

# LET COMMUNITIES LEAD



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**LET COMMUNITIES LEAD**  
**WORLD AIDS DAY REPORT | 2023**

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# FOREWORD BY WINNIE BYANYIMA

## UNAIDS Executive Director and United Nations Under-Secretary-General

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.

**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.**

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



# ABBREVIATIONS

<b>AIDS</b>	acquired immunodeficiency syndrome
<b>CCM</b>	Country Coordinating Mechanism
<b>COVID-19</b>	coronavirus disease 2019
<b>GATE</b>	Global Action for Trans Equality
<b>GIPA</b>	Greater Involvement of People Living with HIV
<b>Global Fund</b>	Global Fund to Fight AIDS, Tuberculosis and Malaria
<b>GNP+</b>	Global Network of People Living with HIV
<b>HIV</b>	human immunodeficiency virus
<b>ICW</b>	International Community of Women Living with HIV
<b>INPUD</b>	International Network of People Who Use Drugs
<b>LGBTQI</b>	lesbian, gay, bisexual, transgender, queer, intersex
<b>PEPFAR</b>	United States President's Emergency Plan for AIDS Relief
<b>PrEP</b>	pre-exposure prophylaxis
<b>REGIPIV</b>	Réseau national pour une grande implication des personnes infectée et affectée par le VIH dans la lutte contre le SIDA
<b>SDG</b>	Sustainable Development Goal
<b>SEEK-GSP</b>	Social, Emotional and Economic Empowerment through Knowledge of Group Support Psychotherapy
<b>TWEET</b>	Transgender Equity Welfare and Empowerment Trust
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organization
<b>UNHCR</b>	United Nations Refugee Agency
<b>UNODC</b>	United Nations Office on Drugs and Crime
<b>UN WOMEN</b>	United Nations Entity for Gender Equality and the Empowerment of Women
<b>U = U</b>	Undetectable = Untransmittable
<b>WHO</b>	World Health Organization
<b>Y+ Global</b>	Global Network of Young People Living with HIV

Terms used by communities to describe themselves vary and evolve. UNAIDS evolves its own usage in recognition of this. The terms "LGBTQI" and "trans" are included in this report on the advice of community members.



# 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)

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!



**WE CAN END AIDS  
AS A PUBLIC HEALTH  
THREAT, WITH  
COMMUNITIES  
LEADING THE WAY**

**1**





**Community-led organizations deliver results that other actors cannot. Their leadership is especially crucial in reaching the people being left behind.**

## Communities have been the critical drivers of progress in the HIV response

From the start of the HIV pandemic, one of the distinguishing features of the HIV response has been the central role played by communities. The invaluable innovation, passion and insight of communities have proven pivotal in getting the world to the point where there is a clear path to end AIDS as a public health threat.

When the HIV pandemic was first recognized in the early 1980s, opportunities to respond effectively were hampered by the dominance in too many places of top-down approaches that combined insufficient engagement with the communities most heavily affected with disrespect and even hostility towards them. Communities, supported by allies, changed this script. In the face of fear, stigma and discrimination, communities of people living with HIV, people from key populations and other affected communities insisted there be room for them at policy-making tables from which they had previously been excluded, echoing the pioneering call of disability rights activists of “nothing about us without us”. Once at these policy-making tables, communities insisted that all parts of the HIV response address the needs and preferences of the communities most heavily affected by HIV.

Community activists, in particular people living with HIV, made clear that HIV would need to be tackled in new ways—that they would not accept decisions made for them, even by the people with the best of intentions. In 1983, the groundbreaking Denver Principles urged the involvement of people living with HIV in “every level of decision-making” (4). At global, regional and country levels, people living with HIV organized networks such as the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW) to provide mutual support, share critical information, and advocate for inclusion of people living with HIV in decision-making processes.

At the Paris AIDS Summit in 1994, activist demands for inclusion of people living with HIV were affirmed and formalized in the Greater Involvement of People Living with HIV (GIPA) principle, which underscored the rights of all people living with HIV to participate fully in HIV-related decision-making (5).

Today, people living with HIV and the communities most heavily affected by HIV are represented on the governing bodies of key global health institutions engaged in the HIV response, including the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), UNAIDS and Unitaid, and are active participants in country-level prioritization processes of the Global Fund and the United States President’s Emergency Plan for AIDS Relief (PEPFAR).





# OUR PEOPLE, OUR PROBLEM, OUR SOLUTION

## Phill Wilson

**United States of America**  
Founder, the Black  
AIDS Institute



I was a 24-year-old Black gay man living in Chicago when the first cases of AIDS were diagnosed in 1981. Like everyone else, I thought then that AIDS was a “white gay disease”. I was wrong.

The truth about the HIV epidemic in the United States of America is that Black gay men, and Black people in general, have been disproportionately affected from the very beginning.

Unknown to me at the time, I was already living with HIV.

I tested positive for HIV in 1985, only a few weeks after the United States Government licensed the first HIV test. My doctors gave me 6 months to live.

When I came out to my father, he told me: “Since you have to do your own dying, you might as well do your own living.” I decided to focus on the living part.

In 1988, my good brister (brother and sister) Reggie Williams, other gay men and I joined together to create the National Task Force on AIDS Prevention to educate Black gay men about HIV, raise awareness of the epidemic’s disproportionate impact on Black gay men, and demand increased funding for HIV prevention. In 1999, I founded the African American AIDS Policy Training Institute (later to become the Black AIDS Institute), the country’s first and only thinktank at the time focused exclusively on ending the AIDS pandemic in Black communities.

For more than two decades, the Black AIDS Institute published policy reports on AIDS in Black America, delivered services in Black communities, and raised HIV awareness and commitment in key sectors of the Black community, including community organizations, political leadership, medicine and research, the media and churches.

Everything the National Task Force and the Black AIDS Institute were able to do was only because people worked shoulder to shoulder with other members of the community. Our empowerment did not come from the “powers that be”. Instead, we found it through collective action.

The motto of the Black AIDS Institute is “Our people, our problem, our solution”. We understood that if the HIV pandemic was ever going to end in our communities, we had to lead the effort. We had to be involved at every level, from conception to execution, promotion and evaluation. It meant that the policies and programmes for us needed to be decided by us, and that our government needed to work with us as full and equal partners. Our slogan emphasized that ending the epidemic requires that communities lead and drive the fight.

Over four decades, I have seen how communities have shaped and, in many cases, transformed the HIV response. People living with and affected by HIV are now included at decision-making tables that once were not open to us. Community advocacy has helped reform HIV research, accelerating the development of transformative HIV treatment and prevention tools.

But AIDS is far from over. Numbers of new HIV infections are declining too slowly, and worldwide more than 9 million people living with HIV are still not receiving treatment. In the United States, rates of viral suppression are lower among Black Americans and other BIPOC communities than white Americans. Among people who are at risk of acquiring HIV, Black gay men are several times less likely than white gay men to have access to pre-exposure prophylaxis (PrEP). Black people in the United States are eight times more likely to be diagnosed with HIV than white Americans.

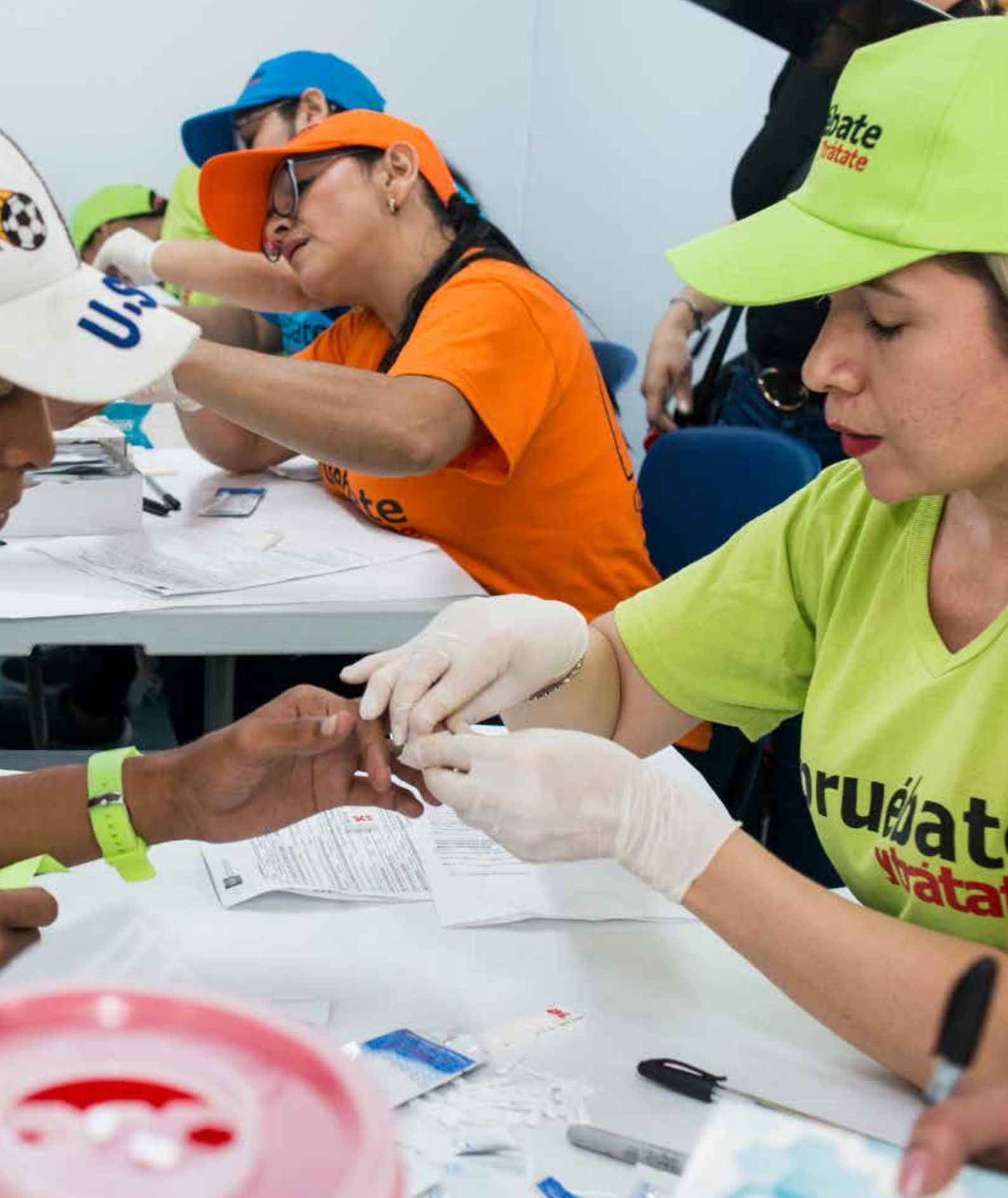
Dr Martin Luther King Jr said: “Injustice anywhere is a threat to justice everywhere. None of us are free until we are all free.” We can never end AIDS until we end the inequalities that perpetuate the pandemic. And we cannot overcome inequalities without the power of community leadership. Communities are truth-tellers, holding governments and others accountable for keeping their commitments. Communities know our own challenges better than anyone, and we also know best how to solve them. When it comes to overcoming access barriers and keeping people engaged in services, the best results are delivered when we support each other.

As I am finishing this essay, I am looking at a couple of pictures in my home. One is a photo from the mid 1980s of me with my friends Ken, Roger and Steven. I am the only one of us still alive. The second photo is of me and my friend David; he died in 1998. My home is filled with photos of dead people, including Reggie Williams, Marlon Riggs, Craig Harris, Fred Garnette, Rory Buchannon and Chris Brownlie.

