

Stanford SOCIAL INNOVATION^{Review}

Centering Disability Supplement
Sponsored by the Disability & Philanthropy Forum

Shrewd Awakening

By Avichai Scher

Stanford Social Innovation Review
Winter 2022

Copyright © 2021 by Leland Stanford Jr. University
All Rights Reserved

Shrewd Awakening

After many years of excluding the disability community, philanthropy is starting to make changes. The Ford Foundation's awakening on disability inclusion offers a model for the rest of the sector.

BY AVICHAH SCHER

For years, Kristy Trautmann was the only one to speak up. Since 2010, she has been the executive director of the FISA Foundation, a small philanthropy in Pittsburgh, Pennsylvania, that takes an intersectional approach to improving the lives of women, girls, and people with disabilities. As part of her role, she often meets with funders and service providers working on a broad range of issues that affect these communities.

In 2020, Trautmann met with census organizers to strategize how to increase the disability community's participation in the census. She asked whether accessible census hubs and printed materials in large type or braille would be provided. Meeting with arts funders, she raised the need for captioning and other accessibility measures for artists with disabilities. Speaking to social service providers, she stressed the importance of reaching children with disabilities.

In every instance, she was met with blank stares from people who hadn't given much, if any, thought to how to include people with disabilities.

"Over and over, I was the only one to say anything," Trautmann says. "It was frustrating, and I felt impotent."

For too long, philanthropy has treated disability as a niche area for specialized foundations, an approach that is rooted in the ableist notion that disability is a separate issue that isn't integral to work that addresses injustice and inequality. "We are so good at silos in philanthropy," Trautmann says. "It has been challenging to get philanthropy to see disability not as some extra thing but as part of the equity agenda."

Disability intersects with every issue because disabled people exist in every community and in greater numbers in those already impacted by oppression. Anti-poverty agendas will never be achieved if they neglect disability. Reproductive justice work is not effective if it leaves disabled people behind.

"After I'd raise the issue of disabilities, there was always somebody who came up and said, 'Thank you for raising that. I have a child who is disabled, or I have an invisible disability,'" Trautmann says.

For decades, Trautmann, like other advocates and smaller organizations, did her work largely without funding, representation, or support from philanthropy's largest donors. So it's not surprising that she was overcome with emotion in 2018 when she was asked to join dozens of disability advocates and foundation presidents in New York City for a first-of-its-kind convening on disability inclusion.

"It was a room full of philanthropic leaders centering the experience of people with disabilities, and not just talking about this as an important issue, but positioning people with disabilities as the

experts, as the leaders," she says. "I'd never seen that. I felt like it was my birthday."

Trautmann felt a new day could be dawning. For decades, philanthropy excluded disabled people. The meeting signaled the possibility of change.

FROM PITY TO POWER

Roughly one billion people around the world have some form of disability. In the United States, more than 25 percent of adults live with a disability. The issues the disabled community faces—from voting rights to accessing employment—are structural inequities that cut across the social justice sector. Yet for years, disability work has been relegated to specialized organizations and excluded from larger movements that address global inequality. To build a world where everyone is equal, organizations fighting for justice—and the funders supporting them—need to understand how society's diverse systems of oppression reinforce one another and center intersectionality and the disability community in their work.

Conchita Hernandez Legorreta is a co-founder of National Coalition for Latinxs with Disabilities and a blind and low-vision specialist. As a Latina who is blind herself, she advocates for the inclusion of disabled people, especially people of color, in all parts of their identity, in social justice movements, and in public and nonprofit services.

"It's very difficult for people of color with disabilities to feel welcome in any space, because most organizations focus on one issue," Legorreta says. "It's, 'Oh, you have a disability? Go to a disability organization—because we don't do disability. But disabled organizations aren't always focused on race. So, where do we go?'"

Advocates like Ella Callow have spent their careers trying to help funders understand people with disabilities as multifaceted—as workers, teachers, and more. Now the director of disability access and compliance at the University of California, Berkeley, she spent the last 20 years running a program that supported parents with disabilities. Callow found it difficult to attract the dollars she needed because disabled people aren't often thought of as parents.

"Issues like improving education, increasing employment, civil rights, and bettering quality of life are not 'classic' disability issues," Callow says. "There wasn't a lot of curiosity from funders to learn about our program and support it."

As a result, she relied on government funding. Red tape and bureaucratic requirements meant the organization spent more time on paperwork and less time with the community. After a decade, the program lost funding, leaving a major void for parents with disabilities.

"I still get calls from parents who saw a webinar I did in 2014 trying to find help," Callow says. "I mean, that's really sad."

