

THE STATE OF WOMEN AND GIRLS WITH DISABILITIES IN NEW YORK



nywf.org

IMAGE: A Black nonbinary person in a black and pink power wheelchair has their eyes closed and is smiling while being hugged from behind by a Black femme wearing compression gloves. The two have their hair tangled together from the embrace.

Photo credit:

Disabled And Here

# **ABOUT THE AUTHOR**



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Jessi Luckett is the Founder and Principal of Kouri-Vini Consulting Inc—a BIPOC-led consulting firm with more than two decades of experience building and implementing programs around gender justice, race equity, LGBTQ+ rights, and disability rights. We support the front lines of social justice issues of our day through a values-based approach, challenging conventions, and pushing the limits of what's possible. She is an accomplished nonprofit and philanthropic consultant with 14-plus years of experience building and implementing programs around gender justice, race equity, LGBTQ+ rights, and disability rights. She has extensive experience in research analysis, program design, implementation, evaluation, grant-making, partnerships, and donor engagement in support of developing and sustaining intersectional programming.

Jessi developed her expertise leading cross-sector social justice initiatives as a consultant for various public and private institutions, including The Ford Foundation, Race Forward, the Mosaic Network and Fund, the Bill & Melinda Gates Foundation, Planned Parenthood Federation of America, The New York Women's Foundation, United Nations Population Fund, and UN Women. Additionally, she brings her expertise as a housing rights organizer at community development organizations and public policy work with high-level political actors working at the state, national and international levels.

Jessi currently holds a B.A. from Hunter College of the City University of New York and a Master of Public Administration from NYU Robert F. Wagner Graduate School of Public Service, specializing in international development, public policy, nonprofit management, and gender equity.

#### **ACKNOWLEDGMENTS**

"I'd like to thank those who generously shared their insight and experiences, and whose contributions of time, perspective, and talent made this landscape analysis possible, in particular, those who took the time to be interviewed and speak honestly about their successes and challenges faced in the field. Tremendous gratitude to my colleagues at Kouri-Vini Consulting Inc. and The New York Women's Foundation. Lastly, this project would not be possible without support from our friends at the Ford Foundation."

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## **EXECUTIVE SUMMARY**

#### WHAT IS THE NEW YORK WOMEN'S FOUNDATION?

As one of the largest women-led grantmaking organizations in the world, The New York Women's Foundation's philanthropic strategy is rooted in advancing gender, racial, and economic justice. The New York Women's Foundation creates an equitable and just future by boldly investing in organizations and leaders that strive for justice, economic security, safety, and health for women, girls, transgender people, gender non-conforming people, and non-binary individuals and their families. We prioritize organizations that promote a holistic approach to women's and genderexpansive people's leadership, gender equity, and asset-based community approaches.

#### ABOUT THEIR DISABILITY JUSTICE AND INCLUSION PROJECT

In 2019, The New York Women's Foundation became a founding member of the Presidents' Council on Disability Inclusion in Philanthropy, convened by the presidents of the Ford Foundation and the Robert Wood Johnson Foundation, a commitment to a continuous learning and implementation process that will advance systemic change within member foundations and serve as models for disability inclusion in the philanthropic sector. Together, members of the council established the Disability Inclusion Fund, a \$10M, five-year collective investment that supports U.S.-based organizations run by and for disabled people to lead transformational change.

Along with other grantmaking organizations, The New York Women's Foundation also signed the Disability Inclusion Pledge in 2021, which recognizes that uplifting disability is a key element required to achieve social justice, equity, and inclusion, and calls for accountability as philanthropic organizations clearly define their efforts in this critical area.

#### **ABOUT THIS LANDSCAPE ANALYSIS**

This landscape analysis focuses on existing and emerging disability justice and inclusion efforts at the intersections of gender and racial justice across New York City and State, and areas for funding that would support the work of disability justice leaders and advocates. In alignment with The Foundation's mission and values, the final report of findings includes an overview of organizations leading this critical work, a spotlight on community-based leadership moving this agenda forward, and information on emerging groups supporting gender and economic equity by and for people with disabilities.



## Goals:



Build relationships and credibility with potential grantees and those in the field.



Identify the breadth of issues impacting organizations serving women and girls with disabilities and their capacity-building needs.



Develop a set of recommendations for The Foundation and other philanthropic organizations to consider, focusing on specific gaps in New York State.

## **Process:**

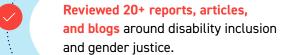


..... Aug. 2022

Led 20+ interviews with disability inclusion funders, policy advocates, movement builders/nonprofits, and disability rights advocates.

#### Attended 10 events

(i.e., convenings, panels, and webinars).



Jan. 2023

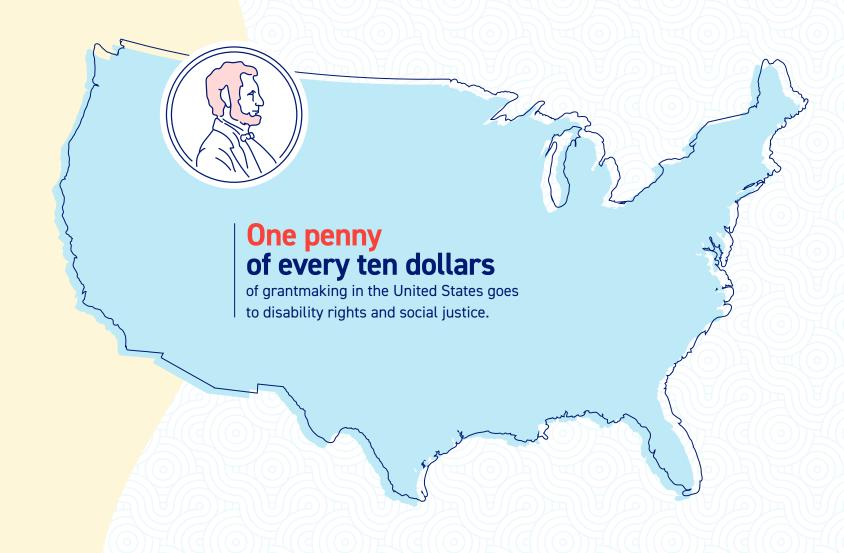


Within New York State, disability rights and justice work is centered in a very small ecosystem. Those from independent living centers and nonprofits focusing on Black, Indigenous, and People of Color (BIPOC)-disabled women were prioritized. Special attention was paid to the New York metropolitan area and key demographics in Buffalo, Albany, and the **Hudson Valley because** early inquiries and existing research signaled that those regions have a higher need.

See appendix for complete lists of interviewees.

This landscape analysis is not, nor does it claim to be, an allencompassing report. Instead, it provides insight into the types of support needed by leaders from the field and organizations working in community with disabled people, primarily with people of color. In terms of the types of support, our team limited the questioning to the types of funding, network infrastructure, organizational development/capacity building, and potential policy advocacy support.

