Structural Inequities, HIV Community-Based Organizations, and the End of the HIV Epidemic

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See also Landers and Bowleg, p. 341.

Community-based organizations (CBOs) are integral to achieving the goal of Ending the HIV epidemic (EHE). Their familiarity with and proximity to communities position them to effectively implement strategies necessary to address determinants of health through their formal and informal medical and social services. However, structural inequities have contributed to the demise of many organizations that were instrumental in early responses to the HIV epidemic.

We define structural inequities for HIV CBOs as systems in which policies, institutional practices, organizational (mis)representations, and other norms work to produce and maintain inequities that affect CBOs' ability to survive and thrive. In this discussion, we describe the organizational threats to grassroots HIV CBOs and the risks to livelihood and longevity, including examples.

The invaluable role of HIV CBOs in EHE and their role in responding to existing and novel infectious diseases like COVID-19 should not be overlooked. Recommendations to promote structural equity are offered. (*Am J Public Health*. 2022;112(3):417–425. https://doi.org/10.2105/AJPH.2021.306688)

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Ending the HIV Epidemic (EHE) in the United States is an initiative of the US Department of Health and Human Services to reduce new HIV infections by 75% in the next 5 years, and by 90% in the next decade, by partnering with local and state health agencies to systematically test, expand access to medication (including pre-exposure prophylaxis), and respond quickly to potential outbreaks.[1] Successful strategies to achieve those goals include culturally appropriate and trauma-informed care, prevention and treatment of individuals at increased risk for acquiring HIV or falling out of care, development and distribution of an effective vaccine and universally accessible HIV cure, and outbreak monitoring and surveillance.[2] Social determinants that drive HIV-related disparities, including stigma, discrimination, poverty, unemployment, geography (regional and rural), and access to health care, also require targeted approaches.[3]

Ending the epidemic is multisectoral in nature.[2] The role of community-based organizations (CBOs) has historically been and continues to be integral in achieving that goal. Community-based nonprofit organizations serving highly vulnerable populations living with or at increased risk for acquiring HIV (subsequently referred to as HIV CBOs) are critical to achieve real-world impact.[4] Their proximity to the communities they serve positions them to effectively implement strategies necessary to EHE, including efforts to address determinants of health through formal and informal medical and social services (e.g., linkages to care, housing, transportation, peer support).[5,6] However, many organizations that were instrumental in responding to the US HIV epidemic have not survived in the changing landscape of prevention, care, and treatment as a result of structural inequities[7–9]—including Black, Indigenous, and people of color (BIPOC)-led CBOs that serve populations within and throughout their communities.

THE EVOLUTION OF GRASSROOTS HIV ORGANIZATIONS

Organizational ecology posits that the emergence and dissolution of organizations depend on selection and adaptation.[10] Selection occurs

when sociopolitical environments create space that optimizes some organizational characteristics over others. Adaptation occurs when organizations change their characteristics to align with evolving environmental conditions[10] for the sake of their survival. HIV CBOs emerged within a sociopolitical climate that warranted a critical response to a novel infectious disease observed initially among White gay men. As the epidemic progressed, it expanded to communities of color, including Black and Latinx communities that remain disproportionately affected and underserved today. Well before clinicians, researchers, or social service providers fully understood the virus or its pathology, local community groups were organizing activist efforts toward support, advocacy, calls for further research, and memorializing those lost within their communities. These local groups established grassroots CBOs that served hybrid purposes: activism and service.[11] They supported people living with HIV (PLWH) physically, socially, and emotionally, often with miniscule resources.