When I first got involved in the AIDS fight, we lacked effective treatments and had few HIV prevention tools. Today, we have the means to end AIDS as a public health threat. We owe it to all those men and women on my walls—to the more than 700 000 people in my own country and the more than 40 million worldwide who have died from AIDS-related diseases—to follow through to the end.

Governments have committed to getting to the end of AIDS as a public health threat by 2030. They can fulfil their promise—but only if they let communities, particularly those most affected, lead the way.





Credit: UNAIDS

## COMMUNITIES AND HIV: DEFINITIONS

Communities are heterogeneous. The discourse about communities too often categorizes people into silos that do not reflect reality. As one example, the community of people living with HIV spans the globe, including people of diverse genders and gender identities, races and ethnicities, ages and socioeconomic status. So too, sex workers may be women or men, may be gay men or other men who have sex with men, may be trans, may use drugs, may be migrants or displaced people.

Young people frequently have issues and challenges that are distinct from those of older adults. Women experience issues and have priorities that may not be effectively addressed by programmes that do not take gender into account. Gender inequity increases HIV-related vulnerabilities and diminishes meaningful service access and engagement in the response (6).

The focus of this report on communities aims to honour and take account of communities in all their complexity, diversity and intersectionality.

It is important but not sufficient that HIV services or responses are in the community. To realize the full potential of communities, key aspects of the response need to be led by them.

To bring clarity to efforts to achieve global commitments to strengthen and effectively support the community-led response to AIDS, the UNAIDS Programme Coordinating Board convened a multistakeholder task team with representatives of governments, civil society organizations and donors. The task team jointly deliberated on definitions and recommendations for scaling up and reporting on community-led AIDS responses and community-led organizations engaged in the AIDS response (7).

The task team defined community-led organizations, groups and networks “whether formally or informally organized, [as] 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”. The task team emphasized that community-led organizations, groups and networks are “self-determining and autonomous, and not influenced by government, commercial or donor agendas”.

Organizations led by people living with HIV, people from key populations, women and young people are all examples of different types of community-led organization.

Community-led responses were defined by the task team as “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 organizations, groups and networks that represent them”.

Much of the earlier research on the benefits of community responses for HIV focused on community-based programmes (with a focus on where services occur), whereas more recent research has increasingly focused on community-led responses. In this report, UNAIDS has strived to differentiate between programmes or activities that are community-based from those that are community-led, with a particular focus on the critical role of community leadership.

## UNAIDS SUPPORT FOR COMMUNITY-LED RESPONSES

Since its early days, UNAIDS, leading by example as the only United Nations organization with communities represented on its board, has highly valued and supported the empowerment, space and active engagement of communities in the HIV response. This became even more prominent in its work to implement the Global AIDS Strategy 2021–2026 and to galvanize accelerated progress towards the 2030 Sustainable Development Goal (SDG) target of ending AIDS as a public health threat. From 2024 onwards, UNAIDS has identified supporting and strengthening community-led responses as one of its four organizational priorities.

In all aspects of its work, UNAIDS elevates the voice of communities. It promotes the leadership of communities for people-centred and rights-based HIV responses and integration of the community-led response in national and global fora and plans. This includes guidance, facilitation and support for the delivery of HIV services, community-led monitoring for better programmes, and closing the gaps and advocacy to mobilize more sustainable domestic and international funding for community-led responses, including through social contracting.

In 2022, the Joint Programme provided technical support to community-led organizations in 77 countries. In Armenia, it trained more than 100 women living with HIV, some of whom use drugs, on a range of priority issues, including gender-based violence, pre-exposure prophylaxis (PrEP) and human rights. In the same year, UNAIDS provided technical support to networks of women living with HIV in 15 countries (8).

The Joint Programme serves as a source of funding for community-led organizations to be more fully part of the HIV response. For example, UNAIDS provided a grant to Positive Young Voices to implement the gender-transformative HIV knowledge Stepping Stones intervention in Kenya. UNAIDS funding enabled community-led HIV organizations in countries such as Argentina and Kenya to obtain registration as nongovernmental organizations. In 2022, UNAIDS supported more than 100 youth-led advocacy and accountability projects (8).

UNAIDS is now mainstreaming across all its work the multistakeholder task team definitions of community-led organizations and responses. It is working with partners, including its Monitoring Technical Advisory Group, to develop consistent standards, indicators and long-term funding strategies to support the sustainability of community-led responses.

The Joint Programme serves as a key knowledge hub for community-led responses. Following close consultation with four networks of people most affected by HIV, the World Health Organization (WHO) in 2022 published consolidated guidelines on prevention, diagnosis, treatment and care of HIV, viral hepatitis and sexually transmitted infections for people from key populations (9). In 2022, the United Nations Refugee Agency (UNHCR) published operational guidance on community health in refugee settings (10). In addition to highlighting community leadership and achievements in all its flagship publications, UNAIDS has extensively documented the role of communities in pandemic preparedness and response (11) and launched a review of case studies of community-led monitoring (12).

Through the National Commitments and Policy Instrument, the engagement of communities in national HIV decision-making processes and the existence of laws and policies that hinder the work of community-led organizations are monitored. In 2022, UNAIDS convened over 500 community-led monitoring implementers, donors and technical assistance providers to share best practices, foster continuous learning, and support understanding of how community-led monitoring is evolving (8).

**Figure 1.** Key UNAIDS results working with and for communities



## COMMUNITY-LED SERVICES ARE KEY TO REACHING PEOPLE

- Extension of community-led differentiated service models, including for HIV testing and treatment, take-home opioid agonist therapy, PrEP and vertical transmission
- Building capacity of civil society organizations for maximum impact
- Innovations to expand services and respond to communities' needs in emergencies, including COVID-19

**700 000 people** living with HIV and key populations were reached with information on human rights, stigma, discrimination, violence, COVID-19 and HIV services (from September 2020 to December 2021) via 60 community-based organizations in 19 countries of Latin America and the Caribbean

**346 000 vulnerable** people were reached with community-led HIV services in western and central Africa by 179 capacitated organizations across the region

**12 396 pregnant** women were reached during antenatal and postnatal care in Eswatini, by 286 community-based mentor mothers trained on prevention of vertical transmission of HIV and syphilis

**24 countries** implemented community-led monitoring systems

**10 countries** completed a regional assessment led by the Eurasian Women's Network on AIDS on COVID-19 impact on sexual and reproductive health and rights, gender-based violence and treatment services for vulnerable women and women living with HIV

**17 countries** rolled out the People Living with HIV Stigma Index 2.0



## COMMUNITY-LED SERVICES ARE KEY TO REACHING PEOPLE

- Communities supported as part of the Global Partnership for Action to Eliminate all Forms of HIV-related Stigma and Discrimination
- Data analyses to generate evidence on the needs of specific population groups
- **24 countries** implemented community-led monitoring systems

Source: Infographic community response: 2020–2021. Geneva: Joint United Nations Programme on HIV/AIDS; 2021 (<https://open.unaids.org/sites/default/files/documents/Infographic%20Community%20Response%20-%202020-21%20PMR.pdf>).



## ELEVATING THE VOICE OF COMMUNITIES AND PROMOTING THEIR LEADERSHIP FOR A PEOPLE-CENTRED AND RIGHTS-BASED HIV RESPONSE

- Empowerment of people living with HIV, women and girls, young people and key populations
- Joint advocacy for more protective HIV-related national laws and policies
- Collaboration to prevent and eliminate stigma and discrimination and gender-based violence and monitor rights violations
- U=U (Undetectable Equals Untransmittable) campaigns in many countries in collaboration with networks of people living with HIV and key populations

**First regional network of people living with HIV** in the Middle East and North Africa region established

**30 000 women** in Zimbabwe were reached with gender-based violence information and services via SASA!, a community mobilization initiative for preventing gender-based violence

**10 countries** explored alternative models for sustainable financing of community-led responses

**5 countries** piloted a social return on investment of social contracting analysis



## INVESTING IN COMMUNITIES IS VALUE FOR MONEY

- Guiding investments, mobilizing resources and promoting sustainable financing models to achieve results at community level



**Communities  
have a unique  
ability to advocate  
for needed  
policy change  
and to serve as  
accountability  
watchdogs.**

Communities have created pioneering service organizations. Communities conceptualized and disseminated the earliest safer sex strategies (13) and founded harm reduction programmes for the prevention of HIV and other bloodborne diseases (14), with early adopters of needle and syringe programming achieving rapid and remarkable reductions in new HIV infections among people who inject drugs (15).

Even before the advent of highly active antiretroviral therapy in the mid-1990s, communities created treatment education programmes that updated communities on the latest HIV-related scientific developments and supported people living with HIV in making informed treatment decisions. Following the International AIDS Conference in Vancouver in 1996, when research definitively demonstrated that antiretroviral therapy could block disease progression, community-led activism to expand treatment access intensified.

In the push to reach the 95–95–95 targets, communities continue to deliver HIV treatment adherence support, using the lens of shared lived experiences to address the adherence barriers that many people confront.

In South Africa, home to the world’s largest HIV epidemic, dynamic and effective advocacy by the Treatment Action Campaign led the Government to reverse its policies and make antiretroviral medicines available for HIV treatment and for prevention of vertical transmission. This victory, which followed years of official denial of HIV by the Government, not only saved the lives of countless people but also turbocharged the broader global HIV response.

Community advocacy has resulted in tectonic shifts in global health policy. Sustained community advocacy contributed to the 2001 Doha Declaration on the TRIPS (Trade-related Aspects of Intellectual Property Rights) Agreement to enable flexibility in intellectual property provisions for life-saving medical products needed to address health emergencies. Further advocacy by Health Gap, the India Lawyers Collective, the International Treatment Preparedness Coalition, the Treatment Action Campaign and other community leaders catalysed the emergence of generic antiretroviral alternatives, ultimately leading to sharp, sustained reductions in medicine costs and enabling the remarkable expansion of HIV treatment access (16, 17). Community advocates have continued to push for patent reform at national levels and for new solutions to ensure ready access to essential medicines and vaccines (18).

Communities have driven historic changes in HIV research. Advocacy by people living with HIV led to major reforms to accelerate evaluation and approval of essential HIV medicines. The People Living with HIV Stigma Index, led by GNP+ and ICW, and conducted by and for people living with HIV in more than 100 countries, is the most authoritative and extensive source of information on how stigma and discrimination affect the lives of people living with HIV.

The currently recommended approach to HIV treatment delivery—known as differentiated service delivery—traces back to innovation by communities on the frontlines of the response. Years before differentiated service delivery was recommended by normative bodies, communities founded HIV adherence clubs, delivered antiretroviral therapy in communities, and worked with clinical partners to implement multimonth dispensing (19). Now this approach is driving scale-up of HIV treatment towards the 95–95–95 targets.



Communities are transforming how HIV services and the broader response are monitored. Using the experiences, priorities and perspectives of the communities that use HIV services, community-led monitoring tracks how and whether HIV services work for people, and the factors that affect service access and outcomes. Increasingly, data from community-led monitoring are used to improve HIV service delivery and to document and address human rights violations (20).

