



CIVIC ENGAGEMENT AND PEOPLE WITH DISABILITIES

A Way Forward through Cross-Movement Building


Brandeis

THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT

Lurie Institute for Disability Policy
Sillerman Center for the Advancement of Philanthropy



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**Civic engagement
must be an essential
element of democratic
practice if government
is ever to be “of the
people, by the people,
for the people.”**

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About the Lurie Institute for Disability Policy

The Lurie Institute for Disability Policy conducts multidisciplinary research on the needs, experiences, and policy priorities of people with disabilities. Our work covers a wide range of topics, including the experiences of parents with disabilities; policies addressing long-term services and supports for people with disabilities; and health and healthcare outcomes. Moreover, the Lurie Institute houses two major federally funded programs of research: the National Research Center for Parents with Disabilities and the Community Living Policy Center. These programs focus on salient issues affecting people with disabilities and the communities around them to ensure the full integration of people with disabilities into society at large. The Lurie Institute was created by a generous gift from the Nancy Lurie Marks Family Foundation in 2007.

About the Sillerman Center for the Advancement of Philanthropy

The Sillerman Center draws upon scholarship and practitioner experience to inform philanthropic practice and giving. Through publications, webinars, public events, courses and fellowships, we engage emerging and established members of the philanthropic community across the United States. The Center was established in 2008 by a generous gift from Laura and Robert Sillerman '69. The Sillerman Center's work includes publications on grantmaking for social justice, seminars and lectures on social justice grantmaking, partnerships with foundations and community leaders, support for graduate students interested in philanthropic careers, and technical assistance for youth philanthropy organizations in Massachusetts.

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Executive Summary

Civic engagement must be an essential element of democratic practice if government is ever to be “of the people, by the people, for the people.” But for people with disabilities, this foundational practice is replete with systemic barriers and challenges. People of color with disabilities, compared to their white disabled counterparts, experience even more limited access to existing pathways of participation and meaningful influence over government and civic life. This is not surprising information, if we note that research in education, health, and employment, has long shown that people of color have limited access to opportunities and services. This social exclusion of people with disabilities and people of color is directly tied to underrepresentation in civic engagement.¹ Consequently, even the public discourse and civic engagement efforts that most directly affect the lives of people with disabilities tend to center and privilege voices of white, nondisabled people. This directly contributes to a systemic imbalance of power and representation across all levels of US government and civic life.

Twenty-six percent of the American adult population has some type of disability.² However, even efforts designed to engage people with disabilities in civic participation and leadership are not typically informed by the lived experiences of disabled people. As a result, members of the disability community experience civic engagement as fragmented, reflective of ableist social attitudes, and full of barriers to participation. This marginalization of disability community voices in civic life has led generations of the disability community to be excluded



from participation in our shared democracy. The lack of a stable foundation for disabled people to access meaningful civic engagement has meant disabled people themselves hold disproportionately little power with respect to their social, economic and political progress.

Both historic and recent social movements teach us that civic engagement practices must center people closest to the challenges those movements are trying to address. **But even the most progressive of efforts, including contemporary civic engagement work, still do not include people with disabilities as active members and leaders.** To disrupt the cycle of social, health, and economic disparities that people with disabilities experience, sustained representation and participation of people with disabilities is necessary. This must include and be led by disabled people inside and outside of traditional democratic processes. A truly democratic system that provides equitable opportunities for civic participation for people with disabilities, including the marginalized disabled communities requires relationship building and allyship across movements, and across the public sector (civic, philanthropic, government, etc.). Philanthropy holds the potential to catalyze conversations around these necessary changes and support efforts led by people with disabilities to challenge ableist norms around power, representation, and participation and increase the influence people with disabilities have over systems, structures, policies and issues.

This report presents a national overview of the barriers to civic engagement that disabled people experience. Drawing on our findings from surveys, a Twitter chat, and interviews, we offer recommendations for the philanthropic sector and for civic engagement organizations aspiring to create a more inclusive and responsive democracy to build civic power among people with disabilities. Civic power in this report

¹ [Robert Wood Johnson Foundation, “Culture of Health Sentinel Community Insights: Health Equity”](#)

² [Centers for Disease Control and Prevention, *Disability Impacts All of Us*](#)

A black and white photograph of a protest. A person in the foreground holds a sign that says 'WANTHER NOW'. The background is filled with a crowd of people, some holding other signs, though they are out of focus. The image has a grainy, high-contrast quality.

**Civic engagement is
an essential element of
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is conceptualized as opportunities for people with disabilities to amplify, mobilize, and elevate their voices and influence within democracy.

This report centers the expertise, insights and lived experiences of people with disabilities, including leaders from various disability communities. Our findings reaffirm that no disability rights issue exists outside the sphere of civic engagement and no meaningful civic engagement strategy can emerge without attention to disability rights.

Supported by the Ford Foundation's Civic Engagement and Government (CEG) program, this report is a collaboration between the Lurie Institute for Disability Policy and the Sillerman Center for the Advancement of Philanthropy, both based at Brandeis University's Heller School for Social Policy. The disability rights mantra "nothing about us, without us" informs the questions, methods and content in this report. We hope the findings and recommendations will inspire new thinking and action within philanthropy and civic engagement spaces, and spark courageous conversations and inform practices within the vital organizations working to strengthen democracy in the United States.

Our Questions & Methods

Our research is guided by four principal questions:



How do people with disabilities and leaders in the disability rights community conceptualize and define civic engagement?



How do disabled people and leaders in the disability rights community characterize current opportunities and activity within the civic engagement ecosystem?



To what extent do traditional civic engagement organizations implement disability rights frameworks into their programs, and practices? What questions do existing civic engagement practitioners have about disability rights?



How might philanthropy, civic engagement practitioners, and disability rights leaders work together to create more opportunities for accessible, equitable, and meaningful civic engagement practice?

These questions were shaped by members of the disability community and by our own assessments of disability-related knowledge gaps, both in the philanthropic sector and among civic engagement practitioners. We sought data and insights from a) disability rights leaders b) disabled people who are involved with the disability community in various capacities, and c) representatives from more broadly focused civic engagement organizations.

We gathered information through interviews, online engagement and an online survey. We conducted 18 interviews across both Ford Foundation's civic engagement grantees and with leaders from the disability rights community.³ We also facilitated a #DisabilityCivics Twitter chat, co-hosted by Alice Wong of Disability Visibility Project. This moderated chat engaged 272 contributors who are a representative slice of disability community members active on Twitter. Finally, an online survey of self-identified people with disabilities living in the U.S. resulted in responses from 360 participants.

The diversity of data sources provides a multidimensional understanding of the perceptions and priorities of people with disabilities, illuminates ongoing harms, and informs our recommendations about how to begin to close these gaps. However, it is crucial to acknowledge the limitations of this research. Because of the layered systemic inequality that bars people with disabilities from full participation and access to public life, many people with disabilities live in institutions and/or have no access to the internet, on which much of this research relies. In considering next-steps to further the work of building an inclusive democracy, we suggest that future research should purposefully oversample disabled people of color and disabled people who are LGBTQ, and identify with other marginalized communities including disabled people living in institutional settings, and/or people with limited access to the internet.

3 Among the 13 disabled people who were interviewed - 6 identify as a disabled person of color, and 3 identify as a disabled LGBTQ person of color.

712

total participants,
including



18 interviews

with Ford Foundation civic
engagement grantees and
disability rights leaders



272 participants

in the #DisabilityCivics
Twitter chat



360 respondents

to our online survey

Diverse data sources lead to...



Understanding

the priorities and
perceptions of people
with disabilities



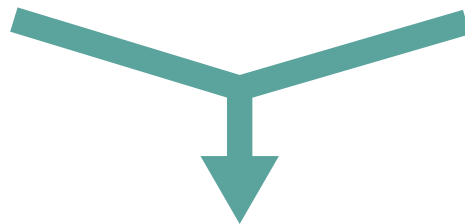
Illuminating

ongoing harms



Informing

our recommendations
to support civic
engagement among
people with disabilities



Further research that
builds on our findings
and includes disabled
people who identify
with multiple marginalized
identities

Findings: Disabled People Experience Democracy as Fragmented, Inaccessible, and Ableist

Our data show that people with disabilities experience our democracy as fragmented, inaccessible, and ableist. Despite the increased focus on inclusion across our society, when it comes to civic engagement, people with disabilities and the disability rights community repeatedly describe being treated as “people with special needs.” Our data repeatedly showed that people with disabilities feel welcome in civic spaces only to provide solutions to immediate physical access barriers or to represent “disability issues,” such as those that manifest in health care or special education. But of course, disabled people and the broader disability rights community are also leaders and participants with ideas, experiences and knowledge to contribute on the full range of issues and challenges in our democracy. Laws designed to integrate people with disabilities in society do indeed exist. But our research illuminates the ways that dominant social notions around disability shape self-identity and limit civic power for people with disabilities. We find, too, that civic engagement practitioners tend to be uninformed about the interconnectedness of disability identity and social justice issues and thus, unsure about how to meaningfully incorporate disability rights into current civic engagement strategies.

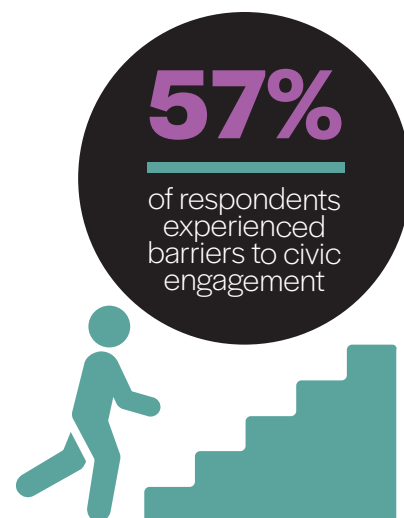
“As a disabled person, I face stereotypes and bigotry about people with disabilities. My credibility is always in question.
No one presumes my competence.

For the 61 million people in the U.S. who live with a disability⁴, democracy is a story about limited and unequal power, voice, and representation, proving that our democracy has yet to fulfill its promise to all. People with disabilities conceptualize civic engagement as

essential for their social, political, and economic livelihoods, and as an integral mechanism that enables a place and a degree of power in a democratic society.

