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Breaking the chains: supporting community leadership and human rights for a sustainable HIV response

55th PCB MEETING

10 - 12 December 2024

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Purpose and context

Intervention delivered by Cecilia Chung

The Global AIDS strategy 2021 - 2026 recognises and promotes the central role that community-led organizations have played and continue to play in the HIV response at all levels. However, the NGO delegation notes with concern that latest data from UNAIDS suggests we are still off track to meet community leadership targets, Three major obstacles stand in the way of community leadership:

- Increasingly restricted civic space
- The rise of a well-funded and well-coordinated 'anti-gender / anti-rights' movement
- Lack of adequate and sustainable funding

In the face of these threats, the NGO Delegation offers a number of overarching recommendations for a paradigm shift in the way community leadership is supported and proposes a number of specific, actionable decision points, for consideration by the PCB.

Methodology and limitations

The report was developed using a qualitative, mixed methods approach that included:

- An online community survey in English, French, Spanish and Russian (90 responses in total)
- 8 regional dialogues (38 participants)
- 19 key informant interviews or dialogues (24 participants)
- An extensive literature review including over 100 reports, journal articles, conference papers, blogs, newspaper articles, etc
- A peer review process by a 9-member civil society expert panel

The report builds on a number of previous NGO Delegation reports and PCB decision points

A challenge for the report was the curtailed timeframe for its development due to lack of funding, which delayed its start date by 4 months.

Community leadership in the HIV response

Definitions: Community leadership*

- **Community-led AIDS responses** are actions and strategies that seek to improve the health and human rights of their constituencies, that are specifically informed and implemented by and for communities themselves and the organisations, groups and networks that represent them
- **Community-led organizations** are entities for which the majority of governance, leadership, staff, spokespeople, membership and volunteers, reflect and represent the experiences, perspectives and voices of their constituencies and who have transparent mechanisms of accountability to their constituencies.
- These definitions are the work of the multistakeholder task team was convened by the UNAIDS PCB with representatives of governments, civil society and donors convened for the purpose of defining community-led AIDS responses in 2021-22. They build on an earlier a technical consultation of experts comprising people living with HIV and key populations from global networks, treatment activists and women's organisations, convened by UNAIDS in 2019.

Community leadership in the HIV response

Historical perspectives

Key milestones and principles

- Denver Principles - 1983
- GIPA principle - 1994
- Central role of communities in UNAIDS (est 1996) and the Global Fund (est 2002)

*"The Denver Principles were the foundation of the GIPA Policy, which placed us, people living with HIV, at the center of the response. It gave us a voice; it gave us a seat at the table. Today, it is no longer enough; it is time to evolve from having a seat at the table to being the leaders of the table, the leaders in the HIV response."
(Erika Castellanos)**

Current global Frameworks

1. **GAS** 2021 - 2026 Result Area 4 envisions '*Fully recognized, empowered, resourced and integrated community-led HIV responses for a transformative and sustainable HIV response.*'
2. In the **Global Fund's** 2023-2027 strategy '*maximising the engagement and leadership of most affected communities to ensure no-one is left behind*' is a contributory objective to reach the primary goal of ending AIDS, TB and malaria
3. In **PEPFAR's** current strategy, community leadership is a key enabler both within PEPFAR and within partner government programs. The strategy emphasises the importance of '*elevating a next generation of community leadership.*'

Relevant commitments in the Global AIDS Strategy

The 30-60-80 community leadership targets

The 30-80-60 targets commit to ensuring that by 2025, communities most affected by HIV deliver:

- 30% of testing and treatment services, with a focus on HIV testing, linkages to treatment, adherence and retention support, and treatment literacy
- 80% of HIV prevention services for people from populations at high risk of HIV infection, including for women within those populations
- *60% of programmes to support the achievement of societal enablers*

The 10-10-10 societal enabler targets

- Less than 10% of women, girls, people living with HIV and key populations experience gender-based inequalities and all forms of gender-based violence
- Less than 10% of countries have punitive legal and policy environment that lead to denial of limitation of access to services, and
- Less than 10% of people living with HIV and key populations experience stigma and discrimination