Credit: UNAIDS

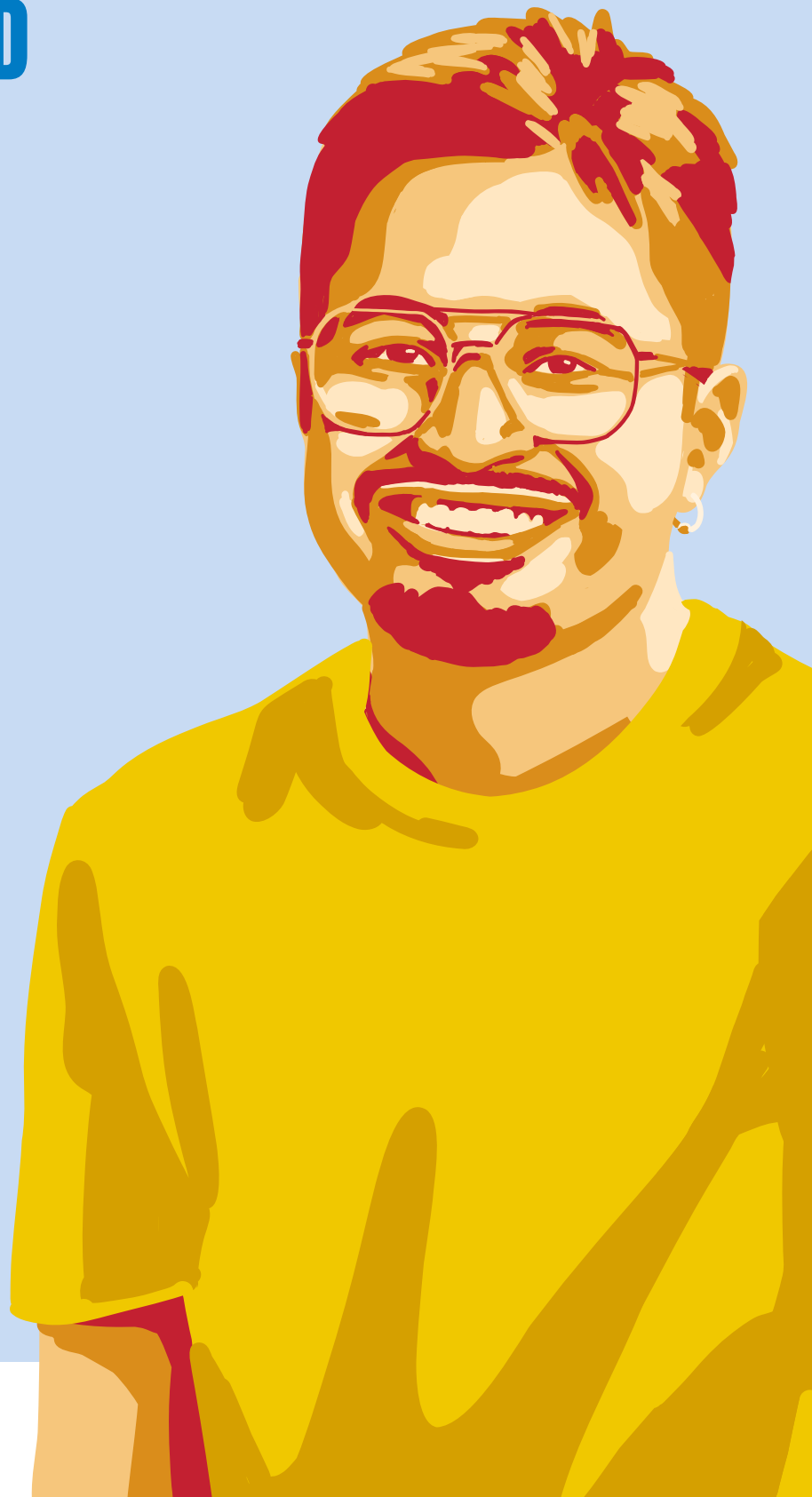


# TO OVERCOME STIGMA, SUPPORT STIGMATIZED PEOPLE TO LEAD

## Axel Bautista

### **Mexico**

Community mobilization coordinator  
for MPact Global Action for Gay  
Men's Health and Rights



If there is one thing I have learned in my decade of HIV activism, it is that progress is possible only if communities lead the way.

I was 21 years old when I was diagnosed with HIV a decade ago in Mexico City. I was studying sociology at university. Connecting my studies with my own experiences as a person living with HIV and as a gay man, I could see how progress on public health is obstructed when affected communities are marginalized. I realized too that we needed to get organized.

I began helping a small student organization. This was my introduction to advocating for the rights of people living with HIV.

When I was finishing my studies, a friend from Colombia invited me to help with a podcast on public radio. For 15 minutes every week, we talked on the radio about HIV and LGBTQI activism in Mexico. I was able to interview many activists and organizations in Mexico. It became clear that the path forward to ensuring our health and our rights was our own activism. No one would do it for us except us.

I joined Inspira, an LGBTQI-led organization that delivers HIV and other health services and advocates for LGBTQI rights.

Mexico's economic growth has not lifted up all Mexicans. The chasms of inequality in Mexico are reflected in our health system. These inequalities have a disproportionate effect on vulnerable communities, including LGBTQI people and people living with HIV. Only solutions designed by marginalized communities can address the inequalities they face.

During the COVID-19 pandemic, Mexico experienced an acute shortage of HIV medicines. This shortage threatened my own health and well-being and that of my community. We were the people who understood this first, because it was about us. And we were the ones who ensured it was addressed. We mobilized our community and took to the streets in Mexico City to demand Government action to close the access gap. We found champions in Congress who helped us find solutions to the problem.

I am still learning how to be an effective HIV activist and LGBTQI community mobilizer. Even as I appreciate the openness of people in the movement to my ideas, I also know I need guidance and support from people with more experience. I am so grateful for the many people who have invested in me as a community leader by helping to show me the way.

Community-led HIV and LGBTQI activism and programme design are vital to counter homophobia, serophobia, misogyny and racism. Reaching and mobilizing our communities require that we speak in the language of the community—the same slang, the same cultural references, the same shared experiences.

This also means we need to keep changing as new generations emerge. I am a millennial, but what has worked for people of my generation is not going to be the most effective way for younger generations. We need to make space to hear the voices of the new generation.

Today, I am working as the community mobilization coordinator at MPact Global Action for Gay Men's Health and Rights. In this role, I am trying to take the lessons I have learned as a community HIV activist and support other communities in increasing the visibility of gay, bi and queer men, including those who are living with HIV.

In addition to building community, my work with MPact aims to normalize discussions of sexual diversity and sexuality. In Mexico, and in much of the world, it is still a big challenge to talk about these things. This has led many people to hide themselves. Shame, stigma and fear of being seen are factors that drive the conditions for the HIV pandemic.

If we do not talk about sexuality, in non-stigmatizing, open ways, people are not going to know the facts about HIV or be able to make informed, empowered decisions about their lives. If we are able to build acceptance and safety, we can protect everyone's health and end this pandemic. This cannot be done for us—it has to be done by us.





Credit: UNAIDS

# Community-led advocacy continues to transform the HIV response

Community-led advocacy has shaped and defined the HIV response, which in turn has transformed global perceptions of health as a human right. Communities have successfully advocated for HIV and health funding, expedited scale-up of priority interventions, fought against discriminatory and criminalizing laws and policies, and worked to make HIV services more focused and more people-centred. Community-led advocacy has paved the way for investments required to reach 29.8 million people with HIV treatment services by the end of 2022. Community-led advocacy motivated by the HIV pandemic has catalysed and accelerated global human rights movements, with the worldwide movement for dignity for people who use drugs offering just one example (21).

As efforts intensify to end AIDS as a public health threat, community advocacy continues to drive progress and remove bottlenecks. Advocacy by communities led Côte d'Ivoire to remove user fees from HIV testing and treatment services; drove Malawi to facilitate additional antiretroviral therapy provision in underserved areas and remove identification requirements that impeded service access among sex workers; and persuaded Togo to scale up multimonth dispensing of medicines (12). Community-led advocacy contributed to the decision by Kazakhstan to change laws to allow people living with HIV to adopt children, and to policy reforms in Armenia and Belarus to soften previously harsh measures criminalizing HIV exposure, nondisclosure or transmission (information provided by UNAIDS Regional Support Team for Eastern Europe and Central Asia, 2023).

In the Middle East and North Africa, where comparatively low HIV prevalence and persistent stigma often position HIV low on the regional political agenda, MENA Rosa, a regional network for women affected by HIV, uses personal stories, multiple media platforms and consistent advocacy to raise awareness of HIV and galvanize action to address the HIV-related needs of women and girls (22).

In five African and two Caribbean countries, community-led advocacy initiatives were found to have improved access to affirming HIV services for gay men and other men who have sex with men and transgender women and increased government commitment to equitable HIV service access (23).

Community-led advocacy is accelerating progress towards the removal of legal barriers that burden people most affected by HIV. In the Cook Islands, years-long advocacy by Pride Cook Islands, the Te Tiare Association and other community activists resulted in 2023 in the Parliamentary decision to remove laws prohibiting consensual sex between men (24).

In the Australian state of Victoria and in Belgium, community advocacy led to the decriminalization of sex work (25). Tireless advocacy by the transgender community in Brazil culminated in a 2018 decision by the Supreme Federal Court to grant transgender people the right to officially change their name and gender without obtaining a court order (26). In Malawi, the Civil Society Advocacy Forum proved influential in helping shape the country's milestone-driven national HIV prevention roadmap (information provided by UNAIDS Regional Support Team for Eastern and Southern Africa, 2023).

**When an  
emergency  
strikes,  
communities  
are the first  
responders.**



Strategic litigation by communities has expanded recognition and protection of human rights, including in India, where the Supreme Court invalidated criminalization of same-sex relations (27) and also ruled that sex workers have equal protection under the law. Strategic litigation is achieving breakthrough results in the Caribbean, where courts in Antigua and Barbuda, Barbados and Saint Kitts and Nevis have invalidated laws criminalizing same-sex relations, thanks to coordination efforts by the Eastern Caribbean Alliance for Diversity and Equality (information provided by UNAIDS Regional Support Team for Latin America and the Caribbean, 2023).

In 2023, litigation filed by Abdool Ridwan Firaas Ah Seek, President of the LGBTQI human rights organization Arc-en-Ciel, led the Supreme Court of Mauritius to decriminalize same-sex relations (28).

A complaint filed by ICW and ICW Southern Africa led to a finding by the South African Commission for Gender Equality that sterilization without consent is a violation of the rights of women living with HIV. Follow-up negotiations have helped ensure that available remedies for such violations meet the needs of women living with HIV (information provided by UNAIDS Country Office, South Africa, 2023).

## HOW CHANGE HAPPENS: THE EXAMPLE OF PEOPLE WHO USE DRUGS

The HIV response has given rise to a global movement of people who use drugs. In 2020, the International Network of People Who Use Drugs (INPUD) surveyed activists in 22 countries to obtain their insights on how they work to drive change towards decriminalization, authorization, and uptake of harm reduction services and other measures to protect the health and well-being of people who use drugs (21).

Informants agreed that a mix of strategies tailored to specific contexts are needed, and that strategies must adapt as circumstances change and as new opportunities or challenges emerge. “Sometimes, protest, civil disobedience and radical action may be appropriate, while at other times or simultaneously, strategic litigation or negotiation may be a route to change,” the INPUD survey found.

With respect to advocacy, people who use drugs report that value can be found working within and outside decision-making institutions. Overall, informants agreed that building diverse coalitions is critical to prepare the ground for legal and policy change.

# WHO KNOWS HOW TO HELP WOMEN WHO USE DRUGS? WOMEN WHO USE DRUGS DO

**Valentina Mankiyeva**

**Kazakhstan**

Activist, Kazakhstan Forum  
of People Who Use Drugs



Women who use drugs are one of society's most stigmatized groups, burdened with multiple vulnerabilities. I know. I am one of them. I have been living with HIV for 26 years. For nine of those years, I kept my diagnosis hidden, did not seek help, and battled a paralyzing fear of death. I lost loved ones and endured perpetual shame and despair.