Across interviews with disability rights leaders, responses to descriptions of civic engagement and disability rights were frequently tied

to social experiences of daily living. Several disability rights leaders shared stories about what compelled their initial involvement in disability rights and civic engagement. These stories often depicted moments when their rights as a disabled person were denied and required them to become civically involved in order to access basic opportunities at work, school and other settings. In listening to disabled people describe what civic engagement means to them, it is clear that whether it is through voting, attending town halls, writing letters to public officials, joining rallies, coming together with other disabled people, or participating in online discussions -- people with disabilities are consciously motivated by gaining access to civic power in order to meaningfully participate in, be represented by, and contribute their leadership towards a more inclusive democracy. Despite this deep connection and commitment to civic engagement, our survey responses revealed that 57 percent of respondents “Experienced barriers to participate in civic engagement.” This signifies that the barriers and challenges to civic engagement prevent disabled people from accessing civic life, and highlights the ways civic engagement practitioners are ineffectual in engaging people with disabilities in their work.



exclusion **stigma**
discrimination **money** *racism*
homophobia *xenophobia* **time** *antisemitism*
transportation stereotyping
social isolation
ableism tokenizing **physical barriers**
classism *marginalization* **bias**
misogyny transphobia
voter suppression *shame* oppression
inaccessibility islamophobia

This word cloud represents barriers to civic engagement that people with disabilities listed on our survey and in interviews.

Discrete Networks, Civic Engagement & Disability Rights

20%

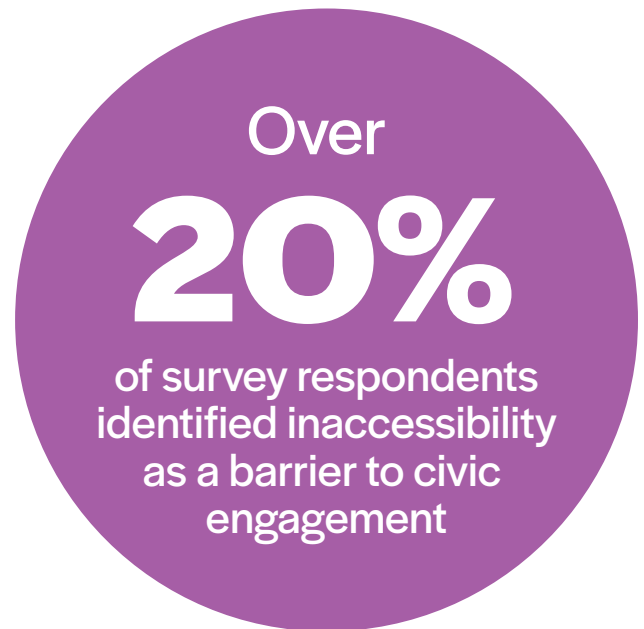
of survey respondents with disabilities work in disability rights with other members of the disability community

8%

of survey respondents work with non-disability civic engagement organizations

13%

work with civic engagement organizations that address disability rights



Ableist Attitudes Toward Civic Engagement



Legally obligated to include disability rights



Intention, but not action, to include disabled people



Act from preconceived ideas of disability



Expect disability groups to come to them

Cross-Movement Attitudes Toward Civic Engagement



Framework is incomplete without disability inclusion



Intention and partnership with disability organizations



Elevate disabled leaders



Go to the accessible spaces

Our research highlights three principal barriers to civic engagement for people with disabilities.

1. Social stigma and ableism are obstacles to civic participation for people with disabilities, and in particular for disabled people who also experience oppression due to racism, homophobia, or transphobia and other forms of othering.

Thirty-four percent of our survey respondents indicated that “othering” related to various aspects of their identity -- including religious affiliation, race/ethnicity, disability status, gender identity, and/or sexual orientation – made them feel unwelcome or invisible in civic engagement spaces. When asked to elaborate, one respondent wrote *“As a disabled person I face stereotypes and bigotry about people with disabilities. My credibility is always in question. No one presumes my competence.”* Ableist attitudes, including those that send a message that people with disabilities are not already active contributors towards a more inclusive democracy, discourage disabled people from participating in democratic pathways. Additionally, more than twenty percent of our survey respondents identified “Inaccessibility” as a barrier of civic engagement.

2. Discrete networks and lack of intentional overlap of civic engagement and disability rights ecosystems impede opportunities for shared learning, collaboration and equitable, effective allyship.

Twenty percent of people with disabilities from our survey reported that they engage in disability rights work with “Members of the disability community.”⁵ This is compared to 8 percent who work with “Civic engagement organizations that are not disability rights groups,” and 13 percent who work with “Civic engagement organizations that are disability rights groups.” In other words, when it comes to civic engagement people with disabilities are more likely to be involved in disability advocacy with other disabled people, and disability organizations than they are with traditional civic engagement organizations. This suggests mainstream civic engagement organizations are not engaged with, or informed by the insights and lived experiences of disability rights leaders, who deeply understand and can act upon the inextricable link

5 This data point suggests the necessity of further research about groups and organizations disabled people work with to access opportunities.

between disability rights and civic engagement. This lack of overlap between movements creates silos that obstruct cross-movement collaboration, and erect barriers to civic participation for disabled people - many of whom elaborated on feelings of being “tokenized” in their experiences of civic participation.

3. Leaders of civic engagement organizations and movements recognize the need to include disability rights in their work. However, the realities of civic participation for people with disabilities suggest that this recognition is not translated into practice.

However, the realities of civic participation for people with disabilities suggest that this recognition is not translated into practice. Interviews with both disabled leaders in community-based organizations, and leaders from nondisabled civic engagement organizations suggest that the different types of organizations view each other as existing in separate spheres. Disability rights leaders and community members emphasized that inclusive practices require intentional, and meaningful allyship that infuse cross-movement collaboration. Disabled leaders shared that they observed typical disability rights practices are often framed as an obligation, and not a fundamental pathway to democracy and civic power. Civic engagement practitioners shared the gaps in their knowledge around infusing disability rights within existing strategies beyond the framework of disability accommodations. Despite the calls from people with disabilities for cross-movement strategies, and effective allyship, embedding disability rights work in civic engagement strategies remains a challenge for the field.

Recommendations

Our respondents offered several forward-looking ideas for how to best advance the entwined goals of advancing disability rights and empowering underrepresented and marginalized people with disabilities to influence, participate, and engage in democracy.

Empower disability pride, voice, and identity through narrative change that include elevation of stories/experiences that challenge the ableist norms that inhibit civic power for people with disabilities.

Our participants identified stigma and ableism as barriers that prevent, minimize, and dismiss the participation and contributions of disabled people in civic leadership. Reversing these entrenched biases requires more than

policy and rights enforcement, but a narrative shift that is disability-led, upends norms and challenges ableism is needed. For instance, one disabled queer and Latinx woman described the impact a disability pride program had on the development of her own self-identity, *“At first there was this fear that if I do anything disability-related that’s all I’ll ever do. And then I joined the program and I realized this whole other layer of oppression that I didn’t even realize existed.”*

This particular program she noted was led by a disabled person, and fundamentally changed her perceptions around who in our society have leadership roles. Traditional narratives about who holds power in our democracy are rarely informed or led by people with disabilities. Work that changes dominant narratives around power and roles in democracy, one that elevates examples of people with disabilities leading movements, that is informed by the identities and histories of the disability rights communities they reflect, can as a result, foster notions of belonging and empower the disability community. Civic engagement is made more influential through the power a community wields to influence systems of government. Thus, it is critical that a narrative strategy to advance disability leadership, power, and voice is disabled-led and elevated as a value within cross-movement work. In the face of social stigma and ableist attitudes, grant makers can fund work that emboldens narrative change within social justice movements and civic engagement work to bolster disability pride and representation.

“Come to where we are:
the accessible spaces.

Facilitate cross-movement collaboration to encourage knowledge sharing, relationship building, and to illuminate shared values and goals between disability rights and civic engagement ecosystems.

Philanthropy is well positioned to convene, inform, and resource movement leaders to encourage knowledge sharing that would mitigate the harm caused by the siloed sectors of civic engagement and disability rights.

A Twitter chat participant provided an example of how to structure cross-movement collaboration: *“Come to where we are: the accessible spaces.”*

Grantmakers who support work that advances civic engagement will need to also support intentional efforts in cross-movement building and network weaving. Suggestions from survey respondents from both disability and non-disability groups included “provide disability rights history workshops,” “Anti-ableism trainings, webinars,” and “Disability history awareness, knowing how existing rights work, knowing how existing systems work, training that actually prepares people for advocacy work...”

“At first there was this fear that if I do anything disability-related that’s all I’ll ever do. And then I joined the program and **I realized this whole other layer of oppression that I didn’t even realize existed.**

Support disabled leaders who also identify with other marginalized communities across all areas of social justice issues.

Overwhelmingly, disability rights leaders shared that the limited or outright absence of a focus on disability rights are manifestations of civic engagement practices implemented without an intersectional lens. Repeatedly, marginalized disabled people emphasized that disability is embodied and represented across all demographics and social issues. Marginalized disabled leaders, such as disabled leaders of color, experience stark barriers in participation and representation across social movements in comparison to their white disabled counterparts. This gap in disabled leadership impedes cross-movement growth because it leaves out the vital intersectional expertise of disabled leaders of color who experience both ableism and racism for example. For instance, many as twenty percent of prison inmates reportedly have a serious mental illness.⁶ When considering police violence and the criminal justice system across race, disability, and

6 [Rebecca Vallas, *Disabled Behind Bars: The Mass Incarceration of People with Disabilities in America’s Jails and Prisons*](#)

poverty having the ability to apply multiple frameworks helps to deeply understand the cause and impact of these systems. This understanding is important to creating the solutions that will fight against, eliminate, and reimagine more just and inclusive alternatives. This level of knowledge and expertise can be provided by leadership that comes from disabled leaders of color and their communities who experience the greatest injustice within carceral systems. It is thus imperative that disabled leaders with marginalized identities have access to sustained support, training, and power to build coalitions and initiatives across social justice movements. Some ways this support can be bolstered and more intentional is by examining the traditional internships and leadership development opportunities in the civic engagement field that often are not geared towards people with disabilities. More specifically, in interviews with marginalized disabled leaders, several recommended that existing civic engagement programs that have traditionally provided coveted internships or other exclusive professional opportunities should re-evaluate their outreach, and recruitment processes to be inclusive and accessible for people with disabilities. Thus, increasing access to democratic power.



Position disabled-led organizations and coalitions as valued, equal partners in efforts to build a more inclusive democracy.



