Emily Ladau:

Hello. Hello, everyone. Welcome to the very first episode of Disability Inclusion Required. We are going to dive into the topic of foundation giving and disability today, but first, I had to take a moment to celebrate just how cool our intro music is. Huge shoutout to RAMPD, it's the Recording Artists and Music Professionals with Disabilities organization for getting us connected with two really incredible musicians with disabilities. Andre Louis, who created the instrumentals, which I think are such a jam, and Precious Perez, who shared really beautiful vocals with us. So, now that we are all excited and jazzed from that music, I cannot wait to get into the conversation with our two really amazing guests, Dr. Richard Besser, and Sandy Ho. Thank you so much to both of you for joining me today, I'm thrilled to have you. We will kick things off by having you both introduce yourselves, so first, I will turn it over to Rich.

Dr. Richard Besser:

Thanks very much, Emily. It's a real honor to be here with you, and Sandy. I'm Rich Besser, my pronouns are he and him. I'm president and CEO of the Robert Wood Johnson Foundation, and we work with others in partnership to build a culture of health that's rooted in equity. I'm excited to be part of the conversation, because we know that there is no true equity without full inclusion for people with disabilities. I've also had the honor, for the last several years, of co-chairing the Presidents' Council on Disability Inclusion and Philanthropy, along with Darren Walker at the Ford Foundation. The Council is comprised of 16 foundation CEOs, who are committed to doing a better job dismantling ableism, and removing structural barriers for people with disabilities within our institutions, and throughout philanthropy. The Presidents' Council created the Disability Inclusion Fund, which is how I have got to know Sandy.

Emily Ladau:

Sandy, I would love, with that segue, for you to introduce yourself. I think it's the perfect moment to bring you in.

Sandy Ho:

Thank you. Thank you, Emily, so much for having us here, and hi, Rich. My name is Sandy Ho, my pronouns are she, hers, and I identify as a disabled queer Asian American woman, and I'm the program director of the Disability Inclusion Fund, which is housed at Borealis Philanthropy. I joined the team late 2021, and so the Disability Inclusion Fund that Rich was just referring to, provides capacity-building and funding for US-based disability-led organization that are working to expand access to self-determination, human dignity, civic participation, and joy towards a more equitable and liberated society. This is my first role in philanthropy, but the experiences that I bring include my background as a disability policy researcher, and a community organizer. What really got me started as a disabled activist and organizer though, is quite frankly I am an impatient person, especially when it comes to waiting for change to happen. I know that this is a shared sentiment among many of the movement and grassroots organizers, including the disabled-led organizations that the Disability Inclusion Fund makes grants to. So, that's me.

Emily Ladau:

Sandy, I really appreciate you naming, quite honestly, that you are an impatient person, and I think that so many of us who are immersed in this work around disability and grant-making really share that sentiment. We wish that we were already much further ahead, but I'm also really excited because I think that we're doing some important work to lay a lot of the necessary groundwork. As we do that, I think it really helps for us to take a step back and recognize that many people may be new to talking about disability and philanthropy, and that's okay. We are meeting people where they're at. So let's just offer some foundation for this conversation. One in four adult Americans, and an estimated 1 billion people, more than a billion people globally, have some kind of disability, and so you, and I, the three of us, we know why it's so important that philanthropy uses a disability lens across our operations, across our grant-making practices, but let's clue everyone else in, why is it so important to use this disability lens? Rich, I'd love to hear your perspective first.

Dr. Richard Besser:

Thanks, Emily. I think we can agree that we all want to live in a nation where everyone has the opportunity to lead their healthiest life, and has access to healthcare that meets their needs. At the foundation, as we think about health and the drivers of health, it's about a lot more than healthcare, it's about what takes place in the communities in which we live, where we work, where our kids go to school, where we play, it's all of that, that is so important to the opportunity to lead a healthy life. In America, when you think about that opportunity, we see a society in which some are privileged and have incredible opportunity, and others face unbelievable structural barriers to health and well-being. That includes barriers such as ableism, racism, sexism, all the isms that are there that make it harder for many people to lead their healthiest life. The philanthropic community has to do a better job at funding efforts that dismantle multiple barriers, not just one, not just two, and that's where applying a disability lens is so important, and where, we as a foundation, are doing a lot of learning.