Women who use drugs face even harsher judgement than men who use drugs. Women have shared with me their stories of being demonized and disregarded, deemed unworthy of attention and support, of being forced into sex to pay for drugs, or of experiencing abuse from partners. Many feel defenceless against police brutality. They endure a loss of human dignity and face bullying in families, society and medical facilities. For women who use drugs living with HIV, that adds an extra layer of stigma. Too many of us face loathing and self-loathing.

People who use drugs are often scared to access HIV prevention, testing and treatment services because of the criminalization and discrimination they face.

And yet, there is one approach that keeps being shown to work in enabling people who use drugs to access essential services—when people like us lead, design and oversee those services.

My life was transformed a few years ago when I encountered a community of people coming together to help each other. Groups including the Eurasian Harm Reduction Association, the Eurasian Network of People Who Use Drugs, the Eurasian Women's Network on AIDS, and the Kazakhstan Union of People Living with HIV helped me see myself as a worthy individual deserving respect and a decent life. Now, as part of the movement, I hear daily from peer clients who share why this approach matters.

Even when you think you are unworthy and undeserving of a better life, you meet people who say, "No, you are accepted. Let us move forward together."

As part of the Eurasian Network of People Who Use Drugs, we established the Expert Feminist Council, uniting women activists from five countries in eastern Europe and central Asia. The goal of the Council is to shape drug policies that uphold human rights, are grounded in scientific evidence, and consider the well-being of every woman.

We have helped shine a light on the harm caused by repressive drug policies and how decriminalization saves lives.

Collective leadership by my community has empowered me and my peers to develop services that enable us to protect our health. Together, we are much stronger.

Yet, major challenges remain. Although HIV prevention, testing and treatment services are available in Kazakhstan and other countries, stigma, discrimination and criminalization continue to prevent people from key groups from accessing vital services. For example, in our country, women who use drugs and are living with HIV often cannot use shelters or crisis centres—but these are people who truly need a safe space, a place to find refuge, assistance and HIV services.

We take pride in our resilience. But we need authorities to back us. Women who use drugs have established peer organizations that have succeeded in reaching people who had not been reached, have innovated services to strengthen their impact, and have set out how policy changes can help protect our health. But we are still regarded by many in authority across the world as problems to be fixed instead of problem-solvers to be supported.

We know what needs to be done and how to do it. Who, if not us? HIV and drug use do not define our worth as people and should not overshadow our abilities. We deserve to be treated with dignity and respect. We deserve equal access to health care, social security and economic development. And we deserve to be at the decision-making table, shaping approaches that will work to protect our health. If you care for us, do not decide for us. Let us lead.





Credit: UNAIDS

## THE GLOBAL U = U MOVEMENT: COMMUNITIES LEAD AND THE WORLD FOLLOWS

Community-led activists have reshaped the world's understanding of HIV treatment and prevention and better aligned efforts to end AIDS as a public health threat with scientific evidence on the prevention benefits of antiretroviral therapy. Launched by the Prevention Access Campaign in 2016, the Undetectable = Untransmittable (U = U) movement set out to build an evidence-based consensus on the fact that a person living with HIV who has an undetectable viral load cannot transmit HIV sexually (29).

In the following years, leading medical journals and public health agencies endorsed U = U, prompting a number of jurisdictions to pursue a strategy of status-neutral approaches to HIV prevention. Today, U = U education is a core standard required of all countries supported by the Global Fund (30) and PEPFAR (31).

In 2022, the UNAIDS Programme Coordinating Board called on the Joint Programme to promote U = U as an evidence-based strategy for health equity and called on countries to incorporate U = U in national health plans and guidelines (32). In 2023, the World Health Organization built on 20 years of promoting the use of treatment as prevention to reconfirm that there is a "zero chance" of sexual transmission to the HIV-negative partner of a person living with HIV who has an undetectable viral load (33). In addition to influencing HIV prevention programming, U = U has been described as one of the most effective and historic counter-narratives to HIV stigma and an accelerator of each stage of 95–95–95 (34).

U = U shows how community-led responses can literally change the world. Since the Prevention Access Campaign, a small community-led group, first approached the United States Centers for Disease Control and Prevention in 2016 about changing its prevention guidance to emphasize U = U, the campaign has grown into a global grassroots movement, embraced by community-led organizations across the world.

"U = U belongs to everyone," says Bruce Richman, the founding Executive Director of the Prevention Access Campaign. "It is a global community."



Source: U = U campaign.

Protests at International AIDS Society conferences increased awareness of U = U. Through social media and other means, community members spread the word, and the movement caught fire. Musical artists in Malaysia and Zambia have focused on U = U in their songs. Cartoons in China and children's songs in Japan promote U = U. Visual artists in Spain and the United Kingdom of Great Britain and Northern Ireland have incorporated U = U in their artwork. The movement has become the focus of local organizing in countries in almost every region. Numerous Fast-Track Cities and national health ministries have leveraged the U = U movement as a centrepiece of strategies to end AIDS as a public health threat.

"A focus on the health and dignity of people living with HIV also contributes to the health and well-being of their partners, families and communities, and, in and of itself, should act as significant step towards HIV prevention," says Florence Raiko Anam, Co-executive Director of GNP+. "All these community-led campaigns follow the science and communicate the science in a language that communities understand and can contextualize to their country experience. It's the resilience of communities to persistently change perceptions of health providers, policy-makers, governments, and general public despite limited resources and conservatism, and how U = U has become a central argument in national HIV responses in many countries."

"U = U took off because for so long people living with HIV have been treated like vectors of disease," Richman said. "U = U is giving us our full lives back, showing that we are able to have sex, to have intimacy, to have babies without fear. And now science proves that ensuring that we remain healthy is the key to end the epidemic."

## PRIORITIZING CHOICE IN HIV PREVENTION FOR WOMEN

Although the toolkit for HIV prevention continues to expand, the reality is that many people at risk of acquiring HIV do not have meaningful access to HIV prevention technologies. This is especially true for many women living with HIV. The CHOICE Manifesto, launched by the African Women's HIV Prevention Community Accountability Board, aims to change this reality (35).

The community-led Manifesto demands that HIV prevention efforts shift their focus from individual products to the needs of the people who could benefit from HIV prevention services. The Manifesto states that women and girls in Africa have the right to choose the prevention option(s) that are best for them—including oral PrEP, the dapivirine vaginal ring, injectable cabotegravir, and traditional methods such as condoms.

In addition, the Manifesto advocates for continued investments to develop new and better prevention tools that meet women's needs.

# Communities drive service uptake and improve outcomes

Community-led organizations help their members understand why HIV services are important and where they can be accessed. A systematic review and meta-analysis found that many community-led demand-creation interventions, such as community mobilization and peer-led approaches, markedly increase HIV testing uptake (36).

Communities deliver essential services. Their advocacy and hands-on service delivery have made services more people-centred, contributing to improved service uptake and retention, especially among the people who are most socially, economically and politically marginalized.

A review by the World Bank found that programmes delivered by community-based organizations are associated with a 64% increase in access to HIV treatment in rural areas of Nigeria and a doubling of the likelihood of prevention service use. Communities with high engagement of community-based organizations had a four-fold increase in consistent condom use with all partners in the previous 12 months in Kenya (37).

A 2021 scoping analysis found that peer- and community-led programmes are linked with a broad array of beneficial outcomes, including reduced risk behaviours, improved health literacy, increased adherence and viral suppression (38).

In west Africa, a demand-creation and community-led initiative supported by the International Treatment Preparedness Coalition increased the number of people initiating HIV treatment in 16 health facilities by nearly 18-fold over 18 months (39).

**Communities are typically the first to detect and respond to important changes in epidemic dynamics.**

Peer-driven approaches in HIV and harm reduction programmes have been linked with improvements in health outcomes (40). Among women living with HIV enrolled in programmes to prevent vertical transmission, peer support cut by more than half the dropout rate in Uganda (41); increased linkages to antiretroviral therapy in Uganda (from 86% in 2016–2017 to 99.7% in April–December 2022); and increased by more than a third the share of infants exposed to HIV tested within 2 months of birth across 13 states in India (42). Compared with standard approaches, interventions involving communities markedly increased HIV testing among young people in Mangochi district in Malawi (43) and in two urban communities in Lusaka, Zambia (44).

Community engagement in HIV service delivery often takes multiple forms. For HIV prevention programmes, peer-led and community-led programmes have a comparative advantage over other approaches (38). Among sex workers in Iringa in the United Republic of Tanzania, HIV incidence among people reached by a package of peer-based interventions was less than half the incidence among people who did not participate in the programme (5.0% v. 10.4%) (45).

Community mobilization and peer-to-peer interventions were associated with increased condom use among sex workers in Karnataka state in India (46). Community participation (engagement with a community organization or peer-based initiative) was associated with one-third lower odds of having a sexually transmitted infection among sex workers in the Canadian province of British Columbia (47).



Community-led programmes are vital to accelerating the scale-up of PrEP to prevent HIV acquisition. In Chirundu, Zambia, a peer-to-peer programme significantly increased PrEP uptake among female sex workers compared with the routine approach (91.1% v. 22%) (48).

An epidemiological modelling study in Thailand found key population-led PrEP to have the strongest impact on averting HIV infections among the delivery models considered (49). In the Philippines, peer-led demedicalized PrEP services more than doubled quarterly PrEP enrolment in one year (50).

In Brazil, the youth-guided Viva Melhor Sabendo Jovem (Youth Aware) initiative brings HIV information, testing and prevention services to young people in ways that are shaped by and resonate with young people, who account for one in four new HIV infections in the country (51).

For HIV treatment services, community engagement plays a critical role, including through community distribution of medicines, community-led health monitoring, adherence support, and integration of peer- and community-led components in clinical services. Peer antiretroviral therapy champions (trained peer supporters who receive empathy-based training) reduced HIV treatment interruptions by 23% in selected health facilities in Malawi, compared with people contacted by standard trained expert clients (52). Over a 6-month period in 2022, a community-based programme in Uganda improved viral suppression among children aged 0–14 years living with HIV from 79% to 94% (53).

Community-led responses address social and structural issues that are not always prioritized by government- or donor-funded services. In Burundi and Uganda, ICW East Africa rolled out a peer-to-peer model to combat self-stigma among 500 adolescent girls and young women, including creation of safe spaces and sponsoring activities such as music, games and sports to build resilience, self-efficacy and advocacy skills of young girls and women (information provided by ICW East Africa, 2023). With the support of the United Nations Entity for Gender Equality and the Empowerment of Women (UN Women), the Indonesia Network of Women Living with HIV actively works to integrate HIV services for women and services for survivors of gender-based violence.

# THE EXTRAORDINARY POWER OF ORDINARY WOMEN

**Lillian Mworeko**

**Uganda**

Executive Director, International  
Community of Women Living  
with HIV Eastern Africa (ICWEA)



When I was diagnosed with HIV, I received no kind of counselling from the hospital about what my new diagnosis meant, and no information about what I could do about it. The response of many people who had been close to me was to blame and shame me. Broken emotionally and financially, I had to leave my home.

I was brought back from isolation and despair because of the warmth and solidarity of other women living with HIV. The help and support from community-led organizations enabled me to share my fears and anxieties and to get strength and support to move forward. Being part of them also raised my awareness of what was happening to other women living with HIV. Holding each other and working together, the community of women living with HIV continues to drive transformational changes for our community in ways no one else can.

Women understand our own bodies. We understand the things that are going on around us that affect our vulnerability to HIV and our ability to access the services we need. Our insight and our determination have enabled organizations of women living with HIV to have a profound and continuing effect in reshaping the global response to HIV.

