

Stanford SOCIAL INNOVATION^{Review}

Centering Disability Supplement
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Time for Philanthropy to Confront Ableism

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organizations have rarely responded to this type of response, in no small part because the disability community was not considered formidable or worth listening to. But in this instance, Ford Foundation CEO Darren Walker expressed his commitment to “embracing risk and reflecting honesty,” which led the organization to examine disability bias, investigate the history of philanthropy’s negligence and harm to the community, and determine a course of action to address historic harms with solutions.

We must seize this moment to advance and recognize the promise of disability justice in America.

Rep. Pressley and Cokley: The disability community has lived segregation, from specialized educational settings to community service programs and restricted employment opportunities. Our demand to philanthropy, government, and other sectors is not to be treated as a special case. Government and foundations alike must fund efforts to develop housing proposals to ensure a supply of affordable and accessible housing. Funders exploring ways to organize efforts in criminal justice reform must remember that 60 to 80 percent of people who are currently incarcerated have a disability, including individuals who acquired a disability while incarcerated. No effective approach to reentry, abolition, or de-escalation will be successful if disability is not included.

Disability is a cause and consequence of poverty. Philanthropic organizations that are committed to fighting poverty and inequality in the United States or globally will never meet their goals as long as disability is missing from their work. Even if a foundation is discomfited by the idea of putting up a neon sign that says “We fund disability,” any philanthropic entity that addresses inequality or injustice in effective and comprehensive ways must include disability in its work. Any demographic data that is collected to understand populations served, affected, or employed must include disability if true diversity is to be reflected in the numbers.

Similarly, the federal government must move away from the bureaucratic excuses of the past, which required disabled folks to fit into specific boxes when it comes to data and benefits. This bias has resulted in public policy that does not acknowledge the community’s diversity or recognize the fundamental rights of all people to pursue liberty, justice, livable wages, marriage equality, and fair housing.

The novel coronavirus has surfaced many existing inequities, and the impact on the disability community is clear. More than a third of all deaths tied to COVID-19 come from congregate settings, where people with disabilities make up a large percentage of all residents. More than one-third of individuals impacted by the novel coronavirus are likely to experience long-haul symptoms, a brand-new category of disability. COVID-19 has exacerbated existing mental illnesses due to increases in anxiety and social isolation, and for many individuals, there have been new diagnoses. The need for flexibility and rethinking how we work, how we receive health care, and how we learn has required us all to take a moment to ask ourselves why there isn’t greater accessibility and flexibility to support how we live so that we may thrive.

Together, we can meet the moment, center individuals who are most impacted, and rebuild as a more just nation if we see disability as part of the continuing struggle for our full civil rights and liberties. We recognize that there is no justice that neglects disability. ♦

Time for Philanthropy to Confront Ableism

If philanthropy is to build a more just and equal society, it must combat ableism in its own institutions and practices.

BY SANDY HO & JEN BOKOFF

SANDY’S INTRODUCTION

“What kind of funding are you looking for, and do you have a budget for this year?” a staff person from a foundation asked me. We were talking about the 2018 Disability & Intersectionality Summit (DIS). It came as a shock when I, the event’s founder, landed a meeting with this foundation to discuss DIS.

It was one of my earliest interactions with a foundation as a community organizer and I recall trying my hardest to impress this staff person. As a disabled and queer Asian American woman, I felt such shock partly because our ableist society has conditioned me and millions of disabled people to wait and be told what would be best for our lives, rather than asking directly for what we need.

Ableism is a system of oppression that devalues and discriminates against people with disabilities. Individuals as well as institutions, policies, and communications can be sources of ableism.

JEN’S INTRODUCTION

For years, I have been part of and an observer to ableist gatekeeping in philanthropy. From a “go, go, go” work culture to the invitation of proposals and office and event design, the philanthropy sector is not without its share of ableism. I’ve spent much of my career operating in systems that have not honored what my body needs to be successful, because of both structural ableism and ableism that I’ve internalized. As a person with chronic illnesses, I didn’t know about accommodations I could request or boundaries I could set, because I didn’t see them modeled around me. When I once tried to share my experiences with pain, fatigue, sensory sensitivity, and digestive needs at a former team retreat, I was met with disbelief and laughter. The awkwardness sent a clear message: It’s easier just to keep it to yourself.