Empower

disability pride, voice, and narratives



Build

cross-movement relationships between philanthropy, civic engagement, and civil rights organizations



Foster

leadership skills among marginalized disabled people

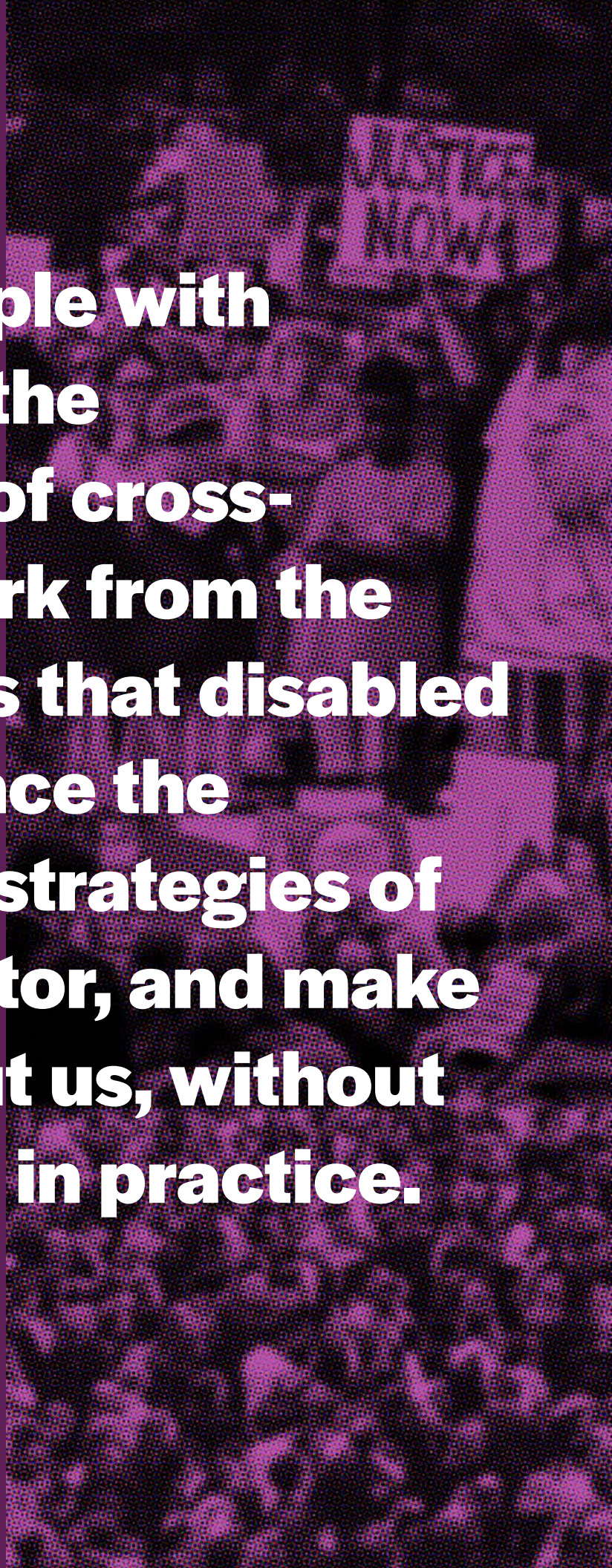


Ally

with people with disabilities from start to finish, rather than retrofitting disability inclusion in public engagement

Disability rights is a powerful conduit for civic engagement as the history of the disability rights and independent living movement has demonstrated. Still, in spite of those victories, disabled people have limited access to power, privilege, and influence within democratic processes compared to nondisabled counterparts. Intentionally elevating disabled leaders and disabled-led organizations might help reverse the tendency to retrofit disability rights as an afterthought to civic engagement strategies. Engaging people with disabilities in the development of cross-movement work from the outset ensures that disabled people influence the priorities and strategies of the public sector, and make “nothing about us, without us” actualized in practice.

Engaging people with disabilities in the development of cross-movement work from the outset ensures that disabled people influence the priorities and strategies of the public sector, and make “nothing about us, without us” actualized in practice.



MAKING CHANGE IN OUR COMMUNITIES

Many disabled people work to make their communities better. Working to make your community better is called “civic engagement.” Civic engagement includes voting, taking collective action, activism, and engaging with your community.

Civic engagement organizations often work with people with disabilities, but they don’t always know exactly what disabled people want and need. We heard from over 700 people who told us about the problems they had working with civic engagement organizations. They also shared ideas with us about how organizations can help them make lasting change in their communities.

Source: <https://youth.gov/youth-topics/civic-engagement-and-volunteering>



Courtesy of ADAPT/James O'Connell

People with disabilities face

3 major problems



when working with civic engagement organizations.

1

Discrimination

Discrimination makes it harder for people to feel confident about using their own voice to change their communities. Some kinds of discrimination include racism, sexism, ableism, homophobia, and transphobia.

2

Organizations Not Working Together

Civic engagement organizations and disability organizations may not work together on the same projects. Working together helps organizations learn from each other.

3

Organizations Not Listening to Disabled People

When organizations don’t listen to disabled people, they don’t know what they need and want to make their communities better.

“

I have a feeling that some people will view the disabled community and say, ‘Wow. The disabled community probably has enough challenges to deal with in their daily life. How can they even think about civic engagement and participation?’

“

Often when we talk about disability issues, we talk about charity, [the] poor, less than everyone else. We are the largest minority group in the world, but still, our rights, wishes, dreams are still unheard.



More than half the people we learned from told us that it was hard for them to get involved with civic engagement.

“ Nondisabled people still come from this baseline of pity a lot of the time. Thinking that we want special services, special places to live and special jobs for special people as opposed to access and integration.



How can civic engagement organizations help support people with disabilities who want to get involved in their communities?



Respect

disabled people's ideas, stories, and experiences. Let them lead the discussion about civic engagement and disability.



Support

leadership skills among people with disabilities who experience other kinds of discrimination like racism, homophobia, or sexism.



Build

relationships between disability rights groups and civic engagement groups.



Include

people with disabilities from the beginning instead of treating disability as an afterthought.

Introduction

Civic engagement must be an essential element of democratic practice if government is ever to be “of the people, by the people, for the people.” But for people with disabilities, this foundational practice is replete with barriers and challenges. People of color with disabilities, compared to their white nondisabled counterparts, experience even more limited access to existing pathways of participation and meaningful influence over government and civic life. Research in education, health, and employment, meanwhile, has long shown that people of color have limited access to opportunities and services. This social exclusion of people with disabilities and people of color is directly tied to underrepresentation in civic engagement.⁷ Consequently, even the public discourse and civic engagement efforts that most directly affect the lives of people with disabilities tend to center and privilege voices of white, nondisabled people. This directly contributes to a systemic imbalance of power and representation across all levels of US government and civic life.

Twenty-six percent of adults in the country have some type of disability.⁸ However, resources and avenues that engage people with disabilities in civic participation and leadership are rarely informed by the lived experiences from disability community members; rather, existing approaches may often be fragmented and/or influenced by social attitudes rooted in discriminatory barriers that people with disabilities continuously face. This perpetual marginalization of disability community voices in civic life has led generations of the disability community to be excluded from participation in our shared democracy. The lack of a stable foundation for meaningful civic engagement



for disabled people has meant disabled people hold disproportionately little power with respect to their social, economic and political progress. Both historic and recent social movements provide insight that civic engagement practices must center people closest to the problems and challenges those movements are trying to address. But many of even the most progressive of efforts, including contemporary civic engagement work, still do not include people with disabilities as active members and leaders. To disrupt the cycle of social, health, and economic disparities that systematically oppress people with disabilities, sustained representation and participation of people with disabilities in decision-making spaces is necessary. This must include and be led by disabled people inside and outside of traditional democratic processes. A truly democratic system that provides equitable opportunities for civic participation among marginalized disabled communities requires relationship building and allyship across movements, and across the public sector (civic, philanthropic, government, etc.). Philanthropy holds the potential to catalyze conversations around these necessary changes and support efforts led by people with disabilities to challenge ableist norms around power, representation, and participation and increase the influence people with disabilities have over systems, structures, policies and issues.

A democracy is, in theory, a system of shared power. But people with disabilities and disabled people of color have historically been disproportionately barred from this shared power and representation in comparison to their nondisabled counterparts. Civic engagement is one tool to navigate pathways of a democratic system. This practice comes in a wide variety of forms, which can result in various outcomes. But at its core, civic participation is about elevating and activating the voices and needs of all members of society to help shape a political and cultural world that is responsive and representative of its people. Despite efforts from the public sector (civic society, civil rights and civic engagement groups, etc.) to ensure our democracy is inclusive and durable, people with

⁷ [Robert Wood Johnson Foundation, “Culture of Health Sentinel Community Insights: Health Equity”](#)

⁸ [Centers for Disease Control and Prevention, *Disability Impacts All of Us*, 1](#)

No disability rights issue exists outside the sphere of civic engagement and no meaningful civic engagement strategy can emerge without attention to disability rights.



disabilities continue to be excluded by the very systems of power that promote egalitarian ideals.

This report presents a national overview of the barriers to civic engagement experienced by people with disabilities. Our learning comes from the expertise, insights and lived experiences of people with disabilities, including leaders from various disability communities. Drawing on our findings from surveys and interviews, we offer recommendations for the philanthropic and civic engagement sectors that aspire to a more inclusive democracy. Collectively, our findings reaffirm that no disability rights issue exists outside the sphere of civic engagement and no meaningful civic engagement strategy can emerge without attention to disability rights.

This report outlines the methodology implemented, data collected, and a set of recommendations derived from the qualitative and quantitative data synthesized. Below you will find the driving questions that shaped the process we used to gather the information through a variety of methods including an online survey, a Twitter chat, and interviews with leaders from civic engagement and disability rights communities. The second section, presents the insights and observations we gathered to inform our findings that characterize three principal challenges people with disabilities experience in civic engagement. The third section includes recommendations in response to these barriers. We conclude with concrete next-steps that philanthropy and civic engagement practitioners might take to move toward cross-movement allyship that would expand access to civic power among people with disabilities, and strengthen democracy.

For the 61 million people in the U.S. who live with a disability⁹, democracy is a story about limited and unequal power, voice, and representation, proving that our democracy has yet to fulfill its promise to all. For decades, disabled people have convened on local, state and national levels to fight against barriers that denigrated their personhood and denied their access to participate in a democratic society. These actions, led by people with disabilities, built the disability rights movement and often involved confrontations with ableist attitudes, and traditional institutions of democracy that have contributed to building civic power among people with disabilities. Civic power in this report is conceptualized as opportunities for people with disabilities to amplify, mobilize, and elevate their voices and influence within democracy. To this day, the disability rights movement continues to advocate for the rights of people with

disabilities to access health care, housing, voting, employment, public transportation, education, and other rights that other populations in this country also struggle to secure.