I don't want to overstate where we are as a foundation. When I joined the Presidents' Council, it was in a real learning mode, and having the opportunity to learn from some foundations that were further along than we are, but coming in with a commitment, doubling down on our commitment to health equity by targeting the elimination of structural racism. But in addition to that, recognizing that if we truly want to live in a society that values everybody, we need to apply a disability lens, we have to think intersectionally about these barriers. Philanthropy and other institutions, many times have reinforced these structural barriers to access for people with disabilities, that includes us at the Robert Wood Johnson Foundation. We don't have a program focus area that's dedicated to disability rights, what we're learning to do, and what we want to do is see how can we be inclusive of people with disabilities in all the programming that we do. That's the conversations that we're engaged in, and that's where I think we can have a lot of progress.

It's so important that philanthropy is inclusive, and is accountable to communities that we serve and work alongside, and that's part of what we're trying to accomplish through the Presidents' Council and this work. It means looking at disability as a dimension in each of the areas in which we work, whether it's issues around housing or food insecurity, reproductive health. If you add a disability identity on top of any other identity, you're going to see more barriers, and without asking that question of what does it mean to be inclusive of people with disabilities in this domain, we're going to miss the opportunities to move towards what we want to see.

For us, a challenge has been engaging directly with the disability community, and it's one of ... We're a large national philanthropy, and our work with the Disability Inclusion Fund has been terrific because we can provide resources to the Disability Inclusion Fund, and they use a form of participatory grant-making that ensures that the funding that is taking place reflects what the disability community feels should be addressed. That's what we want to do, and having that as a vehicle for us has been really terrific.

Emily Ladau:

Rich, I want to say thank you for stating so honestly that the Robert Wood Johnson Foundation is coming to this in a learning mode, because I think that's really what people need to hear. It's not that there are foundations who are just already done with this work, and have checked off all the boxes, it's that we are all engaging in an ongoing process. So when you name having some challenges connecting with the disability community, I think this is the perfect moment to really uplift the work, again, of the Disability Inclusion Fund, and to say that there are so many disabled people who are out there doing incredible work, and it's really important to connect with those disabled leaders. So Sandy, I'd love to bring you in here to share your perspective about why and how philanthropy can incorporate a disability lens across their operations, across their grant-making practices, and what that really looks like in action and in practice.

Sandy Ho:

Yeah, I totally agree with Emily, and also Rich, thank you for naming, so clearly, again, ableism, and that this work is more than just about access to healthcare, but also the environment, and social roles that each of us in the society have. I think that, also the other point that Rich touched upon was as funders who are on their own disability, including learning journey, that also involve considering what are the levers, and responsibility, and commitments individuals have, and also at the programmatic and systemic levels when it comes to the commitment to dismantling ableism.

My response to this question, we would want to consider we are now in year three of this ongoing pandemic, the Disability Inclusion Fund, our first round of grant-making was in response to the COVID-19 pandemic. We have seen from our cohort of grantee partners the very real and direct consequences that can occur when policies and decisions are made without guidance or leadership from disabled community, which is why it is so critical and important that as a fund that is movement-aligned, and is an opportunity for funders to be on that learning journey, the Disability Inclusion Fund uses a participatory grant-making model to inform our funding decisions. This means that we invite advocates from the disability community from a wide range of background and experiences, and also from cross-disability communities, along with some funders, including those who are on the President's Council to review applications and proposals.