Part 2

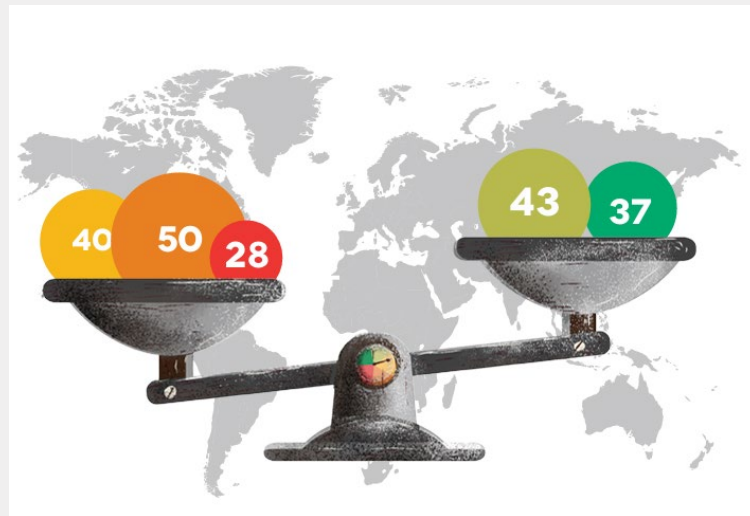
Obstacles and challenges to community leadership

Restricted civic space

The rapid deterioration of civic space is a global crisis that requires a comprehensive and collective response
(CIVICUS)

In 2023, 30.6% of the world's population lived in countries with closed civic space. 2.1% lived in countries with open civic space, down from 4% in 2018.
(CIVICUS Monitor)

- Restrictive laws are being used as tools to limit the activities of civil society.
- This has had a particular impact on the ability of LGBTQI+ groups to organise.
- These laws also impact other key populations and women and girls



'If you are doing work that goes against cultural or religious values – what are the chances that you will be able to re-register?' (ESA regional dialogue).

Anti-gender / anti-rights movements

Some of the Delegation's observations on how anti-gender / anti rights mobilisation undermine community leadership include

- A wave of punitive anti LGBTQI legislation in sub-Saharan Africa, and anti-LGBTQI sentiment in other parts of the world creating an extremely hostile environment
- A rollback on CSE, SRHR and women's rights, including in UN normative language
- Mis- and disinformation regarding the work of community-led organizations, especially LGBTQI+ -led or -serving organizations, including co-option of child protection language to support a pushback on CSE, LGBTQI rights and reproductive rights

- A tightening of drug laws, including in some places, re-criminalization of drug use
- The development of alternative non-binding normative frameworks such as the 'Geneva Convention' and the use of 'first lady advocacy' to gain traction for its launch and implementation
- Reinforcement of conservative gender norms and binarisms, including HIV-related stigma and discrimination

How do we push back on marginalisation and against ideologies that undermine human dignity – and ideologies that make communities seem irrelevant – or worse, criminals?' (ESA regional dialogue)

Who is afraid of Gender?

Study on “gender ideology”
and the anti-gender
campaigns that support it in
Burkina Faso, Ghana and
Senegal

ISDAO and QAYN, 2022



Lack of sustainable funding for CLOs

Dwindling resources for HIV

Funding is the biggest challenge for communities

- There has been a drop in overall funding going to communities from 31% in 2011 to 20% in 2021 (source: UNAIDS Let Communities Lead)
- Funding going for Key Population constituted only 2% of HIV funding in 2020, and has dropped even further in the interim four years (Source: Aidsfonds)
- Funding is often unobtainable by smaller organizations due to donor criteria and compliance

Lack of core financing and reliance on voluntarism

- Most funding for community-led organizations is project based, resulting in a lack of core funding

'The lack of core funding creates operational challenges, limiting our ability to cover essential costs like staff salaries, rent, and utilities, which undermines service quality and consistency. It restricts program sustainability, forcing us to rely on short-term, project-based funding. The increased administrative burden to secure funds diverts focus from core activities, while the lack of resources stifles innovation, limiting our ability to address emerging needs.' (Rwanda Network of people living with HIV/AIDS (RRP+) - from survey)

Lack of sustainable funding for CLOs

Shift to domestic financing

Growing pressure on countries to use domestic financing to fund their HIV response, is a cause for concern in a context of increasing restricted civic space and hostility towards key population communities.

