

LET COMMUNITIES LEAD



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Around the world, 9.2 million people living with HIV do not have access to life-saving antiretroviral therapy. Every minute, a life is lost to AIDS. This is not fate. We can change it. Indeed, we can end AIDS as a public health threat by 2030 by unleashing the full potential of community leadership.

The evidence in the new Joint United Nations Programme on HIV/AIDS (UNAIDS) World AIDS Day Report is crystal clear. Communities play a critical role in connecting people with HIV services and in reaching key populations most affected by HIV with health, HIV and support services. The innovation and determination of communities improve access to and quality of services. Communities have built an inspirational movement for change. Communities are the extraordinary ordinary heroes of the AIDS response. They have helped tackle other pandemics too, including COVID-19.

This report is not only a celebration of the critical role of communities. It is a call to action to decision-makers to fully support the life-saving work of communities and to clear away the barriers that stand in their way. Underfunding of community-led initiatives means many are struggling to continue operating or being held back from expanding. There has been an unprecedented backsliding in financial commitments to community-led organizations, and it is costing lives. Crackdowns on civil society and on the human rights of people from marginalized communities are obstructing the progress of HIV prevention and treatment services, putting the fight against AIDS at risk. Harmful laws and policies towards people from populations at risk of HIV threaten the lives of community activists trying to reach them with HIV services.

Too often, decision-makers treat communities as problems to be managed, rather than as leaders to be recognized and supported. The HIV response is hurt when community leadership—the greatest power for progress—is unacknowledged, undersupported, underresourced, underremunerated, and in some places even under attack. If the obstacles to the work of communities are removed, community-led organizations can add even greater impetus to the global HIV response, advancing progress towards ending AIDS.

It has been a long-standing principle of the HIV response for people living with or affected by HIV to have a place at the decision-making table. Where this principle is followed, progress is being made. Supporting communities in their leadership is not only the right thing to do—it is essential for advancing public health. In the 2021 Political Declaration on HIV and AIDS, Member States renewed their commitment to supporting the critical role played by communities in the HIV response, particularly for populations most at risk. This commitment needs to be matched by courageous action, everywhere.

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Communities' leadership roles need to be made core in all HIV plans and programmes. They need to be fully and reliably funded. Barriers to communities' leadership roles need to be removed. Communities are not in the way—they light the way to the end of AIDS. Let communities lead!

Credit: UNAIDS





INTRODUCTION

We have an extraordinary, historic opportunity. We can end AIDS as a public health threat by 2030 and sustain these gains in future decades. We even know how—by enabling the leadership of the communities at the frontlines.

This report shows how community-led interventions are central to achieving the end of AIDS and to sustaining the gains into the future. People living with or affected by HIV have driven progress in the HIV response—reaching people who have not been reached; connecting people with the services they need; pioneering innovations; holding providers, governments, international organizations and donors to account; and spearheading inspirational movements for health, dignity and human rights for all. They are the trusted voices.

Communities understand what is most needed, what works, and what needs to change. Communities have not waited to be handed their leadership roles—they have taken the roles on themselves and held fast in their insistence on doing so. They have applied their skills and determination to help tackle other pandemics and health crises too, including COVID-19, Ebola and mpox. Letting communities lead builds healthier and stronger societies.

This report shines a light on the underreported story of the everyday heroes of the HIV response. But it is much more than a celebration of the achievements of communities. It is an urgent call to action for governments and international partners to enable and support communities in their leadership roles.

Credit: Elizabeth Carecchio



The barriers holding back communities' leadership roles can be removed, unleashing the full potential of community-led responses.

Many communities face barriers to their leadership. Community-led responses are underrecognized, underresourced, and in some places under attack. Globally, funding channelled through communities has fallen in the past 10 years from 31% in 2012 to 20% in 2021 (1). These funding shortages, policy and regulatory hurdles, and crackdowns on civil society and the human rights of women and marginalized communities are obstructing progress on HIV prevention, treatment and care services. It is in everyone's interests to fully fund community-led organizations and to remove the many obstacles they face. By enabling communities in their leadership, the promise to end AIDS as a public health threat can be realized.

Community leaders have expressed it like this: "We should not be seen as a target of interventions, but as the principal intervention. We should not be seen as the problem, but as the key to the solution."

This report sets out why and how we must:

- Make communities' leadership roles central to the formulation, budgeting, implementation, monitoring and evaluation of all plans, policies and programmes that will affect communities and that impact the HIV response—"nothing about us without us".
- Fully and sustainably fund communities' leadership roles so that programmes can be scaled up, and the people implementing them can be properly supported and remunerated.
- Remove barriers to communities' leadership roles by ensuring civil society space and protecting the human rights of all people, including people from marginalized and criminalized communities.

The UNAIDS Global AIDS Update released in July 2023 demonstrates that there is a path that ends AIDS. The data showed that enabling community-led responses—by people living with HIV, key populations and priority populations, including adolescent girls and young women—is key to ensuring success (2).

