would be great, and then we will start to dive deeper.

Jen Matheson:

Thanks, Emily. It's so great to be with you here today, and with you, Julie. Yeah, again, I'm Jen Matheson. Use she and her. And I am with Northwest Health Foundation. We're a small regional funder based in Oregon and Southwest Washington. I'm joining you here today from Portland, Oregon looking out at a beautiful day with little clouds, not so much rain, which is unusual for us in the winter. And we're a foundation that really looks to focus our work around supporting Black, Indigenous and communities of color to build power. And so for us, that means helping folks who want to hold elected office, sitting at decision-making tables to our region. It also means uplifting disabled BIPOC leaders. And we also do some work around working to reduce incarceration and racial disparities in the criminal legal system, and more; a lot of things. But really, it's around this belief that when BIPOC communities have power, they can change the systems and institutions to repair the historic and wrongs that we have in our society and create a future where everyone has the ability to thrive. That's kind of our approach around our work.

Emily Ladau:

Absolutely. Thank you so much for introducing yourself. And Julie, we'd love to hear from you too. Tell us more about yourself.

Julie Farrar:

My name is Julie Farrar. I use she/her pronouns. And I like to believe, I like to think of myself as a human rights activist. I'm really excited about working within what people are calling the fusion movement to ensure that the disability perspective and our leadership experience, it becomes part of the larger social justice movement. I work with a local independent living center on systems change and fusion organizing with the Poor People's Campaign and Caring Majority.

Like I said, I've been involved with disability rights since I was 16. I am now 55. I really like what Jen said about all of the things that we should focus on funding and why. Rather than advocating for it, is really working together. I feel like we've reached critical mass and we must come together and we must work together and we must recognize the different leadership qualities that people bring to the table and also make sure that we are very cognizant of the need to maintain our identities in however we identify and at the same time promote the leadership of people who, in a lot of ways, were represented by groups not in a benevolent but in some ways destructive perpetuation of stereotypes or of actually using tactics for fundraising that are actually disempowering and, in a lot of ways, pretty disrespectful of the people that organizations are purported to be representing.

I think I'm really excited to be part of this fusion movement. And I feel like I have moved hopefully from being a disability rights activist to a human rights activist to someone who is working in the larger arena of social justice.

Emily Ladau:

I really appreciate the work that both of you are doing. And Julie, I think you point to such an important concept of nothing about us without us. I heard that come through, really, in the idea of not just working for but all working together and collaboratively. And I think, Jen, that is something that has definitely been a priority, at least in my understanding, for the Northwest Health Foundation. And I know that the foundation has directly funded work to increase organizing skills and capacity of disabled leaders of color in your region, as you were mentioning, so could you share a little bit more about how and why that area of focus came to be?

Jen Matheson:

Sure. Yeah. And I just want to comment, Julie, I love the idea of fusion organizing and fusion movement. I haven't heard that before, and I love that. I think that really does speak to the ways that our organization is trying to think about stuff that sometimes we call cross movement or just, again, what you named around thinking about people as whole people. They're not issue-based, they're not single identities, people have complex lives and complex communities. And we believe that movements and communities should hold that complexity. And we think philanthropy can too, but we got to do a little work to get there.

And so for us at Northwest Health Foundation, it's been a journey. It's been a little over five years for us that we've been really more deliberately thinking and learning about what does disability equity, disability inclusion mean? And one of our places that we started was to really lean in and hear from folks that came out of the disability justice movement. We were introduced to Stacey Milbern Park, who folks may know her writing and the work that she did as an activist. She unfortunately passed away in 2020. But she came and met with our board and really helped us understand what that movements framework was about and how it doesn't seek to divide people by identity, that it seeks to work across movement. And it really resonated for our board who really was grounded in a racial justice focus but really hadn't really thought about what does it mean when we also are intersecting with disability and disability movements? And so that really helped inspire our board to say, "Okay, there's this work happening out there. We need to do more."

And so one of the first things that we did was said, "Who's in our region? Who are the people doing this work? Let's get to know them." And we, by no means, were the place that we thought we could be the ones to lead leadership development or lead anything, but we really wanted to be more in the receptive mode around it, and so we put a call out to disability leaders. And what was amazing is we had about 120 people apply, over half of them being BIPOC, disabled folks. And so we were able to put together a cohort of about 16 to 18 people that we said, "Come be with each other and also come be with us, and let's build an analysis together about what this means."

And so we met with that group over two years, working with Stacey as well as with Leah Lakshmi Piepzna-Samarasinha and said, "Yeah, let's build something together." And that group helped us develop something called Our Recommendations to Advance Disability Justice, which is really a playbook for folks like us in philanthropy and other sectors to think about how they can step into this work and find a place to be adjacent, to be an ally, to build learning. And so that's kind of the origins of our story.