As countries achieve 95-95-95 targets, external funding declines.

'I feel we have cornered ourselves with the 2030 ending AIDS principle because the governments will be doing everything to end it. Which will never happen and the funding for UNAIDS, I'm afraid, on the global level will be close to zero.' (EECA regional dialogue)

Impact on women- youth- and key-population led organisations

WROs receive only 0.13% of the total Official Development Assistance (ODA) and 0.4% of all gender-related aid; LGBTIQ, indigenous, migrant and refugees, young feminists, and sex workers - even less (*AWID 2021: Where's the money for feminist organising?*)

Harm Reduction International's report 'The Cost of Complacency' found that domestic investment in harm reduction accounted for a mere 0.4% of the entire domestic investment in the HIV response, globally.

Part 3

A paradigm shift for the next phase of the HIV response

Sustainable and equitable financing for communities

Revolutionise funding models

Community leadership needs to be supported by funding models that are more flexible, responsive, context specific, unrestricted and open to different kinds of organizations and movements.

The consultation also called for funding to go directly to community-led organizations rather than being channeled through intermediaries. *Love Alliance* provides a good case study of participatory grantmaking which is trust-based and flexible, centering community knowledge and priorities.

Community members also highlighted the importance of the Robert Carr Fund for supporting community leadership

Retain 'exceptional' funding for communities, and safety and security funds

The shift towards domestic financing for HIV as part of universal health coverage is welcome in many respects, but - as noted above - raises concern about the likelihood of key population organizations being fully supported by hostile governments

'We need a dual system for continuing the HIV response - a single stream of funding for biomedical aspects and a communities fund to keep the work of communities going.' (LAC regional dialogue)

The report also highlights the need for the availability of safety and security funds in the contexts of hostile environments

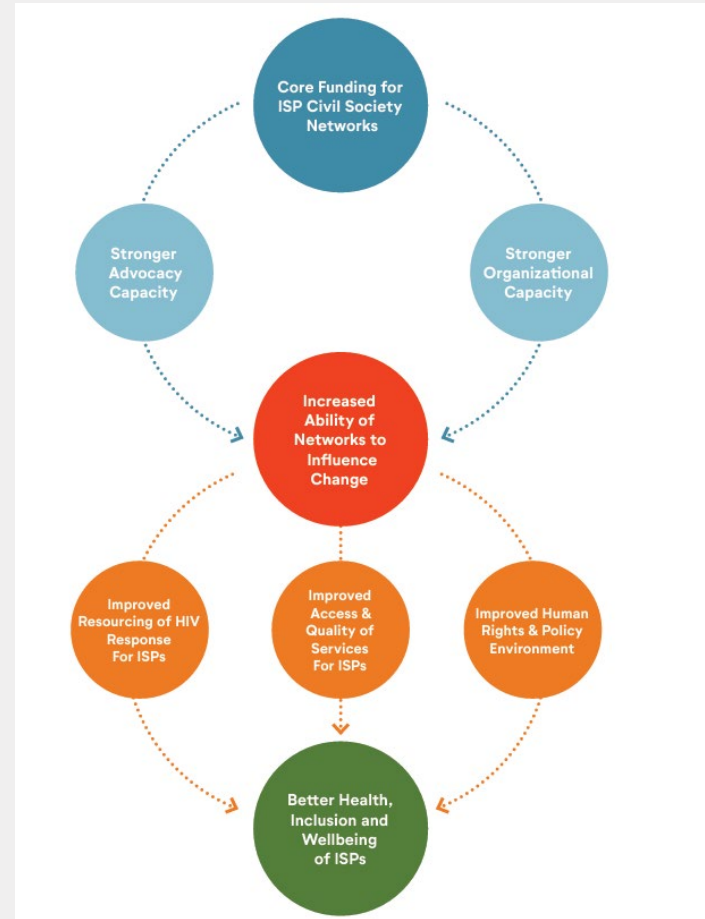
Case study: Robert Carr Fund

The Robert Carr Fund provides a good model of core/strategic funding for regional and global network and was cited by many participants in the community consultation as a 'lifeline' for networks of people living with HIV and key populations.