This role was not handed to us. Women had to fight for our place at the table. And we had to navigate for ourselves how to connect our engagement in our districts with our advocacy in our national capitals and in decision-making platforms in Geneva, New York and Washington. If we had not, everything would have already been decided by the time programmes reached us.

We learned that when people are challenging the status quo, it can be easy for the powerful to break an individual person. It is not so easy to break a movement. We women living with HIV cannot be leaders alone—only together with each other.

The initial assumption made about ordinary women living with HIV is that we are ignorant. But when we have reshaped policies, those policies have worked more effectively. Efforts to prevent mother-to-child transmission offer a perfect example of the power of women's leadership. For years, when it came to trying to prevent children from acquiring HIV, women living with HIV were treated only as transmitters of disease, not as people in our own right. It was as if things needed to be done to us—not with us, or by us.

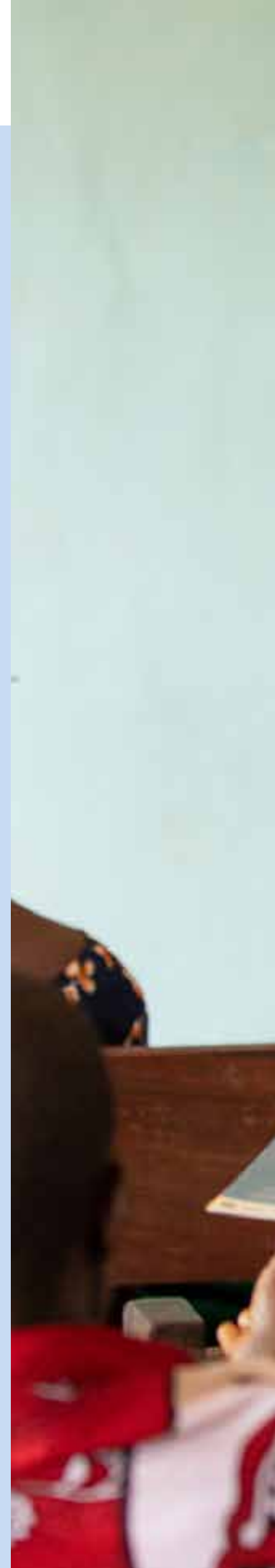
But this held back progress in preventing new HIV infections among children. Women living with HIV stepped into the breach. Because authorities were not supportive of our efforts, we needed to organize to push for this support. Recognizing women at the very centre of these efforts, we argued, would help advance gains in preventing new HIV infections among children. Mothers living with HIV were best positioned to understand how to help other mothers. Women knew how to provide trusted information to other women, to understand the complicated life situations, and to offer practical solutions that

mothers could use to protect their own health and the health of their newborns. A shift towards the approach we called for has helped reduce the rates of vertical HIV transmission.

In my many years as a community organizer and AIDS advocate, I have seen countless overconfident decision-makers attempt to roll out new technologies or approaches without listening to women—and then fail. In contrast, programmes shaped by women living with HIV have been at the heart of breakthroughs. From ensuring appropriate treatment for pregnant women to expanding access to prevention, women living with HIV spoke up, and helped to demand and to inform rigorous studies, to ensure services succeeded in their public health goals.

Just as we have learned that women are more powerful when we work together, we have also learned that the communities most affected by HIV have a greater ability to influence decisions when we work together. This is why different movements have brought our struggles together. This is why, as an organization led by women living with HIV, we speak out in support of the rights and services of all key populations and of adolescent girls and young women. They know that we will always be their allies, and we know that they will always be ours.

We have learned too the art of finding out who in authority is or could be our friend to work together to effect change. We have been inspired by people in authority who have recognized that a determined civil society is not an obstacle to public health planning but the way to ensure public health planning succeeds. I would like to encourage them to help share the exciting good news—that there is a path that end AIDS, with communities leading the way.





Credit: The Global Fund/Vincent Becker

## COMMUNITY LEADERSHIP AMONG PEOPLE CURRENTLY OR FORMERLY IN PRISONS AND OTHER CLOSED SETTINGS

Globally, people in prisons and other closed settings are markedly more likely to be living with HIV than people in the general population (54). A technical review by the United Nations Office on Drugs and Crime (UNODC) and other United Nations agencies found that few countries have comprehensive HIV prevention, treatment and care programmes in place in prisons and other closed settings (55).

These failures imperil the health and well-being of people in these settings, and violate the international obligation of countries to provide the people with health services comparable to those available to the general population, making it harder to end AIDS as a public health threat (56).

Although incarceration by definition involves a curtailment of freedom, health programmes in prisons and other closed settings are strengthened, and HIV responses improved, when the people in them are enabled to help and support their peers. The value of community health leadership is evident also in programmes led by formerly incarcerated people to support health service access and quality of life to help others who have recently been released from prison (57).

StreetLawPH, a civil society organization providing access to justice for people who use drugs in the Philippines, trains people in prisons and other closed settings to act as jail paralegals to navigate cases through the justice system and to document concerns around access to justice (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023).

In Zambia, the nongovernmental organization Prisoner Reintegration and Empowerment Organization works directly with the national correctional service to support educational programmes, income-generating activities, skills development and computer laboratories to enable people's successful transition back into the community and to avoid the deprivation and social and service disruptions that undermine their health and social outcomes (58).

In eastern Europe and central Asia, the Eurasian Movement for the Right to Health in Prisons works to remove barriers to health and social services among people currently or formerly in prisons and other closed settings (information provided by UNAIDS Regional Support Team for Eastern Europe and Central Asia, 2023).

Ending AIDS as a public health threat requires focused efforts to reach the people least likely to benefit from existing service approaches. It is here that community-led approaches are most critical. Marginalized, stigmatized communities understand their own needs and the barriers they face, and they are best equipped to identify strategies to reach the people most in need.

A community-led initiative by the Transgender Welfare Equity and Empowerment Trust (TWEET) in India supports the socioeconomic inclusion of the transgender community by increasing awareness of the business sector regarding transgender issues and by helping connect community members to well-paid jobs. In addition to promoting dialogue between government, civil society and businesses, the community-led TWEET initiative links community members to skills training, career counselling, entrepreneurship support and mentorship. TWEET complements its work on socioeconomic welfare with advocacy for specific solutions to challenges experienced by marginalized transgender people of all identities (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023).

In Indonesia, the Surabaya Transwomen Association undertakes advocacy and extensive outreach to provide the transgender community with the knowledge,

resources and support needed to embrace and access PrEP as an HIV prevention option (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023).

The 30–80–60 targets call for major investments in community-led service delivery across key aspects of the HIV response. As existing monitoring systems generally do not track the proportion of services and programmes delivered by community-led organizations, UNAIDS has convened an expert advisory group to guide development of a monitoring framework for these targets, including identification of proxy measures or development of new metrics.

## COMMUNITIES LEADING ON EFFORTS TO ELIMINATE NEW HIV INFECTIONS AMONG CHILDREN

One of the signal achievements of the HIV response has been the reduction in the annual number of children newly infected with HIV. Since 2000, the number of children acquiring HIV each year has declined by 75%.

Communities—especially women living with HIV—have played a vital role in protecting children from HIV. By placing women at the centre of efforts to eliminate new HIV infections among children, communities have made services for pregnant and breastfeeding women more person-centred, driving rapid gains.

A review identifying promising community engagement practices to strengthen prevention of vertical transmission recommended community health worker cadres, peer support, community-led social and behaviour change communication, community-led monitoring and participatory leadership to devise locally tailored solutions (59).

Mothers are best equipped to support other mothers in their infant feeding choices, navigate HIV stigma, and devise individualized, culturally tailored strategies for overcoming barriers to regular antenatal and paediatric clinic attendance and other aspects of prevention of vertical transmission and the health and well-being of women and their babies.

In Indonesia, the Emak Club, led by the Ikatan Perempuan Positif Indonesia network of women living with HIV, provides peer support for pregnant women living with HIV.

Through the Mãe Acompanhada, Bebê Protegido (“Mother Accompanied, Baby Protected”) programme initiated by the Brazilian nongovernmental organization Casa Fonte Colombo under the umbrella of the Fast-Track Cities initiative, women living with HIV are trained and supported to provide navigation assistance and ongoing support to pregnant and breastfeeding women living with HIV (information provided by UNAIDS Regional Support Team for Latin America and the Caribbean, 2023).

The importance of community leadership in preventing new HIV infections in children has never been more important. Although gains to date are historic, progress has largely stalled in recent years. In 2022, one in five pregnant or breastfeeding women living with HIV did not receive antiretroviral therapy, and approximately 120 000 women acquired HIV during pregnancy or breastfeeding and were consequently missed by early antenatal screening. In 2022, an estimated 660 000 children living with HIV were not receiving antiretroviral therapy, as many children are missed by early infant HIV screening protocols. Other children acquire HIV later in childhood and some are lost to follow-up (information provided by UNAIDS Programme Team, 2023).

Only by letting women living with HIV lead the way will it be possible to jumpstart further progress, ensure the rights, health and well-being of women and their babies, and achieve the goal of eliminating vertical transmission.

## COMMUNITY LEADERSHIP TO CLOSE HEALTH CARE GAPS IN THE EASTERN CAPE

The Eastern Cape is home to 13.5% of all people living with HIV in South Africa. Formed in large part from traditional Xhosa homelands, the province includes large cities and extensive, remote rural areas.

In the rural stretches of the Eastern Cape, people often have to travel long distances to access health care or to pursue their schooling. The community-led Bulunga Incubator works in the Nqileni village and three other rural villages. Health facilities run by community health-care workers have been established by Bulunga Incubator to ensure access to health services, five educational centres, and an independent school to improve literacy and rates of school completion.

Bulunga Incubator derives its strength from its roots in the local community, which donates materials to build health centres, which in turn provide general health checks, maternal care, child immunizations, and HIV care and treatment. Services are provided in the local language and actively promoted by a local community radio station. Bulunga Incubator programmes have benefited from strong support of the local chief, who is a woman passionate about the advancement of the community (information provided by UNAIDS Regional Support Team for Eastern and Southern Africa, 2023).

## Communities drive progress in making HIV medicines affordable

When the HIV treatment revolution occurred in the mid-1990s, antiretroviral therapy combinations rapidly transformed HIV from an invariably fatal disease to one that was chronic and manageable in high-income countries—but not in low- and middle-income countries, where treatment was affordable for only a handful of people. This inequality echoed what had been experienced in many other health challenges, in which many years and sometimes several decades were required for the prices of medical innovations to decline sufficiently to enable meaningful uptake in resource-limited settings.

Communities engaged in the HIV response insisted that this unjust “business as usual” would not be tolerated. Communities undertook concerted advocacy at global, regional and country levels; pursued strategic litigation; and engaged with multilateral trade and intellectual property processes. These efforts catalysed a cascade of actions that cut the annual per-person cost of antiretroviral therapy by more than 99%—from US\$ 10 000 in 2000 to less than US\$ 50 for the recommended first-line regimen in 2023 (60). These price declines in turn spurred the historic, worldwide expansion of HIV treatment access.

In 2023, community-led advocacy contributed to another landmark advance in the global push for affordable, universally accessible medicines—the decision by the Government of Colombia to list the antiretroviral dolutegravir as a medicine of public interest, which will enable the purchase of generic versions. Community advocates had strategized and mobilized to encourage Colombia to take this step, which is projected to markedly lower the price of the medicine, and communities continue to lead the advocacy to ensure it is not blocked (information provided by UNAIDS Regional Support Team for Latin America and the Caribbean, 2023).