But it shouldn’t be awkward. The philanthropy sector has waved the banner of “diversity, equity, and inclusion” for years, and yet ableism continues to affect staffing and talent development, knowledge generation and sharing, and governance and funding. I have even inadvertently perpetuated ableism. For example, I never knew to ask direct reports if they needed accommodations, and I have readily spoken at inaccessible events. I’ve been on my own learning—and action—journey to change this.

ABLEISM IN OUR HISTORY, POLICIES, AND STRUCTURES

Philanthropy is no stranger to the ways that ableism is deeply embedded

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in the perceptions and treatment of disabled people. Historically, many charitable foundations have solicited or made donations intending to “cure” disabled people, based on the so-called “medical model” of disability. While some of these organizations enabled access to services, much of their work framed disability in a way that contributed to notions that disabled people are in pitiable positions and are in need of fixing—also known as the “charity model” of disability. Both the medical and charity models portray people with disabilities as objects rather than subjects, which can contribute to ableism and impede the achievement of and access to rights and justice.

The philanthropic sector has started to show improvement in its understanding of disability and has made marginal increases in disability-inclusive grantmaking. These efforts aren’t enough, however, given that one in four adults in the United States has a disability. For philanthropy to address systemic ableism head-on, it must put meaningful action behind the banner of diversity, equity, and inclusion.

Funders must elevate and expand their practice so that they’re not only combating ableism but also being actively anti-ableist in their efforts to achieve a just society. Solutions to inequality cannot happen without addressing ableism. Unless there is an increase in intentional, transparent anti-ableist practices from the sector, philanthropy’s aims to resource cross-movement work, minimize inequality for marginalized communities, and move equity forward will remain unfulfilled.

This isn’t easy work. But there’s good news: *Once you start the work of disability inclusion and disability justice, the broader work of building collective power and equity goes deeper and becomes readily apparent.*

IDEAS FOR DISMANTLING ABLEISM IN PHILANTHROPY

Rooting out embedded systematic oppression will take more than one program officer, funding priority, or call for proposals. It requires a collaborative and dedicated multilayered strategy. Based on our experiences, here are seven ideas for philanthropy to consider:

- **Ableism doesn’t exist in a vacuum.** For philanthropy to play a role in systems change, it must first understand that disability coexists with other identities, and that other forms of systemic oppression also contribute to and intersect with ableism. Philanthropy must replace charity- and medical-model lenses with both justice- and rights-based¹ understandings. Cross-movement disability strategies should become the norm within grantmaking and funding. Siloing disability from other movements and justice work only serves to further isolate multimarginalized disabled people. When foundations address ableism separately from other forms of oppression, they can’t achieve systems change.
- **Hire, support, and promote disabled talent.** Nondiscrimination hiring policies are important, but actively hiring disabled talent is crucial. This commitment means supporting disabled people to take

on roles across organizations, beyond those with a disability focus. To shift workplace culture, foundation staff must actively make space and listen with openness to disabled team members on matters ranging from human resource practices to grantmaking policies. Rather than treating disability like a secret shame, foundations should also realize the statistical likelihood that disabled staff and leadership already exist within their organization. Third Wave Fund, a philanthropy that supports youth-led, intersectional gender justice activism, demonstrates how learnings from disabled leaders in their organization and their communities have created an organization that is more resilient and in line with their social justice values.

