

2024 NGO Report

Concept Note

22 March 2024



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Preliminary Title: Breaking the Chains: Community Leadership, Sustainability, Human Rights and the HIV Response

Relevance to the HIV and AIDS community in general

The importance of involving communities - key and marginalized populations, people living with HIV, and other communities hard hit by the AIDS pandemic - in the HIV response is a topic that has long been discussed by multilateral organizations, donors, national governments, and of course, communities themselves. However, community leadership across planning, implementation, monitoring, evaluation, and dissemination of HIV and other interventions remains limited, with communities still not being equitably or sustainably financed for their essential work as service providers, researchers, advocates, consultants, and leaders.

Increasingly, they are also subject to government restrictions leading to shrinking civil society space. Additionally, while human rights violations and gender inequality have been barriers to ending AIDS since the earliest days of this pandemic, the emergence of focused and well-resourced anti-SRHR and anti-LGBT+ movements poses new challenges. Active in every region, anti-rights groups have become increasingly vociferous opponents of communities and community-led organizations, branding them as a danger to children, families, and society itself and campaigning directly against essential components of an effective HIV response, from condoms and PrEP to comprehensive sexuality education, alongside pushing a narrow, patriarchal and binary view of identity, sex and relationships that confounds harmful social and gender norms and is behind the push for new anti-gay laws in several countries, and the rollback on transgender rights.

Equally critical is sustainable financing for community-led responses, including frontline service delivery especially during humanitarian emergencies, high-impact advocacy, cutting-edge research, game-changing monitoring work, and innovative community-led financing solutions. Removing barriers to communities' leadership, particularly the criminalization of key population communities and restrictions on the ability of community-led organizations to organize and mobilize, must also be non-negotiables, all the more so given rising opposition from anti-SRHR and anti-LGBT+ movements.

It is no longer enough for communities to have an often hard-fought seat at the decision-making table or be included as optional, tokenistic, and frequently unpaid consultants on specific issues in the broader environment of criminalization, civic space restrictions, and an anti-rights movement that threatens not only the work of

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community-led organizations and the health of community members but also their basic safety and survival. It is high time for a community leadership to speak truth to power.

Relevance to the Global AIDS Strategy

UNAIDS' most recent World AIDS report had the compelling slogan "Let Communities Lead," and Results Area 4 of the Global AIDS Strategy focuses on "Fully recognized, empowered, resourced, and integrated community-led HIV responses for a transformative and sustainable HIV response."

The 2024 NGO Delegation report will be dedicated to community leadership. It will showcase the leading contribution that communities are making to the three pillars of the Global AIDS Strategy—maximizing equitable and equal access to HIV services and solutions, breaking down barriers to achieving HIV outcomes, and fully resourcing and sustaining efficient, integrated HIV responses—and highlight the greatest obstacles to community leadership.

Looking ahead to the development and implementation of the next Global AIDS strategy, it will seek to ensure that the unique value of sustained and meaningful engagement with communities is fully understood as an essential pathway to a stronger HIV response at both the country and international levels and more resilient health systems, bringing about the true paradigm shift that has remained out of reach for too long.

What can we expect from it?

The report will document stories of community leadership - and of meaningful engagement and partnerships with communities - that have contributed to the three pillars of the Global AIDS strategy and the corresponding Results Areas. Drawing on examples from different regions and contexts, it will show how community leadership involves actions that are consciously reflected on, and informed by practical wisdom and theory, to ensure participation in every step of the HIV response, generate new learning and catalyze further action.

Some examples will showcase communities focusing their interventions on service delivery, science, education, and behavior change communication. In contrast, others will focus more on community mobilization, political advocacy, and influencing public perceptions and narratives. They will also showcase examples of community-led monitoring strategies, community-led research projects, and community financing initiatives, pointing to the unique impact they have and addressing how leadership functions as systematic and accountable planning for the community and strengthens the infrastructure needed in health, policy and development sectors.

At the same time, alongside these stories of success and impact, the report will offer an analysis of the significant challenges and obstacles facing community leadership,

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emphasizing, in particular, the historical impact of criminalization (of people who use drugs, of HIV transmission, on same-sex relationships, to name a few) and the ongoing rise of a coordinated and well-resourced anti-rights movement, with an emphasis on clearly defining this movement and on securing explicit recognition of its impact towards HIV response, with agreed UN language going forward. As noted in section 1, it will also include a few case studies showing the effects of the recent expansion of government restrictions on civic space on community leadership in the HIV response.

It will then go on to put forward a set of recommendations for actions needed at the country level, within the global AIDS and health infrastructures, to deliver on the Global AIDS strategy's promise of "Fully recognized, empowered, resourced and integrated community-led HIV responses for a transformative and sustainable HIV response," as set out in Results Area 4. Looking further ahead to the next Global AIDS Strategy, it will argue for a paradigm shift in how community leadership is understood and supported in this next framework. Additionally, it will seek to position the removal of barriers faced by communities, including the increasing threats posed by civic space restrictions and anti-rights mobilization, as non-negotiables in the future global HIV response.

Proposed Decision Points (DPs)

Recognizing the unique and fundamental contribution of community leadership to the HIV response over more than four decades and to the delivery of the current Global AIDS Strategy and UBRAF indicators, as well as the growing impact of civic space restrictions and anti-rights movements mobilization on community leadership, and calls on the Joint Programme to take the following steps:

- A. Commit to prioritizing the meaningful involvement of communities, including key and marginalized populations, people living with HIV, most at risk of and most affected by the AIDS pandemic, in all aspects of decision-making, planning, implementation, and monitoring relating to the global and national HIV responses.
- B. Recognize and address the intersectional nature of human rights violations, gender inequality, and anti-rights activism, which pose significant challenges to ending AIDS and achieving health equity.
- C. Support the transition of communities from service beneficiaries to meaningful stakeholders and leaders in the HIV response, fostering trust, acceptance of services, and social change within affected populations.
- D. Commit to providing sustainable and equitable financing for community-led responses, recognizing communities as essential service providers, researchers, advocates, and leaders in the fight against HIV, including collaborating with national stakeholders and international donors to increase financing community-led responses significantly, and requiring annual reporting on the

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proportion of national HIV budgets allocated to and spent on community-led responses.

- E. Condemn government restrictions on civic space and anti-rights activism that hinder community leadership and commit to removing such barriers to ensure meaningful community participation.
- F. Work towards removing unnecessary restrictions on civic space that impede community leadership in the HIV response while also building the capacity of stakeholders to counteract anti-rights actors and mobilization.
- G. Encourage all relevant stakeholders to invest in building the leadership of affected communities, including LGBTQ+ communities, women and girls, and young people, to mitigate the impact of anti-rights mobilization on the HIV response and to advocate for support, including funding for communities to deliver community-led human rights monitoring, response, and advocacy;
- H. Revitalize and strengthen collaboration across Cosponsors and partners through the UNAIDS Reference Group on HIV and Human Rights, ensuring collective efforts to address and counter the impacts of civic space restrictions and anti-rights mobilization on the HIV response, including, where applicable, through further collaboration with the Office of the High Commission on Human Rights (OHCHR).
- I. Provide regular updates to the PCB on the impacts of civic space restrictions and anti-rights activity on human rights results outlined in the global AIDS strategy, along with actions taken to counteract these impacts, promoting transparency and accountability in addressing emerging challenges.
- J. Prioritize meaningful engagement of communities in the development of the next Global AIDS Strategy and ensure that this pledges concrete action to enhance further and support community leadership and commitments to remove the barriers that stand in the way of communities' leadership, including human rights and civic space barriers.

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