the Stephen Lewis FOUNDATION

Investing in Healing, Health, and Hope:

A call to action for anti-colonial funding of HIV-related community-based care



(Wonai Haruperi/Musasa Project, Zimbabwe)

Across sub-Saharan Africa, community-based organizations (CBOs) reach the most marginalized community members and provide diversified community and home-based care that responds to people's unique needs. For decades, CBOs have successfully connected people who are living with HIV to care, treatment, and support systems while dismantling systemic inequities and championing human rights. Investing in these organizations and their expressed priorities is key to ending the AIDS pandemic as a public health threat by 2030.

Call to Action:

We call on funders to commit to an ongoing process of organizational reflection and to take concrete steps toward decolonizing funding practices. Using the lens of the five anti-colonial funding principles outlined in this document, funding organizations can strengthen their support of CBOs and shift power into their hands.

Everyone has the right to trusted and well-resourced health care. To support this fundamental human right, national efforts to strengthen formal health systems must be paired with long-term investments in community-based care. Community-based care approaches do not replace or diminish the need for clinical health care; rather, they are an essential part of a comprehensive health care system. Investing in CBOs and their community-based care models fundamentally contributes to universal health care, including mental health care for all, maternal and child health, and the prevention and treatment of non-communicable diseases.



(Wambui Gathee/Bar Hostess Empowerment Support Program (BHESP), Kenya)

Nowhere is this impact better demonstrated than in the AIDS pandemic, which CBOs have been responding to for 30 years. More recently, their experience and skills have been critical to reaching communities affected by COVID-19. The COVID-19 pandemic has underscored the limitations and vulnerabilities of relying solely on centralized health systems and has highlighted the need for the agility, responsiveness, and human connection that CBOs provide.

COVID-19 has also underscored that CBOs and the holistic care they deliver are sorely underfunded. To ensure that marginalized communities have access to critical health care, governments and the donor community must invest in the long-term sustainability of CBOs, and create funding conditions that prioritize communities' needs and help prevent future pandemics.

It is not a question of *whether* to fund CBOs, but *how*.



(Wambui Gathee/Young Women Campaign Against AIDS (YWCAA), Kenya)

The gap we see is that funders do not support CBOs citing lack of capacity as a reason. Instead, funders support bigger organizations that rely on the same CBOs for implementation. Which capacity do they look for? This perception towards CBOs must change.

– Justin Chimangeni, Golomoti Active AIDS Support Organization (GASO)

In 2021, the Stephen Lewis Foundation convened a group of funders and community-based organizations to look at how funders can meaningfully support community-based care in the response to HIV and AIDS across sub-Saharan Africa. The call to action and funding principles outlined here are informed by this group's experience and learnings.

A clear point of agreement is that colonial ways of thinking, motivated by systemic racism, have shaped the status quo of funding relationships in international development.

CBOs at the forefront of the HIV movement in countries across sub-Saharan Africa are experts in local epidemics; however, conventional models of philanthropy and international development, driven by organizations based in the Global North, de-value this expertise and experience. They ignore the systemic racism embedded in top-down approaches to grant-making and funding practices, which undermines the value and impact of CBOs' work in community and home-based care.

To correct this, we must acknowledge and unpack the historical power imbalances inherent in funding relationships. To shift power dynamics in philanthropy and international development, funders need to trust that communities are experts in their own needs, and approach partnerships with that trust.

Truly prioritizing community needs and community ownership in funding approaches will require a paradigm shift in grant management, including redefining what constitutes due diligence and risk. Traditional approaches to philanthropy and international development give more weight to the *perceived* risk that CBOs may "mismanage" funds, intentionally or unintentionally, than to the *real* risk that programs directed by organizations that are not community-based will fail to meet communities' needs. This racist, colonial approach to funding keeps power in the hands of funders, infantilizes communities, and disregards the significant and continuous investment communities make in their own development.





(Museruka Emmanuel/MU-JHU, Uganda)

To realize universal health care and end AIDS as a public health threat by 2030, funders must increase their support for CBOs delivering community-based care, reflect on their own funding practices through an anti-colonial lens, and take concrete action to change their approach.

This report presents both roadblocks to funding CBOs and their work in community-based care, and five principles funders can follow to remove them. It is intended to contribute to ongoing conversations within funding organizations and networks as well as between funders and CBOs.

5 Anti-Colonial Funding Principles













Anti-Colonial Funding Principle

1

Respect the agency and expertise of CBOs by responding directly to their needs and priorities; implementing co-decision-making processes; and providing flexible, context-specific funding.

Supporting community-based care isn't just about utilizing the access that CBOs have to community members and their ability to reach rural areas. It is about recognizing that CBOs bring significant expertise and experience to the table and that community-based care programs are most effective when they reflect that expertise. When funders determine a project's priorities and implementation strategy, it constrains CBOs by undermining their ability to deliver effective programming and respond to changing circumstances. Grant agreements and funding relationships must be rooted in trust and the belief that CBOs know what their communities need.