- **Ensure that your grantmaking processes and technologies are accessible.** Philanthropy must eliminate gatekeeping in how funding opportunities are structured, shared, and applied for. The design of funding opportunities matters: Does the framing of requests for proposals take into account the needs and perspectives of persons with disabilities? Does it consider multiple layers of identity including disability, or is disability excluded? Are there requirements that might exclude organizations of persons with disabilities? Technology matters, too. In the latest *A Consumer Guide to Grants Management Systems*, only 5 of the 14 evaluated products mention accessibility. A fully accessible technology platform might mean that people who use screen readers and other assistive devices can access the application, and that it is available in plain language and multiple languages. For the Disability Rights Fund (DRF), this accessibility is critical not only because inclusion is a value, but also because persons with disabilities participate at all levels of the organization. DRF uses a participatory grantmaking approach that puts disability activists in the grants decision-making seat. Participatory approaches like these deviate from traditional philanthropic processes and are directly anti-ableist.
- **Be in active partnership with disability communities.** The disability community is not a monolith and the diversity within this community across disability types and social/cultural identities is important to bear in mind. Regularly connecting with and listening to people with all types of disabilities who reflect a range of identities matters, not only for disability-specific funding priorities, but also for including disability in meaningful ways across all work. Disability-specific organizations often take on the uncompensated labor of educating donors. Pay disabled people for their time and labor to engage in ongoing dialogue and consulting. Listening with the intent to learn will help frame challenges, approaches, and theories of change in new ways, and will help foundations reconsider existing structures and the support they provide. Remember: Humility is essential. Even though Sandy identifies as disabled, and Jen as a person with chronic illness, we're still constantly listening and learning.
- **Build data about disability.** Data is critical for awareness and advocacy. Right now, there is a dearth of data about how many persons with disabilities work in or serve on boards in the philanthropy sector, and there is limited data on funding that supports disabled people or disability-led organizations. (CHANGE Philanthropy's *The 2020 Diversity Among Philanthropic Professionals Report* has some data on sector talent, and Candid and the Human Rights Funders Network house data online on foundation funding.) Addressing this lack of data, which suggests that disabled

talent and disability-focused initiatives remain largely excluded, would make it possible to demonstrate gaps in ways that cannot be ignored. While developing and deepening the data, it's also important to consider the ethics of doing so. Who contributes to and sources data? Is the data properly framed and used? Who is it available to? Who does it benefit, and who does it hurt? These are key considerations to confront and build from.

■ **Proactively support disabled-led initiatives and organizations.**

Resourcing grassroots disability initiatives with funding and networks is essential. Disabled leaders and organizations of persons with disabilities may have limited bandwidth and networks to seek out and apply for funding opportunities. Many simply ignore opportunities that don't explicitly mention disability because the funding doesn't appear to be intended for them. Go out and find them; active partnership with disability communities is important and can help funders understand existing work led by disability communities. "Nothing about us without us"—the mantra of the disability rights movement—should be a guiding principle. Be wary of organizations that talk about disability but do not have people with disabilities in leadership positions, including governance. These organizations tend to practice the charity mindset. Make sure this work has a home within your foundation, whether through dedicated portfolios, such as the ones Third Wave Fund and Open Society Foundations maintain, or as a priority that is embedded across portfolios, which is how the Ford Foundation operates. Furthermore, make sure that every portfolio recognizes intersections with disability. For example, if a foundation has a women and girls portfolio, is there awareness that one in five women around the world has a disability, and that this intersection must be understood and supported for the portfolio to be successful?

- **Call peers and stakeholders into learning and constant improvement.** The Presidents' Council on Disability Inclusion in Philanthropy consists of foundation presidents who are committed to disability inclusion as part of improving diversity, equity, and inclusion in philanthropy. The council established the Disability Inclusion Fund, housed at Borealis Philanthropy, to start moving more resources, and created the Disability & Philanthropy Forum, which is dedicated to fostering community learning through field-wide conversations and reflections on the disability inclusion journey. The forum is available for all practitioners to join. Beyond the forum, we can all be active advocates and learners. When a funder talks about the inclusion of marginalized communities, ask what they are doing for people with disabilities. When they inevitably look perplexed and say that's not an explicit focus, be prepared to have a conversation about why this is important. Keep learning and bringing your colleagues on the learning journey, too.

Dismantling ableism in philanthropy is not a nice-to-do; it's a must-do. Without concerted efforts to root out ableist oppression, we cannot meaningfully address injustice and inequality. The ideas we offer here are just some steps that philanthropy can take to become anti-ableist to move toward transformation. ♦

Endnote

- ¹ In May 2008, the United Nations enshrined the Convention on the Rights of Persons with Disabilities as the first comprehensive human rights treaty of the 21st century. According to the UN website, "It takes to a new height the movement from viewing persons with disabilities as 'objects' of charity, medical treatment, and social protection toward viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society."