One penny of every ten dollars of grantmaking in the United States goes to disability rights and social justice—and an even smaller amount goes to disability on the regional and state levels. In the context of COVID-19, resources from government entities, intermediaries, and other philanthropic institutions flooded the nonprofit sector to help combat historical barriers to disability movement work-predominantly from the perspective of mental health services. As the nation begins to shift its focus away from policies implemented during COVID-19, the disparities exacerbated by lack of accessibility to vital resources have closed some of the existing gaps and initiated conversations about workplace culture, equitable access to public information, and redefining what it means to be a person living with a disability in a U.S. context.



<sup>&</sup>lt;sup>1</sup> Disability & Philanthropy Forum, Disability Rights History: A Brief Introduction (2020).

New York State has a significant growth in its disabled population, with over 3.2 million or one in five adults who have cognitive disabilities, physical disabilities and/or a combination of both.<sup>2</sup> BIPOC LGBTQIA+ individuals represent the largest population of the disabled within New York City, currently 66.7 percent. The unpredictability of having a disability can be a driving factor of economic insecurity-indicators of living below the poverty line—which can further impede access to health care and preventive services. With one in five New Yorkers living

below the poverty line, the pandemic has played a key role in improving employment outcomes for New York State. For persons living with a disability, virtual access to employment, health services, and education had been a part of daily life. After decades of being overlooked by ableist workplace policies, the disabled community has seen record growth in employment, up nearly 25 percent since the pandemic began. However, the promising employment gains vary based on race, gender, and age.

# Over 3.2 million or one in five adults

have cognitive disabilities, physical disabilities and/or a combination of both.



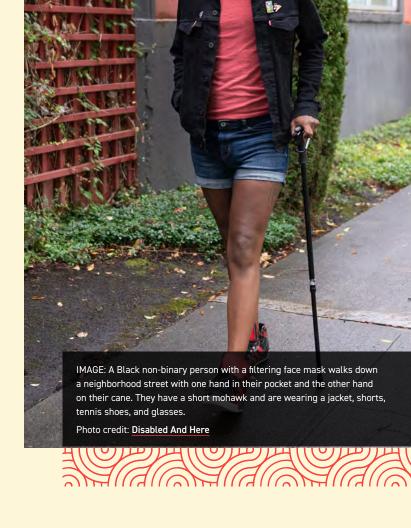












<sup>&</sup>lt;sup>2</sup> CDC. Disability & Health U.S. State Profile Data: New York. Centers for Disease Control and Prevention (2022).



## **Expanding the disability ecosystem** through network building

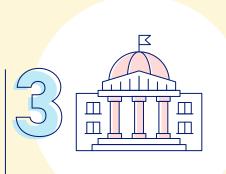
An example of this would be to support peer-to-peer learning opportunities through persistent advocacy, technical assistance, and by offering training and education opportunities to inform communities about legislative reform and access to services.

A second example would be to identify under-resourced leaders and organizations from the field and create new ways to work across issue areas.



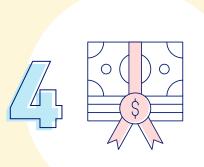
## **Deep investment in revenue** diversification to sustain and expand organizational infrastructure

Two thirds of funding for disabled leaders and organizations come from government sources. There is a need to educate philanthropic institutions on what a disability is and how this work currently fits into their liberation strategies.



## Increasing collaborative efforts to address policy and legislative campaigns to accelerate transformative change

For example, participants asked for more clarity in understanding what policy efforts can be taken as 501(c)3s.



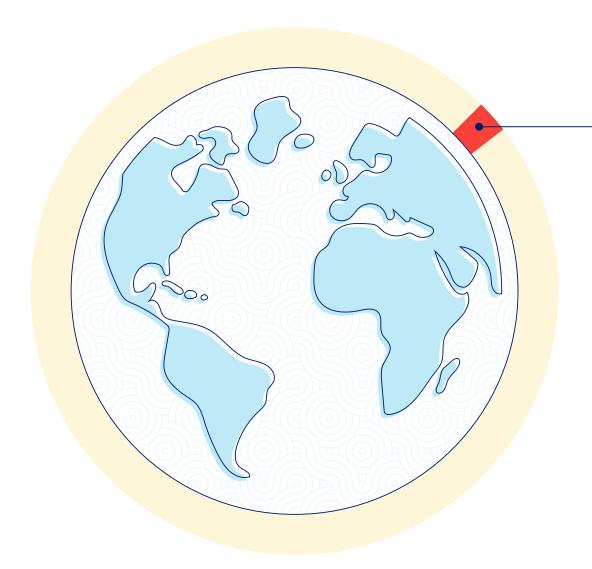
## A need to invest in early-stage organizations (small to medium-sized) through general operating support

Most small to medium-sized organizations are fiscally sponsored and rarely receive philanthropic funding. We will need to educate funders and intermediaries who provide fiscal sponsorship services on how to support these groups.

#### INTRODUCTION

The New York Women's Foundation specializes in early investment strategies that set the stage for community leaders to flourish. Their philanthropic approach means engaging on day one and taking a chance on women-led strategies before others do. Rooted in the values-based practice of Trust-Based Philanthropy, The Foundation trusts its grantee partners to know the best solutions for their communities. By breaking down barriers and facilitating conversations at the deepest level, The Foundation develops a nimble approach to continued support and sustaining forward progress.

The philanthropic community has historically ignored disability-focused organizations, representing just 2% of global grantmaking for human rights. Additionally, just 1% of human rights funding for women and girls or Indigenous peoples references persons with disabilities.3 Over the last decade, philanthropy has adopted an intersectional approach in theory. Nonetheless, these data show that, while "intersectionality" is a buzzword in the philanthropic sector, many donors have been slow to translate words into actions in their strategies and portfolios. In recent years, collaborative funds such as The Disability Inclusion Fund (DIF) at Borealis Philanthropy have played a role in reversing unintended harm caused by the lack of philanthropic resources and visibility of U.S.based disabled-led organizations across the social sector.



# Just 2% of global grantmaking for human rights.

Just 1% of human rights funding for women and girls or Indigenous peoples references persons with disabilities.



<sup>3</sup> Candid, Advancing Human Rights: Annual Review Of Global Foundation Grantmaking, 2019 Key Findings (2022).

Through this process, The Foundation hopes to honor the previous contributions to the disability movement with a firm understanding that this work is not all-inclusive and will evolve as the field continues to grow. First and foremost, this will serve as a guidance tool for The Foundation's internal and external strategic priorities in hopes that other philanthropic institutions will find elements of this report just as valuable.



## Landscape Analysis: Approach and Questions

Rooted in the principles of disability justice, this project centered on the needs of the Queer, Trans, Black, Indigenous, and People of Color (QTBIPOC) in the disabled community whose shared insights on successes and challenges are reflected in the findings. The New York Women's Foundation's current grant portfolio predominantly focuses on the metropolitan area/ downstate. We considered the five boroughs and key demographics in Buffalo, Albany, and the Hudson Valley because early inquiries and existing research signaled that those regions have a higher need.

