

Fostering the Civil Rights of Health

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SUMMARY. Pandemics, like climate disasters, thrive on inequality. COVID-19 is no exception, flourishing where inequality has weakened the social fabric. One of these weaknesses is long-standing racial discrimination, which has produced unjust, racialized disparities in COVID-19 transmission and mortality, and disproportionate economic harm to people of color. Efforts to address these racial disparities have been hindered by a series of governance and advocacy disconnects. Some of these disconnects are well-known and widely discussed, such as fractures in federal, state, and local leadership that have politicized basic public health measures such as wearing masks. Less-well understood is the society-wide failure to adequately address racial discrimination in all its forms. This has perpetuated the disconnection of public health and civil rights advocacy from one another, and the disconnection of public health and civil rights professionals from anti-discrimination social movements. One promising tool to bridge these disconnects is research on the social determinants of health. Highlighting the ways in which discrimination is a public health problem allows legal advocates to use civil rights law as a health intervention and public health advocates to squarely challenge discrimination. In keeping with the emergent health justice movement, civil rights and public health advocates can amplify their effectiveness by partnering with organizations that fight discrimination. We call this approach “the civil rights of health.” This agenda for action requires (1) integrating civil rights and public health initiatives and (2) fostering three-way partnerships among civil rights, public health, and justice movement leaders (Harris & Pamukcu, 2019).

Introduction

Although COVID-19 has spared no geography or walk of life—inflicting heads of state as well as low-wage workers around the world—it has taken a disproportionate toll on people of color in the United States. Black Americans have been hardest hit, with a death rate currently at 2.5 times that of their white counterparts (The COVID Tracking Project, 2020).

The reasons for these disparities in COVID-19 transmission and mortality are various, interrelated, and compounding. There are racial disparities in the rates of chronic diseases and conditions that interact harmfully with the virus, such as diabetes, heart disease, and obesity. Due to a legacy of discrimination and disinvestment, people of color are disproportionately likely to live in communities segregated from white populations, and to live in conditions conducive to the spread of infectious disease, such as overcrowded or substandard housing. Under the current system of mass incarceration, U.S. prisons and immigration detention centers are overpopulated by Black and Latino people—inmates, detainees, and staff.

Pre-existing economic disparities also compound the virus’s racial effects. These disparities include a widening racial wealth

gap and employment inequalities, such as the fact that so-called essential workers are more likely to be people of color. So far, the disastrous economic effects of the pandemic are reflecting the racially disparate health outcomes of the virus. For example, more than 40% of Black business owners reported they were not working in April, while only 17% of white business owners said the same (Fairlie, 2020).

The pandemic is disproportionately costly to the longevity, health, and prosperity of people of color. Yet many government entities, particularly at the federal level, have been slow to measure—let alone address—the racialized consequences of COVID-19. The Centers for Disease Control and Prevention (CDC), for example, has not provided complete race and ethnicity information in their released COVID-19 data, even after being sued by the New York Times (Oppel Jr. et al., 2020). Economically, federal stimulus programs appear to have benefited business owners of color less than other business owners (Flitter, 2020). We still need more data, however, to understand the full impact of economic mitigation measures on marginalized communities.

Disconnects in Governance and Advocacy

A series of disconnects in American governance has exacerbated

the problem. Some of these disconnects are longstanding and structural, such as tensions over the boundaries of federal, state, and local government authority. Others involve debates between whether resources constitute public or private goods, like the fractured governance of health insurance and health care between state and market provision. There are even growing rifts between scientific experts and research on the one hand, and political leadership and governance on the other.

Some of these disconnects appear to have been intentionally deepened, particularly at the federal level. For example, the Trump administration has disclaimed responsibility for coordinating provision of personal protective equipment (see Chapter 20 for more discussion), withdrawn support for the World Health Organization (WHO) discussed in Chapter 11, and undermined the credibility of the director of the National Institute of Allergy and Infectious Diseases (NIAID).

A less recognized, conceptual disconnect plays an important role in the disproportionate toll of COVID-19 on people of color. What we know about the structural nature of discrimination does not align with how American legal and policy advocacy has actually responded to discrimination.

Notably, civil rights legal advocacy and public health initiatives have conventionally been disconnected from one another—and each, for different reasons, has failed to fully engage with all forms of racial discrimination. While there has been increasing recognition of the connection between health and discrimination, both civil rights and public health advocates are struggling to close a persistent and, by some measures, widening racial health gap (National Academies for Sciences, Engineering, and Medicine, 2017).