This World AIDS Day Report takes a deeper dive into how community leadership advances progress, how that leadership is being obstructed, and how it can be fully unleashed. Importantly, alongside the UNAIDS analysis, the report includes nine guest essays by community leaders that reveal how they have been able to drive change, how they experience obstacles in their way, and the actions they are urging governments and international partners to take to enable communities to lead us to the end of AIDS by 2030.

The approach that this report calls for is not new. It has been promised by world leaders. The 2021 Political Declaration on HIV and AIDS: Ending Inequalities and Getting on Track to End AIDS by 2030 commits decision-makers to actions to support communities to lead the way (3).

The targets agreed include that, by 2025, community-led organizations should deliver 30% of testing and treatment services, 80% of HIV prevention services for people from populations at high risk of infection, and 60% of programmes to support societal changes that enable an effective and sustainable HIV response (3). In addition, they agreed on the 10–10–10 targets to remove punitive laws against LGBTQI people, people who use drugs, sex workers and people from other often criminalized populations, and to reduce stigma and discrimination, gender inequality and violence experienced by people living with HIV and people from key populations and priority populations (Table 1).

Table 1. Topline targets for 2025

HIV services

- Achieve the 95–95–95 testing, treatment and viral suppression targets within all demographics and groups and geographical settings, including children and adolescents living with HIV
- Ensure all pregnant and breastfeeding women living with HIV are receiving lifelong antiretroviral therapy, with 95% achieving and sustaining viral suppression before delivery and during breastfeeding
- Ensure 95% of people at risk of HIV infection, within all epidemiologically relevant groups, age groups and geographical settings, have access to and use appropriate, prioritized, person-centred and effective combination prevention options

Community leadership

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

Integration

- Invest in robust, resilient, equitable and publicly funded systems for health and social protection that provide 90% of people living with, at risk of or affected by HIV with people-centred and context-specific integrated services for HIV

Societal enablers

- Reduce to no more than 10% the number of women, girls, and people living with, at risk of or affected by HIV who experience gender-based inequalities and sexual or gender-based violence
- Ensure less than 10% of countries have restrictive legal and policy frameworks that unfairly target people living with, at risk of or affected by HIV, such as age of consent laws; laws related to HIV nondisclosure, exposure and transmission; laws that impose HIV-related travel restrictions; and mandatory testing and laws that lead to denial or limitation of access to services
- Ensure less than 10% of people living with, at risk of or affected by HIV experience stigma and discrimination, including by leveraging the potential of Undetectable = Untransmittable (U = U)

Source: Ending inequalities and getting on track to end AIDS by 2030: a summary of the commitments and targets within the United Nations General Assembly's 2021 Political Declaration on HIV and AIDS. Geneva: Joint United Nations Programme on HIV/AIDS; 2022 (https://www.unaids.org/sites/default/files/media_asset/2021-political-declaration_summary-10-targets_en.pdf, accessed 13 November 2023).

The world has yet to follow through on these commitments fully. There has been notable progress in the removal of anti-LGBTQI laws around the world, but much is yet to be done. Community-led responses are obstructed by a host of barriers, including an untenable reliance on uncompensated work, failure to provide the operational support needed to sustain community-led organizations over the long term, persistence of stigma and discrimination, failure to leverage societal enablers such as legal reform and anti-stigma initiatives, difficulties in obtaining registration as a community-led organization (which in turn can block access to essential funding), and inadequate integration and engagement of community systems and actors in decision-making bodies and health systems.

This report synthesizes the available data and evidence to highlight three vital lessons about community leadership:

- AIDS can be ended as a public health threat, with communities leading the way. Communities deliver essential HIV and sexual and reproductive health and rights services that are accessible, grounded in people's needs, and able to reach the most marginalized people. Communities have a unique ability to advocate for needed policy change and to serve as accountability watchdogs. Community-led responses drive progress across all aspects of the HIV response, but their role will be especially critical in travelling the last mile to reach the 2030 target and in sustaining these gains beyond 2030. Across the HIV response, no other actor can deliver what communities can.
- The path to end the AIDS pandemic is being obstructed because communities' leadership roles are being held back. The issue is not principally one of capacity—communities have the knowledge, innovation and solidarity needed to transform national HIV responses. The issue is that they are often blocked from fully leveraging this capacity.
- The barriers holding back communities' leadership roles can be removed, unleashing the full potential of community-led responses. It is within the power of authorities to clear away the obstructions to communities' leadership roles. National governments, donors and other stakeholders need to follow through on their commitments to let communities lead. This means providing community-led organizations with the resources they need, including core funding to build sustainable institutions, and removing complexity in funding processes. It means recognizing that communities are not in the way, but that they light the way forward. It means governments need to ensure safe and meaningful space for communities to do their essential work. Punitive laws and other policy barriers to effective community-led responses must be removed.

The message of this report is one of active hope. Although the world is not currently on track to end AIDS as a public health threat, it can get on track. Communities can lead the world to end AIDS, if the barriers obstructing them are cleared away. For the HIV response to succeed, let communities lead!



REFERENCES

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The full report can be downloaded at [unaids.org](https://www.unaids.org)





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