Organizational evolution is a theoretical variation of organizational ecology that highlights the role of contextual, environmental, and interorganizational factors that influence how organizations develop, change, and survive.[12] Studies of nongovernmental organizations have examined their ability to adapt in the interest of longevity, emphasizing their active agency in doing so.[13–15] As the HIV epidemic evolved, many organizations expanded their focus from solely primary prevention to include secondary prevention strategies, such as case management and other support services for PLWH. CBOs focusing on HIV today offer services that include prevention education, HIV and sexually transmitted infection testing, harm reduction, behavioral health, substance use counseling and treatment, mental health services, patient navigation, case management, and medical care and treatment. These HIV organizations evolved because their adaptation was a necessary consequence of the changing landscape of HIV and the widening network of institutions involved in the response.[16] This has kept organizational mortality at the forefront for many HIV CBOs, and caused the dissolution of many others. Grassroots organizations helped to shape early social and political responses to HIV.[17] However, based on our collective observations, many have not survived.

STRUCTURAL INEQUITIES

Structural inequities are defined as the policies and practices embedded in systems that operate to produce inequitable distribution of the determinants of health.[18] Borrowing from definitions of structural racism,[19,20] we describe structural inequities as systems in which policies, institutional practices, organizational (mis)representations, and other norms work to produce and maintain inequities that affect CBOs' ability to survive and thrive. These inequities manifest economically, politically, socially, and culturally in ways that usurp autonomy and minimize CBOs' capacity by virtue of their proximity to the often-minoritized communities they serve. We see these inequities persist and manifest with the COVID-19 pandemic, during which, despite disproportionate burdens of risk and incidence among BIPOC populations, responses largely failed to consider the integral role of CBOs in reaching vulnerable groups.

CBOs must be centered and supported as we focus on ending the HIV epidemic. As representatives of and advocates for HIV CBOs, we offer this reflection to highlight the critical role of structural equity among grassroots organizations toward achieving EHE's goals. We describe the organizational mortality of HIV CBOs and threats to livelihood and longevity, including examples from our own collective experiences and observations. We then discuss the invaluable role of HIV CBOs in ending the epidemic, their role in responding to existing and novel infectious diseases like COVID-19, and recommendations to promote structural equity.

ORGANIZATIONAL MORTALITY: THREATS TO SURVIVAL

Advances in prevention and treatment paved the way for game-changing developments that reshaped the landscape of confronting the HIV epidemic.[21] The advent of the Affordable Care Act (ACA) necessitated consideration of changes in funding streams. The National HIV/AIDS Strategy and the Centers for Disease Control and Prevention's (CDC's) High-Impact HIV Prevention interventions shifted attention and funding to key populations and select strategies in areas with a high burden of disease. The "treatment-as-prevention" approach demonstrated effectiveness in improving health outcomes for PLWH as well as interrupting transmission.[22] Lastly, changes in the economy decreased access to government funding and private foundations for nonprofit organizations.[21]

A 2013 report examined the impact of changes in HIV prevention, funding, and treatment on the stability and sustainability of AIDS service organizations and CBOs, with emphasis on fiscal health, capacity to deliver and link to medical care, and leadership and governance.[21] Many organizations reported

struggling financially. The report also indicated that organizations were concerned about the levels of knowledge and engagement of their administration and boards of directors and their ability to lead through a changing landscape. Such changes necessitated a fundamental restructuring of organizational business models not only to better serve clients, but also to remain viable.[23] We were unable to find a formal examination of the organizational mortality of HIV CBOs; therefore, it is difficult to know the number of organizations that have not survived. Recent findings from a national annual survey of HIV/AIDS service organizations and CBOs indicate that stability and sustainability remain concerns.[24] Environmental and organizational challenges affect sustainability, broadly categorized as (1) financial threats, (2) organizational capacity and the ability to provide and link to medical care, (3) leadership and governance, and (4) organizational biases. We examine each through the lens of our collective professional leadership experiences.