'Without [the RCF] we would have nothing for the regional and global networks. The voices of community wouldn't be heard at all. Or there would be very few activists from a few countries.' (EECA regional dialogue)

RCF complements service delivery grants, and enables advocacy, participation in decision making spaces and holding governments to account, and bring about structural change.

Image: RCF Theory of Change, 2025-2030
[Strategy rcf_2025-2030_strategy.pdf](#)



Community leadership in global and national AIDS strategies

Strengthen accountability to communities

The Global AIDS Strategy we have now is good enough; it just needs implementing (EECA regional dialogue)

Commitments towards community leadership need to be reinforced by strengthening accountability frameworks that monitor the level of community leadership and participation at national and global levels

Communities also need to be supported better to maximise their leadership potential in decision-making at national and global levels - for example to make full use of Global Fund tools and processes that promote community leadership, such as CCMs

Value communities knowledge and expertise, and support community-led research and monitoring

Despite commitments enshrined in global HIV frameworks, communities are not consistently granted leadership space in decision-making processes. Communities must be meaningfully involved at all levels of decision making, and in a timely manner.

This includes continued support for community led monitoring to inform service delivery and human rights advocacy

CLM provides space for community leadership to call out what good services should look like, for people accessing the service, but also how the powers are accountable for services provided to the community' (ESA regional dialogue)

Case study: Representation, Inclusion, Sustainability, Equity: RISE

Independent research study led by CCM representatives, advocates and international research partners, looking at CCMs as a vital point for community engagement.*

Results highlighted the need for:

- Community participation at all stages of the Global Fund cycle
- Greater financial support to community engagement, better transparency, and stronger mechanisms for reporting abuse
- More equitable and meaningful participation of women in their diversity in Global Fund consultations

*Study supported by L'Initiative and amfAR



Image: Lao PDR CCM Meeting April 2021 -
<https://ccmlaopdr.org/>

Human rights, civic space and countering the anti-gender / anti-rights movement

Build the resilience of community-led organizations

To counter the anti-gender / anti-rights movements, people living with HIV, key populations and women and girls in their diversity need solidarity and allyship centred around a counter narrative based in science and evidence.

Financial resilience implies long term flexible funding to respond to local contexts and priorities

Support for mental health and mentorship of a new generation of leaders are also critical to build the resilience of CLOs

Hold the line on rights-centred language and build intersectional movements

It is important that we use person-centred, rights-promoting language both within our movements, in external facing advocacy and communications, and in normative frameworks.

The pressure that community led organisations are under can cause splintering and fragmentation; we need to build our movements on common ground, taking an intersectional approach, and seeking cross-movement collaboration

Case study: Rise and Decriminalize

In the EECA region, the Rise and Decriminalize movement has united sex workers, people who use drugs, LGBTQI+ people, women in their diversity and people living with HIV to develop a joint advocacy agenda calling on the international community (including development agencies, donor governments and private philanthropies) to:

- Acknowledge the shrinking space faced by communities in EECA and the need for action to safeguard civic spaces
- Provide flexible funding to sustain the 'low threshold' comprehensive work of communities, and ensure safety and security of community activists and advocates
- Ensure advocacy and fundraising is inclusive of a broad range of stakeholders for a coordinated, intersectional and holistic response
- Support communities in addressing issues of criminalisation
- Take leadership and coordinate meaningful dialogue to ensure the sustainability of services, meaningful participation of communities, decriminalisation and space for civil society



Conclusion and recommendations

Targets promoting community leadership (the ‘30-80-60’ targets) and societal enablers (the ‘10-10’10’ targets) have been enshrined in the 2021 Political Declaration on HIV and AIDS, and in the 2021-2026 Global AIDS Strategy.

These are in danger of not being met, due to the current global retrenchment of human rights, manifested in restricted civic space and the rise of the anti-gender / anti-rights movement, and inadequate funding for community-led organisations.

Beyond these specific targets, the curtailment of community leadership has implications for meeting ALL the targets in the Political Declaration, and ending AIDS as a public health threat.

Based on an extensive consultation and literature review, the following mutually reinforcing recommendations have emerged:

1. Ensure sustainable and equitable financing for communities
2. Centre community leadership in global and national AIDS strategies
3. Build communities’ resilience to hold civic space and counter the anti-gender and anti-rights movements



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