

# DISABILITY INCLUSION IN PHILANTHROPY

A WORKING PAPER FOR GRANTMAKERS  
AND THE CONSULTANTS WHO SUPPORT THEIR WORK

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OCTOBER 2020



NATIONAL NETWORK OF  
CONSULTANTS TO GRANTMAKERS

Dear Colleagues,

Thank you for your interest in learning more about disability inclusion within the philanthropic sector. We are each individually and collectively on a journey to center the principles of diversity, inclusion, and equity in the work we do on behalf of our philanthropic clients.

Consequently, we offer this working paper as a starting place of learning for the Disability Inclusion Working Group and its colleagues of the National Network of Consultants to Grantmakers. This discrete environmental scan provides a bird's-eye view of how the philanthropic sector is generally addressing disability inclusion and presents a few examples of grantmaker initiatives and projects.

While we recognize its limitations as a learning tool, this paper identifies gaps in analysis with the intention of developing additional learning opportunities as well as peer exchange and sharing among philanthropy consultants. For example, language around disability inclusion continues to evolve; we have attempted to capture current terminology and welcome corrections. Additionally, there may be other areas that require further exploration, particularly as related to policy and advocacy issues. We look forward to offering collective learning opportunities over the next year to dig deeper.

As this is a working paper, we welcome your feedback and suggestions and invite you to consider the following questions as you read:

**What role can philanthropy consultants play in advancing disability inclusion?**

**Where is your work already helping to shift practices within philanthropy?**

**How can philanthropy further deepen its ability to apply a disability inclusion lens to its work?**

Thank you again for your interest, and we look forward to continuing on this learning journey together.

Sincerely,

Disability Inclusion Working Group  
National Network of Consultants to Grantmakers

Whether we live with a disability ourselves, work with someone with a disability, or have a family member or friend who lives with a disability, we will all be touched by disability in our lifetimes. This is all the more true given that disability is not a static experience, it's a porous state. Those who live with a disability may go through periods where their disability impacts day-to-day functioning significantly and other periods where the impacts are less pronounced. And people who are "able-bodied" can develop a disability after an accident or illness, or as they age. As disability rights activist Judith Heumann notes, "Disability is a family you can join at any point in your life" (Heumann, 2016).

Indeed, about a quarter of Americans—approximately 61 million—have a disability. For those above the age of 65, the figure hovers closer to 40 percent (Centers for Disease Control and Prevention, 2019). Despite the prevalence of disability in our lives as well as the ubiquity of diversity, equity, and inclusion (DEI) initiatives in the workplace, disability is often not considered at all or remains an afterthought in many sectors, including philanthropy.

In 2015, the Ford Foundation announced that it would focus its work squarely on inequality. After an 18-month process of researching, developing, and planning this new strategic framework, disability was not referenced anywhere in the foundation's strategy, even though data show that people with disabilities face persistent inequities. The Ford Foundation, of course, was not alone. Research shows that social-sector organizations are less likely to name disability as a component of their DEI initiatives than other identities, such as race, gender, and sexuality.

Following feedback from the disability community that the Ford Foundation's initiative was not inclusive of their experiences, its president, Darren Walker, wrote in September 2016:

Those who courageously—and correctly—raised this complicated set of issues pointed out that the 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 strategy; and does not even provide those with physical disabilities with adequate access to our website, events, social media, or building. (Walker, 2016)

Acknowledging the foundation's need to change and be more inclusive of people with disabilities, Walker made an institutional commitment to shift its policies and practices. The foundation, in partnership with leaders in the disability community, took a critical look at its broad accessibility to the disability community from its building to its hiring practices, and its grantees' and vendors' commitment to disability inclusion. In addition, rather than initiating a new program on disabilities, the Ford Foundation pledged to "integrate an inclusive perspective across all of [its] grantmaking." Walker (2016) called on others in the field to "open our eyes, ears, minds, and hearts in order to embrace a complete and intersectional view of inequality."

Numerous smaller foundations, such as the FISA Foundation and the WITH Foundation, have been leading on the issue of disability inclusion for years. With the Ford Foundation's public call to action, it was able to offer the

influence and resources of the second largest foundation in the country to build on existing philanthropic efforts and challenge the field to move the needle sector-wide. With Richard Besser, president of the [Robert Wood Johnson Foundation \(RWJF\)](#), Walker co-chairs the Presidents' Council on Disability Inclusion in Philanthropy, launched in March 2019 with more than a dozen other foundation presidents committed to its advancement in the field and within their own organizations. Most recently, the Ford Foundation affirmed its commitment in a robust Disability Demands Justice campaign seeking to further lift the voices and contribution of its partners within the disability justice and disability rights spaces.

An element of the Ford Foundation's journey on disability inclusion that has not been discussed as widely is the role of consultants—both those with lived experience with disabilities and those who are incorporating disability into their existing practice. Consultants were called upon to partner with program teams and staff to think deeply, over time, on concrete ways to transform systems, grantmaking, and institutional culture. This work complemented and enhanced the incentives the foundation gave to program teams to increase their disability-focused grantmaking.