The disability rights movement was historically founded and led by white disabled leaders. This foundation has circumscribed disability rights practices, and perpetuated the falsehood that disability communities are homogenous and disability rights is one dimensional. The reality is that disability communities are diverse on all dimensions of human experience and identity. As several interviews with disabled leaders point out, disabled people come from every demographic across race/ethnicity, genders, sexual orientation, age, and among others. To be meaningful and effective, it is vital that disability inclusion is aligned with this intersectional understanding of disability identities. Still, thirty years after the passage of the landmark, Americans with Disabilities Act, much of our society perceives solutions to disability inclusion and disability rights as little more than the installment of ramps and elevators, or other architectural “fixes.” An intersectional lens is important to apply in efforts to build democratic participation and civic power because it illuminates the points, systems, and structures in our democracy that may privilege or restrain access to civic engagement for some and more so for disabled people. An intersectional disability approach to civic engagement would shift ongoing efforts towards a more representative society to involve many underrepresented disability groups in our democracy. This includes, for example, disabled people of color, people with disabilities who identify as members of the LGBTQ community, Native Americans with disabilities, formerly incarcerated disabled people, Deaf communities, youth who are disabled people of color, self-advocates with intellectual disabilities among many. A theme across our findings points to cross-movement building between disability rights and civic engagement as an area for growth, and that existing work must be amplified by guidance from disabled leaders to increase civic power with allyship from the philanthropic and civic. This report is structured to provide civic engagement practitioners and grant makers access to an array of perspectives that characterize existing challenges, and inform recommendations for cross-movement collaboration between disability rights and civic participation fields towards a more inclusive democracy.

I. Our Questions & Methods

To further the commitment of philanthropic and civic engagement practices towards an inclusive democracy, disabled people must inform collaborative strategies from the beginning. This understanding guided our research process and ultimately our findings. The findings and recommendations in this report intentionally elevate the voices of disabled people including disability rights leaders who are also LGBTQ, people of color, and young people among other identities.

Our report explored four areas of inquiry:



How do people with disabilities and leaders in the disability rights community conceptualize and define civic engagement?



How do disabled people and leaders in the disability rights community characterize current opportunities and activity within the civic engagement ecosystem?



To what extent do traditional civic engagement organizations implement disability rights frameworks into their programs, and practices? What questions do existing civic engagement practitioners have about disability rights?



How might philanthropy, civic engagement practitioners, and disability rights leaders work together to create more opportunities for accessible, equitable, and meaningful civic engagement practice?

These questions were shaped by members of the disability community and by our own assessments of disability-related knowledge gaps, both in the philanthropic sector and among civic engagement practitioners. We sought data and insights from the following groups:

- **disability rights leaders,**
- **disabled people who are involved with the disability community** in various capacities,
- and **representatives from civic engagement groups** that are not directly focused on disability rights.

Our avenues to gather information were informed by existing practices commonly used by the broader disability community, including an online survey, a facilitated Twitter chat, and interviews over-the-phone or via video chat with disabled leaders and civic engagement practitioners. Each of these data collecting methods has its limitations. Our information comes from those who have internet access, are native English speakers, do not live in institutional settings such as nursing homes, and those who have the privilege of internet access and computer literacy. Because of the layered systemic inequality that bars people with disabilities from full participation and access to public life, many people with disabilities live in institutions and/or have no access to the internet, on which much of this research relies. As a result, this report does not embody a full picture of disability rights in civic engagement. In considering next steps to further the work of building an inclusive democracy, we suggest that future research should purposefully oversample for disabled people of color and disabled people who are LGBTQ, and identify with other marginalized communities including disabled people living in institutional settings, and/or people with limited access to the internet.

II. Findings: Disabled People Experience Democracy as Fragmented, Inaccessible, and Ableist

Our data show that for people with disabilities, our democracy is a fragmented, inaccessible, and ableist system. Despite the increased focus on inclusion across our society, when it comes to civic engagement, people with disabilities and the disability rights community are treated as a group of “people with special needs.” People with disabilities are typically welcomed in civic spaces only to provide solutions to immediate physical access barriers or to represent “disability issues” such as those that manifest in health care or special education. This limited engagement, dismisses the fact, that disabled people and the larger disability rights community are also leaders, participants, and contributors throughout our democracy. Although laws and policies exist to integrate people with disabilities in society, there remain significant barriers to full and consistent inclusion of people with disabilities as equal participants, and leaders in our civic life. We discovered a need for increased understanding about the ways that social notions around disability inform self-identity and civic participation. Participants elaborated on the ways in which damaging stereotypes

around disability prevents positive self-identity among disabled people, and as a result, dissuades disabled people from participating in the collective civic power of advocating for disability rights. The insights from these findings indicate civic engagement practitioners are routinely uninformed about how to meaningfully incorporate disability rights within current civic engagement strategies.

The failure to holistically integrate people with disabilities and a disability rights lens in civic engagement approaches and social justice issues is a missed opportunity to strengthen the social justice movement by truly incorporating an intersectional approach to the work and an opportunity to activate a large population. **People with disabilities in our study conceptualize civic engagement as essential for their social, political, and economic livelihoods, and as an integral mechanism that enables a place and a degree of power in a democratic society.** Insights from interviews, online engagement and survey find that people with disabilities and leaders in the disability rights community conceptualize civic engagement as a necessity for their existence. Despite this deep commitment to civic engagement, our survey taken by people with disabilities living in the U.S. revealed that 57 percent of respondents “Experienced barriers to participate in civic engagement.”

Across our interviews with disability rights leaders, descriptions of civic engagement and disability rights were frequently tied to social experiences of daily living. For example, a disabled woman who ran for public office shares: *“I think like a lot of people with disabilities, (civic engagement) is one of those things that you kind of inherit whether you want to or not. It’s really hard to separate (disability rights and civic engagement).”*

We sought data and insights from a) disability rights leaders b) disabled people who are involved with the disability community in various capacities, and c) representatives from more broadly focused civic engagement organizations.

We gathered information through interviews, online engagement and an online survey. We conducted 18 interviews across both Ford Foundation’s civic engagement grantees and with leaders from the disability rights community¹⁰. We also facilitated a #DisabilityCivics Twitter chat, co-hosted by Alice Wong of Disability Visibility Project. This moderated chat engaged 272

contributors who are a representative slice of disability community members active on Twitter. Finally, an online survey of self-identified people with disabilities living in the U.S. resulted in responses from 360 participants.

We learned that the drive for people with disabilities to be civically engaged is two-fold: inclusion through opportunities to participate in the community, and the power to drive change to improve the quality of life for themselves, the disability community, and the people they care about. An autistic queer woman who is a disability rights leader elaborates on the entwined nature of these two concepts: “[civic engagement] *should be a participatory process. There are going to be rules and policies and decisions that affect my life and I should be able to have a say in them and civic engagement is how I do that.*”

“ **There are going to be rules and policies and decisions that affect my life and I should be able to have a say in them and civic engagement is how I do that.**

Many disabled research participants described civic engagement as a direct route to influence and social change. Others evoked connectedness to community as a product of being civically engaged and thus helping them affect positive changes in their everyday life. According to an autistic disability rights leader who identifies as black and transgender: *“it is about being connected to the community around you and making steps to either change policies, laws, or the culture around you.”* Several disability rights leaders shared stories about what compelled their initial involvement in disability rights and civic engagement. These stories often depicted moments when their rights as a disabled person were denied and they were required to use pathways to democratic participation to access equal opportunities for work, school, health and other settings. Listening to disabled people describe what civic engagement means to them, it is clear that whether it is through voting, attending town halls, writing letters to public officials, joining rallies, coming together with other disabled people, or participating in online discussions they are quite consciously motivated by gaining access to

¹⁰ Among the 13 disabled people who were interviewed - 6 identify as a disabled person of color, and 3 identify as a disabled LGBTQ person of color.



People with disabilities in our study conceptualize civic engagement as essential for their social, political, and economic livelihoods, and as an integral mechanism that enables a place and a degree of power in a democratic society.

power in order to generate changes that lead to a more inclusive society.

This framing of civic engagement -- access to civic power in order to expand equal opportunities to participate in and be represented in a democratic system -- is rooted within disability rights advocacy, and guides the disability rights movement. Disability rights leaders have consistently and constantly fought for improvements in our democracy that safeguard, and ensure people with disabilities have equal rights and opportunities to participate in our society. To people in the disability rights community and disabled leaders we spoke with, civic engagement and disability rights are closely related in their aims to direct change through an inclusive process towards a more responsive, representative, and equal society. Many disability rights leaders we interviewed noted the phrase “Nothing about us without us” which is an often-repeated statement that crystallizes the driving principle of the disability rights movement. It refers to the fact that people with disabilities have the right to actively participate, be informed about, and be represented in all matters and sectors of society. Our research, however, illuminated gaps between this driving principle and the on-the-ground experience of people with disabilities in civic engagement spaces. We elaborate on each of these below.

1. Social stigma and ableism are obstacles to civic participation for people with disabilities, and in particular for disabled people who also experience oppression due to racism, homophobia or transphobia, and other socially marginalized identities.

To dismantle systemic discrimination that people with disabilities experience across all sectors of society, including democratic participation, we must first understand the harm of pervasive stigmas that contribute to ableism and normalize discrimination. Thirty-four percent of our survey respondents indicated that various aspects of their identity, including religious affiliation, race/ethnicity, disability status, gender identity, and/or sexual orientation has “A lot of impact” on their participation in civic engagement. Specifically, several participants pointed to experiencing ableism because of their disability status. Another participant mentioned the gaps in accessing opportunities to participate in internships as a black disabled woman. Among other examples that are provided throughout this report, it underscores the barriers to civic power for people with disabilities that stem from social stigma and ableism.

Our interview participants in this project revealed that civic engagement practices have a limited understanding around the way disability identity is conceptualized and intersects with other identities shared by people with disabilities.

Attitudes shaped by cultural norms devalue, isolate, and “other” people with disabilities, thus inhibiting access to civic engagement.

Ableist attitudes, including those that send a message that people with disabilities are not already active contributors towards a more inclusive democracy, prevent disabled people from participating in democratic pathways to social change. Our respondents identified several conditions that engender and sustain stigma and ableism.

One survey respondent further emphasized this point, “*As a disabled person I face stereotypes and bigotry about people with disabilities. My credibility is always in question. No one presumes my competence.*” In other words, negative stigma and perceptions of disabled people obstruct meaningful civic participation in society. Importantly, disabled people we spoke with view disability as a contributor to human diversity, rather than only as a consequence or outcome of illness. On the contrary, disability in our broader society is often misconstrued as an aspect of a person that is “less than,” or should be pitied, or “overcome,” or “cured.”