Financial Threats

HIV CBOs depend on funding for stability and sustainability. Many were negatively affected by funding changes wrought by the changing HIV landscape, resulting in less funding for health departments and thus less funding for their local HIV CBOs, even as private funding for HIV CBOs also became scarce. Changes in federal mandates that no longer defined "minority organizations" as having executive directors of color and boards of directors at least 50% minority in makeup, shifted funding potential away from smaller minority-led CBOs, making it nearly impossible to compete with larger, more well-resourced organizations. These larger organizations were also able to pursue highly technical, high-magnitude funding opportunities with application turnaround time frames that could not realistically be met by smaller organizations with limited grant-writing resources. Recent decreases in funding for the Ryan White program[25] likely will most adversely affect smaller grassroots organizations. Furthermore, a lack of political champions willing to advocate for and challenge opposition to funding can also have adverse implications for the financial health of HIV CBOs.

Many HIV CBOs' efforts are hindered by circumstances such as disproportionately low funding compared with services provided, or unclear parameters for obtaining funding from state and local health departments. Being underresourced also has implications for being able to pay and retain staff. Delays in funding from health departments can be problematic for organizations that are experiencing financial difficulties as they attempt to bridge the gap between periods of limited funding. Systems of remuneration that require HIV CBOs to wait for reimbursements further jeopardize CBOs' ability to provide uninterrupted essential services to clients.

Anxiety about organizational survival is acute in contexts of high interorganizational competition, particularly for organizations that heavily depend on government funding.[26] When large, well-funded entities with clinical services are newly established in communities, they are better positioned to solicit additional funding, leaving less for organizations with longer, deeper histories of service within the local community. Large corporate-structured HIV-focused organizations, with financial profiles much different from those of CBOs, also threaten the stability and sustainability of local HIV CBOs by creating a competitive climate that can lean unfairly toward more well-funded entities.[27] Among local HIV CBOs, these entities have been likened to "big-box shops" that put "mom-and-pop shops" out of business.

With the advent of programs like 340B, a federal government discount drug program that provides reimbursements directly to organizations for patient pharmaceuticals, organizations are able to secure funding to support their programs and their organizations. This "franchisement of HIV" was a boon for organizations that were equipped to take advantage of it. For other organizations, however, stipulations for organizational enrollment into 340B programs were stringent, and interpretation of those requirements by gatekeepers like health departments and other entities either erroneously excluded them or hampered capacity-building efforts toward that end. The ACA and Ryan White program also created new possibilities for funding that larger corporate-structured or hospital-based entities and federally qualified health centers (FQHCs) were able to take advantage of quickly and with ease—building financial reserves that smaller organizations could not access. Some organizations, like FQHCs, are targeted for federal funding. However, intraorganizational differences within FQHCs can negatively affect CBOs. For example, where program staff of FQHCs may be amenable to partnerships with CBOs, FQHC administrators balk if partnerships result in a loss of revenue. Furthermore, CBOs' capacity to expand and diversify themselves to integrate HIV into general and mainstream public health practices and services is dependent on their ability to sustain themselves financially to expand. Unfortunately, these varied financial threats were a death knell for some

long-standing organizations that were either shuttered or co-opted.[8,9]

Organizational Capacity

Despite their expertise, grassroots HIV CBOs in underserved communities often have limited access to the resources and services needed for them to thrive. Most nonprofit HIV CBOs were started by individuals with a passion to prevent HIV and support PLWH. However, this passion has not always been complemented by business acumen or fund-raising skills, stymieing sustainability. Many organizations had limited understanding of how to acquire and manage grant money or manage staff, including volunteers. Access to capacity-building assistance (CBA) was limited although the need was high.[28] Prior to a concerted effort from the CDC, no-cost CBA did not exist. Once available, it was incredibly beneficial, but has again become more difficult to access. Coordinated by health departments on behalf of all HIV-serving organizations, CBA can be delayed or inconsistent with the type of CBA that is most needed. CBA access is a persistent need for HIV CBOs, especially as prevention and treatment shifts indicate that CBA will become focused on organizational sunsetting and sustainability as the HIV epidemic ends.