Historically, supporting people with disabilities has been considered charity, whether it meant pitying disabled people or understanding disability as a problem to cure or fix with medical care. Instead, the disability community wants to build individual and collective power and achieve justice for disabled people. Embedding disability rights in the work of nonprofits and philanthropy requires including disabled people as decision-makers and leaders on social issues. This level of inclusion will benefit both people with disabilities and society at large, including individuals who may become disabled in the future.

"We have expertise to teach others, we are a partner," said Andraea LaVant, a disability advocate. "That's the full advantage of inclusion."

Building a ramp so LaVant can access a meeting begins to open the doors but does not achieve inclusion. Making a place for her

AVICHAH SCHER is a writer and editor at The Ford Foundation based in New York City. He has previously written for *The New York Times*, *HuffPost*, *NBC News*, and *The Daily Beast*.



wheelchair at the table, valuing her ideas and experience, and using that information to guide funding decisions is the goal.

Achieving this objective requires a full assessment of an organization's work to identify how ableism shows up and to determine what concrete changes can be made. Some important steps include establishing an advisory panel of disabled advocates that represents diverse perspectives and experiences; hiring disabled people as full-time staff, not just consultants; and, for philanthropies, asking grantees about disability inclusion in their organization and in their programs—and making funds available for it.

These measures, which may be new to many, are achievable over time when pursued in partnership with the disability community. Sometimes, the right push can have a domino effect.

CONFRONTING ABLEISM

Disability advocates have promoted this message of inclusion for years, but the response from funders was usually tepid. But in early 2016, their message—and their ire—made a profound impact.

In 2015, Darren Walker, president of the Ford Foundation, announced a new focus on challenging inequality in all its forms that would guide all programs. The plan was comprehensive, identifying five drivers of inequality across seven areas—without mentioning disability. Advocates took note and didn't mince words, calling the foundation hypocritical for claiming to tackle inequality without considering disability.

"We spent months devising a framework for equality and justice and didn't think to include disability," Walker says. "Disability advo-

cates, rightly, weren't shy to tell me we had made a critical error."

How does Walker explain neglecting a massive swath of the population? He acknowledges that power and privilege perpetuate ignorance—and systemic ableism. There was no empowered disability representation at Ford to check this privilege and call out the ableism that prevented the foundation from including disability in its new vision.

Fully admitting that Ford missed the mark, Walker responded to advocates: "Ford Foundation does not have a person with visible disabilities on our leadership team; takes no affirmative effort to hire people with disabilities; does not consider them in our [grantmaking] strategy; and does not even provide those with physical disabilities with adequate access to our website, events, social media, or building ... All of this is at odds with our mission."

Ford was not alone—disability is often not on philanthropy's radar. While total grant dollars for global human rights rose by 13 percent

between 2017 and 2018, it declined by 14 percent for people with disabilities, a 2021 report by the Human Rights Funders Network and Candid found. "In an era where more funders are talking about disability rights, we wonder whether rhetoric will translate to grant dollars in the years ahead," the report said.

Ever since advocates confronted him, Walker has implemented considerable changes to advance disability inclusion at the institution at every level. After an audit of its hiring practices, the foundation made changes, such as a revamping the accommodations process to increase recruitment of people with disabilities, adding captioning and alt text to its website and events, installing best-in-class accessibility features at its landmarked headquarters in New York, and bringing on disabled advisors to deepen the organization's understanding of disability. From 2018 to 2020, Ford has invested more than \$50 million toward projects and organizations focused on disability and an additional \$125 million to social justice organizations working toward disability inclusion. Ford recently hired disability advocate Rebecca Cokley to lead the foundation's first-ever US disability rights portfolio.

A JOURNEY TO INCLUSION

The deep change the Ford Foundation has undertaken requires recognizing shortcomings and taking time to listen and learn from advocates. But a willingness to do this work isn't yet the norm.

"Sometimes people get offended at the message that they are not approaching this correctly, because they are trying to help," Legorreta says. "But the truth is they have never included people with disabilities in a meaningful way."

The foundation's awakening on disability was so meaningful because Ford is one of the world's largest foundations. If the foundation could acknowledge its errors and take on the long work of change, would the rest of the sector follow?

"Darren Walker was willing to learn in public and that sends a signal," Trautmann says. "In philanthropy we think we can only have influence through our grants. But setting the agenda, asking questions, educating people, and making connections is also a major way to make a difference."