A response from our survey further elaborated on these attitudes, “*So often when we talk about disability issues, we talk about charity, [the] poor, less than everyone else. We are the largest minority group in the world, but still, our rights, wishes, dreams are still unheard.*”

The typical framing of people with disabilities in mainstream society perpetuates the idea that individuals themselves need to “rise above” challenges. But those challenges are, in actuality, created by systemic ableism, and negative stigma that marginalizes people with disabilities. Consequently, our research suggests that the message that it is up to disabled people to “overcome challenges” becomes internalized by people with disabilities. As a young queer disabled Latinx woman described during an interview: “*I thought, you know, based on what everything in society was telling me, if I’m just really productive and I’m really positive, I can overcome disability-related oppression.*”

These socialized norms and attitudes about people with disabilities may stem from ignorance about the transformative contributions disabled leaders have made to strengthen our democracy. One disability rights leader who is a woman of color spoke of ahistorical assumptions

about disabled people's contributions: *"I have a feeling that some people will view the disabled community and say, 'Wow. The disabled community probably has enough challenges to deal with in their daily life. How can they even think about civic engagement and participation?'"*

Ableist attitudes, including those that imply that people with disabilities have not been -- and cannot be -- active contributors towards a more inclusive democracy creates obstructions that discourage, and limit disabled people from civic participation. But as many disability rights leaders pointed out in our research, it is these very barriers to civic engagement that create the disparities and inequities that people with disabilities experience in their daily life. For instance, a voter requires access to transportation in order to exercise the right to vote; however, for many people with disabilities, accessible transportation including living in a community that presumes their self-autonomy, are barriers to exercising this fundamental right. These barriers are contributors to the cycle of disenfranchised voters with disabilities whose voices and access to rights become routinely unrepresented during elections. Other barriers that contribute to diminished civic power include: quality health care, appropriate supports for community living, competitive gainful employment, education, among other examples.

These pervasive narratives prevent many people with disabilities from developing a positive disability identity. In turn, the stigma attached to disability identity, culture, and live experiences makes it more difficult for the disability rights community and its organizations to grow civic power among disabled people. Our survey of disabled people living in the U.S. shows that 65 percent "Strongly Agree" that "Having leaders in government who identify as people with disabilities is important." Despite this importance of disability representation in government, our findings point to the ways that attitudes prevent greater civic participation for disabled people, which in turn results in limited representation.

A disability rights leader who is a woman of color elaborated on this relationship between identity and civic engagement:

"In order for us to show up for disability rights work, we need to feel like we have some sense of belonging and some sense of community outside of that work. We have a lot of people who by textbook definition are disabled, don't want to identify as disabled, they perceive it as a negative thing."

This illustrates the harm that uninformed narratives

and stigma around disability can have upon people with disabilities' self-concepts and their chances of connecting to a broader disability community. Three ways that civic engagement yields change and grows power is through community-building, expanding social movements, and establishing coalitions. Disability stigma and its harmful impact on disability identity effectively inhibits access to these pathways to social change and power building.

A disabled staff member at a disability rights organization working to expand voting access elaborated on this connection: *"If our people do not identify as being a part of our community, do not connect with a movement, then they are not necessarily out there advocating for disability rights. They are not necessarily even voting in their own best interest."*



*"If our people do not identify as being a part of our community, do not connect with a movement, then they are not necessarily out there advocating for disability rights. **They are not necessarily even voting in their own best interest.**"*

Inauthentic narratives about disability embedded in public life prop up harmful stigmas that prevent access to civic engagement.

People with disabilities are rarely reflected in the narratives and experiences that exist in mainstream society. And when stories about disabled people do appear in the news or media for instance, the reporters are not typically themselves disabled nor are news stories informed by people with disabilities. In doing so, this widely accepted practice in our society continues to perpetuate harmful and damaging perceptions of people with disabilities. Stories about people with disabilities and the social conditions and challenges that affect disabled people must centralize disability as an active contributor rather than provocative subjects for headlines. For example, one Twitter chat participant wrote: *"I would like to see members and established community representatives and organizers supporting disabled people who are running for a local office instead of treating it like it's a media stunt."*

Representation of people with disabilities in mainstream news is so woefully misguided that the focus is often superficially related only to that person's disability rather than reporting on the issues that are important to

people with disabilities or drawing upon the expertise, knowledge, and ideas that people with disabilities offer. To illustrate this point, a disabled woman who ran for public office in her state noted the condescension in articles written on her candidacy by nondisabled reporters: *“They were like ‘oh my gosh, she can speak and she can speak intelligently.’ And then people were impressed.”* She noticed that nondisabled candidates for public office are not expected to first prove their ability to speak; these perceptions of people with disabilities sets a low bar for inclusion in the democratic process. This adds to harmful attitudes and detracts from civic power and voice for people with disabilities.

People with disabilities are often depicted as inspirational, pitiful, and given other patronizing characteristics that minimize their intellectual contributions to debates around social issues and their work to society more generally. For example, a disability rights leader who identifies as a queer and autistic woman offered this observation: *“Nondisabled people still come from this baseline of pity a lot of the time. Thinking that we want special services, special places to live and special jobs for special people as opposed to access and integration.”*

Another example of this is the notion that people with disabilities need to be “fixed.” This fallacy, that disabled people who “overcome” disability are somehow absolved from the challenges they experience, results in misguided approaches to disability rights and disability inclusion practices. Disability rights protect and empower equal opportunities for disabled people such as education, housing, public transportation, and the right to vote. However, our research participants report that ostensible “disability inclusion” efforts in various sectors of society frame disability rights as a solution – or a “fix” -- for being disabled rather than a civil rights-oriented approach to an unequal society.

A disabled woman of color who is a leader in both civic and philanthropic spaces reflected on this idea of “fixing something”: *“When we come together [in my work] we’re not trying to fix our disability, or change physical environments to adapt to us, or change work spaces, or change physical spaces. We’re just coming to say, ‘This is my experience. It is valid as it is.’”*

The work she described elevates disability community pride by sharing and integrating the lived experiences of people with disabilities as an important component of broader diversity and inclusion initiatives.

Another illustration that surfaced of the problematic

approach to “fixing” a person with disabilities as opposed to addressing systemic problems in our society was in the context of when a disabled person shows up at the polls to vote. Voting should be a routine and fundamental pathway to civic engagement, but for too many disabled people, the experience of voting comes with being presumed incompetent. Several disabled people in our research shared moments when poll workers have insisted they “assist” by completing the ballot for the disabled person. This effectively dissolves the right of a private and independent vote, a right that is made possible and empowered by accessible voting equipment for people with disabilities.

A consequence of assuming the inability of disabled people and overlooking disability civil rights is that nondisabled civic leaders come to advocate for people with disabilities versus advocating with people with disabilities.

A disabled woman who ran for public office elaborated: *“People have often tried to control the message for the disability community – of wanting to ‘provide a voice for the voiceless.’ Well, whoever said that there weren’t voices in the disability community? There’s plenty of voices, you’re just not providing an outlet or a seat at the table for that community.”*

People with disabilities are patronized and/or dismissed in mainstream civic engagement practices, making collaborative movement-building work more difficult.



People are impatient with my communication difficulties.
They assume I have nothing worthwhile to say.

An integration of disability rights in social justice issues would involve disabled people as equal contributors to inform the strategies that would yield desirable outcomes. But typical attitudes and practices presume disabled people are passively waiting for their “special needs” to be addressed, or dismiss their civic role completely. A comment from our survey highlights an example how this dismissive behavior shows up in exchanges, *“People are impatient with my communication difficulties. They assume I have nothing worthwhile to say.”*

Our research also pointed to the specific ways that ableism

limits the capacity organizations have for meaningful disability rights practices. Often times, ableist ideas and practices underpin organizational structures, cultures, and principles that obstruct engagement and access to power for disabled people. Examples of this challenge that our participants shared involved, an organization's board including disabled people without providing appropriately accessible materials for meaningful participation during meetings, or utilizing internal evaluations on diversity efforts that do not include questions about disability. These examples, illustrate some of the ways organizational procedures can prevent meaningful engagement and true integration of people with disabilities.

Harmful attitudes and stigma contribute to these normalized conditions. A woman who is a disability rights leader within city government, articulated the harmful ways ableism erases disability rights from societal conversations: *"People just don't see us [disabled people]. We're totally there but I feel like that is part of structural ableism. We're not even on the radar. But we are part of everything that you are doing. Ableism is the problem. Disability is not the problem."*

She shared a story of being invited to advise a municipal group on disability inclusion efforts. She noticed that their existing survey mechanism was inaccessible to people who speak ASL, and/or who were blind and thus not inclusive of people with disabilities. A different research participant who is a queer disabled attorney shared that despite wanting to work for a candidate's campaign, she was unsure how to access the supportive infrastructure she needed in order to become involved. *"The core things that people seemed to be doing were either door-to-door canvassing or phone banking, and neither of those things felt accessible to me. I couldn't do that sort of on the ground work because I wasn't sure who to ask to figure out what that could be like for me."*



... The disabled community is so much more than broken ramps and broken elevators. And I feel like if I could be freed from that obligation, then I could be much more engaged.

She added that much of her civic engagement efforts are spent on navigating failures in infrastructure: *"... The*

disabled community is so much more than broken ramps and broken elevators. And I feel like if I could be freed from that obligation, then I could be much more engaged."

Our respondents suggest that ableist attitudes contribute to the underrepresentation of disabled leaders in traditional democratic institutions. This barrier is aligned with findings from a 2017 report from Rutgers University, which found that people with disabilities are vastly underrepresented in government.

Only about 10 percent of elected officials self-report having a disability while 26 percent of adults in the US have a disability.¹¹

2. Discrete networks and lack of intentional overlap of civic engagement and disability rights ecosystems impede opportunities for shared learning, collaboration and equitable, effective allyship.

Twenty percent of people with disabilities from our survey reported that they engage in disability rights work with "Members of the disability community."¹² This is compared to eight percent who work with "Civic engagement organizations that are not disability rights groups," and 13 percent who work with "Civic engagement organizations that are disability rights groups." In other words, when it comes to civic engagement people with disabilities are more likely to be involved in disability advocacy with other disabled people, and disability organizations than they are with traditional civic engagement organizations. This suggests mainstream civic engagement organizations are not engaged with, or informed by the insights and lived experiences of disability rights leaders, who deeply understand and can act upon the inextricable link between disability rights and civic engagement. This lack of overlap between movements creates silos that obstruct cross-movement collaboration, and erect barriers to civic participation for disabled people - many of whom elaborated on feelings of being "tokenized" in their experiences of civic participation.