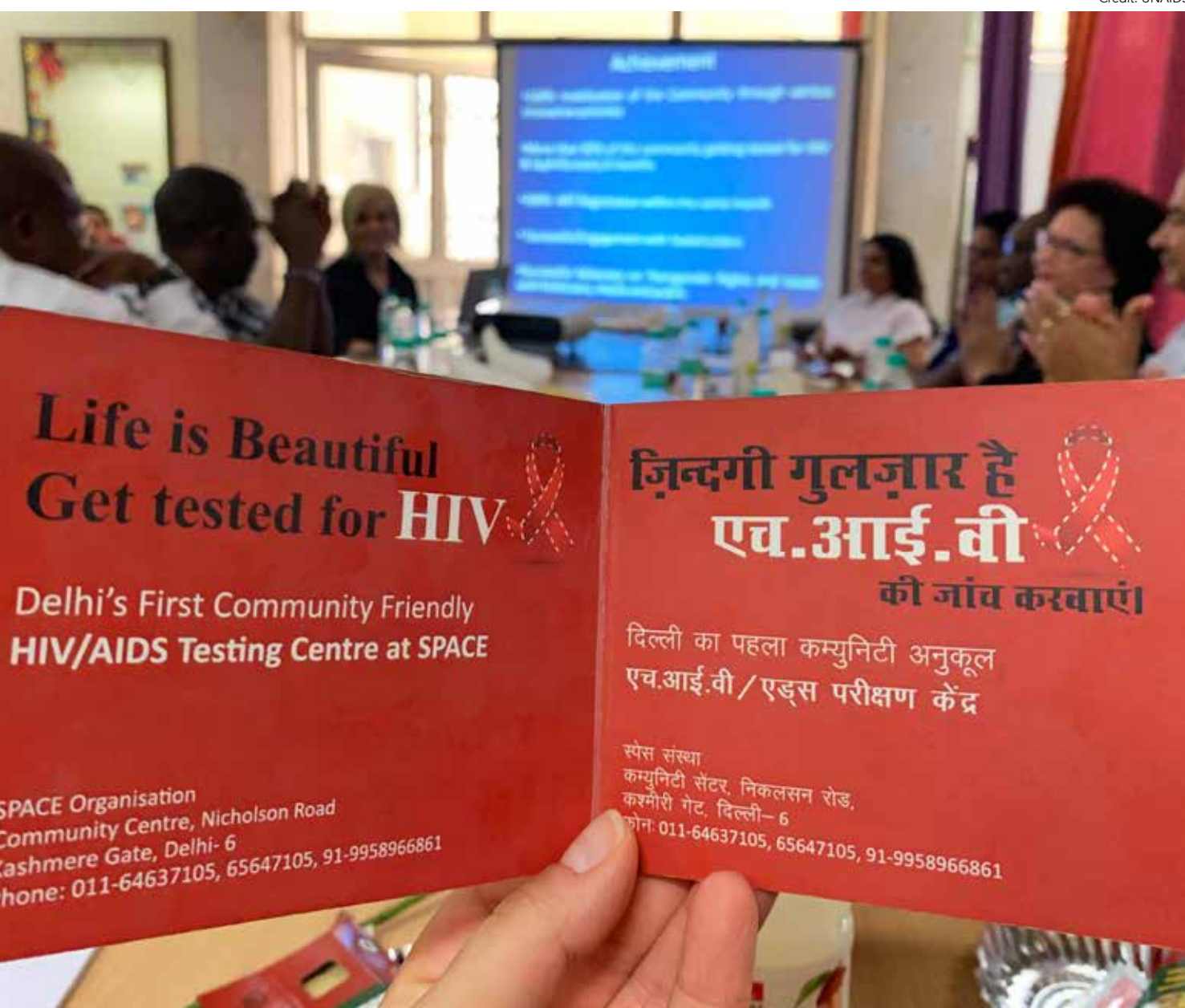


## Communities pioneer innovation

Communities are innovators in the response to HIV. Communities have been pathfinders in the use of social media and other virtual tools to extend the reach and impact of HIV services. In Windhoek in Namibia, a self-funded project by the Youth Empowerment Group uses e-bikes to deliver antiretroviral medicines, food and adherence support to young people who often cannot attend clinics because their hours conflict with school (information provided by UNAIDS Regional Support Team for Eastern and Southern Africa, 2023).

Community-led organizations in China have developed smartphone apps that link people to self-testing, contributing to a more than four-fold increase in HIV tests across the country from 2009 to 2020 (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023). Globally, the Innovation Hub of Frontline AIDS serves as a clearinghouse for innovative approaches to HIV service delivery, especially for marginalized communities (61).

Credit: UNAIDS

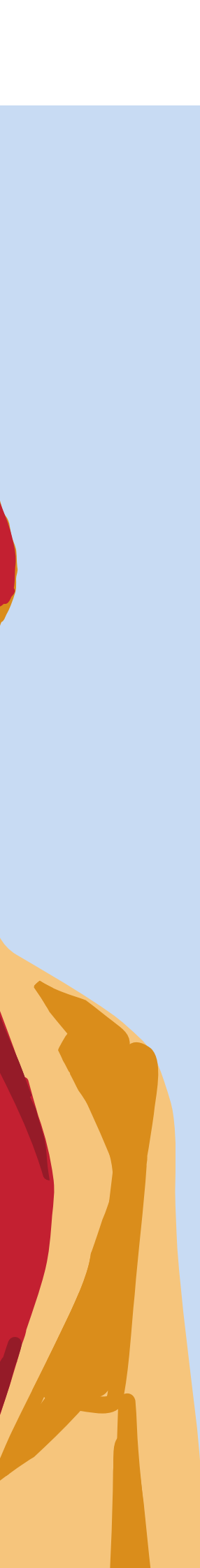


**COMMUNITIES ARE NOT  
WAITING FOR THEIR  
CAPACITY TO BE BUILT—  
THEY ARE THE ONES  
WITH CAPACITY**

**Gibstar Makangila**

**Zambia**  
Executive Director, Circle of Hope





If anyone wants to witness the power of communities to drive progress towards ending AIDS, I recommend they visit my country, Zambia. Through approaches that support the leadership role of communities, Zambia has been able to make remarkable gains towards the 95–95–95 targets on the road to epidemic control.

The success of these approaches highlights three lessons. The first is that ensuring access to vital prevention, testing, treatment and care services is driven not only by the clinical context but also by the community context. The second is that because people in a community understand and connect with their peers in deep ways, communities have many capacities and forms of social capital that others lack—they are experts. The third is that the most effective programmes do not only involve communities in outreach and delivery—they are led by them in shaping the cycle of design, monitoring, learning and improvement.

In 2018, Circle of Hope rolled out a new HIV service model in Lusaka—the community post. The community post model, which community members designed and developed, decentralized HIV service delivery to bring it to where people were. This meant doing two things. The first thing was to close physical distance: the community post model was designed so that no person in need of HIV services would be required to travel for services more than 10 minutes from where they live. The second thing was to close social distance: the community posts were set up across the places where people already congregated—where they went to sell or buy goods in the market, where they went to socialize, and where they went to practise their faith.

For many communities affected by HIV in our region, faith is an important aspect of the texture of community life. Places of worship are where communities gather every week; where cultural, social and self-help organizations are built; where vital aspects of community life are celebrated; and where bonds of trust are developed. If you want to talk with people, that is where you can find them. If you want them to listen, that is where they are ready to hear, and where you will find the people they are ready to hear from.

This community-led approach has brought huge gains. The posts in hospitals were not delivering the results needed to tackle HIV, but the posts in the community are delivering those results. Today, we have 150 community posts in eight of the 10 provinces of Zambia, with each post including a physician, a data analyst and a psychosocial counsellor, all of them recruited from the communities they serve. Within 18 months of the rollout of the community post model in Lusaka, which started in 2018, we saw a 12-fold increase in the number of people diagnosed with HIV.

We have found that our community-led approach has helped overcome the stigma that often deters people from learning their HIV status or seeking the services they need. In this regard, we have seen especially good results among men living with HIV. While men across sub-Saharan Africa are less likely to know their HIV status or to obtain antiretroviral therapy compared with women, we have seen when the community post model is rolled out that the gap in HIV treatment cascade results is reduced. The community post model has been so successful that it is now being expanded in other countries.

The community post model is successful not only because it involves communities but because its design is led by communities. We were reminded of that lesson again recently working to develop tailored services for adolescent girls and boys. Youth-friendly spaces within the service delivery sites were not bringing in young people in the numbers expected. It was young people who understood why these were not working and what needed to change. It was being inside a site with adults that for many young people made them fearful to attend. A youth corner or a youth room was not enough to overcome this fear. Separate youth posts needed to be established. Adults—even the most sympathetic and experienced—had not understood this need.

Community leadership is already driving remarkable results. If supported more fully, it can lead the world towards ending AIDS as a public health threat. It is vital that the leadership role of communities is properly resourced and remunerated. Too often, work is resourced in ways that fail to recognize the contributions of communities or provide economic security for their work. Only communities are ever expected to work for little or no pay. This can leave the people on whom the HIV response depends unsure of how they will take care of themselves and their families. This is not the way to support people to achieve their greatest potential. Communities in Africa have a saying—“If you want to keep on getting milk from the cow, you have to feed the cow.” Fully supporting community leadership also means recognizing that communities are not there to implement predesigned projects. The transformative power of community leadership cannot be achieved through involving people in service delivery, or through merely consulting on the details after the plan is designed. Communities need to shape the plans.

Communities are not waiting for their capacities to be built by others—they have capacities that others do not have.





Credit: The Global Fund/Vincent Becker

The spirit of innovation in community-led responses was never more apparent than during the COVID-19 pandemic, when communities pivoted services from in-person to virtual, became the primary distributors of HIV medicines in many settings, and provided emergency tools for HIV and COVID-19 prevention (11, 62). A 2022 study found that interventions by people who use drugs were critical in preserving HIV and harm reduction services during lockdowns and in addressing other pressing issues, such as food security, economic livelihood and an increase in violence (63).

As another example of innovation in the era of COVID-19, the Rwanda Network of People Living with HIV acquired a call centre to enable people living with HIV to make free calls to request support to maintain service access during COVID-19 lockdowns. Over a 3-month period, 321 people living with HIV and peer navigators obtained support on issues such as access to medicines, economic and social well-being and human rights (information provided by UNAIDS Regional Support Team for Eastern and Southern Africa, 2023).

## COMMUNITY-LED INNOVATION WITH SOCIAL MEDIA TO INCREASE ACCESS TO HIV PREVENTION IN SOUTHEAST ASIA

Based in Bangkok, APCOM is a community-led organization that works to improve the health and rights of gay men and other men who have sex with men and LGBTQI people across the Asia and Pacific region (64). Its work focuses on three pillars—strengthening the HIV response, protecting and promoting the human rights of gay men and other men who have sex with men, and building community and stronger partnership networks.

APCOM is an energetic and innovative implementer of virtual interventions, actively creating demand for HIV services with specifically tailored approaches for community members. Its testBKK Party Pack initiative, which started in Bangkok and is now being replicated in the capital cities of Cambodia, Indonesia and the Philippines, promotes the access of young gay men and other men who have sex with men to sexual health services, including condoms and lubricants, safer sex information, including for people who engage in chemsex, HIV testing and PrEP.

The initiative targets people who fear buying condoms and lubricants from public places—a common issue for young gay men and other men who have sex with men in the region. It is also an effort to reach the people who are hard to reach, who are not identified by conventional in-person outreach, and who regularly find their sexual partners online (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023).



Source: testBKK.

Communities have long confronted a variety of impediments to the further scale-up of HIV treatment programmes, including transportation barriers to distant clinics, congested HIV treatment centres, and unnecessarily onerous treatment attendance requirements for people with long-term viral suppression. In the face of these roadblocks, communities innovated by delivering antiretroviral therapy in their communities, working with local clinics to issue multimonth dispensing, and providing health monitoring for peers in or near their homes. The end result—differentiated service delivery—represents one of the most important changes in the history of HIV service delivery and is now accelerating progress towards the 95–95–95 targets.