A critical asset of HIV CBOs is the ingenuity of staff who are committed to their clients and creative in their interactions with them, including those that may be myopically labeled "hard-to-reach." Often, these staff have deep connections with the communities they serve, and many are themselves PLWH. Their effectiveness can make them targeted hires for better-resourced organizations that are able to pay staff significantly more. When these staff leave, or are pilfered, they take with them crucial institutional knowledge, upending capacity within their former organizations.

A shift to treatment-as-prevention as a high-impact intervention emphasized a medical model that many organizations were unprepared to offer and highlighted the need for capacity-building based on the biomedical model of care.[29] Organizations that were already clinic-based were more prepared for this shift, whereas others with no or limited capacity were marginalized, forcing some to close. Recognition of the effectiveness of a biomedical model also shifted funding toward this approach, while minimizing the role of social services (e.g., housing, employment assistance, food) necessary for patients to sustain medical gains.

Leadership and Governance

Organizational capacity is inextricably tied to organizational leadership. Nonprofit business acumen and tenacity of leadership can help guide organizations through difficult periods and position them for growth and success. A recent example is the response to local shutdowns due to the COVID pandemic and the pursuit of paycheck protection loans. The organizational angst many HIV CBOs experience is carried squarely on the shoulders of executive directors and CEOs who feel both a fiscal and social responsibility to clients and staff; this can be magnified for leadership of color with limited networks from which to draw support. In our experience, small CBOs with racial/ethnic leadership of color have been locked out of opportunities for growth that could sustain their organizations. Their designation as "little organizations" can be perceived as code for "the black or brown organizations," which places organizations led by people of color in a position to be professionally minimized and unsupported. Repeated instances of marginalization affects the mental and emotional health of such leaders, resulting in stress, worry, and anger—and few outlets to express such feelings. In localities where there are multiple organizations led by people of color, efforts to pit executive directors against one another can be divisive. Requests by leadership for capacity-building assistance can also be viewed as weaknesses in areas of support requested. Mistakes made by leadership of color can be amplified in attempts to nullify their capability.

HIV stigma, particularly in rural communities, can make it difficult to identify and recruit board members willing to openly serve as ambassadors. Because of factors such as increased social conservatism and lower levels of HIV awareness,[30] many vulnerable communities may experience a dearth of knowledgeable individuals who have the capacity to provide necessary insight for the sustainability of HIV CBOs; on the other hand, local contextual knowledge of a community is critical to that same sustainability. The meaningful involvement of PLWH, community members, and consumers as board members is critical. Challenges to organizational growth include the selection of well-intentioned but inexperienced board members and difficulty recruiting diverse, heavily networked board members. Blurred lines between executive directors and CEOs and board member responsibilities introduce the potential for additional problems, as leaders' passion for the work may conflict with delineation of roles and responsibilities.

Organizational Biases

Inaccurate perceptions held by decision-making entities about the experience and capabilities of HIV CBOs can affect their access to opportunities for sustainability. Some organizations, seen by decision-makers as smaller less-equipped organizations, are tasked to do the difficult work of outreach to identify PLWH and then refer them to clinics for care; these clinic-based entities benefited financially from this setup. For years, smaller CBOs fed patients into clinics' 340B programs, helping to build income for these organizations, while smaller CBOs were unaware of 340B opportunities. In some instances, leadership from smaller CBOs were explicitly told they were ineligible for participation, and that these opportunities did not exist for them. This inaccurate translation of information denied smaller organizations the opportunity to build organizational capacity and financial infrastructure. Attempts were also made by larger entities to prevent access to 340B for smaller organizations once they were, in fact, determined to be eligible.