*For more background on disability inclusion efforts, particularly as they developed in the United States, check out [Why I Wrote the Americans with Disabilities Act](#), by disability rights scholar Robert L. Burgdorf Jr.; [A Brief History of the Disability Rights Movement](#), from the *Anti-Defamation League*; and [A Brief History of the Americans with Disabilities Act](#), by Jillian Abel of TMI Consulting Inc.*

As a growing number of foundations consider disability inclusion in the context of their internal policies and practices as well as their external-facing work, the need to strengthen the infrastructure and ecosystem that supports those efforts is becoming increasingly important. This working paper, commissioned by the [National Network of Consultants to Grantmakers \(NNCG\)](#), provides a high-level overview of the current philanthropic landscape—the ways in which foundations are incorporating disability inclusion into their work as well as the ways in which consultants have been supporting their efforts. As a network that seeks to help catalyze a more effective philanthropic sector and provide professional development for consultants, NNCG's interest in the issue is central to its mission and complements the network's efforts to advance leading-edge strategies and approaches that integrate equity and inclusion more deeply into the work of foundations.

The paper is based on an online literature review and 15 interviews with funders and consultants who have expertise on disability inclusion. Recommendations for both consultants and funders are shared, as well as profiles of Nakia J. Green and Sofiya Cheyenne, consultants whose practice and advocacy are informed by personal experience.

## DISABILITY INCLUSION: A GLOSSARY

**People with Disabilities (or Disabled People)** are a diverse community that includes those with physical, sensory, intellectual, or psycho-social disabilities as well as chronic illnesses.

**Disability Inclusion** means making sure that policies and practices are in place to ensure that people with disabilities have the opportunity to participate in everyday activities and have roles similar to their peers who do not have a disability (Centers for Disease Control and Prevention, 2019).

**Disability Rights** includes efforts to address the structural barriers and inequalities that people with disabilities face in law, policy, and norms. This work often takes the form of advocacy, rights education, community organizing, power-building, or raising the voices of people with disabilities in public debate, communications to change attitudes, litigation to enforce such rights, inclusive field convenings, and research and accessibility efforts to ensure the rights of people with all disabilities (Anti-Defamation League, 2018).

**Disability Justice** recognizes that ableism intersects with other forms of oppression and understands disability through an intersectional lens. Disability justice centers the following key principles: intersectionality, leadership by those most affected, anti-capitalism, solidarity across different activist causes and movements, recognizing people as whole people, sustainability, solidarity across different disabilities, interdependence, collective access, and collective liberation (Sins Invalid, 2015).

*Note: We've presented these working definitions for reference, but recognize that there are different perspectives and nuances to consider in terminology and encourage funders and consultants to explore their own understanding of these terms.*

*Language can be complicated and is always changing. Writer Esme Mazzeo (2019) explores how conversations with other people with disabilities led to an evolution of her own thinking in [Finding Peace on the Disability Terminology Battlefield](#).*

## 2 | How Philanthropy Is Addressing Disability Inclusion

Data from Candid show that in 2018, U.S. foundations awarded \$1.5 billion to benefit people with disabilities. Approximately 57 percent of these grant dollars focused on health issues. Although Candid’s taxonomy does not have specific codes to determine how much of this funding supports inclusion, keyword searches suggest that grantmaking for disability inclusion and disability rights make up a relatively small portion of overall funding for people with disabilities. A search for “rights” and “people with disabilities” on Candid’s database, for example, yielded grants totaling \$65 million in 2018. A search for “inclusion” and “people with disabilities” resulted in grants totaling \$5.3 million in 2018.

With so much of funding for people with disabilities focused on their medical needs and as “beneficiaries” of services, Jay Ruderman, president of the [Ruderman Family Foundation](#), notes, “There’s a preconceived notion that grantmaking involving disability is only about providing care and support, but we [see] it as an issue of equal opportunity and civil rights. We had to challenge this pervasive notion that disability inclusion is charity” (Presidents’ Council on Disability Inclusion, 2019).

While several larger foundations, such as the [MacArthur Foundation](#) and RWJF, have come to the issue of disability inclusion more recently, their public reflections on their learning journeys have prompted conversations across the field more broadly. And the foundations that are at the forefront of disability inclusion efforts are engaging in a variety of initiatives that view people with disabilities as assets to their communities who need to be given the same opportunities as others to thrive and

contribute. Disability inclusion initiatives in philanthropy run the gamut—from smaller foundations, such as [Ability Central](#) and the WITH Foundation, which have had a longstanding focus on disability, to community foundations like [The Chicago Community Trust](#) and the New York Community Trust, which have not only provided grant dollars but have also played a leadership role in their communities to advance inclusion efforts.

For a number of years, the [Disability Funders Network](#) connected funders working on disability inclusion efforts and helped provide coordinated leadership within philanthropy. The group eventually disbanded due to the inability to sustain itself with a group of primarily small to midsize funders, but there are signs that opportunities for peer sharing and learning are resurfacing. [Exponent Philanthropy](#), for example, hosts an informal learning community that brings together funders from smaller foundations. The Presidents’ Council on Disability Inclusion in Philanthropy plans to create learning opportunities for philanthropy to deepen its work on the topic. In parallel, the council has seeded a new [Disability Inclusion Fund](#), totaling \$10 million over five years, at [Borealis Philanthropy](#).

Foundation efforts to support disability inclusion often focus on three broad areas: 1) examining and changing internal policies and practices; 2) conducting disability-inclusive grantmaking; and 3) supporting grantee partners’ disability inclusion efforts. In each of these three areas, consultants have partnered with foundations to facilitate and amplify their disability inclusion initiatives. Foundations may find that in addition to consultants who have

experience working with philanthropic institutions, they can find valuable support from consultants who typically work with corporate, government, or other nonprofit clients. Foundations can also find support from disabled people’s organizations that

are led by people with disabilities and other advocates who can provide important insight and guidance. Indeed, a number of foundations have awarded grants to these organizations so they can provide technical assistance and expertise to their institutions.