## Communities are the vanguard in responding to emergencies

When an emergency strikes, communities are the first responders. Communities help localize responses to emerging crises, ensuring approaches are grounded in local realities, context-specific and culturally appropriate. Evidence demonstrates that community-based approaches help preserve access to HIV and health services in the face of emergencies (65). This became especially evident during COVID-19, when, for example, organizations of women living with HIV developed innovative, locally tailored strategies to preserve access to HIV and sexual and reproductive health and rights services, respond to gender-based violence, provide peer support, and address the hardships associated with lockdowns (66). Community-led monitoring in 2020 tracked the availability of multimonth dispensing for antiretroviral therapy, providing information of particular relevance to people living with HIV at a challenging time.

Although the COVID-19 pandemic underscored the vigilance, resilience and innovation of communities in responding to a novel health crisis, communities have long served as the first responders when emergencies strike. After the devastating Cyclone Idai in Mozambique, health activists acted swiftly to preserve continuity of HIV services (67).

In response to the acute and continually evolving humanitarian crisis in the Bolivarian Republic of Venezuela, 45 community-led monitors and navigators in 20 states joined together to conduct community-led monitoring to ensure HIV treatment access and quality of care for 40 000 people living with HIV across the country (68).

Communities pivoted rapidly to address the Ebola outbreak in Uganda in 2022, undertaking community-led monitoring to generate data used to shape Ebola management practices to maximize their availability, accessibility, quality and appropriateness.

When landslides caused devastation in the Mbale region of eastern Uganda in 2022, community-led monitoring by the Coalition for Health Promotion and Social Development Uganda and Sexual Minorities Uganda informed successful efforts to maintain access to HIV treatment services among affected households (information provided by Lillian Mworeko, ICW Eastern Africa, 2023).

Organizations of gay men and other men who have sex with men, particularly those involved in HIV service delivery, played critical roles in the response to the

multicountry mpox outbreak in 2022, raising awareness, educating communities on reducing risk, and supporting vaccination efforts. In Peru, among the countries most heavily affected by the mpox outbreak, communities responded swiftly by creating messages specifically crafted for the communities affected and by adapting HIV services to address mpox (69). Communities participated in Peru's development of an information, education and communications campaign and served on the Ministry of Health advisory body for the mpox response.

In Canada, the gay-led organization REZO made extensive use of social media to mobilize the gay and trans communities to respond to mpox (70). The Canadian Government recognized the leadership of REZO by funding it to support the public health response to the outbreak.

In Myanmar, community groups have stepped in to fill gaps in HIV treatment and prevention services in areas affected by conflict (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023). Network members living with HIV collect medicine refills for the coming months on behalf of other network members, preserving service access while reducing transport costs. Community feedback mechanisms have been expanded to areas affected by conflict, helping to document and address delivery challenges experienced by displaced people and other people affected by conflict.

## COMMUNITY-LED ACTION TO ENSURE HIV SERVICE ACCESS IN FRAGILE SETTINGS IN BURKINA FASO

Armed militias currently occupy about 40% of the territory of Burkina Faso (71). In these parts of the country, many health centres have been shuttered. More than 2 million people have been internally displaced as a result of the hostilities.

To ensure HIV service access in the parts of Burkina Faso not under Government control, the Réseau national pour une grande implication des personnes infectée et affectée par le VIH dans la lutte contre le SIDA (REGIPIV) moved quickly at the beginning of the crisis. In zones controlled by militias, REGIPIV organized community distribution of antiretroviral therapy, assigning pairs of educators to work with people living with HIV. HIV medicines have been transported into these zones by car, by helicopter and on foot. Community members accompany and support pregnant women living with HIV and provide point-of-care HIV testing of infants exposed to HIV.

Through these efforts in 2022, 171 infants received point-of-care testing, including four who tested positive for HIV. Nearly 3000 adults received HIV testing, including 15 who tested positive. More than 1000 people living with HIV are receiving their medicines through community delivery in these zones, including 442 who have received their medicines via helicopter transport (information provided by UNAIDS Regional Support Team for Western and Central Africa, 2022).



## COMMUNITY-LED RESPONSES IN UKRAINE: LIFE WINS

Without communities, hundreds of thousands of people living with HIV in Ukraine would be without life-preserving services and the basics of life. In the midst of the war, organizations representing people living with HIV emerged as a vital lifeline for people in desperate need of antiretroviral therapy and other essential HIV services. Before the war, Ukraine had a well-established system for procuring and distributing HIV medicines and providing HIV services to people most in need throughout the country. The war severed supply chains, leaving many people on the brink of running out of essential medicines and services.

Volunteer drivers working closely with local authorities braved dangerous routes to ensure life-saving medicines reached frontline zones. Their dedication came at great personal risk, with some volunteers losing their lives (information provided by UNAIDS Regional Support Team for Eastern Europe and Central Asia, 2023).

Regional branches of 100% LIFE located close to the frontline are continuing to work from bomb shelters and under blackout conditions to deliver HIV services and humanitarian aid. Despite the destruction of many roads as a result of the war, the Alliance for Public Health is using mobile vans to deliver food, HIV medicines and other essentials.

In addition to its ongoing emphasis on public health, human rights monitoring and advocacy, Alliance Global, the largest LGBTQI organization in Ukraine, has focused on helping ensure basic survival for its community. Alliance Global has provided food, financial support and shelter to people displaced by the war and with nowhere to turn for support.

Psychosocial support to LGBTQI people and others has become an important priority for Alliance Global and other LGBTQI groups, such as Cohort, an organization of transgender people that has provided financial, medical and legal assistance to transgender people in all parts of Ukraine. At the same time, LGBTQI activists have confronted a rise in discrimination, violence and other human rights violations since the beginning of the war.

## Communities are the first to recognize emerging issues

The HIV pandemic is constantly changing, in large measure due to its roots in social patterns and human behaviours. Communities are typically the first to detect and respond to important changes in epidemic dynamics.

Throughout much of the HIV pandemic, prevention of HIV associated with drug use was regarded by many people as distinct from prevention of sexual HIV transmission. As drug use patterns evolved, however, community groups flagged that use of methamphetamines, other stimulants and alcohol appeared to have a strong association with sexual behaviours, especially, although not exclusively, among gay men and other men who have sex with men. As a result, communities developed harm reduction initiatives to respond to chemsex (72). In 2022, the Eurasian Coalition on Health, Rights, Gender and Sexual Diversity released a guide for specialists on person-centred approaches to address the health needs of people who practise chemsex (73).

The intersection of drug policy and HIV underscores the need for policy-makers to listen to what communities are saying about emerging issues. In the 1980s, communities advocated for public health attention to the clear links between HIV and use of crack cocaine (74). New York City, like many other settings around the world, was late to embrace and aggressively expand harm reduction programmes for people who use opiates (75). At a time when HIV was spreading rapidly through networks of people who use drugs, official failure in New York to heed the warnings of community activists resulted in thousands of new HIV infections and AIDS-related deaths (76).

Communities of sex workers have leveraged their on-the-ground knowledge to drive shifts in the approach to preventing HIV among sex workers. While many of the most heralded early HIV prevention programmes for sex workers relied on the venue-based 100% condom approach (77), responses led by sex workers recognized that this approach was not appropriate for all sex workers, including those not based in establishments. As a result, the early, singular focus on condom access in sex worker prevention programmes has been complemented by community-led programming that emphasizes decriminalization, recognition that sex workers are legitimate workers, and measures to ensure sex workers enjoy safe working conditions and labour protections (78).

These innovations have had a major impact on the response. UNAIDS has documented that sex workers appear to have benefited more from HIV prevention than other key populations over the past 20 years, although female sex workers continue to experience HIV incidence several times greater compared with women overall (UNAIDS data analysis, 2023).

In Zimbabwe, the success of the community-led Sisters Project in improving HIV prevention and treatment outcomes of female sex workers has prompted the organization to expand its services to transgender and male sex workers (information provided by UNAIDS Country Office, Zimbabwe, 2023).

## COMMUNITY LEADERSHIP IN INDIGENOUS COMMUNITIES

Samuel López, who hails from the Nonualco Pipil Nation located in El Salvador, is a pioneering activist living with HIV in Toronto, Canada. To address the dearth of HIV resources designed by and for affected people who speak Spanish, Samuel helped to found a community-led initiative for people living with HIV, an HIV prevention programme and an LGBTIQI organization. Samuel brings his skills as certified interpreter and filmmaker to the community-led HIV response. One of his films tells the story of person living with HIV who died of neglect while waiting for a hospital bed.

Samuel notes that while many organizations and initiatives want to work with Indigenous people, few actively promote Indigenous leadership. “We have the knowledge and the wisdom,” he said. “If you think of the First Nations, let them do things on their own. We are walking encyclopedias, but what I have inside me doesn’t just belong to me. We need research and programmes that are not just associated with Indigenous people, but are actually Indigenous-led.” Citing the 95–95–95 targets, Samuel worries about the remaining 5–5–5 and believes that without genuine community leadership, Indigenous people will be left behind. “The first to fall behind are those who have experienced the worst,” he said, “and for the last 500 years Indigenous people have experienced the worst.”



# SEX WORKERS ARE NOT PROBLEMS—WE ARE HUMAN BEINGS

**Bhagya Lakshmi**

**India**  
Secretary, Ashodaya Samithi



I have seen a lot of attempts to create programmes for sex workers that have assumed what sex workers need, instead of asking them. These attempts have not helped sex workers, and often have even made sex workers' lives harder or increased risks to their safety and health. I am one of those sex workers.

Top-down programmes by outsiders do not understand this, but sex workers are smart and can discuss and arrive at wise decisions. To advocate for services that work for us, we have joined together to organize. I am part of Ashodaya Samithi, a community-led organization that is by, for and of sex workers. We are based in Mysore, Karnataka, and we work in six districts of the state. We are connected to the All India Network of Sex Workers, a national network.

Twenty years ago I was scared to disclose that I was a sex worker. After I joined the collective that became Ashodaya Samithi, with the help of other sex workers I gained power that I could use. I started introducing myself as a sex worker. I am no longer afraid to say that my work is sex work, and I respect my work. I am not afraid of advocating to officials. Just as the power of community has transformed my life, being part of Ashodaya Samithi has transformed several thousands of my sisters' lives too. Together we have achieved what none of us could have achieved on our own.

Ashodaya Samithi created for the first time a safe space for us to come together, enjoy mutual support, and mobilize to advocate for change. Our organization has a decision-making process, where issues and proposals need to be raised first by a local branch committee and not from the central level. This approach makes sure the organization remains grounded in the lived experiences of sex workers, and that problems are solved in real time.

Joining together in Ashodaya Samithi has improved our safety and security. We used to frequently experience harassment from criminal gangs and from the police. We collectively advocated with the local police, and now we have a much healthier, productive relationship with law enforcement and strengthened protection from violence.

Through constant engagement with authorities, we have improved the design of services provided by the health system so they meet the needs of sex workers. We have successfully advocated with officials for us to be involved in decisions that affect our lives. We have also created important services for ourselves, after consulting our fellow sex workers to make sure they meet the needs of our community.

Working together, we have achieved great advances, but new challenges have emerged. For example, pre-exposure prophylaxis (PrEP) is an essential prevention medicine that sex workers need to protect themselves from HIV. But PrEP is not provided free of charge by the health system, and it is too expensive for many sex workers. Moreover, PrEP requires a series of tests and clinic visits every 3 months, and sex workers who get PrEP have to pay out of pocket for

these services. That is why we continue to advocate that it is necessary to make PrEP and its associated services available free of charge to protect sex workers and others from HIV.