#### CRITERIA FOR QUALITATIVE RESEARCH INTERVIEWS



#### Identification:

A field scan of key influencers, nonprofits, place-based collaboratives, and funders within the ecosystem was performed.



#### **Screening:**

The initial screening process lasted two weeks; we eliminated individuals. groups, and organizations who were no longer directly and/or indirectly associated with collective impact work on a local, national, and international level.



#### **Eligibility:**

We implemented six strategies for trustworthiness, which included respondent validation, peer review, prolonged engagement with collective impact work, their relationship to NYWF, reflexivity (bias assessment), and where they sit in the typical sampling.



#### Inclusion:

We developed inclusion and exclusion criteria that centered on individuals, groups, and organizations working in marginalized communities in hopes of minimizing unproductive/ uninformative feedback.





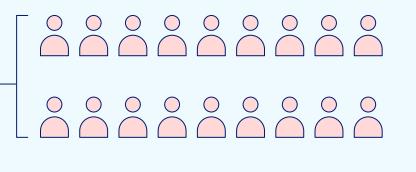
How do you prioritize

disability funding/

programming?

All except four interviewees identified as a person with a mental and/or physical disability.

The remaining four interviewees serve as caretakers for a friend or family member living with a disability.



out of the 22 interviewees identified as persons of color.



Each interviewee was asked a subset of thematic questions that varied based on their individual experiences and insight.

How would you define disability justice?

What are some of

the best practices to

support disabled BIPOC

communities?

Can you name 2 to 3 concerns that you're hearing from the community you serve?

Are you currently engaged with any policy work?

How would you describe your current relationship with the philanthropic community?

How would you describe your wins and/or challenges that you've faced in this work?

should be aware of?

Is there anything you

believe The Foundation

How has COVID-19 impacted your work? What is the impact of long COVID-19 on your community?



### The aforementioned questions were intended to highlight the following learning agenda:

- What's happening on the frontlines, specifically with queer people, non-binary people, trans people, women, and girls of color?
- Where can The Foundation partner with disabled-led organizations on key issues?
- How can other philanthropic institutions support organizations, leaders, and advocates in New York State?
- · What are specific opportunities for COVID-related rapid response support, i.e., community needs during the pandemic and post-lockdown?

"Asking potential grantees what they want and how they want this work to be framed allows us to meet the needs of the community in a more authentic way. For Black and Brown disabled folks, it's about creating a space and getting out of the way. Being humble and realizing that we are not the experts by simply asking, 'What do you want out of this partnership?""

#### Rebecca Cokley

Program Officer, Disability Rights U.S. at Ford Foundation (Paraphrased from Personal Interview, 2022)

IMAGE: Three Black and disabled folx (a non-binary person holding a cane, a non-binary person sitting in a power wheelchair, and a femme sitting in a chair) casually smile at the camera while a rainbow pride flag drapes on the wall behind them.

Photo credit: Disabled And Here

# **FINDINGS AND** RECOMMENDATIONS

According to U.S. Census data, New York State has over 3.2 million or one in five adults who have disabilities. Twenty-six percent of respondents have select functional disabilities such as limited/no mobility, issues with cognitive functions, and require independent living services. 4 In New York's metropolitan area, 11% of the population identifies as a person living with a disability. The Mayor's Office for People with Disabilities (MOPD)'s Disability Statistics data convey that over 66.7% of the disability community identifies as a person of Black/African-American, Asian, Hispanic, or mixed ancestry (see the detailed breakdown in the graphic on this page).5



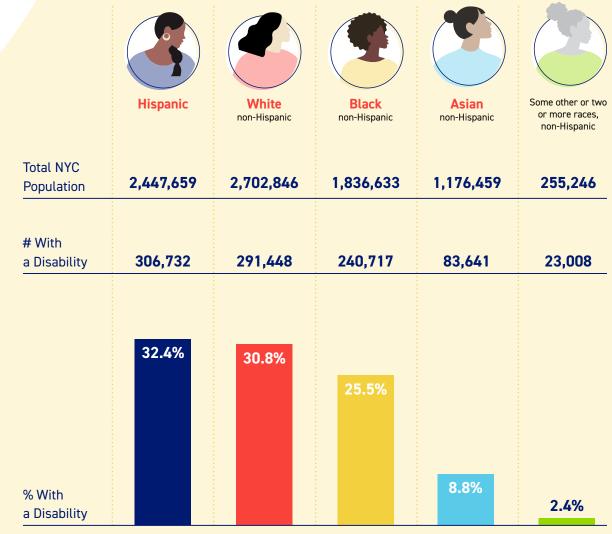
**Total NYC Population** 

8,418,843

# With a Disability

945,546









<sup>&</sup>lt;sup>4</sup> CDC. Disability & Health U.S. state profile data: New York. Centers for Disease Control and Prevention, 2022.

<sup>&</sup>lt;sup>5</sup> Mayor's Office for People with Disabilities (MOPD), Disability Statistics in NYC, 2019.

Outdated data collection methods and evaluation have left an absence of hard data on the status of disabled women at the intersection of racial equity, gender justice, and economic mobility. For example, respondents to the 2019 Census Bureau were only asked if they identified as male or female only. Respondents were not able to report gender identity or sexual orientation. Overall, responses from census data and state entities provide a general picture of the status of disabled persons, but due to systematic barriers in data collection and research, these sources do not recognize the complexity of the disabled QTBIPOC community. This report acknowledges its research limitations and will attempt to fill in the gaps with qualitative data from the field.

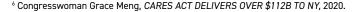
"I cannot separate my non-binary genderqueer identity from my Black identity. I cannot separate my Black identity and my genderqueer identity from my disabled identity."

#### **Phoenix Gray**

Long-term disabled London-based writer and disability activist

While global and national disability advocates have long campaigned for more resources, state, and local disabilityfocused organizations have carried the consequences of being underresourced in communities with a high demand for services and resources. Additionally, the lack of research and consistency from supporters has further contributed to the difficulty in navigating the disability inclusion ecosystem. Nonetheless, for those working in community with their constituency, there's a shared sense of frustration, unmet urgency, and an opportunity to shift the movement towards a disability justice framework. In the context of COVID-19, resources from government entities, intermediaries, and other philanthropic institutions flooded the nonprofit sector to help combat historical barriers to disability movement work—predominantly from the perspective of mental health services. The CARES Act of 2020 delivered more than \$112 billion to New York State. Additionally, the Act provided nearly \$7.4 billion in grants to older adults and persons living with a disability as a means of combating the disruption in services caused by COVID-19. Over the course of two years, the grants funded home-delivered meals; care services in the home; respite care and other support to families and caregivers; and information about and referrals to support organizations and agencies providing services. After decades of neglect, disabledled organizations and city agencies had the funding they needed to reach an expanding demographic in one of the most difficult health crises in our country's recent history.