Emily Ladau:

And I love that what is at the center of it all is that community building and also providing the resources for the work to get done. And I think that is going to be such a key message to get across to philanthropy more broadly is the power of funding this kind of community building and direct action related work. And so Julie, as someone who regularly takes part in direct action and who does this kind of organizing work and community building, I would love if you could talk a little bit about how organizers and activists would benefit from having more philanthropic financial support to do this work that's already being done.

Julie Farrar:

Well, I believe that what was already talked about is it is the start, is reaching out. And I think that's so wonderful that you had so many applicants. The ability to fundraise from, I do want to say from a strength-based perspective is it needs to be done because we all need to see that we're not objects of pity and charity, we're not because I am poor or I have been incarcerated or I am a person of color or I'm a member of the queer community does not make me lesser than in any way. And actually, these are the people that need to come together and sometimes have those uncomfortable conversations with each other. And I'll allow that safe space to learn. And then that's how we really build that fusion movement of people coming together so much stronger than they would be because the system very intentionally divides us up so that we're fighting amongst each other for funding, for exposure, for getting that media attention.

With fusion movement and working with those philanthropic organizations that share our values, we're woven together. And that makes us so much stronger. And obviously if we have the funding to be able to be doing our direct action, to be able to be where we need to be and to be able to organize people... We're looking at organizing on a statewide level here in New York, having a strike team with a fast response. Those are the kinds of things that of course we need funding, but look at where that money is going, and hopefully it is going towards groups that have made this commitment to the fusion movement and fusion organizing.

Emily Ladau:

Julie, I really appreciate you talking about making sure that the organizations that you're funding have values that are in alignment with what you're trying to achieve through that funding, and also recognizing that it's important to be supporting cross movement work. And of course, also talking about the fact that this kind of funding should not come through a lens of charity or pity, but should instead be really focused on a strength-based approach, as you said, and amplifying and uplifting and empowering the disability community. I so appreciate that. And I think that we can take a lot of lessons from that.

And speaking of taking lessons from this work, Jen, I'm wondering if there are any lessons that you've learned from this disability justice focused funding effort that the Northwest Health Foundation has been engaged in. And would you want to share some of those with your colleagues in philanthropy?

Jen Matheson:

Yeah. Thank you. Yeah, moving from working with a group of leaders and a set of recommendations, we knew we wanted to move into some grant making, and so we've done some pretty modest grant making over a few different years. But I think everything that we put into the creation of that grant making program we knew we needed is to think about how we could reimagine things and think differently.

I think one thing that often is a struggle at philanthropy is that we are always looking for a thing to look a certain way. We're looking for a 501(c)(3) that looks a certain way, that organizes themselves in a certain way, that writes the grant application in a certain way. And that doesn't work. We need to be open to folks that are doing this work to be showing up in different forms and formats. And that might be something that might look like a group of leaders who are all organizing with each other online because that's what they can do. It might be a fiscally sponsored project of some folks trying to work on an issue or to build something together that is tied to a different organization. It might be a project embedded within another movement building organization that's really that focused.

And so we had to really remember that things that wouldn't necessarily look the way that we would want... Or not want, but we would expect. And a lot of that comes from the fact that philanthropy has ignored disability movement work for so long, and it's been so underfunded and undervalued that the way that other movements have built that over time is just not there, and so we need to meet people where they're at in that work. And as what you both have said, what was always clear to us is that it's the center of that, that work always needed to be disability led. That disabled people were leading that work, guiding that work, and the work was accountable to disability communities.

We got very clear about what were we looking for in our grant making that we needed to be open to working in different ways and funding groups in different ways? And to recognize too that how people think about what is organizing, what is systems change can be all across a continuum. It could look like being in the legislature and advocating for a specific bill or that piece, but it could also be, again, people building something around leadership development. It could be activists in the streets. It could be people working in cultural or arts ways too. And so that was another lesson for us is to say, "Okay, well, do we want to do everything? Do we want to do some of that? How open are we to all of these different approaches in terms of supporting this work?" I think that's a lot of lessons.

And then I think the lesson that I think we all know, which is being in this COVID pandemic, we always need to think about how to have people be able to show up in the way they can that works for themselves. And if that means calling in from their bed and talking to us as a way to apply for money, that's maybe what they need and how we want to engage with them. Those are just a few thoughts that we've had around organizing our grant making program.