### **DISABILITY INCLUSION EFFORTS IN PHILANTHROPY: SELECT EXAMPLES**

Initiatives to advance disability inclusion range widely among foundations. This table offers illustrative examples of how foundations—large and small—approach disability inclusion. Do you have other great examples of foundations standing up for disability inclusion? If yes, go to <https://nncg.org/disability-inclusion>.

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<b>Ability Central</b>	Ability Central focuses on the communication needs of people with disabilities, recognizing the ability to communicate as a fundamental human right. Ability Central fosters collaboration as an ally and convener and serves as a resource hub for the disability community. Its advisory group advises on grantmaking and strategy and consists of people with disabilities and/or individuals with strong ties to the field of disability and communication.
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<b>Borealis Philanthropy Disability Inclusion Fund</b>	The Disability Inclusion Fund is a \$10 million, 5-year fund that supports U.S. groups run by and for disabled people to lead transformational change. The fund is supported by the Presidents’ Council on Disability Inclusion in Philanthropy, which is composed of foundation presidents who are committed to disability inclusion as part of improving DEI within philanthropy.
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<b>Ford Foundation</b>	The Ford Foundation is expanding participation and inclusion at both the institutional and individual levels through a variety of efforts, including incorporating a disability lens across all of its grantmaking; moving toward greater accessibility in its grantmaking process; ensuring that its physical space and events meet or exceed every standard for accessibility; assessing the accessibility and inclusivity of its communications; and reviewing every aspect of its hiring process with attention to disability inclusion.
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*Examples of disability inclusion efforts continued on the next page.*

**FISA Foundation**

The FISA Foundation has had a long-standing focus on supporting people with disabilities, particularly in the arenas of community inclusion, violence prevention, employment, and health care access. In partnership with The Heinz Endowments, the FISA Foundation sponsors Disability Inclusion & Access: Moving Forward (see description below).

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**The Heinz Endowments**

Disability inclusion is part of The Heinz Endowments' broader equity initiative. It has partnered with the FISA Foundation on Disability Inclusion & Access: Moving Forward, an initiative aimed at encouraging foundations and nonprofit organizations to commit to basic accessibility improvements that make programs and services more welcoming. The initiative includes a directory of online resources, webinars, and a small-grants program.

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**Mitsubishi Electric America Foundation**

The Mitsubishi Electric America Foundation (MEAF) has had a long-standing focus on disability inclusion. Through its M>PWR Initiative, MEAF works with national and community organizations to help youth and veterans with disabilities develop their leadership, self-advocacy, and employment skills, as well as create tools to help employers learn how to successfully recruit, hire, and retain employees with disabilities, with the goal of improving employment outcomes in communities throughout the United States.

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**Northwest Health Foundation**

The Northwest Health Foundation's portfolio on disability justice focuses on supporting disabled leaders of color in Oregon and southwest Washington, and building disability justice understanding and support in racial justice organizations.

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**Ruderman Family Foundation**

The Ruderman Family Foundation focuses on disability inclusion advocacy. Specifically, it seeks to raise awareness of disability inclusion and shift the approach to disability advocacy away from charity and toward civil rights. To that end, the foundation produces press releases commenting on current events, speaking up against discrimination against the disability community; commissions reports that elevate topics of disability inclusion and bring them into the national conversation; and highlights issues related to inclusion through its communications channels.

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**WITH Foundation**

The WITH Foundation (formerly known as the Special Hope Foundation), since its inception, has focused on the disability community. In 2011, the foundation began to emphasize support for organizations and projects that promote the establishment of comprehensive and accessible health care for adults with intellectual and developmental disabilities.

## FISA FOUNDATION: ACCESSIBILITY AND THE ARTS

In 2009, the FISA Foundation, a Pittsburgh-based grantmaker with a long-standing focus on disability inclusion, started to work more deeply and holistically with cultural and arts organizations in the city to become more accessible to people with disabilities. The foundation had already supported several organizations, including City Theatre and Pittsburgh Opera, in specific disability inclusion efforts. But at the community level, there was little focus on accessibility in the sector. The economic downturn of 2008–2009 created an opportunity to introduce a conversation about accessibility because arts organizations were already focusing on audience development.

Through its initiative, the foundation sought to: 1) educate arts organizations about the number of people with disabilities in the community and their spending power; 2) dialogue with funders that support the arts about the importance of accessibility; and 3) support arts managers through professional development opportunities. Now, 10 years later, accessible websites, accessible seating, captioning, assistive listening, and sensory tours, as well as representation of artists with disabilities, have become the norm among Pittsburgh’s arts organizations.

Kristy Trautmann, president of the FISA Foundation, reflects on its efforts:

What I think is really interesting is [our arts work is] a microcosm for what the Ford Foundation is trying to do at a really big level, and what we’re trying to do with the intermediate level—which is, how do you help people who haven’t thought about [disability inclusion] at all to take really small, manageable steps. It’s about breaking down accessibility into small parts and then looking part by part and helping people understand what’s the barrier and what are some solutions that make it doable.