Health departments demonstrate biases toward working with larger, more established entities with greater resources rather than with smaller CBOs with fewer resources and a learning curve regarding organizational capacity. Funding practices by health departments and others that privilege larger clinic-based entities with significant funding, allowing them to decide whether to subcontract with HIV CBOs, construct a hierarchy that empowers them while placing the viability of smaller organizations at risk. Leadership who critique the system on its pointed biases can find themselves penalized—they receive less funding, ultimately resulting in critical voices and perspectives being reduced or eliminated. CBOs attempting to expand their services are regularly met with pushback, including the abrupt cancellation of contracts with larger clinic-based organizations. By expanding services to include access to medical professionals and medication, smaller CBOs are able to address the important biomedical aspects of prevention and treatment while also effectively responding to a variety of social service needs. CBOs are uniquely equipped to view clients through multiple lenses, and respond to the whole person, evidenced by referrals of "difficult" patients from larger entities back to smaller CBOs that can more effectively respond to clients' needs.

The mistaken belief that larger organizations are better equipped to provide community services because they are better resourced minimizes patients who prioritize not only quality health care but also personal care, especially patients labeled "difficult" or "hard-to-reach." In larger organizations, patients may have access to quality care but may not feel "cared for." Furthermore, patients can have adverse experiences with health care providers lacking cultural competence. Patient attitudes about historical medical and research abuses are relevant, but present-day experiences with health care matter for clients. No single organization is ideal for everyone, but CBO options should exist for patients to choose. HIV CBOs working on the frontlines herald innovative approaches that are sometimes ignored unless and until these ideas are promoted by larger, well-resourced organizations. Furthermore, these organizational biases extend into academic–community relationships where CBOs are often used and abused by researchers and universities as sites for participant recruitment without meaningful partnership, investment, and dissemination or translation of findings.[31] Despite being viewed and treated as subordinate to larger organizations, there is much to be learned from HIV CBOs.

INVALUABLE ROLE OF HIV COMMUNITY-BASED ORGANIZATIONS

The collective achievements in reducing HIV incidence rates would not be possible without CBOs, which are community engaged by their very nature. HIV CBOs have been and continue to be critical in meeting the goals of the National HIV/AIDS Strategy. Because of both proximity and staff composition, grassroots HIV CBOs are a natural reflection of the communities they serve where they have deep, long-standing relationships. The epidemic in the United States has been aptly characterized as a "diverse set of microepidemics" across different settings around the nation.[32(p3078)] Extending that logic, communities represent even smaller units of unique epidemiological and structural characteristics that are deeply familiar to HIV CBOs. They use community-informed, community-engaged methods to serve their clients, and they can be better equipped to do so. Staff's personal and professional experiences with HIV in marginalized communities often reflect the contextual knowledge they have of the communities they serve, which also resonates with clients. Their ability to access social networks allows them to build authentic relationships with community members and develop trust.

Because of these sustained relationships, HIV CBOs have a footprint in communities where government and larger organizations may not. Community members and clients benefit from formal services and informal networks (e.g., peer groups) that help them feel seen, heard, welcome, and safe. Not only are HIV CBOs instrumental in treating and supporting PLWH, they are skilled in prevention, including testing and promoting uptake of pre-exposure prophylaxis. HIV CBOs can be instrumental in providing their clients and patients with a wide array of information and considerations necessary to help them make their own personal decisions, and thus CBOs will be essential toward promoting uptake of vaccines (e.g., HIV or COVID-19) and other novel strategies for future cures. HIV CBOs' investment in staff (some who began as clients) has also helped to enhance the overall HIV workforce, expanding their capacity to respond to new professional opportunities.

HIV CBOs are frontrunners of innovation and a source of information for what works. Often, HIV CBOs are already responding long before the completion of efforts to test and evaluate interventions. Access to evidence-based strategies allows them to use what is known and shift quickly in the best interest of their clients, especially for Southern or rural communities—where the failure to expand Medicaid, as made possible by the ACA, has jeopardized access to health care and services for clients. Furthermore, HIV CBOs are tasked with finding and reaching those labeled "hard-to-reach" with outreach strategies that are extensive, comprehensive, and informed by community relationships. HIV CBOs maintain a presence in places deemed untraditional or undesirable. They are equipped to meet those at risk exactly where they are because of trusted relationships that can aid in engagement and retention of care.[5]