While movement building is at the forefront of The New York Women's Foundation's strategic priorities, interview participants advocated that The Foundation considers the following:

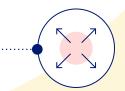
#### **DISABILITY ECOSYSTEM**





The scarcity of resources to regions outside of the five boroughs has left limited opportunities for nonprofits to build infrastructure and regional power via grassroots organizers, advocates, and networks.

89% of New York State's disabled community living beneath the poverty level is located in the Bronx district. Thus most available funding is centered on the metropolitan area and Albany. However, nonprofits and independent living centers are experiencing the effects of inflation and the lack of affordability, which has forced many people with disabilities to seek services in areas such as Buffalo and Hudson Valley.



Expand grantee portfolio beyond usual suspects; invest in early startups and/or fiscally sponsored organizations doing innovative work in communities.



# Regional Investment

Beyond Metropolitan Area Downstate NY

The Foundation can play an important role by supporting collective capacity for smaller community-based nonprofits in these priority regions, with the goal of connecting strategic resources and legislative campaigns with the work already being done in the metropolitan area.

"As disability justice funders, we have to consider disabled-led organizations that are fiscally sponsored or volunteer-led when proposing funding. So many fantastic organizations historically haven't had the resources to build their internal capacity, but are doing the work in the community."

#### **Ryan Easterly**

Executive Director of the WITH Foundation (Personal Interview, 2022)



#### **Definition and Framework of Disability Justice Concept**

Part of the complexity is a lack of consistency in how organizations focused on strengthening the rights, protection, and opportunities for persons living with disabilities within their organization and community. Recognizing the broader landscape of organizations in the disability inclusion/ rights space may uncover significant opportunities not previously identified.

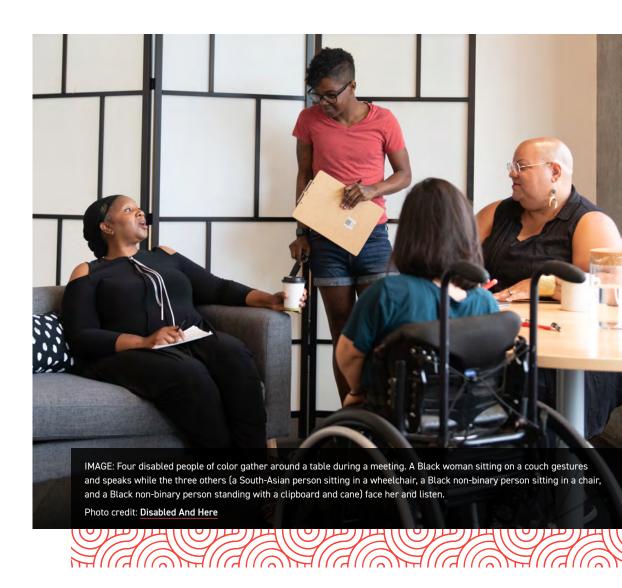
#### **Equity in Funding Opportunities**

- Disability Inclusive and Disability Justice-led organizations need more direct or indirect access to funders who are interested in supporting the intersections of disability.
- Funders need to be more flexible in their application processes and grant agreements, i.e., accessibility of processes (options for oral dictation, video/zoom, and other standard accommodation requests), clear communication on decision-making/feedback, and capacity considerations for organizations that do not have access to grant writers/development professionals.

"As part of the DIF Fund, we prioritize groups with budgets under \$500k who have not traditionally received funding or had a big grant from any major funder. We also prioritize geographic diversity. It's riskier, but the impact has been substantial."

#### Nikki Brown

Program Officer at Borealis Philanthropy (Personal Interview, 2022)





#### **Core Support for Infrastructure**

Flexible general operating support is the most valuable type of funding because it enables investment in organizational infrastructure and hard-to-fund pieces of work like advocacy and movement building. The Foundation has a unique opportunity to act as a convener to deepen the conversation beyond providing basic services (education, access to housing, and services) to areas not previously explored such as youth engagement, reproductive health, and police violence.





Over 70% of funding for disabled-led organizations comes from government grants, which is undesirable both for an organization's independence and its long-term financial sustainability.

There is a need to educate both funders and grantees on revenue diversification opportunities, and to create spaces for shared capacity.

The Foundation should support capacity building as it relates to income diversification work being done in the field, including partnerships with public agencies and various philanthropic institutions. Organizations expressed interest in creating opportunities to convene and explore these opportunities further.



#### Regina Byle

Chief Program and Policy Officer, Christopher and Dana Reeve Foundation (Personal Interview, 2022)

#### **Policy and Legislative Support**

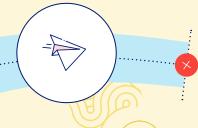
- Increase collaborative efforts amongst living centers and other disabled-led organizations to combat barriers faced by the disabled community.
- Understand what policy efforts can be taken as 501(c)3s.
- · Be equipped with compliance and policy strategy training.



### **STRATEGIC GAPS:**

Lack of resources for policy and legislative change (e.g., financial, legal, compliance, education, strategy, etc.)

Networks and learning communities to help organizations diversify their funding



Investment in early-stage organizations (small to medium-sized) through general operating support

"Be willing to meet potential grantee partners where they are and have a flexible understanding of what disability justice is. Some organizations have a very limited understanding of what a disability is and how they fit into this work. It is not about just educating funders, we also have to educate movement leaders as well."

#### **Rebecca Cokley**

Program Officer of Disability Rights U.S.-based at Ford Foundation (Personal Interview, 2022)

These recommendations are a reflection of stakeholder interviews. See Appendix A for a complete list of interviewees.

The key takeaways from the interview process are aligned with insights from previous national and international landscape analyses. Nonetheless, the process highlights three New York-specific considerations for The Foundation. The report includes an overview of insights, recommendations for impact, organizations to watch, and a field scan for each lesson. Voices from field interviews are uplifted throughout the report and are summarized in statements, and expanded with additional findings.







## Lesson 01:

# The Economics of Being Disabled

#### **FIELD SCAN**

Long-term discriminatory policies and practices impact access to education, employment, health care, housing, and other resources and reinforce barriers to financial stability for people with disabilities. Disabled people of color, in particular, face a series of repetitive structural barriers that keep economic justice out of reach for millions. When we talk about the importance of economic mobility, we can't forget *Economic* Justice is Disability Justice. Anyone can become disabled at any time and one's disability as a result of illness spurs job loss, a reduction in earnings, substantial additional disabilityrelated costs, obstacles to education and training, or possibly some combination of these and other drivers of deprivation and hardship. Meanwhile, disability can be a driving factor of economic insecurity—poverty and economic instability can impede access to health care and preventive services. Subsequently, this increases the chances that an individual lives and/or works in environmental conditions that are harmful to their health. As a result, disability and poverty go hand in hand.