The FISA Foundation has offered eight lessons learned from its efforts that have applicability not just to the arts sector, but also to philanthropy:

- 1. Be humble.** The beginning point for you is rarely the beginning point for others. Assume there are people already engaged in your issue—learn from them and build on their successes.
- 2. Invest time in building relationships and learning the landscape.** In the first year of the arts initiative, the foundation invested less than \$10,000 but built a strong foundation for future work.
- 3. Engage “backbone” organizations to support community collaborations and systematic capacity-building that can occur across many organizations within a sector, not just one or two organizations.** The foundation’s partnerships with key organizations, such as the Pittsburgh Cultural Trust and the Greater Pittsburgh Arts Council, allowed a culture of access and inclusion to develop across the region.
- 4. Include people with disabilities in the process, as experts and advisors.** While arts managers were receptive to learning more about accessibility, the issue took on more urgency when they were face to face with people with disabilities telling

stories and explaining barriers they had encountered and how it felt to be shut out. This provided more leverage than FISA ever could have as a small foundation.

- 5. Join in the risk taking.** The foundation co-produced arts events to help them be more inclusive, and put its own reputation at stake. That deepened partnerships and accelerated learning.
- 6. Be willing to revise the theory of change.** In 2009, the FISA Foundation believed the economic argument for welcoming people with disabilities as a new audience would motivate change. In the end, two other factors were much more transformative: becoming educated and acquiring specific skills. Once arts managers became aware of the barriers and had practical strategies they could implement, things started to change. The momentum didn't come from economic gain; it was ultimately about values: The arts should be for everyone.
- 7. Encourage peer pressure.** As the larger cultural institutions invested in accessibility, their peers began to worry that they were falling behind. This positive peer pressure created by the FISA Foundation's regional effort helped accessibility champions build support within their organizations.
- 8. Commit for the long haul.** Change takes time and there is always a next step.

## INTERNAL POLICIES AND PRACTICES

Many foundations are recognizing that they need to look inward and are re-examining their policies and practices in a variety of realms, from human resources to communications. For foundations interested in taking a critical and holistic look at their policies and practices, a disability inclusion audit can encompass the various facets of disability inclusion highlighted in the following section.

**Professional development and awareness-raising.** Foundations often have a variety of questions as they begin this work. How do we get started? What is considered a disability? What are the legal considerations? What language is best and most respectful to use? Foundations embarking on efforts to integrate disability inclusion into their work often begin with a training session to help them get grounded in the basics, while also getting them comfortable in understanding that it's a

learning journey. Although foundations may start off with a disability etiquette or Disability 101 training, as with most learning experiences it is ongoing training that is most impactful to develop not only awareness, but also shifts in practice and culture. Consultants note the importance of creating and exploring personal connections to the issue. Catherine Hyde Townsend, a consultant to the Ford Foundation, for example, has hosted an informal "disability dish" for foundation staff so they can share their personal experiences, ask questions, and become more comfortable having conversations about disability inclusion. Another resource is a [Disability Inclusion Menu](#) from the Presidents' Council on Disability Inclusion in Philanthropy (n.d.), which offers approaches to strengthening inclusion efforts in grantmaking and funder operations and culture.

**Inclusive hiring and board recruitment practices.** Studies show that people with

disabilities are often overlooked for jobs due to implicit and explicit bias, leaving large pools of untapped talent. As foundations move toward greater DEI in their hiring practices, they are also becoming more intentional about how to attract and retain people with disabilities. Importantly, it is not enough to simply hire people with disabilities; they also need to be represented in executive and board leadership positions. Disability employment is an area of expertise for a number of consulting firms nationally. [Bender Consulting Services](#), for example, houses a database of more than 27,000 candidates with disabilities and provides a range of employment services, including support related to recruitment, executive searches, and workplace mentoring initiatives.

**Website and document accessibility.** All too often, foundation websites and posted documents are not accessible, despite the fact that [Web Content Accessibility Guidelines \(WCAG\)](#) exist for developers and designers. Foundations can work with web design teams that specialize in these standards when refreshing or redesigning their websites to ensure these accessibility features are in place. [WebAIM](#) (AIM stands for “Accessibility in Mind”), for example, holds trainings on document and web accessibility and also provides technical assistance and evaluation and reporting support to its clients. WebAIM worked with the MacArthur Foundation’s team to make its site accessible and partnered with the foundation to create [a guide](#) that other foundations and nonprofits can use to ensure more inclusive design (MacArthur Foundation, n.d.).

**Event accessibility and physical accessibility.** Some foundations have sought support on event accessibility to ensure that conferences, convenings, and other public-facing events are accessible to

people with disabilities. For instance, the [W.K. Kellogg Foundation](#) and others are incorporating best practices such as asking about participant accommodations upfront in their event registrations, signaling a commitment to inclusion. As some foundations, such as the [Wellspring Philanthropic Fund](#), expand their office space, they are seeking to work with firms that can help them increase the accessibility of their physical space, making sure they go beyond compliance with the Americans With Disabilities Act (ADA) to truly make their space inviting and welcoming.

**Communications.** Many foundations are concerned about respectful communication as they embark on their disability inclusion journeys. Communications support can help foundations adopt people-first language (i.e., people with disabilities vs. disabled people) and more generally use terminology that is asset-based and inclusive. For example, it is important to use language that doesn’t assume tragedy or convey pity. At the same time, communications experts also caution against sharing stories of people with disabilities in an inspirational way, but rather conveying respect by acknowledging people with disabilities as equals.