BOX 1— Recommendations to Promote Structural Equity for HIV CBOs in Ending the Epidemic

1.	Protect against the erasure of HIV CBOs by being vocal about what we do, emphasizing the historical and contemporary roles we have played in combating the epidemic. Vocalization can include: a. Direct communication with lawmakers and policymakers. b. Consistent engagement with legacy and new media to document and disseminate "success stories" related to the clients and communities served.
2.	Create space at decision-making tables for the meaningful involvement of people living with HIV who work within HIV CBOs, in determining funding priorities, distribution of funding, and policy development; include HIV CBOs that have direct contact with communities that can help guide and inform effective approaches.
3.	Hold institutions accountable for our equitable inclusion (and meaningful involvement)—at local, state, and federal levels. Include mandates in requests for proposals that CBOs be included in meaningful and fiscally tangible ways.
4.	Build flexibility into federal and other service funding opportunities to allow CBOs equitable access and the ability to use funding in ways that are responsive to diverse clients and patients; craft language that communities can understand. Be sensitive to the fact that clients and patients need significant and varied types of support to achieve viral suppression.
5.	Allow funding to bypass health departments and be distributed directly to CBOs,[3] so that it addresses needs identified by the CBOs.
6.	Fund research for equitable academic and HIV CBO partnerships to develop and test approaches to end the epidemic, especially among those at increased risk for HIV.
7.	Ensure that BIPOC researchers with community-engaged experience and HIV CBO relationships are supported in the development of evidence-based interventions and prioritization of funding decisions at the state and federal level.
8.	Include in the EHE plan a focus on building capacity to maximize benefits inherent in HIV CBOs. This plan should: a. Work with HIV CBOs, including board leadership, to better foresee and react to any opportunities and threats and adapt to change. b. Build capacity of HIV CBOs in (1) combatting existing and novel infectious diseases and (2) organizational planning as the HIV epidemic ends. c. Create a program to build leadership capacity for executive directors of color with less experience; nurture new generations of leaders; invest in succession planning efforts; incorporate a coaching and mentoring program with veteran executive directors who can provide practical support and guidance.
9.	Create a community of HIV CBO leaders of color where intellectual exchange, capacity building, and social support can occur.
10.	Ensure HIV CBOs in rural areas of the country have the training and infrastructure to combat HIV/AIDS; provide opportunities for rural HIV CBOs to apply for and obtain funding to do this.
11.	Involve local and state political leaders in conversations and long-term strategic planning to counter stigma and encourage advocacy to fund and strengthen BIPOC HIV CBO infrastructure.
12.	Promote and reward multilevel intervention approaches that seek to end HIV stigma, racism, homophobia and transphobia, ableism, and sexism.

Note. BIPOC = Black, Indigenous, and people of color; CBO = community-based organization; EHE = ending the HIV epidemic.

In practice, HIV CBOs have flexibility to respond to community needs and are generally not constrained by bureaucracy; they can move quickly and creatively to tailor their approaches beyond the norm (e.g., flexible hours to facilitate "after-hour" services). HIV CBOs do the work that is hard, not the work that is convenient. With access to resources commensurate with their work, they can advance progress even faster. Reports of excellent treatment cascades are possible because of the labor of HIV CBOs. They should be acknowledged with equitable support (fiscal and otherwise) for their contributions toward ending the HIV epidemic.

Several similarities between HIV/AIDS and SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2, the causative agent of COVID-19)—including stark racial/ethnic disparities,[33,34] social and structural drivers of transmission,[33] stigma,[34] and the role of human behavior in prevention,[35,36]—highlight additional notable qualities of HIV CBOs. Strategies outlined in the National HIV/AIDS Strategy parallel those necessary to effectively address the COVID-19 pandemic,[37] thus also highlighting how HIV CBOs are uniquely positioned to respond to COVID-19. HIV CBOs are well suited for implementing daily testing and effective contact tracing. They can easily integrate activities to prevent COVID-19. There is still much that is unknown about COVID-19, although it is now established that PLWH who acquire SARS-CoV-2 have greater adverse outcomes and that health inequities exacerbate them.[38] COVID has altered CBO outreach to existing clients and patients, and affected the availability of services. However, many HIV CBOs have adapted to meet the needs of their clients and patients while facing the dual pandemics of HIV and COVID-19, demonstrating leadership amid unprecedented challenges.[39]