Before I get into of how that process has gone about, I do want to highlight the work of getting back to what we have seen come out of this COVID-19 moment, and our learning that we have also observed from our grantee partners, including New Disabled South in Georgia, the Coalition of Texans with Disabilities, who have been sounding the alarms, who are coming from states where there is not Medicaid expansion, and what that means for the 7,000 people with disabilities in Georgia, for example, who are waiting for services for their essential daily life activities. But, I think one common misconception too, is that it is "good or social justice, or blue state," where this work is most needed, and while that is absolutely true that there are inequities, I also want to point out that in California, disabled people are still mobilizing and organizing as a collective community, to push on the local policies to maintain masking on public transit, and in medical setting. That is the work of Senior and Disability Action, another grantee partner.

What I'm talking about here really is, basically seeing how disabled-led organization and their strategies making that direct connection between lived experiences of how this pandemic has been directly impacting disability communities and advocates, and taking their concerns directly to policy and public health leaders. So even when we have disability rights policies in place that allow us to literally get in the door building and access to care, I think where disability justice is really important, is recognizing that rights alone doesn't necessarily go far enough when it comes to quality of care, to bodily autonomy, things like recognizing human dignity. Really understanding how for disabled people of color, trans disabled people in this moment, people with disabilities who are incarcerated, and other folks who experience ableism most closely, this is why disability justice is so important to being a part of our grant-making strategy, and the social justice chain that needs to happen to upend ableist system.

Getting back to that participatory grant-making, that includes advocates along with some funders, that this is a way, it is a vehicle to put those dots that are being connected into action, and can really move more resources to disability justice movements that are being informed directly by disability community members, and anything that ... When funders and grant-makers in the sector are moving resources into communities, that may be overlooking some of the ways that these dots are connected between health inequity, COVID, disability community power, this is, in effect, limiting their own social justice analysis, but also in doing so that is contributing to some of the ableist barriers in our society.

Emily Ladau:

I think it is so essential to lift up the fact that we are just skimming the surface of talking about disability rights and disability justice, and give a heads-up to our listeners that we are going to dive much more deeply into the differences between the two, and really what it means to practice disability justice in your philanthropic work. So definitely stay tuned for that, as we move forward in the podcast season, but for now, I want to get into the nitty-gritty a little bit. Because we have talked about the overarching look, the 30,000 foot view, if you will, of why incorporating a disability lens across grant-making is important, and why recognizing that disability overlaps with every other identity, and all issues are disability issues, all of these things are so important to recognize, but I think we really need to drive home just how urgent it is to actually recognize what we're talking about.

I want to get to the numbers because we have been here, the Disability Philanthropy Forum doing some number crunching and some analysis of data, and we found that foundation funding for disability only represents approximately 2 cents of every foundation dollar awarded, and specifically only 1/10th of 1 cent of every grant-making dollar goes to disability rights and social justice. It's honestly gutting for me to even say that statistic, although we've got to start somewhere, but I want to hear what are your gut reactions to this number, and Sandy, I'll invite you to share your reflections first.

Sandy Ho:

Thanks. Yeah, I am right there with you, Emily, it is shocking. Also, that impatient community organizer and activist in me also says that it's also unsurprising. When we're talking about numbers and data, I can't help it, but bring that disability policy researcher lens in me to this. Since the Funds' inception, which as I shared earlier was at the start of the pandemic, when the Fund's first rounded grant making was $210,000 for 15 disability-led organizations across the country, and since then the Fund has gone on to award over $8 million in general operating grants to disability justice, rights and inclusion organizations across the country. I cannot underscore that numbers tell a story, and also the breadth of disability-led innovation, whether it's across tech justice, health equity, policy advocacy, community organizing, narrative and culture change of this cohort is incredible, and are some of the organizations that are leading the direction and priorities of disability movement.

But again, that being said though, I think the policy researcher in me is looking at these numbers and saying, "Okay, so on that $8 million though in grants that the Fund has made since 2020, who is being left out of the table, of the conversation, of being able to access resources to really implement those solutions of the disability community?" What that $8 million represent in grants funding is actually less than a quarter of the total funding request that we have received since 2020. To get even more specific though, from the perspective of the Fund, what is that looking grant applications? Well, in 2022, which was our most recent general operation grant-making cycle, we received over 155 applications. Our participatory grant-making committee of advocates and funders recommended 49 disabled-led organizations for funding. When we think about that statistic that you named, the minimal grant-making that actually does go to disability rights and social justice, it's also important that we understand the sector, how that connects to the inequity of access to resources for BIPOC disabled women, trans, queer, young people in movement.