## DISABILITY-INCLUSIVE GRANTMAKING

In addition to re-examining internal policies and practices, foundations can also support disability inclusion via their grantmaking portfolios. In some cases, foundations have dedicated grantmaking portfolios or missions focused on increasing access and inclusion for people with disabilities. This includes foundations such as Ability Central, the [Craig H. Neilsen Foundation](#), the Ruderman Family Foundation, among others. In other cases, a lens of disability inclusion is integrated across portfolios, with the recognition that disability intersects with many of the issues foundations care about, from education to health to criminal justice.

**Strategy and program development.** For foundations that are working on disability inclusion or considering it, strategy, program development, and refinement are important parts of ensuring their work will have its desired impact. The WITH Foundation, for example, has had a focus on supporting people with disabilities since its inception in 2002. In 2011, the organization refined its strategy to focus more squarely on comprehensive and accessible health care for adults with intellectual and developmental disabilities. In recent years, the foundation has also become more focused on its funder education efforts to support other foundations who wish to bring a disability inclusion lens to their grantmaking. Borealis Philanthropy, which in late June announced 15 COVID-19 rapid response grants totaling \$210,000 to groups working to support the needs of people with disabilities, is also in the process of developing the strategic direction of the Disability Inclusion Fund and is conducting a landscape scan, supported by consultant Sandy Ho, to refine its work.

**Grantmaking guidelines/criteria.** Among foundations that do not have a dedicated disability inclusion portfolio, some have undertaken efforts to ensure there are guidelines for considering disability inclusion in their grantmaking decisions. The Ford Foundation, for example, has used consulting support to develop a set of questions and considerations to be used across portfolios to promote disability-inclusive grantmaking, and has also established minimum budgets for each programmatic area to ensure resources for disability inclusion are built into the work and aligned with the foundation's intentions (Townsend & Khan, 2019).

The MacArthur Foundation engaged leaders from Access Living and Mobility International USA, two organizations led by people with disabilities, to review proposals

for its 100&Change initiative and assess applicants' disability inclusion practices. In addition, the foundation continues to work with Mobility International to provide support and guidance to finalists in the second round of *100&Change* in its efforts to make their programs more inclusive. The foundation used this approach to ensure that disability inclusion did not feel like an "add-on," but rather something that was integrated into the design of the program (MacArthur Foundation, 2019).

**Inclusive proposal reviews.** Foundations have also engaged advisory groups composed of people with disabilities to provide feedback on proposals and help make decisions about grantmaking to ensure that grants are meeting the needs of the disability community. As several interviewees noted, the disability field is like any other—there are organizations that may not have credibility in the disability community and engaging those that are closest to the issues can result in better grantmaking decisions. Indeed, almost every foundation interviewed for this project uses an advisory committee to vet its proposals and compensates its committee members for their consulting time.

### **SUPPORT FOR GRANTEE PARTNERS' DISABILITY INCLUSION EFFORTS**

Foundations have also set aside funds to support disability inclusion by its grantee partners. This allows nonprofit organizations to build out documents, websites, and events that are accessible. In some cases, foundations assess prospective or current grantees on their practices and instead of penalizing them for not meeting a set of criteria, they provide support for technical assistance and resources that will help the grantee partner adapt its policies and practices.

One such effort is the Weingart Foundation's Developmental Disabilities Initiative, which has awarded close to \$6 million in grants over a three-year period to 14 organizations supporting people with disabilities. This funding allows organizations to build capacity and infrastructure in their most needed areas, from staffing and leadership to technology. In 2009, the FISA Foundation started an initiative that provided training, grants, and other resources for cultural organizations to improve their accessibility practices. Recently, the foundation teamed with The Heinz Endowments to support nonprofit organizations in southwestern Pennsylvania, where both funders focus their grantmaking, to become more fully inclusive of individuals with disabilities. Awards allow nonprofits to hire consultants who can provide training, needs assessments, and other supports.

### 3 | Opportunities to Deepen Disability Inclusion Efforts in Philanthropy

While our research highlights advances in philanthropy's attention to disability inclusion, it also underscores opportunities to deepen and broaden disability inclusion efforts.

**Greater attention to and focus on disability justice.** Historically, a medical model undergirds much of the conversation around disability. Conversely, a social model with a focus on rights of people with disabilities advances a narrative that centers people with disabilities as leaders in the field who are advocating for equal participation in society. Both philanthropy and the consultants who support the field have an opportunity to be more intentional about harnessing the leadership and expertise of people with disabilities and working with them as partners to address inclusion.

**Greater understanding of intersectionality.** Many of the consultants and funders interviewed for this paper noted that nonprofit leaders, consultants, and foundation staff working on issues of disability inclusion are predominantly white. More attention needs to be paid to the experiences of people of color, LGBTI communities, and people from low-income communities, and the ways in which these identities intersect with one another and can compound experiences with systemic bias. A deeper and fuller understanding of intersectionality can help foundations and philanthropy consultants adopt strategies and approaches that are truly inclusive and recognize the diversity of experiences within the disability community.

**Greater focus on outcomes.** While an increasing number of foundations are on a

learning journey and have made well-intentioned efforts to advance their disability inclusion efforts, fewer foundations have established metrics for success for either their internal or external-facing work. Philanthropy, as a field, can benefit from benchmarks and outcomes that help track progress and establish a sense of accountability. Just as disaggregated data by race and gender has become a best practice in understanding disparities, data can also be disaggregated by disability status. For instance, if a foundation's leaders say they want to hire more people with disabilities, did they disaggregate data to see that they in fact attracted people with disabilities through their recruitment and application process? If not, how can they change their recruitment process to be more inclusive? As the Open Society Foundations points out, "The inclusion of disabled people in your organization is not about 'helping' them come on board while leaving the organization unchanged" (Tardi & Turk, 2019).