Even when public health research or interventions have aligned with the force of law, there is grave potential to perpetuate or even intensify discrimination. This is a particular risk when public health concerns overlap with widespread social biases like racism and sexism. Historical examples range from eugenics statutes such as Puerto Rico's Law 116 (which institutionalized the population control program that resulted in the mass sterilization of Puerto Rican women) to the punitive legal and policy responses to the racialized panic over "crack babies" (which led to the widespread criminalization of pregnant cocaine users, despite being based on inconclusive research) (McGinnis, 1990).

One promising way to bridge these disconnects is to build a sustained partnership between public health, civil rights legal advocacy, and anti-discrimination social movements—a partnership we call "the civil rights of health." Government can play a key role in facilitating this timely alliance.

Bridging the Disconnects with the Civil Rights of Health

As public health advocates have recognized, the root cause of racialized health disparities is discrimination. Individual discrimination, especially stemming from implicit bias, plays a role in sustaining disparities across complex systems, from health care to the labor market. Less visibly and more insidiously, institutional

and structural discrimination deepens these disparities and sustains them over time.

Failure to reckon with our nation's history of racism has weakened the legal tools available to address discrimination and hindered the progress of public health research and interventions. Public health advocacy has too often focused on universal interventions that improve health overall but leave the racial health gap intact, or has pursued individual behavior change campaigns that address the symptoms of discrimination rather than discrimination itself. Meanwhile, civil rights advocacy has been hampered by legal tools that treat explicit interpersonal prejudice as the root cause of racism, ignoring institutional and structural forms of discrimination. Moreover, public health and civil rights advocates have pursued their work in parallel but rarely aligned their anti-discrimination efforts.

The literature on the social determinants of health offers a way beyond these disconnects. This literature documents and analyzes how interpersonal, institutional, and structural discrimination decreases the length and quality of people's lives across populations and geographies. The COVID-19 crisis offers an opportunity to train the attention of civil rights and public health advocates on the shared goal of fighting discrimination in all its forms in the service of better health for all—an approach we call "the civil rights of health."

A Framework for Action

The civil rights of health framework suggests at least three priorities in this pandemic: (1) collecting effective and actionable data, (2) connecting the dots between health disparities and structural discrimination, and (3) partnering with anti-discrimination community organizations.

First, in order to take effective action, it is necessary to have a body of accurate data on COVID-19 racial disparities. State and local public health authorities should track coronavirus racial impact data alongside other relevant demographic categories. Such robust and disaggregated data would enable officials to properly prioritize their efforts. Many local governments have already begun this work. In California's Bay Area, for instance, local governments and health officials are increasingly targeting medical and financial resources where they are most needed based on demographics and place (Palomino & Sanchez, 2020). In another example, Chicago Mayor Lori Lightfoot announced the creation of a "racial equity rapid response team" to collect and share demographic data, and to work with community organizations to prepare what she called a "hyperlocal" response to racialized disparities in illness and death (Chicago Recovery Task Force, 2020). We additionally recommend data collection efforts be coordinated so that advocates can effectively combine data sources to produce a broader picture of the disparate effects of the virus.

Second, government entities should promote conceptual frameworks that connect health disparities to structural discrimination. In recent weeks, for example, local governments have issued declarations that frame racism as a public health crisis. Although these declarations typically have no legal

enforceability, funding mechanisms, or mandates for action, they help lay the conceptual groundwork for establishing partnerships among previously-siloed entities, priorities, and programs. In Chicago, for example, the city's Recovery Task Force Report links ending racial health disparities with the goal of poverty reduction and the expansion of economic opportunity (Chicago Recovery Task Force, 2020).

Third, anti-discrimination community organizations should be equal partners with legal and public health professionals for the resulting initiatives to be effective and just. As an example, the Movement for Black Lives (M4BL) has organized mass public protests against police brutality against Black and other marginalized people, and called for "defunding the police." This demand, along with widespread community mobilization, has sparked vigorous conversations about the underfunding of key social determinants of health, such as education and safety net programs. This, in turn, paves the way for innovative policy conversations and initiatives against structural racism — such as treating community violence as a public health problem rather than a criminal justice problem. The success of M4BL in changing the public conversation illustrates why the civil rights of health is aligned with the emergent health justice movement.