"Funders give funds and predetermine what will change as a result. The reality is that it is the people in that community that know what they need – our funding should align with that and we should be flexible to accommodate the needs in communities as opposed to the needs of the funder."

– Carolyne Ng'eny, Firelight Foundation

Funders must also acknowledge the immense investments communities make in their own development. Flexible and context-specific funding that is responsive to a CBO's evolving needs allows it to pivot activities or adjust budgets when circumstances change, without time-consuming approval processes or burdensome reporting.

"We want to enter into communities with an appreciative model of inquiry, knowing that the challenges communities face can be identified by communities themselves, as well as solutions."

– Chrispin Chomba, SAfAIDS

Voices and perspectives from CBOs must guide funders' programmatic decision-making and priority setting, beyond individual grants. Participatory grant-making and other forms of co-decision-making ensure that community expertise informs the direction funders take.

Grant agreements and funding relationships should begin with asking: *What does your community need and what do you need to support your community?*

Anti-Colonial Funding Principle

2

Provide multi-year grants as part of long-term investment in the people, infrastructure, and growth of community-based organizations and community-based care.



Too often, the funding that CBOs can access is short term and project-specific. By its nature, community-based care is people-centred and ongoing, and therefore requires long-term funding. Funders may cover staff and administrative costs during a project, but there is little long-term funding available for staff salaries, office rent, supplies, security, utilities, and audits. This has led to an unethical reliance on the unpaid work of women care workers, many of whom are living with HIV themselves. Despite the skilled, demanding, and critical nature of their work, few receive any payment at all.

In addition, the lack of funding for ongoing operational costs is detrimental to the long-term growth and sustainability of CBOs and undermines their impact. To pay salaries, repair motorbikes, invest in mobile health units, and keep the office lights on, CBOs often have to string together a number of project-specific grants over the course of each year.

"There needs to be an investment in the organization – the people, the infrastructure, and the equipment that will help the organization to function over the long term."

– Ruth Mapara, ELMA Philanthropies

This creates an environment in which community-based care is precarious, staff are underpaid and burnt out, and CBOs are forced into a process of retrofitting their needs and budgets to match donor priorities rather than their own.

Long-term, multi-year funding is a critical aspect of meaningful support for CBOs. It offers the consistency and stability that allow CBOs to focus on expanding holistic community-based care and create impact over time. Multi-year funding reduces the amount of time CBOs need to spend applying for grants just to survive. It also allows investment in organizational growth and development and facilitates meaningful relationship building between funders and CBOs.

"You get funding from a donor for HIV and AIDS and they say operation costs should not exceed 10%. How do you survive? We have staff members who need to be paid, they need resources."

– Peter Gondwe, Life Concern Organisation (LICO)

CBOs need funding that matches the length of time it realistically takes for meaningful change to occur. Changing behaviour and systems can take years. There is a substantive difference between funding *activities* and funding *change*.



Anti-Colonial Funding Principle

3

Expand traditional approaches to demonstrating impact in community-based health initiatives and ease the burden of reporting.

When CBOs need to tailor their monitoring and reporting to meet a funder's needs, it creates burdens on organizations with already limited resources. Impact evaluation and reporting, like all aspects of responses to HIV, must centre communities. Funders need to reconsider their reporting, monitoring, and evaluation requirements in collaboration with CBOs to ensure the requirements do not detract from the actual work.

Allowing CBOs to determine their own scope and metrics strengthens organizations by producing data that is useful to them, not just the donor, and allows CBOs to apply for more funding. Simple, open-ended questions create an avenue for CBOs to define their own successes — such as: *What activities or programs are you engaged in? What does community-based care look like in your community? What changes do you see?*

"We ask them to look at what success looks like in their own micro-space."
– Cecilia Kihara, ViiV Healthcare Positive Action

When it comes to financial reporting, requiring overly detailed budgets, timesheets for every staff member, receipts for small transactions, and frequent reporting creates an atmosphere of mistrust and surveillance. It also wrongly places the emphasis on accountability to external donors instead of community stakeholders. In this environment, even large and well-established CBOs may be deemed "high risk" and excluded from funding opportunities. Funders can play a tremendously meaningful role in supporting CBOs to develop sound financial management and governance practices that fit their context and strengthen accountability to partners, funders, and the communities they serve.

"The results to us are the changes we see happening in the community – not numbers at all. Where funders are only interested in numbers, it can push the organization to expand the program without having the same changes."
– Moses Zulu, Luapula Foundation

Anti-Colonial Funding Principle

4

Streamline application processes or support intermediary funders who have existing close relationships with CBOs and work in anti-colonial ways.



Researching and applying for funding takes significant time and human resources, especially when calls for proposals require extensive, detailed submissions. CBOs do not always have the capacity to develop proposals that appeal to specific funders when they must demonstrate narrowly defined impact or alignment with a funder's own time-bound strategic priorities. Rigorous due diligence processes can also be too onerous for small CBOs to undertake successfully.