Indeed, a large part of the Ford leadership team's commitment was raising the topic with other foundation leaders. Walker asked Rich Besser, president and CEO of the Robert Wood Johnson Foundation, the largest health-care foundation in the United States, what his organization was doing to address disability justice. Initially, there wasn't much to speak of, but Besser joined Walker on his quest to make changes, and together, they convened foundation presidents to form the Presidents' Council on Disability Inclusion in Philanthropy.

"We can't get anything done alone," Walker says. "We all want to be able to tell our boards that we are doing something unique and special. But that model stands in the way of progress. I tell other presidents, 'Join us, let's do this together.'"

Launched in 2019, the council consists of 17 presidents of foundations, including The Heinz Endowments, the John D. and Catherine T. MacArthur Foundation, and Open Society Foundations, which are committed to increasing disability inclusion in their organizations and grantmaking. With the goal of influencing the wider sector, the council launched the Disability & Philanthropy Forum, a learning hub to guide funders on their journey to inclusion.

To help meet immediate needs, the council launched a \$12 million Disability Inclusion Fund, which is housed at Borealis Philanthropy. The funds are beginning to be invested in the disability movement, supporting disability justice groups and fostering partnerships with other rights groups and philanthropy.

"When it comes to philanthropy, I don't feel that there's any better way to show that you value a group of people than to invest in them," LaVant says.

Yet weaving disability inclusion into the fabric of philanthropy requires building a movement beyond a single fund. The council has challenged peer donors to commit to integrating a disability lens across their work through a disability inclusion pledge, a first for philanthropy. As of September 2021, the pledge had more than 50 signatories including the Bush Foundation, The Pittsburgh Foundation, and the Silicon Valley Community Foundation.

Some of the signatures were an easy sell, like Trautmann's for FISA. Others took more convincing. Some have declined.

"There are people I've approached who haven't signed," Trautmann says. "There's always competing priorities in our work, and it will take time for people to understand the imperative and opportunity here."

For Callow, just the presence of the council is evidence of a turning tide.

"I am wildly hopeful that this organization can change that dynamic and really create better support for the grass roots," she says.

Légorreta is already seeing greater representation for disability in the racial justice movement.

"I see organizations integrating racial equity and disability justice components in their messaging that never touched on disability," she says. "There has been an awakening." ♦

Participatory Grant-making Is Your Future

Funders must abandon top-down, one-sided funding approaches in favor of partnerships with the disability community.

BY NIKKI BROWN-BOOKER

For those of us who have participated in a half-century of powerful activism by people with disabilities, a familiar slogan summarizes our call to action: *Nothing about us without us.*

As a woman of color with a disability and the former executive director of a nonprofit organization serving people with disabilities, I have seen the disconnect between funder strategies and the needs of community-based nonprofits. Quite often, funding does not come with a cultural understanding of the disability community, and this ignorance can impede direct and efficient service. For instance, many organizations in the United States collect wheelchairs and send them to people with disabilities in areas of the world where there are no roads or sidewalks. Inexpensive equipment designed for a paved world barely lasts a few weeks on rough terrain. This altruistic strategy quite literally crumbles when put into practice.

A more effective strategy can be seen in the work of Whirlwind Wheelchair International, an organization based in Berkeley, California, that takes a community-based approach and honors the logistical needs of people with disabilities where they live. Whirlwind Wheelchair brings its expertise into a community, determines what local materials are available, and teaches people to make their own wheelchairs. While addressing a need for dignified independence, the organization provides skills that translate into additional income.

If we want to serve people with disabilities, our work must be directly informed by them. Most of the grantmaking advocates I work with at the Disability Inclusion Fund (DIF) at Borealis Philanthropy are Black, Indigenous, and people of color (BIPOC) with disabilities. To be fully inclusive, we must move beyond a basic understanding that an individual who is blind has different needs than an individual with cerebral palsy.

In the example of Whirlwind Wheelchair International we see that instead of sending wheelchairs to a community where they can't be used, a solution has been found to utilize local resources that also recognizes the local terrain and people. Historically, organizations that serve people with disabilities have decided what those people need—without their input. This one-sided approach has resulted in wasted funds, time, and equipment. Understanding the logistics of serving a community requires expertise from the field. Using funds equitably requires recognizing the intersectional nature of what it is to be human and developing targeted solutions informed by those who need them. The all-too-common strategy of throwing money at a problem without including stakeholders is a waste of resources. Even

NIKKI BROWN-BOOKER is a program officer for the Disability Inclusion Fund at Borealis Philanthropy, a five-year, \$20 million fund that supports US groups run by and for people with disabilities to lead transformational change. The DIF is the first and only fund working on disability inclusion in philanthropy.