## 4 | How Consultants Can Help Advance a Disability Inclusion Agenda

As foundations begin to deepen their disability inclusion efforts, they may feel uncertain about how to get it right. Our field scan suggests that consultants and their expertise can be leveraged to help foundations navigate the journey.

Below, we highlight two examples of consultants who have brought their experiences, passion, and know-how to support organizational and community change. These are two of many shared during our interviews with consultants and grantmakers. Some key takeaways:

- When brought on board to support DEI efforts, be intentional in pulling disability into the work. As Nakia J. Green points out, too often disability “is near, if not at, the bottom” when it comes to awareness, resources, and outreach.
- Encourage foundations to provide platforms for organizations that do disability inclusion work, with special outreach efforts to smaller nonprofits.
- Emphasize the need for internal, ongoing anti-bias training. “HR is often left to its own devices” on access and inclusion, says Sofiya Cheyenne.
- Educate grantmakers—even if you’re not explicitly asked to do so. But first, educate yourself. An overview of the ADA is available [here](#).

For every example of a foundation leaning in to drive disability inclusion, as noted above, there was often a consultant or team of consultants supporting the success of the effort.

### THE MANTLE OF DISABILITY JUSTICE Nakia J. Green



When she was diagnosed with multiple sclerosis in 2008, Nakia J. Green says she expected her life to be “turned upside down.” Still, she continued to pursue a corporate career

and a graduate degree in leadership, moving into increasingly demanding positions in the telecommunications and finance industries.

“My teams were excelling. My customers were engaged. My co-workers were supported, and I had a reputation for developing leaders,” she recalls. “But the success I worked so tirelessly to achieve came at a cost to my body. Each year my MS would flare up, I would be hospitalized, and it would take months to recover.”

Her colleagues knew what she was up against, and they worked together to maintain momentum during Green’s absences. Also absent, however, was any awareness or support from organizational leadership. Each step of the way, she recalls, “I ultimately crashed into a glass ceiling. And I came to realize that it was not because I am Black, or because I am a woman. It was because I am disabled.”

For Green, a member of NNCG’s Disability Inclusion Working Group, that clarity brought about a profound shift in focus and was the impetus to commit her established skills toward transformational change on the

individual and organizational levels. Four years ago, she founded Nakia J Consulting Inc., a firm that specializes in working with organizations around leadership and organizational development and DEI implementation. She is also the founder of Culture Solutions and the nonprofit Culture Solutions In Action, organizations aimed at reducing unemployment and under-employment among college graduates who identify as people of color and people with disabilities.

As Green sees it, her life wasn't "turned upside down" by MS. Instead, it "was strategically placed on the path toward disability justice."

Among the identities represented under the DEI umbrella, Green came to discover, "disability is near, if not at, the bottom" when it comes to awareness, resources, and outreach. "This reality has directly informed what I do as a consultant, and how I do it," she says. "When I speak of disability in DEI spaces, I use the word 'justice' intentionally."

She observes that when organizations are looking for DEI support, "it is typically at that moment when they realize they have issues regarding race, gender, or the LGBTQIA+ community. It is my job, as the consultant, to ensure that disability is also a part of the work; to educate leaders and bring disability inclusion to the forefront."

Green wants foundations to recognize their power to lead the way in shifting the organizational approach to DEI to one that centers disability inclusion. She suggests grantmakers create learning tools to educate their grantees about disability inclusion and build accountability into grantmaking to ensure disability inclusion and outreach efforts are prioritized. Green also encourages foundations to provide platforms for organizations that do disability

inclusion work. "Be intentional in your outreach to smaller organizations," she says.

The work of guiding this new approach also extends to the community of consultants, she emphasizes. "It is our responsibility as consultants to become educated on the topic and enact change—even when we are not asked to do so," Green argues. "This is where to begin as we take up the mantle of disability justice."

She also encourages every consultant to "look at this work through their personal lens. My personal experience identifying as a Black woman with a disability creates a very different lens," she observes. "Having seen disability as very white, my knowledge of the disability movement and its roots in the civil rights movement has informed my view of myself and others as a part of those movements. Where I used to equate disability only to accessibility, my knowledge of the Americans with Disability Act has also informed my imagination to see myself as a person with a disability."

"Every time I facilitate a training, lead a conversation, or sit on a panel, I make a point to reference the ADA," Green says. "It gives disability a breadth and depth beyond the anecdotal."

The range of experience the ADA identifies—learning disabilities, deafness, blindness and low vision, depression, alcoholism, cancer, MS, and post-traumatic stress disorder among them—underscores the diversity within the disability community. "How would the lives of those within an organization we support as consultants be different if we led with this full scope?" she asks. "In changing the narrative of disability and deepening our understanding of who needs access to resources and support, we must be bold."

## TELLING OUR OWN STORIES:

### Sofiya Cheyenne



As a consultant and a multidisciplinary performance artist, Sofiya Cheyenne can offer funders and her colleagues unique insights into advancing disability inclusion through support for the arts.

But the fundamentals are universally applicable—work is work, organizations are organizations, expertise is expertise. No matter the field, the pertinent and promising fact, she says, is this: “An untapped pool of talent is waiting for us.”