To work meaningfully with CBOs, funders must streamline their applications and revise their due diligence. Until that is accomplished, intermediary funders with a proven record of supporting CBOs with multi-year partnerships can play a crucial role and shoulder some of the administrative burden. By developing simplified grant-making systems, intermediaries can also help CBOs access the funding they need. They are strategically positioned to meet the intensive due diligence requirements of large funders.

"Due diligence is often so strict that small organizations can't pass it. For organizations that aren't registered yet, it can be helpful to go through an intermediary funder. It can be a way to get more funding to key populations-led and youth-led organizations."

– Martine Weve, Aidsfonds

However, funding through intermediaries is not a stand-in for grappling with the principles outlined in this report. Ultimately, simplified processes and a more fit-for-purpose funding approach in philanthropy should directly support CBO partners as they work toward their own long-term goals. Intermediary funders also have a responsibility to advocate upstream to their own funders about the need to address burdensome processes, and to prevent passing bureaucratic requirements along to CBOs whenever possible.

"We keep hearing about huge funding for HIV and AIDS. Most of it is supposed to work through CBOs but it never actually reaches a CBO. Sometimes it's given to NGOs but you do not see it trickling down to communities."

– Ndinini Kimesera Sikar, Maasai Women Development Organization (MWEDO)



Anti-Colonial Funding Principle

5

Build partnerships with CBOs that extend beyond funding to include capacity building, peer learning, and advocacy.

In philanthropy and international development, grantees are too often expected to create "sustainable" change that allows a funder to wrap up support for one project and move on to another. However, building sustainable access to community-based care requires funders moving beyond relationships where they treat CBOs as local *implementers* of, or *contributors* to, the funder's mission. Instead, funders and CBOs should be *collaborators*, working in solidarity to fundamentally dismantle inequitable systems that prevent people from realizing the right to health.

While there is value in funding seed grants that allow new grassroots organizations to grow, building sustained change in communities and health systems requires long-term and patient partnerships. These partnerships should extend beyond funding individual organizations to active solidarity on the part of funders, including support for CBOs to build collective movements, alongside advocacy within the philanthropic community and with governments. In addition, funders can support long-term growth and sustainability by both facilitating and funding peer learning and capacity building, aligned with priorities identified by the CBOs.

"We need to advocate for community [health worker] cadres, recognizing the tremendous role that they play in improving outcomes and remunerating them fairly."

– Nicola Willis, Zvandiri

CBO concerns should be at the centre of advocacy efforts, shaping relevant policy changes. For example, CBOs have made it clear that community health workers (CHWs) should be compensated for their work. The ultimate responsibility to provide this pay, consistently and across the board, lies with national governments. Funders and CBOs need to work together to advocate for the recognition of CHWs as health professionals and the prioritization of their pay within fully resourced national health systems.

"A funder's responsibility does not end with a financial contribution. We have the opportunity and obligation to work in solidarity with CBOs, other funders, and like-minded stakeholders for transformative change."

– Healy Thompson, Stephen Lewis Foundation

The inequitable power dynamic that currently exists in traditional funding relationships will not change if funders engage in this process alone. A joint dialogue with community partners is necessary to rebuild partnerships based on trust, allyship, and meaningful integration of community perspectives. The paradigm shift begins with conversations about how a funder works with its partners — how self-reflection and active efforts to centre communities will inform the funder's approach, mission, and values. As power shifts into the hands of the CBOs, the racism, colonialism, and misogyny that keep community-based health care from achieving its true potential can be dismantled, and the right to health can be realized for all.



(Museruka Emmanuel/Reach Out Mbuya, Uganda)

Read the report that provides evidence for this Call to Action, *Healing, Health, and Hope: Prioritizing Home-Based Care and Community-Based Responses to HIV and AIDS*

Visit www.stephenlewisfoundation.org/healing-health-and-hope



(ROTOM, Uganda)

Acknowledgements

This Call to Action grew out of a series of conversations with funders and community-based organizations working in the context of the HIV and AIDS pandemic in sub-Saharan Africa. Their contributions helped shape the content of this document and we are extremely grateful for their time, insights, and collaboration.

Participants include:

Community-based Organizations

GALZ: An Association of LGBTI People, Zimbabwe

Golomoti Active AIDS Support Organization (GASO), Malawi

Health Options for Young Men on HIV, AIDS & STIs (HOYMAS), Kenya

Kawempe Home Care, Uganda

Kiambu People Living with HIV/AIDS (KIPEWA), Kenya

Life Concern Organisation (LICO), Malawi

Luapula Foundation, Zambia

Maasai Women Development Organization (MWEDO), Tanzania

Matunkha Development Trust (MDT), Malawi

SAfAIDS, South Africa

Zvandiri, Zimbabwe

Funders

Aidsfonds

ELMA Philanthropies

Firelight Foundation

Stephen Lewis Foundation

ViiV Healthcare Positive Action

We would also like to extend a special thank you to Siobhan Bradley and Danielle Denwood for their contributions to this process.

The SLF received generous support from an anonymous funder for this work, including the production of our report, *Healing, Health, and Hope: Prioritizing Home-based Care and Community-based Responses to HIV and AIDS.*

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Report published July 2022

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