People within civic engagement organizations typically perceive disability rights as "disability issues."

Disabled people are somehow seen as separate from broader efforts to build a fairer, more representative and inclusive democracy.

¹¹ [Lisa Schur and Douglas Kruse, "Elected Officials with Disabilities"](#) (October 3, 2019)

¹² This data is indicative that further research around the groups and organizations disabled people work with to access opportunities for civic involvement is necessary.

One of our survey respondents described this experience of separation in practice, *“Disability is often ignored as a perspective, not understood as relevant to critical social issues.”*

Our research indicates that cross community movement-building efforts between civic engagement and disability rights groups are inconsistent, and not embedded across civic engagement priorities. Typically, disability rights are considered an extension of the disabled person’s “needs” rather than a means to empower, and a pathway to equal access for participation in the democratic process. This has resulted in perfunctory disability rights practices, ineffective allyship between disability rights and civic engagement efforts, and an incomplete understanding of shared concerns related to democracy.

This disconnect further marginalizes disabled people. A disabled lesbian at a disability rights organization made this point: *“every issue is a disability issue and making sure representation on these issues reflect that is important. Disabled folks should actually be at the table not just as representatives of disability, but as issue experts who are also disabled.”* This connection, if implemented into civic strategies, would demonstrate an understanding of disability rights, and an acknowledgement of a disability community as a powerful group whose role in democracy is vital. Additionally, it would also strengthen civic engagement strategies by demanding more robust strategies that would also activate and engage new communities for their campaigns and social justice efforts. A young black disabled woman who is a disability rights leader pointed to the problem of a lack of transportation access for disabled voters in rural areas. This is a voting rights issue, a transportation issue, and a disability rights problem, and could be most effectively addressed through partnership among various organizations. An informed intersectional strategy to reduce voter suppression could engage both civic engagement efforts in rural areas, and develop improvements to public transportation access for disabled people in rural communities.

The separation of disability rights from existing mainstream civic engagement work means that our democracy will not fully represent and be responsive to everyone. Civic engagement approaches that are inclusive of disability rights strategies would more meaningfully address challenges related to various social justice and civil rights issues, including disability rights. These include racism, ableism, poverty, white supremacy, social stigma, and civic apathy among others that leaders from both sectors have been working to abolish within their own

spheres. Cross-movement building work between civic engagement and disability rights spheres would build the bridges to turn our nation’s promise of a government that is by the people and thus represented of the diversity in communities. As a black disabled woman at a disability rights organization said: *“I think that we have to constantly remind all the different civil rights organizations that people with disabilities exist. We are a part of your communities. There is a lot of power in our collaboration.”*

Across civic engagement spaces, nondisabled people continue to erroneously view the disability community as homogenous.

Disabled leaders of color we spoke with described the ways that intentional cross movement collaboration would more accurately reflect the ways they perceive themselves, and their place in civic engagement activities. In typical civic engagement spaces, disabled people of color feel they are expected to “juggle” multiple identities, for example racial and ethnic identities separately from their disability identity.

The perception among many disabled people of color who participated in our research is that current civic engagement strategies are established with a one-sided understanding of disability rather than being expansive, inclusive, and welcoming of the identities many multiple-marginalized disabled people hold. As an example, an autistic black woman talked about the decisions she needed to make when participating in Black Lives Matter protests. *“A lot of the rallies weren’t always very accessible. Black me would love to be up there, but you know disabled me can’t do that. And they are still me.”* Needing to choose – or being forced to choose – between identities is an experience that limits civic participation, particularly for disabled people of color. It’s important to note that the impact of this can also be felt in disability rights spaces too. One queer Latinx disabled woman commented on how this is present in disability rights work: *“if you’re doing disability work, it’s on disability only. And if you try to bring something else to the pot, especially older disabled people get real mad.”* Another response from our survey was shared to illustrate this challenge within the disability rights community, *“As a trans person, most of the disability rights movement has NO clue who we/I are. Most of the conversation exclude us through language use and binary ways of thinking. I am tired of feeling alienated in these spaces.”*

Disabled people represent and hold a multitude of identities. Many people with disabilities shared their perceptions of a civic engagement ecosystem absent of

this understanding, and where people with disabilities are perceived as a homogenous group. As a mother who is a black autistic woman and a disability rights leader noted: *“The disability community cuts across every single community in terms of gender, socioeconomic status, race, and so forth. I think that’s something that is not recognized and understood well.”*



The disability community cuts across every single community in terms of gender, socioeconomic status, race, and so forth. I think that’s something that is not recognized and understood well.

Even when disabled people of color participate and contribute in mainstream civic engagement spaces, many have felt tokenized there due to the ways that civic engagement practitioners view disability inclusion. A disabled woman of color who acknowledges her privileges in being asked to speak in civic engagement spaces said: *“I’ve been given access to spaces that a lot of people who look like me haven’t. And I feel extremely grateful, and privileged, and honored to be in those spaces.”* This sense that being included in certain civic engagement convenings is like breathing rarified air reveals that the work of disability inclusion has yet to become standardized practice. She went on to describe the risk involved in these environments, *“But I know the responsibility that I hold to try and open the door for more people to be able to come in. We need to do a really good job because if we don’t do a good job, then we further perpetuate negative stereotypes around disability.”* Many disabled leaders of color we spoke with echoed these risks due to the limited and infrequent opportunities to be present in mainstream civic engagement efforts. Moreover, this quote illustrates the multitude of expectations that land on disabled people of color that compound this pressure. A disabled leader who is a white woman working in local government highlighted the need to elevate the perspectives and expertise of disabled people of color, *“not only do [disabled people of color] have to deal with all of the ableism in the universe, but you have to deal with all of the racism too. Then when [a disabled person of color] is invited, they’re expected to do all of the work around it.”* This work includes the prerequisites acquired to be invited to these spaces, as well as, being on the agenda, networking with other civic leaders, and simultaneously furthering the priorities of disability rights. Our collective efforts to create a truly representative democracy will fail until the disability

rights and other civil rights groups can implement the understanding from the outset that disabled people have diverse and intersecting identities.

3. Leaders of civic engagement organizations and movements recognize the need to include disability rights in their work. However, the realities of civic participation for people with disabilities suggest that this recognition is not translated into practice.

Our findings showed that disability rights leaders and community members understand the ways disability-related issues manifest in the civic engagement realm. This includes concerns about access to polls, a lack of meaningful early-career opportunities in the workforce, including government, accessible organizing and advocacy, challenges of participating in rallies, and barriers to testifying before local government and state government bodies. However, disabled people often become an addendum to existing practices. In this sense their contributions, leadership, knowledge, and lived-experiences are at best, presumed an exception that comes with “special needs” and accommodations. At worst, disabled people become non-existent despite a democracy that extols equal representation of everyone. This perception was widely held among people with disabilities and leaders from the disability rights community.

Using a cross-movement building approach requires leaders from both sectors to share knowledge in order to identify mutual challenges. This provides an equal opportunity for disabled people to shape strategies. Currently, civic engagement practices are, at best, typically retrofitted for people with disabilities and the responsibility to name the exclusion of a disability lens is oftentimes placed on the disability community. Thus, the responsibility is not shared across movements. In our interviews, a staff member at a civil rights organization provided an example on how previous messaging for a civic engagement campaign contained ableist language about “standing” up. After conversations with disability rights organizations in their coalition, this messaging was corrected to become more inclusive and welcoming to disabled people. This story, along with others that were shared, is an example that usually addressing exclusion of people with disabilities from civic engagement efforts is often the responsibility of the disability rights community, and its leaders, instead of a shared responsibility among leaders across various movements.

While people with disabilities have particular vantage points that allow for them to illuminate barriers to

access pathways to democratic participation, this does not mean that they are always able, themselves, to shift well-established processes within civic engagement and government spaces. This requires cross-movement awareness raising and action. The lack of awareness and practice from the public sector, inadvertently leaves people with disabilities out of these spaces and opportunities. When civic engagement practitioners do not acknowledge that people with disabilities are a core contingency to democratic representation, this communicates that disabled people are inconsequential to democracy and civil liberties. Cross-movement building work can help correct this problem by amplifying the vitality of the disability rights community within civic engagement practices. For instance, civic engagement organizations that retweet messages from disability rights organizations is a small example of carrying disability rights into civic engagement spheres. It demonstrates allyship by signaling that disability rights issues belong within civic engagement. But instances of even this easy allyship are few and far between, while also frequently requiring that the disability rights community initiate. Civic engagement organizations that are not disability rights focused often described disability rights groups as partners they rely upon for expertise in “disability issues.” This practice is in conflict with the insight from disabled people that disability rights must be present in all civic strategies because people with disabilities exist in every area of public life.

Inaccessibility is a prominent challenge across pathways of civic engagement and obstructs access to fundamental ways of participating in democracy, including voting.

Our research participants shared their perceptions of inaccessible civic engagement practices. Among those who participate in some form of civic engagement, more than 20 percent of our survey respondents identified “inaccessibility” as a barrier to civic engagement. This data from our survey embodies multiple considerations to accessibility challenges beyond physical and architectural barriers.¹³ As people with disabilities reiterated in earlier findings, disability communities are not homogenous. For example, people with intellectual disabilities encounter inaccessibility in civic engagement, but this is not necessarily related to a lack of ramps or a broken elevator. A disability rights leader who is autistic, black, and trans noted the importance of a broad understanding

of accessibility: *“creating accessible materials is a form of epistemic justice. It allows people to have access to knowledge that they would not have had otherwise.”*

Many disabled leaders we interviewed pointed out that in



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Creating accessible materials is a form of epistemic justice. **It allows people to have access to knowledge that they would not have had otherwise.**

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civic engagement spaces, the access needs for people with physical disabilities are prioritized over accommodations for people with multiple and/or intellectual disabilities. Wheelchair users, for instance, may experience few physical barriers while attending conferences, but typically in these settings, conferences presume attendees have skills in navigating conference rooms, absorbing content in a traditional presenter-to-audience structural format, negotiating social networks, and all the while maintaining an often overly demanding schedule. Despite the fact that conferences are privileged places, for people with disabilities they typically are also rife with multiple access challenges that compromise full participation. Conferences are environments that have the potential to generate effective cross-movement allyship, but when access is implemented merely as a “fix” to physical accommodations, this can serve to further marginalize people with disabilities.