This is why the Fund being housed at Borealis Philanthropy, which is an intermediary, and through our participatory grant-making processes, we are in this position of being able to shift the stories that these numbers are telling us about disability-led movement. The hopeful side of me is looking ahead to what is so exciting, and what some of those shifts are happening in the grant-making space.

Emily Ladau:

Sandy, I think what you just did so beautifully was both give some hope to our listeners, and to me, but also really remind us that we have some tough questions to be asking ourselves, and so I appreciate how well you struck that balance. Rich, I want to bring you in as well to get your gut reaction to that statistic, because I think we need to talk about the realities of where we are, and where we're looking to go.

Dr. Richard Besser:

I think that's right. When I saw the report and saw those statistics, my first reaction is clearly, "This is unacceptable. This is shameful. This is wrong." It also is very motivating because we can, and we should do so much better, and having numbers that we hadn't had before, it really moves us on a path of accountability that's so important. It's important for us internally to be able to hold each other accountable, and it's important across the sector. It's important for those in the disability justice community to be able to look and say, "Okay, who is engaging and who is not?" We don't have all the answers at the foundation, we're still learning, but I am proud that we're moving in the right direction. I'm not satisfied with where we are, but we have increased the amount of funding that we're doing directly to disability justice organizations.

When I saw the report, so much of the funding that is there is going to provide support for services for people with disabilities, most of that two-step level that you mentioned, Emily, and that is needed support. I don't want to under undercut that. I think though that if we're able to change the systems and structures in America, that support from philanthropy won't be needed because it will be provided. There's also something inherent when you think about that model of providing supports, that suggests, at least implicitly, that disability is a condition to be cured, and that's not true, that's not the lens that should be applied here. When I think about the funding for services for people with disabilities, it is an important piece alongside the funding that's looking at rights and social justice, so both are important.

Our work is focused on systems changes, and funding medical services and supports will be needed until the healthcare system is more equitable, and accountable to all of the communities that it serves. That means healthcare systems that provide full access to appropriate services for the disabled community, and that's not the case now. We saw that very clearly during COVID, but you see it every day. It doesn't have to be during a pandemic, you see every day the lack of appropriate services for disabled communities. So our work is expanding to look at the intersections of barriers to health that are there from structural racism, as well as structural ableism. As we are working to center equity in every part of the foundation, we have been partnering to a greater extent, and with intentionality, with social justice organizations.

We have a cohort, we have a group that we call our Equity and Social Justice Relationship Cohort, and as part of that cohort, there are two incredible disability justice organizations. We have Sins Invalid, which is many of you know, but for those of you who don't, they are a disability justice-based movement building organization that uses organizing and performance to lift up, to amplify the stories and experiences of non-binary, queer, and people of color with disabilities. The other organization is the American Association of People with Disabilities, which is a national disability rights organization that advocates for a full civil rights of more than 60 million Americans with disabilities. Having those organizations there, along with other civil rights organizations is allowing for connections to occur that would otherwise occur. I'm learning a lot through that participation.

Emily Ladau:

Rich, I think what I'm taking away from what you've shared is the importance of accountability, but also recognizing that accountability doesn't happen without collaboration. If you are not engaging with broader communities, if you are not bringing people into the conversation, then you don't have those mechanisms in place to hold yourself accountable. I think that is an essential takeaway for everyone today.

But that being said, there's so much more to this conversation, there's so much more work to be done, and I don't want to leave people on the note of feeling overwhelmed, and not really knowing where to begin, or how to continue if they're already on this journey. I am hopeful that we can, in fact, instill some more hope in people as they move forward, and really leave everyone with some motivation to continue, so I'd love to know from both of you, what do you feel really needs to happen across the philanthropic sector so that we can ensure that we are moving in the right directions? Basically, if you could give a key takeaway or a key call to action, what is it that you would want to leave our listeners with? Rich, I'll invite you to share that takeaway with us first.