For disabled persons in high-cost-of-living states such as New York, even with an increase in the minimum wage, it is still not enough to keep New Yorkers above the poverty line. One in five New Yorkers (2,167,144)<sup>7</sup> with a disability lives below the poverty line. Twenty percent of New Yorkers below the poverty line were disabled in 2021, compared to 12 percent with a disability in the population. However, Asset Limited, Income Constrained, Employed (ALICE) data shows that another 37% (795,609) were also experiencing financial hardship in households that earned above the Federal Poverty Line (FPL), but not enough to afford the basics in the communities where they lived in 2019.8 Furthermore, women are only slightly (12 percent identify as disabled females vs. 11 percent identify as disabled males) more likely to self-identify as disabled and live below the poverty line, with a higher percentage of disabled people of color, and children that were launched into the deep end by the COVID-19 pandemic and had to adapt rather guickly.9

<sup>&</sup>lt;sup>7</sup> ALICE in focus (n.d.). United For ALICE: New York Research Brief (2020).

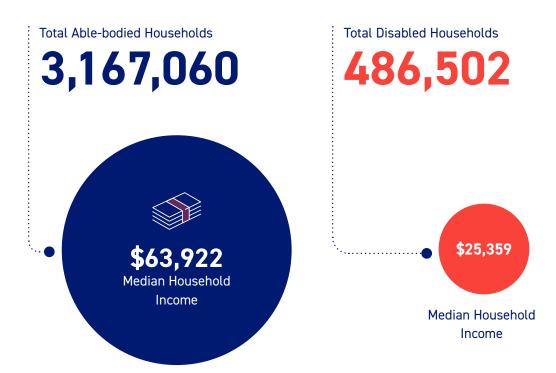
<sup>9</sup> Office of Budget Policy and Analysis (n.d.). New Yorkers in need: A look at poverty trends in New York State for the last decade. Office of the New York State Comptroller.

According to the Century Foundation's Disability Economic Justice Collaborative, the poverty rate amongst Black disabled people was 10 percent higher than among White disabled adults. The Hispanic/Spanish-speaking populations within the disabled community experienced a reduction in poverty rates during the pandemic by 42 percent.

Despite the gloomy outlook, New York City has seen a significant improvement in the employment of disabled persons. According to data from the U.S. Census Bureau, only 41 percent of workingage people with disabilities in New York City were in the labor force in 2017—including those who were unemployed or actively seeking employment. The pandemic has played a key role in improving employment outcomes for New York State. After decades of being overlooked by ableist workplace policies, the disabled community has seen record numbers in employment, up nearly 25 percent since the pandemic began. The acceptance of remote work and labor shortages caused by "the Great Resignation" has allowed people with physical and mental disabilities to enter the workforce after long absences for various reasons. Daily tasks such as commuting and navigating an office space can be difficult for people depending on their disabilities. As companies adopted remote and hybrid work arrangements, more disabled people applied for and landed jobs—sometimes for the first time in years.

In New York City, the average income of able-bodied households surveyed is \$63,922.00, but disabled households earn an average of \$25,359 per year.10

## Median Household Income Surveyed





<sup>10</sup> Source: U.S. Census Bureau, 2015-2019 American Community Survey—Public Use Microdata File Population Division — New York City Department of City Planning.

Rates of employment and wages for people with disabilities in New York State vary based on the type of disability, as well as age, sex, race/ethnicity, and educational attainment. Current state laws also permit employers to pay some workers with disabilities less than minimum wage, referred to as subminimum wage. Legislation to eliminate subminimum wages for employees based on their disability was introduced to the New York State Senate Labor Committee in January 2021 and is still under review. As of April 1, 2022, 1,417 workers with disabilities in New York earned a subminimum wage.

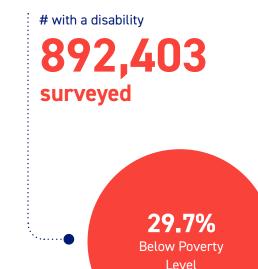
# 1,417 workers with disabilities in New York

earned a subminimum wage.

# **Below Poverty**









#### LONG COVID'S IMPACT ON DISABLED WORKERS

Between 6 to 8 million adults in the U.S. are currently suffering the effects of long COVID. Based on research from the New York State Insurance Fund, an analysis of workers' compensation claims in New York found that 71 percent of claimants with long COVID needed continuing medical treatment or were unable to work for six months or more. The report classified a case as long COVID if, after infection, a patient required medical treatment for 60 days or more or lost 60 or more days of work. 11 Additionally, the report also notes that this is probably an underestimation and does not include individuals who may face additional barriers to testing, such as low income workers. Furthermore, Black/African-American and Asian women are more likely to remain out of the workforce to act as caretakers of someone suffering from long COVID. This significant increase in individuals diagnosed with long COVID has pushed employers and policymakers to embrace new approaches to meeting the needs of disabled workers. This would require businesses; organizations; and local, state, and federal agencies to work together to create comprehensive policies that address the varying needs of the disabled community—which takes considerable time.

In the meantime, independent living centers, nonprofits, and community organizers are advocating at local and state levels to embrace work policies that are for all employees. For example, Disability Rights New York has partnered with community

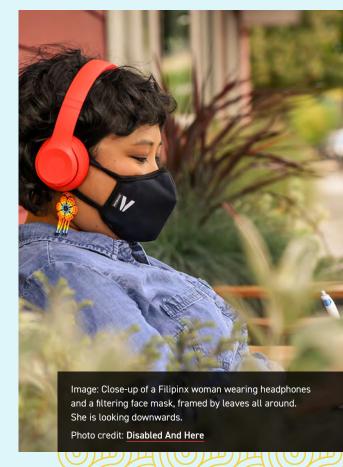
partners and healthcare professionals to provide resources on long COVID, which include patient advocacy education, how to request a reasonable accommodation, how to file a claim with the State Insurance Fund, and how to access peer-support groups.

"Under the ADA individuals may qualify for special protections, which creates a new crop of individuals who identify as disabled. There's a lot about COVID that we still don't know. But we are learning every day."

#### Jessica Richwalder, Esq.

Senior Staff Attorney, Disability Rights New York (Event Attended)12

Utilizing a disability lens when discussing changes to work environment and policy can improve the lives of all workers, removing barriers and obstacles that may have previously been invisible or hidden. U.S. policymakers, unions, and workers' rights advocates have an opportunity to create an environment that provides vital accommodations, safety, protections, and living wages with a disability lens.





<sup>&</sup>lt;sup>11</sup> Belluck, P. Long covid is keeping significant numbers of people out of work, study finds. The New York Times (2023).

<sup>&</sup>lt;sup>12</sup> York, D. R. N. Long COVID & Your Rights: A roundtable discussion about long COVID as a disability (ASL) [Video], (2023).