Like environmental justice, reproductive justice, and other "[x] justice" movements, health justice embraces the leadership of frontline communities in systemic change efforts alongside professionals in law and science. Frontline communities, represented by anti-discrimination social movements, have the capacity to change the political landscape, making public space in which to imagine bold new initiatives and creating the political for implementation. These movements can also challenge abuses of power, including abuses by legal and public health actors. Finally, movement leaders often have the ability to reach marginalized communities and populations who may have good reason to distrust public officials and expert advice.

The civil rights of health is premised on the recognition that ending structural racial discrimination is necessary to ending racial health disparities. Government entities and advocates tasked with the protection of civil rights should draw on the social determinants of health literature to pinpoint the ways that racial discrimination and marginalization across systems create and sustain differential vulnerability to COVID-19. Conversely, public health advocates, many of whom have been slow to address discrimination as a health issue, must wholeheartedly embrace anti-discrimination law and policy as an essential public good necessary for health equity. Both civil rights and public health professionals should accept the expertise and leadership of frontline communities in planning and advocacy rooted in anti-racist values.

As noted previously, an endemic challenge in social change work is the tension between universal policies and policies targeted to benefit marginalized populations. Policies addressing the health and economic harms of COVID-19 can use a "targeted universalism" approach to effectively address the racialized impact of the virus. Targeted universalism recognizes that policies directed toward supporting stigmatized populations are politically vulnerable

for that very reason. It is therefore advisable to look for ways to combine universal objectives and programs with targeted corrective justice projects. The targeted universalism framework breaks the approach down to five steps:

1. Set a universal goal.
2. Assess the general population performance relative to the universal goal.
3. Assess and identify the performance of groups that are performing differently with respect to the universal goal.
4. Assess and understand the structures and other factors that support or interfere each group from achieving the universal goal.
5. Develop and implement targeted strategies for each group to reach the goal (Powell et al., 2019).

Targeted universalism does not preclude the possibility of backlash — as officials in Harris County, TX discovered, for example, when they decided to focus flood control efforts on the least resilient communities rather than prioritizing the communities with the highest property values. But the targeted universalism framework, especially in the context of a global health pandemic, helps make visible the links between the corrective justice goal of anti-discrimination and the universal goal of better health for all. 🌞

Recommendations for Action

Federal government:

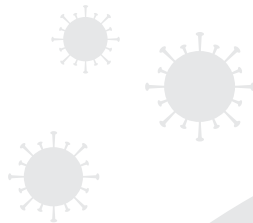
- Should improve data collection efforts across agencies to ensure critical demographic data about health outcomes and the broader impacts of the pandemic (including results of mitigation efforts) is collected and analyzed, while privacy is protected.
- Agencies, including the CDC, should coordinate and standardize data collection efforts so that data sets can be effectively combined, and ensure that complete data is made publicly available.
- Congress should dedicate and increase resources to federal agencies to coordinate with civil rights and public health organizations to inform, enforce, and further civil rights protections.
- Agencies should develop guidance for the use of “targeted universalism” as a policy and planning frame in order to benefit all populations while specifically addressing the harms of racism.

State governments:

- Should improve data collection efforts across agencies and departments to ensure critical demographic data is collected and analyzed to properly inform policy decisions.
- Should work in tandem with local governments to identify and address racial health disparities and support the distribution of resources to eliminate them.
- Should devote resources to supporting community-based organizations working to address the social determinants of health, the racial health gap, and/or anti-discrimination efforts.
- Should realign government budgets around preventive health and provide community budgeting participation and oversight.
- Should work with agencies and departments to develop guidance on the use “targeted universalism” as a policy and planning frame, in order to benefit all populations while specifically addressing the harms of racism.

Local governments:

- Should collect detailed data on the populations and geographies most affected by COVID-19 and use this data to effectively allocate resources to the most impacted people and places; where possible, pursue coordinated regional data collection efforts.
- Should recognize and address racism as an institutional and systemic issue, such as the proliferation of local government declarations characterizing racism as a public health crisis.
- Should use “targeted universalism” as a policy and planning frame in order to benefit all populations while specifically addressing the harms of racism.
- Should foster three-way partnership among civil rights, public health, and anti-discrimination movement leaders.
- Should pursue “hyperlocal” rapid responses in partnership with community organizations.
- Should realign government budgets around preventive health and provide community budgeting participation and oversight.



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