Dr. Richard Besser:

Well, thanks, Emily, and thanks for the conversation. I think those of us in philanthropy, we need to work together, we need to be accountable to the communities we serve in advancing a field that is more inclusive. At our foundation, we are really trying to live this, and not just talk it. We're working to make real progress in our hiring, in how we operate as a convener through the research we support, through our operational accessibility aspects of our building, and other operational domains. Participating in the forum using the many resources that are available through that forum, that's a valuable step.

I want to encourage others in philanthropy to sign the Disability Inclusion Pledge, because it has concrete steps in there that you can look at to say, "Okay, how do I move forward in this area?" If it's an area that you haven't thought about getting engaged in, it is welcome. Joining this group, I never felt judged that we hadn't done enough, I felt welcomed and called in that we wanted to do more. So increasing our disability grant-making, whether through disability-specific funding like the Disability Inclusion Fund, or explicitly adopting a disability lens with an existing grant-making focus, that is huge and can make a really big difference. Working together to share the learning, and to hold each other accountable is going to have big impact in the field, and hopefully change the way philanthropy is so that we are more inclusive overall.

Emily Ladau:

Rich, I love the fact that you said that you felt welcomed, and also called in because that's really what we're trying to do across all of this work, and especially with this podcast. This is not meant to call someone out, we're calling you in, we want you to be part of this work and this conversation. So on that note, Sandy, what is your call to action? How would you call people in to join us in this work?

Sandy Ho:

Well, first off, thank you so much, Emily, and also Rich, for being in conversation today with me, because I think that what is really important, what I also heard from Richard's response was that importance of cross-movement partnership. Oftentimes one of the things that we, and our friends hear from folks in the sector who are just beginning this journey is, "Where do we begin?" What Rich's response just alluded to, which the fact that there is no specific issue area that, again, does not directly have disability justice, rights, and inclusion implication. That being said though, in light of the recent passing of Judith Heumann, whose been on all of our minds lately, and acknowledging that she was really instrumental in being a part of creating the President's Council during her time as a senior fellow at Ford Foundation, I wanted to apply something that I learned from her as my mentor, and the leader in this movement that she's often said, which is that, "We need to make a fuss." So my offering and call to action for both is making a fuss.

So what does that actually look like? Well, one of the things that we talked about, including the partnership with disability communities, the participatory grant-making to really upend historically how decisions have been made and informed that had not included disabled people, and prioritizing our experiences. Also, the work of the Forum, and through that disability inclusion pledge of bringing more people with disabilities into the sector, into position where decisions are being made. As Rich also said, this moment of COVID-19 had put a harsh flight on the inequities of the disability community experiences, but what we've also know from movement is that disability justice and disability movement is not a moment. This is a community and a movement that has always existed, and the organization, including those in our fund's cohort, grantee partners, are working towards a multi-generational disability feature, because that is the reality of what is already happening. So the Disability Inclusion Fund welcomes our allies, our comrades, our peers across every sector to join us in making that for us, to ensure thriving disability features.

Emily Ladau:

Sandy, I have just been nodding my head wildly in agreement, and I really am so glad that you named the lesson that Judy shared, which is that we do have to keep making a fuss, but it's the good kind of fuss for a good reason. I'm so glad that we are engaging on this journey together and moving the work ahead. I want to say thank you again to both of you, Sandy and Rich, for taking time out to join me in this first conversation. I'm so thrilled that we got to kick off Disability Inclusion Required together, and I'm so appreciative to everyone who took the time out to listen. If you want to continue your learning journey, the Disability & Philanthropy Forum has you covered with a lot of great starting points and resources that you can check out, and you can also learn more about the disability inclusion pledge there. So if you just go to disabilityphilanthropy.org, wherever you may be on your learning journey, you are welcome to join us. So thank you so, so much for tuning in, and until next time.