Cheyenne, an associate consultant with [Penn Creative Strategy](#), is also a teacher and an advocate for disability access and inclusion in schools and the workplace—including entertainment and the arts. In all her varied professional roles, sharing stories is as much her tool as it is her achievement. Storytelling, she maintains, is a uniquely impactful way to challenge social norms, and inclusion empowers people with disabilities to both create the message and share it.

“In the arts world, specifically,” she says, “what I find to be inclusive is when we see disabled artists telling their stories—not able-bodied artists telling those stories.” And she notes that while people with disabilities make up 20 percent of the population, they comprise only 2 percent of the acting profession.

When grantmakers that fund arts organizations seek guidance on their internal and external DEI efforts, consultants need to center disability inclusion in that work, Cheyenne emphasizes. “Funding work by disabled artists, and by organizations that are led by people with disabilities or with a

disability-focused mission, is a must.” This vital support comes in a variety of forms and formats. To ensure inclusion of artists with disabilities, she says, “fund accessible rehearsal spaces, studios, theaters, and film sets. Support mentorships, apprenticeships, and career development for people with disabilities in all areas of artistic expression.” This means singers, dancers, actors, musicians, visual artists, screenwriters, composers, playwrights. “What I don’t see,” she says, “is enough accurate portrayals of disability in the entertainment industry. We still have able-bodied-person-centered messaging, acting, and stories. This must change.”

Cheyenne notes that for audiences, there have been significant advances in access for people with disabilities and in widening their range of experiences in and of the arts. “In many—but not all—arts organizations and performance venues,” she says, “there are options for ASL interpreters, captioners, audio descriptions, assistive hearing devices, accessible bathrooms, accessible seating.

“What I do not see,” she adds, “is the anti-bias training sinking in. For example, the person you call for ticket services when reserving a seat at a theater must absolutely be ready, willing, and able to handle any accessible accommodation being requested over the phone. If they cannot handle that conversation, then that person is not equipped to do their job.”

Arts management and administration also fall short in ensuring people with disabilities have a meaningful presence in leadership. “I do not see enough people with disabilities in executive positions or boards,” she says. “We need to hold organizations and venues accountable.”

Cheyenne stands 4 feet, 1 inch tall as a result of spondyloepiphyseal dysplasia congenita, a rare skeletal disorder. A graduate of the Professional Performing Arts School in Manhattan, she earned a BFA

in acting and a BA in psychology from Brooklyn College. Her career as an actor and dancer includes performances with dance companies throughout New York City and roles in television and film and on regional and off-Broadway stages. She educates young people not only in the techniques of the performing arts, but also in the skills of social and emotional connection—inclusive play, positive communication, and anti-bullying strategies.

When formulating DEI initiatives internally, Cheyenne says, both consultants and funders must widen the scope that encompasses inclusivity with regard to race, ethnicity, sexuality, and gender “to also consider the value disability brings to their DEI work. We must not be afraid to call out ableism and name it for what it is.”

And she stresses the need for organizations to institute ongoing anti-oppression and

anti-bias training. “It is important that we crack open policies around hiring practices, discrimination in the workplace, and reporting and repairing harm,” she says. “HR is often an area of an organization that is left to its own devices when issues concerning disability access and inclusion surface and that receives no support on how to accommodate a person with a disability.”

Funders can also benefit from closer partnerships with grantees that are intentional in successfully implementing “realistic equity,” Cheyenne says. “Grantmakers must know those organizations that integrate disability access and inclusion at all levels of their operations—and learn from them.”

*To advance DEI, you have to take an intersectional approach. Check out this [source list from Project Lets for readings on disability justice to learn more about disability inclusion and intersectionality.](#)*

## INCORPORATING DISABILITY INCLUSION INTO DEI CONSULTING WORK

- **Do your homework.** Seek out resources to become grounded in the basics of disability inclusion, particularly those curated by the Presidents’ Council on Disability Inclusion in Philanthropy and those created by disabled people’s organizations, such as local [Centers for Independent Living](#) and [Mobility International USA](#), to learn from organizations that are led by those with lived experience.
- **Participate in professional development opportunities to gain a deeper understanding of disability inclusion.** NNCG is hosting a learning circle to support consultants who want to integrate disability inclusion into their practice. On-demand webinars are available through the FISA Foundation, [Employer Assistance and Resource Network on Disability Inclusion](#) (EARN), and a host of other organizations.
- **Ask your clients how disability inclusion fits into their DEI work.** Despite the prevalence of DEI initiatives in philanthropy, few pay close attention to disability. Sometimes asking the question is hugely important as a strategic advisor.
- **Partner with a disability inclusion consultant or expert in your next DEI engagement.** NNCG is developing a list of individuals and organizations with expertise on disability inclusion. By collaborating with a colleague, both of you can learn and deepen your expertise.
- **Take action to make your own shop inclusive of people with disabilities.** If you are an employer, follow the practices for organizations highlighted above.

## AN OPPORTUNITY

One of the biggest takeaways from our scan is the opportunity for consultants and foundations to work in partnership to support field building and strengthen disability inclusion efforts among nonprofit partners and in communities.

Foundations in particular have a unique opportunity to support and sustain this infrastructure by not only partnering with consultants (and grantees, of course), but also by spearheading efforts to build the bench of consultants in philanthropy who can serve as technical assistance providers, capacity builders, and advocates for the importance of disability inclusion across the sector.