There are inclusive practices that have become standard within most disability rights communities. This ranges from hosting civic events in locations with accessible unisex restrooms (as opposed to separate gender-neutral and accessible bathrooms, requiring individuals to choose between one or the other) to having CART and ASL interpreters at all public events. But our research indicates that civic engagement practitioners have yet to universally adopt these types of practices unless it is requested by a disabled person, and/or the event has specific relevance to disability rights. People who are Deaf and/or hard-of-hearing often need to disclose their disability-status in civic engagement spaces in order to have some semblance of equal access, as they must request an ASL interpreter, CART, captions, and/or request that speakers use microphones at all times. Access facilitates knowledge, communication, representation, agenda-setting, and thus enables active participation in a democratic process.

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<sup>13</sup> This data indicates that further research and understanding is needed around the ways that people with disabilities who participate in civic engagement perceive these challenges.



Another example around access was illuminated by a young black disabled woman at a disability rights organization talked about difficult choices she had to make while exploring early-career options. Considering two internship opportunities, she recognized that one provided a stipend and supportive information for applicants to find accessible housing. The other offered neither. Both provided early career professionals with experience in democratic institutions, but the program that provided intentional support for finding accessible housing was the one that enabled her to participate. This program was instrumental in the early stages of her disability rights career. Programs that are truly embedding disability rights inclusion strategies expand access to participate; however, instances like the one she described typically require disabled participants themselves to ‘piece together’ their own avenues of accessible pathways to participate such as resources for accessible housing, and learning to navigate public transportation in a new city. Another perspective on this comes from a disability rights advocate who worked for a member of Congress: *“There just has not been the level of care and attention given by hiring managers within Congress to making sure that disabled people are included as part of the diversity initiative... we’re never going to get anywhere until we start making it a priority...”*


Democracy requires informed decision making, accurate and accessible information about choices, and the freedom to make choices to participate in a democratic process. Without accessible information and the knowledge to empower participation, many people with intellectual disabilities may be shut out from meaningful democratic participation. Even when people with intellectual disabilities, Deaf people, people who are nonverbal, or neurodivergent people are included in civic life, the information to participate and make informed choices is presented in ways that do not empower their civic life.

A disability rights leader with intellectual disabilities shared: *“All means all. And when you do not use words that I can understand in meetings – even when I am in the room – you are not being inclusive.”*

Among civic engagement practitioners it is vital that this framing of access is broadened to create increased opportunities for all members of our society to participate in the choices that have lasting impact on their well-being. During a Twitter chat discussion, one participant recommended ways to expand access and outreach through the use of plain language and Easy Read materials.

This person also suggested ways to broaden the framing of access in practice by suggesting that all events that are open to the public should be as physically, financially, and cognitively accessible as possible. An autistic disability rights leader who is a person of color and trans added: *“When the information is written in a way that is understandable and accessible without attempting to talk down to people or speak over them that is meaningful access to content. Particularly content that has been made within the disability community is a really large piece that’s missing.”* This example demonstrates how allies in civic engagement spheres can move beyond “parroting” the disability rights mantra “nothing about us without us,” towards actualizing civic power for people with disabilities. For example, more broadly defining “access” can generate civic power for people with disabilities. However, our findings suggest that civic engagement practitioners lack understanding of the varied ways that access is understood and experienced by disabled people.

For disabled leaders and the disability rights community, access is integral to inclusion which also enables visibility, participation, and representation. Having access means having civic power to influence practices and policies that affect people’s lives.

 **When the information is written in a way that is understandable and accessible without attempting to talk down to people or speak over them that is meaningful access to content.** Particularly content that has been made within the disability community is a really large piece that’s missing.

***Mainstream civic engagement practices often implement minimum-standard disability rights frequently without the leadership of disabled people.***

By involving disabled leaders from across disability communities at the start of developing civic engagement strategies, implementing disability rights moves away from an obligation towards actualizing disability rights within civic engagement efforts. This statement from a member of the disability rights community who is a disabled lesbian illuminates the lack of meaningful commitment many disabled leaders perceive among civic engagement allies: *“Changing people’s attitudes around*

*disabled people's participation in civic life is important, understanding that we do have a right not just in legalese, but to be fully integrated into this experience above and beyond legal obligations is important."*



**All means all. And when you do not use words that I can understand in meetings – even when I am in the room – you are not being inclusive.**

Several research participants suggested that efforts to volunteer during natural disasters should be coordinated with informed disability groups and leaders already doing this work across disability communities. Unfortunately, it is commonly the case that only after media attention is drawn to instances of disabled people who are left behind and/or isolated that coordinated, and inclusive planning becomes a priority.

An autistic disability rights leader who at the time of the interview worked as a congressional staffer shared experiences of this in practice: *"People start out crafting policies and then they have to double back and incorporate the disability community's concerns. We're not at the table from the beginning. We always need to be."*

Twenty percent of people with disabilities from our survey reported that they engage in disability rights work with "Members of the disability community." This is compared to eight percent who work with "Civic engagement organizations that are not disability rights groups," and 13 percent who work with "Civic engagement organizations that are disability rights groups."<sup>14</sup> This suggests that people with disabilities are more likely to be involved in disability rights work with other disabled people, and other disability rights affiliated organizations than with traditional civic engagement organizations that do not have a specific disability rights focus. It is also an indication that mainstream civic engagement organizations are neither exposed to nor informed by the insights and lived experiences of disability rights leaders who understand and act upon the inextricable link between disability rights and civic engagement efforts.

Disability rights are civil rights, and disabled people have power to wield these rights to contribute to and be represented in our democracy. Disability inclusion, although it may be an abstract principle of civic life, is

always going to be limited by the extent to which disability rights are embedded in civic engagement practices. A respondent from our survey wrote: *"We need our allies to not just parrot 'nothing about us without us' but to respect that and push for that engagement."*

### III. Recommendations: Forging Cross-Movement Pathways Towards an Inclusive Democracy

Throughout the process of gathering information for this report, disabled people shared concrete examples of ways that cross-movement strategies could more effectively build durable systems of democratic participation and civic power for marginalized people. Disabled people who informed this study ask us to imagine standardized practices such as remote access for Congressional, state house, or town hall testimonies. Several disabled leaders spoke about the power that could come from a network of disability cultural centers across the country. Still, other people with disabilities hoped for a future where disability history was included in curriculums within mainstream youth leadership development programs. These concrete suggestions and several others that we share below come from disabled people who have faced barriers to full civic participation.



## Empower

disability pride, voice, and narratives



## Build

cross-movement relationships between philanthropy, civic engagement, and civil rights organizations



## Foster

leadership skills among marginalized disabled people



## Ally

with people with disabilities from start to finish, rather than retrofitting disability inclusion in public engagement

<sup>14</sup> This low response in our data is indicative that further research is necessary to better understand the groups and organizations disabled people work with to build civic power.



The following recommendations seek to inform civic engagement practitioners and funders who want to expand access to democratic participation for and with people with disabilities.

***Empower disability pride, voice, and identity through narrative change that includes elevation of stories/experiences that challenge the ableist norms that inhibit civic power for people with disabilities.***

Our participants identified stigma and ableism as barriers that prevent, minimize, and dismiss the contributions of disabled people in civic engagement and leadership. Reversing these entrenched biases requires more than policy and rights enforcement. It also requires, a narrative shift that is disability-led that would upend norms that give rise to pervasive ableism.

The espoused underpinning values of our democracy include equality, representation, and inclusive membership. To actualize these values for a truly inclusive and representative democracy - disability history, leadership, and stories about disabled people wielding power - as told by people with disabilities, should be a fundamental strategy for the civic engagement field. By elevating disabled narratives and disabled storytellers, funders and civic leaders have an opportunity to address ableism, and reverse the effects of stigma that diminishes civic power for people with disabilities. To this point, one survey respondent recommended greater intention around building disability community. *“Help more disabled people incorporate their disability into their identity. Educating disabled people about the discrimination they face to understand their own experience. Make disabled identity ‘cool’ and ‘desirable.’”* Among existing examples of this work, several of our research participants mentioned podcasts that are produced by people with disabilities. These include podcasts that interview a variety of disabled artists and community leaders, those that discuss issues of accessibility with candid humor; and still others that specifically interview disabled people of color to elevate their leadership and work. This is an example of a powerful way that people with disabilities are already using media and working to shift the dominant narrative and share disability rights practices in our society. Funders, for instance, could bridge relationships between disabled podcasters with mainstream podcasts whose topics and audiences overlap with disability rights; and in doing so, would move disabled narratives from the niche margins of our society and further into public life.

The Culture Group’s report, *Making Waves: A Guide to Cultural Strategy*, demonstrates the necessity of making culture integral to movement-building work that shapes norms and drives social justice progress.<sup>15</sup> An example of the importance of narrative and a demand to shift the status quo can be found in a Massachusetts program in which youth with disabilities are learning about the history of the independent living and disability rights movement. Youth in this program learned that their state’s education curriculum requires civic education but the curriculum typically does not include any lessons about the disability rights movement. Youth participants launched a statewide campaign to draw attention to this gap, provided resources for educators - including the documentary “The Great Fight for Disability Rights” and educated public school teachers in the state about the importance of teaching disability history. This initiative is one of the many strategies of this youth program that both creates a sense of belonging for youth with disabilities, and directly facilitates power for young people to shape their education and, by extension, the society.

One research participant in our project noted the differences in reporting between disabled and nondisabled journalists. Among nondisabled journalists, the newsworthiness of her campaign hinged on the visible characteristics of her physical disability; in comparison, disabled journalists delved into her actual campaign platform and focused on the issues she wanted to fight for and improve when in office. Civic engagement is, in part, made more accessible by the diverse perspectives that inform pathways to our democracy. In this way, disabled journalists who, for instance, report on the impact of natural disasters, COVID-19 pandemic, the trauma of gun-violence prevention drills in our schools, and other mainstream news issues infuse disabled perspectives which becomes integral to actualizing civic power for people with disabilities. These examples celebrate, amplify, and instill a disability narrative and its transformative impact on democracy while leveraging the disability community’s voice in building power.