RECOMMENDATIONS

In a year marked by a growing acknowledgment of systemic racism, the United States is being pushed to confront its past in its pursuit of equity. If we are to take advantage of this inflection point, we must advance structural equity where it has lagged. HIV CBOs must be involved in meaningful ways if the EHE plan is to be achieved and sustained. We offer recommendations in Box 1 to protect and promote the sustainability and viability of HIV CBOs to meet this goal. These recommendations also serve to validate HIV CBOs (past and present) whose experiences related to structural equity have been trivialized or doubted. Table 1 highlights barriers to structural equity and related recommendations.

TABLE 1— Barriers to HIV CBO Sustainability and Recommendations for Redress

Barrier	Examples	Recommendations
Financial threats	Reduced public & private HIV funding Changes in federal eligibility for grants Limited internal grant-writing resources Lack of political champions to advocate for funding Unclear parameters for obtaining funding Reimbursement-based grant structures and delays Competition with other organizations (e.g., larger corporate-structured agencies, multiple agencies in 1 jurisdiction) Inequitable access to programs that generate funding (e.g., third-party billing, 340B)	2, 3, 4, 5, 6, 10, 11
Organizational capacity	Limited understanding of resource acquisition and management Limited access to low- or no-cost capacity-building assistance Loss of highly effective staff to better-resourced organizations Increased emphasis on biomedical model	1, 7, 8, 10, 11, 12
Leadership and governance	Lack of nonprofit business acumen and tenacity of leadership Heightened fiscal and social responsibility shouldered by executive directors and CEOs Marginalization of BIPOC leadership and their organizations based on race/ethnicity Lack of mental and emotional support for CBO leadership Difficulty recruiting board members because of HIV stigma Meaningful involvement of PLWH in leadership and governance Lack of clarity about board member responsibilities	1, 2, 6, 7, 8, 9
Organizational biases	Discounted perceptions of HIV CBO experience and capability held by decision-makers Institutional funding biases toward larger clinic-based entities that contribute to hierarchy Risk of being penalized for critiquing existing resource allocation structures	1, 2, 4, 10

Note. BIPOC = Black, Indigenous, and people of color; CBO = community-based organization; PLWH = people living with HIV.

CONCLUSION

Early in the epidemic, the concept of "ending" HIV was an idea that few, if any, could grasp. Both activist- and service-oriented grassroots organizations were early responders to the epidemic to protect the human rights of stigmatized groups. During that period, grassroots organizations were established by people for whom this work was personal; their passion was—and continues to translate into—a relentless commitment to ending the epidemic. Nonprofit HIV-focused CBOs have encountered numerous threats to survival. Over the past 2 decades, many (including those with long histories of service) have either shuttered their doors or been faced with the threat of ceasing operations. For each high-profile organizational closure, there are likely many others that quietly close down with little public acknowledgment of their years of service. When this happens, clients lose spaces for social support, and staff who are living with HIV lose not only their jobs but their sense of purpose.[40]

Many of us have been actively responding to the HIV epidemic since its inception and have seen firsthand how it has ravaged communities and continues to disproportionately affect communities of color, especially Black communities. For HIV CBOs, ending the epidemic means "putting ourselves out of business"; this is our goal. However, we want to be "put out of the HIV business" or to "shift our missions" because the epidemic has ended, not because of structural inequities that privilege some and disadvantage others. We call for structural equity that supports the stability and sustainability of HIV CBOs across all efforts to end the epidemic. This is what we believe is necessary to get to zero and stay there. AJPH

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