Specifically, foundations—along with their investments in operations, grantmaking, and community partnerships—can help through:

- **Identifying the ideal consultants to support disability inclusion efforts.** It is important to recognize that different consultants with different areas of expertise are needed for various aspects of the work. NNCG has created a running list of consultants who can support disability inclusion efforts, ranging from document accessibility and disability awareness trainings to grantmaking and strategy development. NNCG took care to identify consultants recommended by field leaders, while also looking outside the box to identify individuals and firms who may have worked in the nonprofit or corporate sector but have the potential to serve philanthropy.
- **Providing professional development and collaboration opportunities for consultants to expand their DEI and disability inclusion services.** Although there is increasing discourse about both DEI and disability inclusion initiatives in philanthropy, these conversations are largely siloed. Disability inclusion efforts could use greater attention to equity conversations that tend to center on race, gender, and sexual identity and vice versa—mainstream DEI conversations can benefit from greater understanding and integration of disability inclusion in their work. NNCG, affinity groups, and other philanthropy-serving organizations can facilitate peer learning and professional development opportunities that marry the two, and consultants with differing areas of expertise can work in partnership to learn from one another while offering additional value and perspective to their clients.

- **Supporting disability inclusion consultants who come from other sectors.** Like any sector, philanthropy has its own language and its own norms. In particular, organizations led by people with disabilities or disability advocates can serve as an excellent resource for foundations and be retained to provide technical assistance and expert guidance, even if consulting is not a service they typically provide. At the same time, organizations and individuals without experience serving philanthropy may need a primer on philanthropic context. Both foundations and NNCG can be mindful of this need and be intentional about providing support around how foundations operate and the ways in which they function differently from other sectors.

## MOVING FORWARD

As social-sector organizations have continued to broaden and deepen their focus on internal and external-facing DEI efforts, research shows that they have been less likely to name disability as a component of their initiatives than other identities, such as race, gender, and sexuality. Despite its prevalence in our lives, disability has often remained an afterthought—if considered at all—in many sectors, including philanthropy.

But this has begun to change.

This working paper shares research that highlights advances in philanthropy's attention to disability inclusion. By doing so, it seeks to facilitate further action in this direction by strengthening the infrastructure and ecosystem that informs and supports new initiatives.

For foundations, there may be the need to re-examine their own inclusivity policies and practices through professional development and awareness-raising; review hiring and board recruitment; and ensure accessibility to their websites, documents, and events—both on-site and virtual. Grantmakers can also take a supportive role in similar assessments by their grantee partners. There are opportunities to deepen and advance disability inclusion through more attention to disability justice and the functions of intersectionality, and a greater focus on outcomes. Examples of a few projects and grantmaking initiatives offer lessons learned for funding grantee disability inclusion initiatives, and the valuable contributions to be found in partnering with the right consultant.

For the consulting sector, gaps in analysis are identified with the intention to develop additional learning opportunities, particularly for peer exchange. In their daily work, consultants can ground themselves in the basics of disability inclusion by seeking out resources to gain a deeper understanding through professional development opportunities. Plus, in firms where they are employers, consultants are positioned to center the principles of disability inclusion in structuring their own workplaces.

A number of organizations are offering webinars and other learning opportunities to support foundations and consultants that want to integrate disability inclusion into

their policies and practices. NNCG is also facilitating this outreach with a learning circle to support consultants in these efforts and developing a source list of individuals and groups with expertise in disability inclusion. As this learning journey continues, there will be still more opportunities to advance this urgent work.

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## Acknowledgements

NNCG would like to thank the following people who were interviewed as part of the environmental scan for this working paper.

### FUNDERS AND CONSULTANTS

Seema Bahl, Independent Consultant  
Silke Brendel-Evan, Ability Central  
Nikki Brown-Booker, Borealis Philanthropy  
Ryan Easterly, WITH Foundation  
Kym Eisner, Craig H. Neilsen Foundation  
Lisa Galloway, Ability Central  
Emily Harris, Harris Strategies  
Alexandra McArthur, Taproot Foundation  
Jennifer Laszlo Mizrahi, RespectAbility  
Kristen J. Molyneaux, MacArthur Foundation  
Debra Ruh, Ruh Global Impact  
Catherine Hyde Townsend, Townsend Consulting  
Kristy Trautmann, FISA Foundation  
Alison Warner, Robert Wood Johnson Foundation  
Kevin Webb, Mitsubishi Electric America Foundation

### DISABILITY INCLUSION WORKING GROUP

Wanda Casillas, Equal Measure  
Sofiya Cheyenne, Penn Creative Strategy  
Stephanie Clohesy, Clohesy Consulting  
Marcia Coné, Equitable Evaluation Initiative  
Nakia J. Green, Nakia J. Consulting  
Gita Gulati-Partee, Open Source Leadership  
Carly Hare, CHANGE Philanthropy  
Emily Harris, Harris Strategies  
Shannon Johnson, Blue Garnet  
Becky Lentz, University of Texas Austin  
Dara Major, Dara Major Philanthropy Consulting  
Lisa McGill, LM Strategies Consulting  
Mary Elizabeth Rider, Rider Consulting  
Seema Shah, CommVeda Consulting  
Tammy Tai, Tai Consulting  
Sharmila Rao Thakkar, SRT Advising Consulting

### SPECIAL THANKS

This working paper was made possible through a grant from the Ford Foundation. The views expressed here do not necessarily reflect the views of the Ford Foundation.

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Suggested Citation: Shah, S. (2020). *Disability Inclusion in Philanthropy*. Cleveland, OH: National Network of Consultants to Grantmakers.