#### Lesson 01:

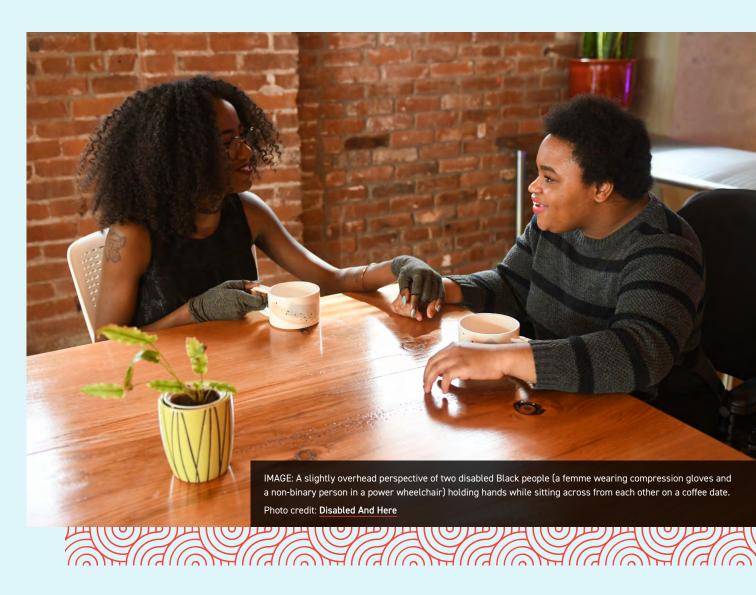
The **Economics** of Being Disabled

#### Insights

- There is a lack of consistency in how organizations focus on strengthening the rights, protections, and economic opportunities for disabled QTBIPOC people.
- Despite small gains in employment opportunities, disabled QTBIPOC workers are more likely to live below the poverty line and ALICE threshold than their white counterparts.
- The disabled community is still grappling with the effects of COVID-19, which includes new economic opportunities through remote work, integrating a new crop of disabled workers thanks to long COVID, and educating change-makers, e.g., small businesses, policymakers, funders and movement leaders.

#### Recommendations

- Funders in the economic justice space or those focused on disability rights should prioritize any organization aimed at strengthening protections of the disabled, even if they do not identify as a disability justice-focused organization.
- Further exploring the role of multi-issue organizations that do base-building and disability rights organizing is recommended. In future years, bringing this group of organizations into the disability rights space will broaden and strengthen the rights, protections, and economic opportunities for disabled women and girls of color in New York State.











## Lesson 02:

# **Youth Empowerment and the Foster Care System**

#### **FIELD SCAN**

As one of the most vulnerable populations within the United States, adolescents (ages 0–18) within the foster care system across all states represent the largest demographic of disabled youth. According to the National Council on Disability, between 35-40 percent of children in the foster care system receive special education services and another 8 percent have physical impairments. 13 Despite representing a small percentage of the overall population, Black and Latinx/e adolescents are overrepresented in the child welfare system and have been identified as a person lying with a disability. Based on data provided by the Casey Family Programs, a foster care service and advocacy organization, African-Americans only make up 13% of the United States adolescent population. However, they represent more than 80 percent of youths in foster care, even though abuse and neglect are believed to occur at the same rate for white, Black, and Hispanic adolescents when all other characteristics are accounted for. 14 This statistic is largely attributed to the systematic racism and barriers faced

by marginalized communities who interact with various court systems and public agencies. According to 2020–21 New York State Education data, students in New York State's foster system are 52 percent female and 48 percent male. They are predominantly students of color, with the largest percentage being Black students at 43 percent, followed by Latinx/e students at 31 percent, Asian students at 2 percent, and Native students at 1 percent. Twenty-one percent of students in the foster system are white. Nearly half, 47 percent, of students in the foster system, suffer from mental and/ or physical disabilities.

For those transitioning out of the foster care system, the outcomes for women and girls with disabilities are dreary. Nationally, nearly 50 percent of young women in foster care have been pregnant, compared to 20 percent of their non-foster care peers, and 38 percent have been arrested, compared to the national average of about 7 percent. Other national studies have estimated that about 22 percent of former foster youth

<sup>13</sup> National Council on Disability, Youth with disabilities in the foster care system: Barriers to success and proposed policy solutions (2015).

<sup>14</sup> Casey Family Programs, Disproportionality Fact Sheet (June 16, 2006), available at http://www.casey.org/MediaCenter/MediaKit/DisproportionalityFactSheet.html.

experience homelessness, 33 percent have no health insurance, and only 43 percent are employed upon transitioning out of the system. On a state level, the shift towards homelessness and inadequate healthcare demographics start within the school system. For New York State, there were 16,686 children in the foster system as of June 2021. The American Bar Association's Legal Center for Foster Care and Education indicates that only about 33 percent of 17-to-18-year-old students in the foster system are reading on grade level; these students are also suspended at a rate of 2.5 to three times higher than students overall and are chronically absent at about twice the rate of students not in the foster system.

Recently federal and state agencies have tried to combat these outcomes with the 2014 Workforce Innovation and Opportunity Act (WIOA), which expanded access for people with disabilities to education and training programs, programs for transition-age youth and young adults transitioning to adulthood, vocational rehabilitation, and more. Over the years, New York State has seen an increase in youth-led movement-building activities, particularly for child welfare participants and transitioning youth due to this expansion. For example, Families Together for New York State, a family-run organization that represents families of children with social, emotional, behavioral, and cross-systems challenges in New York State, represents a large network of youth in Albany, New York. The organization's Youth Power Program offers peer support through persistent advocacy, technical assistance, and by offering training and education opportunities to inform communities about legislative reform, mental health issues, and criminal reform organizing.

This youth-led expansion would not be possible without this additional government support. As described by Tara Springer-Love, Director of Youth Power (Personal Interview, 2022), "We're a statewide network of young (ages 13-30) people who identify as people with a disability. Mental health issues are a big driver of juvenile justice involvement. We're one of the few organizations that go to 30 years of age because we have folks who need guardianship and additional support well after 18 or 24. We're working across agencies to provide immigration services, juvenile justice, sexuality education, and policy/ legislation advocacy in combination with traditional services. Whatever your recovery looks like, we're there." Unlike their peers, Youth Power provides training on systems advocacy, e.g., "How to Run for Office," and routinely invests in start-up youth-led collaboratives throughout the state, but have slowed down due to the effects of COVID-19 and social distancing.

According to the study done by the New York City Bar Association and The Fund for Modern Courts, thousands of families had to wait extra months, if not years, for decisions about findings of child maltreatment, visitation, adoption, domestic violence, foster care, and termination of parental rights due to COVID-19 court slowdowns. The foster care system has seen the biggest delay in services than any other city/state agency, which has caused a trickle-down effect in communities. For example, Buffalo saw the largest spike in substance abuse amongst adolescent youth-disproportionately amongst fostered youth-in New York's history. To combat this crisis, Families Together for New York State and Youth Voices Matter, a substance abuse/ recovery advocacy nonprofit, launched a rural community-based



of 17-to-18-year-old students in the foster system are reading on grade level.

Lesson 02: Youth **Empowerment** and the Foster **Care System** 

program to address teen drug use. "I'm of the 2010 generation. I don't know what it is to do virtual learning, digital proms, and delayed graduation ceremonies. This new reality is something that nonprofits need the flexibility in resources and strategies to address," says Tara Springer-Love (Personal Interview, 2022).