***Facilitate cross-movement collaboration to encourage knowledge sharing, relationship building, and to illuminate shared goals between disability rights and civic engagement ecosystems.***

Philanthropy is well positioned to convene, inform, and resource movement leaders to encourage knowledge sharing that would mitigate the harm caused by the siloed sectors of civic engagement and disability rights. A Twitter chat participant provided a practical example of how to structure cross-movement collaboration: *“Come to where we are: the accessible spaces.”* To this point, another Twitter participant added *“You need to be meeting us where we are [already] reaching out to [access] the resources and services to connect with us. We are worth it.”*

Grantmakers who support work that advances civic engagement could prioritize funding strategies that simultaneously engage disability rights, and civic engagement ecosystems. This process will require critical reflection around the way disability is embodied in concurrent practices, followed by necessary operational changes and adjustments that reflect new understandings. As one Twitter chat participant suggested: *“We need to do the hard work of institutional analysis to consider why spaces are welcoming to some & not others. This takes time & a willingness to transform ways of doing things we take for granted.”* Another participant gave an example of how this mindset can be transformed into practice. Instead of requiring or expecting that disabled people request accessible materials, civic practitioners should have accessible materials readily available, including transparent avenues to request accommodations. This is one way to remove the need for disabled people to navigate discrete channels and infrastructures of organizations, thereby freeing them to meaningfully participate on a wide range of social concerns. Other suggestions from our survey respondents about ways disability rights could be included within ongoing civic engagement strategies are: *“provide disability rights history workshops,” “Anti-ableism trainings, webinars,” and “Disability history awareness, knowing how existing rights work, knowing how existing systems work, training that actually prepares people for advocacy work...”* Cross-movement strategies bolster meaningful allyship by embedding disability rights into strategies across movements with the intention of increasing civic participation.

To generate meaningful access to civic power for people with disabilities, disabled people need to be leaders in cross-movement building work. The result will be civic engagement advocacy that responds to the challenges of disability rights, and advocates for proposed policies of disability rights groups that elevates disability-rights campaigns from the start. For instance, civic engagement leaders can exemplify meaningful allyship by inviting disabled movement leaders for all manner of strategy sessions and not just for sessions related to “disability rights issues.”

 *Come to where we are:  
the accessible spaces.*

Funders interested in supporting cross-movement collaboration can standardize questions about implementing disability rights strategies and lens and/or ask their grantees about partnerships they may have with disability advocacy groups. In doing so, they would begin to elevate the importance of collaboration and integration of people with disabilities. Additionally, our participants in this project suggested that grant makers can practice allyship by standardizing accessible operations whether they are inviting grantees to a convening, sharing a new call to action on websites, or hosting webinars with resources to support program impact.

***Support marginalized disabled leaders to participate, and build allyship and power across all areas of civic engagement.***

Overwhelmingly, disability rights leaders shared that the limited or outright absence of a focus on disability rights are manifestations of civic engagement practices implemented without an intersectional lens. Repeatedly, marginalized disabled people emphasized that disability is embodied and represented across all demographics and social issues. Still, marginalized disabled leaders, such as disabled leaders of color, experience barriers in participation and representation across social justice issues. This gap in disabled leadership impedes cross-movement growth. For example, as many as twenty percent of prison inmates reportedly have a serious mental illness.<sup>16</sup> To substantially and meaningfully address the disproportionate prevalence of people with disabilities

16 [\*Rebecca Vallas, Disabled Behind Bars: The Mass Incarceration of People with Disabilities in America's Jails and Prisons\*](#)



who are also racial and ethnic minorities in prisons, leadership in this area must involve the community most impacted - disabled leaders of color - when considering police violence across race, poverty, and the criminal justice system. It is thus imperative that disabled leaders with marginalized identities have access to sustained support, training, and power to build coalitions and initiatives across social justice movements. Some ways this support can be bolstered and more intentional is by examining the traditional internships and leadership development opportunities in the civic engagement field that often are not geared towards people with disabilities. More specifically, in interviews with marginalized disabled leaders, several recommended that some existing civic engagement programs that provide coveted internships or other exclusive professional opportunities should re-evaluate their outreach, and recruitment processes to be inclusive and accessible for people with disabilities. Thus, increasing access to democratic power.

In interviews, several marginalized disabled leaders recommended that organizations that offer government or civic engagement-related internships and professional opportunities should develop disability-rights informed outreach and recruitment strategies. One participant specifically suggested changing recruitment strategies and interview questions to prospective intern candidates. For instance, a typical internship program may presume prior experience and exposure to democracy, and opportunities of civic leadership. By broadening interview questions to include questions pertaining to life experiences in advocacy, or asking candidates to share a story about a time they removed barriers for themselves and/or others to participate in their community. These changes could widen traditional program recruitment strategies, and expand the ways in which the lived experiences of people with disabilities can be lifted and valued in relation to democratic participation. Additionally, some marginalized disabled leaders we spoke to mentioned that many early-career programs focus on connecting people who are just starting in the field with more established leaders in the profession through networking events, loosely structured mentorships, or inviting panels of guest speakers to share experiences. All early-career programs in the public sector can and should endeavor to invite people with disabilities currently in civic leadership roles into the conversation through these kinds of programming events, and objectives.

Disability rights leaders urged that civic engagement practitioners develop materials that enable people with intellectual disabilities, a community typically

marginalized in civic spaces, to understand information about voting and other issues that affect their civic power. Related to this, funders looking to build capacity for leaders with intellectual disabilities, should issue requests for proposals in plain language and accept applications in different formats (via video or recordings) to ensure that people with intellectual disabilities can respond to the requests.

### ***Position disabled-led organizations and coalitions as valued, equal partners in efforts to build a more inclusive democracy.***

The disability community is already actively engaged and highly experienced in numerous civic efforts. Participants in this research shared countless examples of ranging from local grassroots actions among youth with disabilities advocating for a more accessible and inclusive school setting, people with intellectual disabilities writing and illustrating self-advocacy publications, a center for independent living in which youth are advocating for disability history to be taught in classrooms, and numerous disabled people reaching out to local campaigns about accessible opportunities to get involved. By intentionally broadening outreach and resources within disability communities, funders can help to elevate this existing work.

Throughout our history, disability communities have demonstrated that leadership on disability rights is a powerful conduit for civic engagement. Gallaudet University student's campaign called, "Deaf President Now" in the 1980's illustrates one among many such instances. Deaf students mobilized and pushed the university's leadership and board to install its first Deaf president of the university. This event signified the connection between a university that enables Deaf students with opportunities to access higher education, and the power of having a Deaf leader to promote the importance of Deaf-led culture and education.

This transformed public perceptions of Deaf leaders and positioned Deaf leadership as equals among other institutions of higher education.

As mentioned by several disabled participants in our research, funding, elevating and using materials written by and for self-advocates empower the people in self-advocacy communities and signals their value in our democracy. This is in part because even within disability rights work, people with intellectual and/or developmental disabilities are typically advocated "on behalf of" rather than being positioned as leaders in disability rights, and in

civic engagement. Intentionally elevating disabled leaders, disabled-led organizations and groups will facilitate direct access to civic power for people with disabilities.

## IV. Conclusion

These four recommendations are launching points for encouraging cross-movement collaboration among civic engagement and disability groups, calling for true integration and an intersectional lens in the work. These recommendations also illuminate ways that philanthropy can support these efforts and apply funding strategies to enable and elevate cross-movement efforts. As leaders across fields strategize in partnership with disability rights communities, trust must be developed to acknowledge historical harms, forge allyship, build upon existing movements, and recognize gaps in understanding in order to build a civically engaged, all inclusive, and vigorous collective. We hope that this report, shaped by the knowledge and lived experiences of disabled people, will be enthusiastically shared, and supported by the public sector, including grant makers.

The agitation and struggle for access to civic power among people with disabilities began at the first instance of ableism, discrimination, institutionalization, segregation, and stigma perpetuated to oppress generations of disabled people. And over the past decades, the demand for more diverse democratic representation within the general population has proven a vital and transformative force. Still, this impact has yet to be actualized for 26 percent of U.S. adults with disabilities<sup>17</sup>. Both civic engagement and disability rights groups must ensure that all members of society, and more importantly those communities that are most marginalized, which includes people with disabilities will be empowered to participate, lead and make an impact in the ongoing struggle for an enduring, and inclusive democracy.

To move this work into the field with the intention of expanding access to civic engagement among people with disabilities, we envision a multifaceted partnership across disability rights communities, civic engagement organizations, and the broader philanthropic sector. The charge below offers suggestions for initial concrete steps that each stakeholder can pursue together.

## Civic Engagement Practitioners and Organizations

***Establish relationships with disabled leaders and/or disability rights groups within areas of focus.***

**Example:** Civic leadership programs for youth can seek out programs that work with youth with disabilities.

***Manifest disability rights and inclusion principles within internal organizational practices and culture.***

**Example:** Hiring practices within civic organizations can include accessible job application processes, and engage cross-community professional networks such as disabled leaders.

***Foster meaningful allyship with disability rights leaders by committing to learning from and sharing knowledge of civic engagement work.***

**Example:** Institute accessible social media practices, or spotlighting a disabled leader that has contributed to a shared area of disability rights and civic engagement.

## Philanthropic Sector

Invite disability rights leaders to inform funding priorities within areas outside of the traditional scope of “disability issues.” Example: Host workshop sessions for grantees led by disabled leaders who are knowledgeable in areas such as natural disaster relief efforts, gun violence prevention, disability culture informed practices, etc.

***Establish a network of cross-disability representative coalitions that regularly, and consistently guide grant development across civic engagement efforts.***

**Example:** Embed meetings with disability coalitions within the grantmaking cycle that are at the beginning and at the end of a funding year, rather than just reviewing gaps and challenges later on or as they come up.

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<sup>17</sup> [Centers for Disease Control and Prevention, \*Disability Impacts All of Us\*, 1](#)



## ***Standardize disability inclusion practices within request for proposals.***

Example: Explicitly review grantee proposals with disability inclusion criteria. For instance, one criterion could be considering proposals that demonstrate varied and openly accessible pathways to civic life, and make this criteria transparent during the proposal submissions process.

These suggested actions construct infrastructure and commit resources for cross-movement learning opportunities, demonstrate effective and integrated allyship, and work towards a norm inclusive disability rights practices within grantmaking and civic engagement ecosystems.

In addition, we also recommend that future research on our questions purposefully oversample disabled people of color and disabled people who are LGBTQ, formerly incarcerated, immigrants, and/or identify with other marginalized communities. Despite our concerted intention to gather insights using accessible approaches, we recognize limitations in fully reaching people who experience multiple points of oppression.

Collectively, we present these findings and recommendations to the philanthropic sector, civic engagement practitioners, and disability rights communities in an effort to elevate both the work that has been accomplished by the disability rights community and our shared aspirations to build a more inclusive democracy.

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