Emily Ladau:

Jen, you named so many important things, and one really overarching thread for me in everything that you were talking about, as you mentioned, was meeting people where they're at. And I think that comes through in terms of how we create connections with communities that we're funding, I think it comes through in how we are inviting those communities into our spaces to engage and to learn and to have the resources that they need, and really just recognizing, as you said, that we all show up in different ways. And part of really driving that point home, at least for me, is telling stories about the work. I think that it is storytelling that really reminds us of our humanity. We can talk all about funding and data and numbers, but it means nothing if we're not talking about the human beings behind it. And it also really helps to shift attitudes.

Julie, I'm actually wondering if you have a specific story that you'd like to share about an outcome from the direct action or organizing work that you've done. Something that you think would really resonate with funders and encourage them to take action to support this work and to engage more broadly with the disability community.

Julie Farrar:

Well, I think that what comes to mind for me is the Capitol Crawl. And the Capitol Crawl was pivotal in pushing public perspective. I don't know if it was opinion, but public perspective on disability. And also, to be honest, shaming the legislators into doing the right thing. The Capitol Crawl took place in 1990. The Americans with Disabilities Act was stalled, and so we crawled up the steps to the Capitol. We literally crawled up the steps to the Capitol or had assistance, from our personal care aides or our loved ones or our family members getting up the step, literally crawling up the steps to the Capitol, which was this visual to show the world how inaccessible our world is. And it also was a way to demonstrate there were all these people working on the inside, but a way to demonstrate that we're on the outside, we're paying attention.

And Barbara Toomer, who was a great activist, an adapt activist from Utah, she taught me about the sandwich method. And so you have people on the outside working on things outside the system, which would be us with our direct action, you have people on the inside working on changing the system, and then you have the policy folks, people like Justin Dart whispering in people's ears so that they really understand what it means to be able to have access to the world, what it means to be able to have access to the schools, to restaurants. I'm old enough that I do absolutely remember. I went to a segregated school, Boettcher School for Crippled Children. And I remember as a young child being told with my parents that we had to leave restaurants or we had to leave movie theaters because we were a fire and safety hazard. I guess we turned it around and we intentionally became fire and safety hazards by literally stopping the business of the government in DC and saying, "Pay attention. Pay attention to this."

I also really did want to mention that the storytelling is critical. I think all disenfranchised groups have a hidden history because we're written about, we're not... And Emily, I am so grateful for you and all of the work that you've done to add to the academic resources from the perspective of someone who is living with a disability, has that lived experience. Part of the Poor People's Campaign is to change the narrative by changing the narrator. And that's critically important, I think especially now when we have elders like myself, these stories, especially stories from Black and brown and other folks that were very active in the history of the disability rights, disability justice movement, but we're ignored. We're ignored by media, we're ignored for whatever reason. That we need to collect these stories before our elders become our ancestors. And I think that's critical.

And at the same time, working with younger folks and listening to younger folks, because like I said, I'm so glad you mentioned Stacey and the work of Sins Invalid or Sins Invalid. I still don't know how to pronounce it. And I think either pronunciation is great. But their work is very cutting edge. They use the arts. But they absolutely come from a disability justice perspective that is so incredibly important. And I believe that the philanthropic groups that want to fund these sort of things reach out, find out what's going on and where they can fund the folks and the groups and the organizations and the little ragtag groups of people that are coming together to fund the critical social justice components of that. And I think part of that is also contributing to funding so that people can tell their stories and we have our oral histories recorded so that they are part of history.

Emily Ladau:

Julie, you shared so much wisdom and so many great stories about what is unfortunately all too often, as you said, the hidden history of the disability community. And something that you said particularly really resonated with me, changing the narrative by changing the narrator. I think that is such a great and catchy way to remind people that those most impacted need to be at the center of the conversation. And too often, we overlook the importance of bringing disabled people to the center of conversations about social justice issues. But disability is not a niche issue, and every issue is a disability issue, as so many of us say, because every issue impacts disabled people.

To wrap up this conversation, I always like to ask my guests for a brief takeaway, a call to action towards equity and inclusion, specifically for what needs to happen across the philanthropic sector to ensure that we are moving in the right direction towards disability inclusion. Jen, I will turn to you first. What is your call to action that you'd like to leave our listeners with?

Jen Matheson:

Yeah. I guess my call to action to my fellow philanthropists is just really beginning with a recognition that we work in an ableist sector. Ableism is embedded in so much of the structures that form philanthropy, how we operate, how we put money out in the world, how communities engage with us. And then just to accept the responsibilities to change that, and knowing that that can happen in so many different ways, internal practices, our grant making, our community relationships.

But I really want to echo back what I heard from Julie; moving through that in a way where you're okay making mistakes. That you are figuring out how language can evolve and change. Finding ways to move through conflict and setbacks. I think that's been a big lesson for us. And I would say to any other philanthropist is you're not going to get it perfectly. You're going to mess up, and that's okay. What is your role in your community and moving towards disability rights and disability justice? And what do you need to do that, both internally and externally, to get there? And having a sense of ownership and responsibility about that.