This flexibility starts with the expansion of operational and administrative oversight. For nonprofits advocating for legislative reform, acquiring consistent funding and receiving accurate analysis about disabled youth in foster care have proved difficult. As these groups continue to gain momentum, this is an opportunity for funders to provide increased flexibility to states and communities so programs and services can be most effectively structured to meet the needs of youth with disabilities in foster care. In recent years, the child welfare system has seen amazing improvements in the data systems funded by the Federal Government, the type of data collected, and how this data is organized. Nonetheless, there's still work to do. For agencies' information systems to help decision-makers understand the youth who are tracked with the overall goal of improved services and youth outcomes, the following basic needs have been identified: adequate funding to build capacity; identification, consistency, and accuracy within the systems; improvements in collected information; and cross-systems sharing of data. Far too many youths with disabilities in foster care are not transitioning into healthy adulthood and are not becoming productive members of society.

#### **Insights**

- Youth with disabilities suffer higher abuse rates, leading to overrepresentation in the child welfare system. They will likely face further abuse by poorly trained social workers, staff, and/ or foster parents. Adequate funding for training, accessibility to services and resources, and policies based on current research at all levels (local, state, and federal) is essential to support this vulnerable population.
- The lack of data and policy research as it relates to disabled youth in the foster care system has slowed progress.

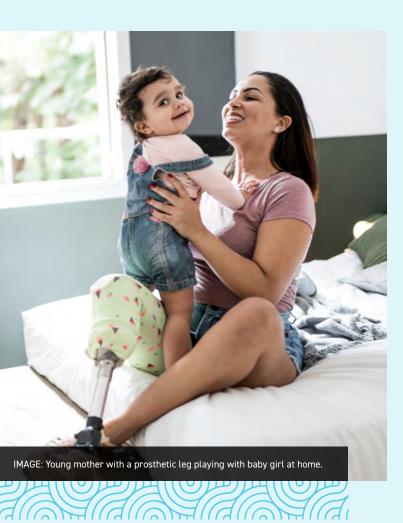
#### Recommendations

- Funders should support more efforts to expand education and training needs, transitions to adulthood and connectivity issues, coordination amongst agencies, and issues around the use and sharing of data.
- Better linking of policy with disability-inclusive research, which includes updated systems and better terminology specific to facilitating clear and consistent reporting of disability status for youth in foster care.
- Support programming that strategically increases collaboration among the education, juvenile justice, child welfare, labor, dependency court, and health and mental health systems—this includes training of youth professionals across systems.









## Lesson 03:

# Reproductive Justice, Health, and Safety

#### **FIELD SCAN**

With over 15 percent of the world's population identifying as physically disabled, at least 10 percent of women with disabilities are of childbearing age. Nonetheless, accessibility to reproductive health and maternity care remains limited due to prejudices and biases that perpetrate the notion that women with physical and mental disabilities are less likely to have children—a belief held by most healthcare providers. 15 Historically from a U.S. context, disabled women of color were restricted from making decisions around their reproductive choices and childbearing responsibilities. As an often-forgotten intersectional community, the lack of data and research on disability, gender, and race has further disrupted any attempts to create comprehensive, long-term policies for a community whose hardships include eugenics, sterilization, segregated education systems, sexual violence, forced institutionalization, and guardianship. 16 These conditions have been exacerbated by the pandemic, specifically as it relates to domestic violence in New York State. As of April 2022, the Governor of New York

expanded access to domestic violence services for individuals with intellectual or developmental disabilities (IDD) who are survivors of domestic violence to include women and girls with developmental disabilities. Commissioner of the New York State Office for People With Developmental Disabilities Kerri E. Neifeld said, "Women with disabilities are three times more likely to experience domestic violence than their non-disabled counterparts. We must work to support and empower people with developmental disabilities who have experienced domestic and intimate partner violence and ensure their voices are heard."17

For women and girls of color with chronic conditions and other disabilities, the "average experience" of a healthy pregnancy swelling, unpredictable hormones, the emotional journey of creating life—can be entirely out of reach and filled with additional barriers, stigmas, and life-threatening risks. People of color with disabilities are less likely to receive comprehensive sexual education and/or access to contraceptives to avoid unwanted pregnancies than their white counterparts.

<sup>15</sup> Heideveld-Geriitsen et. al. Maternity care experiences of women with physical disabilities: A systematic review. Midwifery, 96, 102938 (2021).

<sup>16</sup> Center for American Progress. Reproductive justice for disabled women: Ending systemic discrimination (2022).

<sup>17</sup> Paraphrased from PSG, 360 (n.d.). NYS: Launch of intellectual & developmental disabilities advisory council on domestic violence. Niagara Frontier Publications (2022).

For individuals who choose to become pregnant, the disparities are just as devastating, as disabled women are more likely to have adverse birth outcomes and to experience pregnancy complications, in part because they often are on medications that interact negatively with pregnancy. The overturning of Roe v. Wade has only reinforced harmful practices that have proven detrimental to people's lives long before the legalization of abortion rights in 1973. The feminist movement often fails to address how these issues of autonomy, due process, and control over our bodies permeate reproductive justice case law and disproportionately affect disabled women.

The systemic barriers for disabled people to parent with full autonomy and dignity creates an unwanted trauma cycle for disabled parents, children, and their families, all of which varies from state to state. 18 This inconsistency can be seen policywise on the local, state, and national levels when examining human rights frameworks, such as access to parental rights for the disabled. For example, New York's termination statute allows for termination on the sole basis of a parent's disability, specifically those with disabilities who identify as a person of color, and in many cases have no history or evidence of abuse. Amongst all 50 states and U.S. territories, New York State is the biggest offender of this ADA violation due to the prevalent prejudices and biases against individuals with mental disabilities. While the well-intended statute was adopted to protect the health and wellbeing of minors, the broad application of this statute throughout the court systems has forcibly terminated the rights of disabled

"Sinergia is one of the few independent living centers—possibly the only in New York City providing services for English as a Second Language (ESL) learners and the undocumented. We understand that disabled women with additional barriers such as cultural and language differences are at a higher risk of losing their parental rights than white disabled women. Systematic racism in the court system is alive and well. Therefore our work uplifting the parental rights of the disabled Latinx/e community has been vital and we hope to expand our services into reproductive health as well."

Lore Barcelona

Executive Director, Sinergia 19

18 National Council on Disability. Rocking the Cradle: Ensuring the Rights of parents with disabilities and their children (2012).



<sup>&</sup>lt;sup>19</sup> Paraphrased from an interview (2022).

IMAGE: Volunteers, including woman in a wheelchair, arranging donations at a community center.

parents at a rate that is three times higher than any other states with similar statutes.<sup>20</sup> As a consequence, current disability advocates, independent living centers, and movement leaders have shifted their focus away from the more controversial issues such as reproductive health to supporting existing and future disabled parents with legal advice and education/certification services for effective parenting.

