

Launching Urban's Disability Equity Policy Initiative: A Conversation on Including Disability in Research

Rebecca Cokley Keynote Remarks

Thank you to the team at Urban Institute to Kim, to Susan, to the entire team. My name is Rebecca Cokley and I'm the U.S. Disability Rights program officer at the Ford Foundation. I am a redheaded white woman wearing a black jacket and a white shirt.

I wanted to apologize for my less than awesome background. I'm on Amtrak and had to head down to DC a day early

I want to take a moment to acknowledge all the disabled people in the space today. And i want to note that you count whether or not you self-identify personally or professionally. I see you and our community is infinitely strengthened because of your presence.

Sue Popkin and I spoke years ago, when I first landed at CAP about then need for there to be an understanding of disability across the think tank space. At the time Rebecca Vallas and I had just started building out the disability justice initiative. And everyone we talked to told us it wasn't the right time, no one would fund us, and we'd be unsuccessful in driving policy change. They were wrong.

When I came to Ford, we did something new and different for philanthropy in the creation of the USDR portfolio. We let the community tell us what our focuses should be. Philanthropic investment in disability is so new, we could have chosen to focus on just about anything. Based on the feedback provided by the community, the foci of our strategy is Building the Field, Driving Economic Justice, Narrative Change and continuing to bring our partners in philanthropy to the table.

There is no equity without disability. No well-meaning efforts to end discrimination, eliminate poverty, create a more equitable playing field, are possible while disabled people are not included and ableism is not opposed. We are disproportionately represented in every marginalized community and even more substantially at the intersections between them.

The disability community has lived segregation, from specialized educational settings to community service programs and restricted employment opportunities. Our demand to philanthropy, government, and other sectors is not to be treated as a special case. Government and foundations alike must fund efforts to develop housing proposals to ensure a supply of affordable and accessible housing. Funders exploring ways to organize efforts in criminal justice reform must remember that 60 to 80 percent of people who are currently incarcerated have a

disability, including individuals who acquired a disability while incarcerated. No effective approach to reentry, abolition, or de-escalation will be successful if disability is not included.

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

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

The novel coronavirus has surfaced many existing inequities, and the impact on the disability community is clear. It is the number one cause of death for people with Down Syndrome. [More than a third of all deaths tied to COVID-19 come from congregate settings](#), where people with disabilities make up a large percentage of all residents. More than one-third [of individuals impacted by the novel coronavirus](#) are likely to experience long-haul symptoms, a brand-new category of disability. This is at least 20 million people. COVID-19 has exacerbated existing mental illnesses due to increases in anxiety and social isolation, and for many individuals, there have been new diagnoses. The need for flexibility and rethinking how we work, how we receive health care, and how we learn has required us all to take a moment to ask ourselves why there isn’t greater accessibility and flexibility to support how we live so that we may thrive.

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

Why we need to be empowering disabled researchers?

The phrase “nothing about us without us” while a cliché in social justice spaces, is actually very personal to the disability community, as it comes from the disabled anti-apartheid activists in South Africa.

This work, in the words of my boss Darren Walker, is about embracing risk and reflecting honesty. Exclusion of disabled voices in the room is intentional. And the research and our fields suffer as a result of it. And it must go beyond perpetuating the erasure of gender, race, LGBT identities. and It must go beyond creating space only for those convenient to accommodate. All means all.

Disability Justice includes the tenet of “leadership by the most impacted” Disabled researchers must be leading and driving the research agenda.

A few weeks back I was asked to facilitate a panel of disabled researchers. The panel was all white. I have it as a requirement in my speaking contracts outside of my day job that I will not speak on or

facilitate a panel that is less than 50% disabled people of color. So I pulled out of the panel. Why? Because I see why we have no research on HBCU's and disabled students, because I watch the absence of a disability lens on discussions of the public charge or immigration policy, because I see that equal pay day accounts for every category of women except for us with disabilities. Because if we WERE in the room, you can bet for sure we'd be pushing back against the existence of a subminimum wage.

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