I know that that's a big call to action, but I think philanthropy is up to the challenge. And I know we're going to talk a little bit more about the Disability and Philanthropy Forum, but there's so many resources out there for us to tap into, to learn and hear from peers that there's not an excuse to not start. And so I think that would be my call to action. Thank you.

Emily Ladau:

Jen. I love a big call to action. There's no call to action too big when it comes to the work that needs to be done. And Julie, what about you? If you had to share a brief call to action with the philanthropic community, what would it be to ensure that we are moving in the right direction towards disability inclusion?

Julie Farrar:

I like to point out to people that this is the only group that anyone can join at any time. And if you live long enough, you will join us. And there is, of course, over representation in poor communities that don't have access to healthcare. There's all kinds of inequities. People may live in... People do. Poor people often live in very polluted areas. They live in areas where they are more likely to become disabled from an environmental pollution, things like that.

Ableism and ageism are two areas where I wish we could really come together and work together. That is a struggle for me. I do my best, especially now that I'm 55, so I'm a junior senior. But my call to action is to get involved. We have to get involved; our lives depend on it. Fund us, and do it in a way that allows us to embrace and share our authentic selves. And like I said, the leadership skills that we bring to the table and also that ability to have those uncomfortable conversations and listen to each other.

I like to say we're the critical mass. We are the 97%. We have reached a tipping point that there's no returning from if we don't work together. And so if we recognize and honor the strengths that we have as we also preserve and record our cultural identities, we can come together, learn from each other, know that the system is very intentionally set up to keep us separate, keep us fighting amongst each other for scraps. Austerity measures are death making. And all of these industries are built on keeping us in institutions, keeping us incarcerated in for-profit prisons, in making sure we have to remain poor to live in substandard housing.

The healthcare disparities alone, these affect so many of us. And we must work together to build the social justice movement and learn how to be inclusive, and that our greatest strength is in our ability to work together. At the same time, we are honoring our authentic selves. And we do, we need to have the funding to be able to do this, and we need to be able to work together in equal spaces so that we're not begging for funding. But there are philanthropic organizations that are absolutely committed to social justice.

Emily Ladau:

I want to thank both of you so much for being so generous and giving of your wisdom and for the powerful calls to action. And before we wrap up, can you just let us know where we can find you online? Whether it's telling us what to look up for the work that you're doing or how we can best stay connected. Jen, if you could let us know, how do we find you and the Northwest Health Foundation?

Jen Matheson:

Yeah, I would encourage folks to just get on our website. We're northwesthealth, all spelled out, .org. And if you click through under our work is where you'll see the information about our advancing disability justice program. And so the things that I've referenced, this Leaders Collaborative we work that we did, the recommendations document that that group created is there. There's a little bit about our grant making programs, the kind of grants that we've put out and groups that we've supported.

And then one thing I would highlight there, I'd really encourage folks to check out and download is something we call the Disability Justice Audit Tool, which is a tool that was created, it was again, inspired by Stacey Milbern Park and then written by Leah Lakshmi Piepzna-Samarasinha with some support from other disability justice leaders. But we give examples. What does disability justice work, how does it actually live in our communities? And then there's a set of self-guided questions that community organizations and philanthropists could be as well used to think about how does it show up in the work that they do? And I think it's a great compliment to the inclusion pledge that's put out by the Disability and Philanthropy Forum. Check out our website, northwesthealth.org. Thank you.

Emily Ladau:

I appreciate the plug for the pledge, but also can attest to the fact that the tool that you are talking about is a fantastic resource. And I really encourage people to check it out. And then Julie, what about you? Where can people find you and the work that you are doing online?

Julie Farrar:

I would say that you could find me on Facebook. And I do want to say starting local, I worked very hard with the Poor People's Campaign of the Capitol region, then got involved with the Poor People's Campaign of New York. The same with Hand in Hand, the domestic workers organizations, Jews for Racial and Economic Justice, JFREJ. And you can look up New York Caring Majority. They're all on Facebook. Well, they're on that platform that I refuse to name. They're still involved there. Take a look at what is available and get involved locally because when you're working locally, that helps create that ripple effect and also creates a really good solid base to move forward and to build and to bring in other entities.

Emily Ladau:

Thank you both so much. And what I have heard repeatedly today is get involved, meet people where they're at, and take action. I hope that this has moved you to do just that. And thank you again, Jen and Julie, so, so much for joining me.

If you listening and want to keep your learning journey going, you can visit the Disability and Philanthropy Forum at disabilityphilanthropy.org. Again, I am Emily Ladau. This has been another episode of Disability Inclusion Required. Thank you so much for tuning in, and join us again next time.