Lastly, small nonprofits and reproductive health organizations have a unique opportunity to dismantle the strongly held belief and practice that recreational sex for disabled women and girls isn't a desirable experience. WE LIKE SEX, just like everybody else! Health programming for women and girls with disabilities must include a sexuality education component to allow women to live their full lives. It starts with inclusivity and intentionality.

#### Insights

- Access to health education is not universal. Still, the disability perspective is relatively non-existent when it relates to accessing specific types of health care, e.g., sexuality facilitation, preventative screenings, contraceptives, and maternal health.
- There is a critical opportunity to build the collective capacity of smaller reproductive rights community-based nonprofits to the larger independent living centers—connecting strategic resources and legislative campaigns with the work already being done to safeguard access to abortion.

"Life, liberty, and the pursuit of happiness look like many things, but for me, the right to sexual autonomy and expression was of particular interest. For me, it started as a grassroots effort. My first talk about sex was during an ADA and Disability series held at Charis Books and More, a bookstore in Atlanta, GA. I was on a panel with people with different disabilities and we openly discussed our sex life. Participating on that panel encouraged me to seek more opportunities to talk..."

**Robin Wilson-Beattie** 

Leading BIPOC disability and sex expert<sup>2</sup>

IMAGE: Portrait of a smiling lesbian couple.





<sup>&</sup>lt;sup>20</sup> White, B. Termination of Parental Rights of Mentally Disabled Parents in New York: Suggestions for Fixing an Overbroad (2015).

<sup>&</sup>lt;sup>21</sup> Paraphrased from Interview with Wilson-Beattle. How the ADA gave birth to a black sexpert (2020).

#### Recommendations

- Most independent living centers in New York State provide their constituents with parenting courses; one of the most critical opportunities to accelerate reproductive justice and maternal health in the disability community is to provide resources to help expand existing parenting courses to include sexual and maternal health information.
- Funders should engage in long-term investments aimed at strengthening the relationship between reproductive rights and the disability justice movement, which has a very complicated history due to the reproductive rights movement's early tolerance of eugenics arguments in legal fights for contraception and abortion access, which excluded people with disabilities as key constituencies. This disconnect has led to an absence of women with disabilities in leadership positions at sexual and reproductive rights organizations and, consequently, neglect of disability perspectives in the movement.

# **ADDITIONAL FINDINGS**

#### **EXPANDING OUR UNDERSTANDING OF DISABILITY JUSTICE**

A recurring theme from the field highlighted a lack of consistency regarding what defines a disability justice versus disability inclusion organization. Many organizations aimed at improving conditions for people living with a disability do not have the appropriate framework to identify as disability justice-led organizations.

#### The two most common themes from interviews indicated:

- 1) Community organizations are serving as a "one-stop shop" because of community demand for services and the limited capacity of the local nonprofit sector to meet that demand. Community organizations are often "doing it all" in part because of a lack of resources organizationally and regionally. For example, the vibrant disabled community has complex needs depending on the type of disability an individual possesses. A person with a cognitive disability will differ greatly from someone who has issues with hearing, vision, or ambulatory disability, or one that makes self-care or independent living difficult.
- 2) Organizations are exploring the intersection of multiple issues to promote system-level changes, e.g., education for those with cognitive issues, parenting curriculums for disabled parents, disabled transitioning youth (14-24), independent living services, financial stability, access to public assistance (housing, food, transportation), and advocacy/legislative reform amongst others. For example, the Independent Living Center of Hudson Valley is a multi-issue organization that offers at least 17 programs to its constituents that increases engagement and education for their communities. This ensures that members are prepared to act when situations arise.

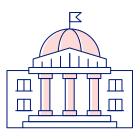




"In almost all of our grant cycles, we've encountered several organizations who are doing the work. However, they are not using the disability justice framework or may not be familiar with the language—but they are also addressing DJ priorities. We usually prioritize how a potential grantee describes their work. They may not use the language, but the activities are definitely in alignment with disability justice work."

#### Nikki Brown

Program Officer at Borealis Philanthropy (Personal Interview, 2022)





#### POLICY AND LEGISLATIVE CHANGE IS A GROWING PRIORITY

As the disability community begins to gain ground on issues like employment policy, police brutality against the disabled, reproductive health, and expanded eligibility for disabled ABLE accounts, there is an opportunity to shift policy and legislation to benefit disabled workers by taking multiplepronged approaches to change-making. Base-building organizations that have historically stayed out of elections are seeking increased community influence through participating in the political arena. Many disabled-led organizations expressed the importance of having a clear strategy for policy change that works in parallel with what is happening on the ground; the lack of flexible investment from government, state, and philanthropic institutions does not allow them to pursue 501(c)4 interests. The philanthropic community has a unique opportunity to help foster partnerships with multiple stakeholders to provide capacity-building and technical assistance opportunities to grantees.

#### REVENUE DIVERSIFICATION IS KEY FOR FINANCIAL SUSTAINABILITY

Over the last few years, the boom (COVID-19 relief funding) and bust (the shift to new strategic priorities) have created a critical need to support long-term organizational capacity to improve fundraising. One of the most common ways organizations are diversifying revenue is by partnering with public agencies, but the approval process can be painstakingly long for start-up organizations and does not provide the flexible funding needed to support innovative projects. There is a need to educate funders and grantees on revenue diversification opportunities and create spaces for shared capacity. Consequently, funders can help organizations diversify their revenue sources and support collective learning opportunities through network weaving and narrative building.

As part of our values-centered approach, we uplifted the voices of those most marginalized and vulnerable. This report is a snapshot of the conditions and lived experiences of women and girls living with a disability in New York State, most of whom are members of the QTBIPOC disabled community. The Foundation trusts its potential and existing grantee partners to know the solutions for their communities best, which means investing heavily in the most marginalized and underserved as the center of its movement-building strategy. Additionally, The Foundation hopes that the findings and recommendations in this report are used as a guide star for other funders interested in starting or going deeper into disability justice.

Inclusivity and accountability within the disability community are paramount to building relationships amongst organizations and influencers, diversifying/sustaining long-term resources for nonprofits, and expanding the disability justice grantmaking landscape to hard-to-reach geographically significant areas. The organizations, geographic areas, and strategic priorities mentioned in this report could move support of the field in the right direction—toward the disability justice framework—with intentionality in mind. While inclusivity should be practiced by the field and funders alike, the accountability component sits squarely within the philanthropic community. Overwhelmingly, the participants and research from the field indicate that the drivers of innovation and sustainability are not rooted in philanthropic trends/funding cycles, which only contribute to a boom or bust financial infrastructure for movement builders in the disability community. Rather than focusing exclusively on providing services, disabilityled organizations and their allies would like to explore more advocacy-based work—meaning local, regional, and national systematic change—led by youth, QTBIPOC, coalitions, and network weavers from the field.

We recognize that this report is written in English from one perspective. With additional resources, we urge The Foundation to consider the cultural and linguistic diversity of the community in the next iteration of this report.



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