We continue to be held back by barriers to our inclusion in decisions that affect us. Although it is a major step forward that decision-makers now talk to us, they tend to engage us only in relation to HIV services. But like other people, sex workers have a range of health needs, and no one issue can be solved in isolation. For example, we need to improve access to and help design mental health services. We need to be protected from hunger and homelessness. These are all connected. The national movement that we are part of helped in the legal process that led to the Supreme Court of India's judgment in 2022 that sex workers have the same right to human dignity and access to social protection schemes as all other people. This judgment has already led to positive changes on the ground, but we still have a long struggle ahead for our humanity to be fully recognized. We must reach the last woman in the line.

We are not problems—we are human beings, and we know our needs.





Credit: UNAIDS



Source: SEEK-GSP.

Although HIV treatment programmes rightly focus considerable attention on medical interventions, community-led programmes have recognized the need to complement these with attention to the mental health needs of people living with HIV. Mental health services not only improve the general health and well-being of people living with HIV, but also improve treatment adherence and retention in care.

In Uganda, the Social, Emotional and Economic Empowerment through Knowledge of Group Support Psychotherapy (SEEK-GSP) programme uses community outreach and lay health workers to deliver group support psychotherapy to people living with HIV who experience depression. A rigorous evaluation found that participants in SEEK-GSP experienced a notably greater reduction in depression than people enrolled in group HIV education (79). At 6 and 24 months, 99% of the 1140 people living with HIV who participated in SEEK-GSP were found to be free from depression (80). This reduction in depression was linked with improved antiretroviral therapy adherence and a significant increase in viral load suppression.



## KEY POPULATION-LED PROGRAMMES IN KENYA

Hoymas was founded in 2009 by 14 male sex workers in Nairobi, most of them living with HIV. Over time it has expanded to become an essential safe place and service provider and a critical component of Kenya's efforts to end AIDS as a public health threat. In 2023, more than 10 500 people received services from Hoymas at service sites in Kajiado, Kirinyaga, Meru, Nairobi, Nyeri and Therakanithi. From its roots as a service provider of male sex workers, Hoymas has expanded its reach to address the HIV and other health needs of people from key populations more generally.

In 2016, Hoymas opened its first clinic to serve as a one-stop shop for people who need services. The clinic is certified by the national Government, and Hoymas collaborates with Government partners at the national and county levels. Doctors and other medical professional work at Hoymas clinics and provide care aligned with national and international guidelines. Through the one-stop shop model, Hoymas provides HIV differentiated care, PrEP, entrepreneurial training and employment support, and mental health services, including screening and treatment for depression, trauma, and use of alcohol and other substances.

The reason for the founding of Hoymas—and the reason why it has grown and expanded—is that LGBTQI people often fear receiving services run by the Government or the private sector. For example, mainstream health service providers are frequently unaware of anal health and may adopt stigmatizing attitudes towards people who present with such issues: “If I have a problem with anal health, a lot of people may wonder how I can bring it up with my health-care provider,” says Maina J of Hoymas. “Will they call my next of kin? At Hoymas, the majority of staff and volunteers are queer. We understand these issues and are better able to provide care in a way that makes people comfortable.”

Pascal Irungu, Monitoring And Evaluation Specialist at Hoymas, says: “[Hoymas] is not just about health. It also provides a space for our community. There is a lot of stigma towards gay men and sex workers. Not only do people who come to our clinics get medical services, but they also receive economic empowerment, companionship and mental health from a community angle.”

## Communities drive improvements to the accountability and responsiveness of health services

Communities have long served as accountability watchdogs in the HIV response (81). Community reporting on national HIV responses under the National Commitments and Policy Instrument has served as a check on government-reported information on HIV. For the Global Fund and PEPFAR, communities have monitored and influenced how finite HIV funding is spent, helping ensure community needs are met (82, 83).

Communities shine a light on human rights abuses and help community members obtain legal relief if their rights have been violated. In the Philippines, the Community Access to Redress and Empowerment network of paralegals provides legal literacy training for people living with HIV and people from key populations, and legal assistance to people who experience discrimination based on their HIV status or identity (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023). In Kenya, data from community-led monitoring resulted in the referral of 757 cases to pro bono lawyers or the country's HIV Tribunal (84).

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The growing attention in the HIV response to community-led monitoring underscores how communities promote improvements in quality, transparency and accountability in the response. Through community-led monitoring, the communities most heavily affected by HIV inequities monitor services, analyse the data they collect, and undertake evidence-based advocacy to improve service access, equity and outcomes. In dozens of countries, community-led monitoring has successfully supported advocacy for policy change, such as removal of user fees for health services; systems improvements, such as reform to procurement and supply chain systems to reduce the incidence of medication stockouts; and improvement in clinical operations, such as measures to reduce waiting times and make viral load testing routine.

Regional collaboration among community partners is helping to disseminate knowledge and lessons learned and support community-led monitoring, such as the 11-country Regional Community Treatment Observatory in West Africa, implemented by the International Treatment Preparedness Coalition (information provided by UNAIDS Regional Support Team for Western and Central Africa, 2023). In the Asia and Pacific region, the Seven Alliance regional consortium, composed of the seven regional networks of people living with HIV and people from key populations, hosted a webinar series to support community-led monitoring, encouraging cross-learning and effective use of monitoring results for advocacy (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023).

Community-led monitoring has catalysed practical reforms to improve HIV service access and enhance health outcomes. In Uganda, data generated by a community-led monitoring consortium have contributed to scale-up of point-of-care infant diagnostic services, an expansion by PEPFAR of harm reduction programmes, and the launch of remuneration for community health workers (information provided by Lillian Mworeko, ICW Eastern Africa, 2023). In Namibia, after community-led monitoring found that 33% of people living with HIV did not access or continue on antiretroviral therapy due to food insecurity or lack of nutritional support, the Society for Family Health collaborated with partners to revive a garden for people enrolled at local clinics, benefiting 70 people, and to sustain four community kitchens established by the World Food Programme (information provided by UNAIDS Country Office, Namibia, 2023). Documentation of long clinic waiting times, often in the hot sun, prompted the Epako clinic to collaborate with civil society organizations to erect shade nets to reduce the deterrent effects of waiting times (information provided by UNAIDS Regional Support Team for Eastern and Southern Africa, 2023).

One of the most extensive community-led monitoring initiatives is in South Africa, home to nearly one in five people living with HIV globally (information provided by UNAIDS Regional Support Team for Eastern and Southern Africa, 2023). In 2019, five community networks of people living with HIV came together to create Ritshidze, a community-led monitoring project in the highest-burden health facilities. Ritshidze (“Saving Our Lives” in the TshiVenda language) launched by inspecting 400 sites across 29 districts and by conducting more than 33 000 interviews with people living with HIV. Findings from Ritshidze are now institutionalized at national, provincial, district and facility levels, enabling community-led monitoring to drive policy and programmatic change and facilitating the triangulation of data from multiple sources. In the Free State province, Ritshidze findings led provincial health officials to implement new appointment protocols to reduce clinic waiting times and to implement 3- and 6-month dispensing of antiretroviral medicines. Across 949 facility members, clinics made more than 1800 commitments to improve services (information provided by UNAIDS Country Office, South Africa, 2023).

## COMMUNITY-LED MONITORING CATALYSES IMPROVEMENTS IN CLINICAL SERVICES IN UGANDA

The SAUTI Network, an association of rural-based independent LGBTQI and sex worker community organizations in Uganda, has generated remarkable findings through its community-led monitoring of health services. These findings have spurred concrete reforms to improve the quality, responsiveness and reach of services. SAUTI reports, “We are the people who experience these issues, day in and day out” (information provided by SAUTI Network, 2023).

SAUTI uses three forms of community-led monitoring: participatory monitoring, an online feedback tool and peer-based monitoring. Since 2021, monitoring has been conducted in health facilities in Arua, Gulu, Maska and Mbarara.

Compared with how health facilities view their services, SAUTI monitoring has found that community perceptions and experiences are seldom similar and often markedly different. In particular, community members using these facilities are often substantially less likely to report that services are available, affordable, accessible, acceptable and accountable.

A striking finding of SAUTI community-led monitoring is the stark differences in perspectives and perceptions between different key populations receiving services in the same geographical area. For example, in one health facility monitored by the community, all female sex workers found that services were accessible, but fewer than one in four transgender people agreed.

The SAUTI findings are having an immediate impact, in part through the direct engagement of and dialogue with district health offices and health facilities. In Gulu, for example, one service provider has created a key population room in response to privacy concerns; another service provider has taken steps to prevent medicine stockouts; and an inclusive partnership has been formed at the district level, enabling regular consultation with key population communities on budgeting issues. Significantly, the monitoring exercises have had the added effect of increasing community demand for health services.

Credit: UNAIDS



**THE PATH TO  
END THE AIDS  
PANDEMIC IS BEING  
OBSTRUCTED BECAUSE  
COMMUNITIES'  
LEADERSHIP ROLES  
ARE BEING HELD BACK**

2





**Although the evidence from the past four decades has demonstrated that community leadership is key to driving progress in the HIV response, the world has yet to provide the full range of support communities need to optimize their contributions. Urgent, sustained efforts are needed to remove the barriers obstructing community-led responses.**

## Community-led responses are underresourced

To fulfil their potential in leading efforts to end AIDS as a public health threat, communities require sufficient resources. The Global Fund (85) and PEPFAR (86) provide financial and technical support to community-led responses, including funding for community-led monitoring. A growing number of countries are increasing public funding for community-led responses through means such as social contracting (87).



Despite these encouraging steps, existing resources fall vastly short of what is needed for community-led responses. Whereas 31% of all HIV resources were channelled through civil society organizations in 2012, civil society (including community-led organizations and large international nongovernmental organizations) accounted for only 20% of HIV funding in 2021 (1).

Credit: The Global Fund/Yousuf Tushar



# TO SUPPORT COMMUNITIES, INVEST IN THEM

## Harry Prabowo

**Indonesia and Thailand**  
Programme Manager, Asia  
Pacific Network of People Living  
with HIV/AIDS (APN+)





I am alive because of community. When I was diagnosed with HIV in Jakarta in 2010, I had a CD4 count of 20. Staff at my nongovernmental organization took me to the doctor. They took turns looking after me. They were with me as I took my first steps after starting treatment. They held my hand. They made me laugh.

Today, I not only have an undetectable viral load, but I also have the confidence to embrace life fully and proudly as a gay man living with HIV. Treatment on its own could not get me here.

I have been lucky. But to ensure the world can end AIDS as a public health threat, community-led support cannot be left to luck.

For too many people, showing up for HIV services remains a lonely act of courage. Treatment services are still missing over 9 million people worldwide. We know that people living with HIV who anticipate high levels of stigma are more than twice as likely to delay enrolment in care until they become very ill.

The success of HIV programmes is reliant on the voices and reach of communities.

Communities help drive demand for services. They mobilize political leadership. They ensure that people not reached by formal health systems can get support. They monitor the quality of HIV services and help shape solutions. They help create an enabling environment that promotes equitable access.

Thankfully, treatment is now recognized as an essential investment. But it is disgraceful and dangerous that all too often, peer navigation and community-led service delivery are regarded as optional extras. Investments in community leadership are essential to the success of prevention, testing, linkages to care, retention and adherence results. This is not just a nice thing to do—it ensures the programmes work and makes financial sense.

The countries in our region that are closest to achieving the 95–95–95 targets have embraced the power of communities to supercharge results. In Cambodia, inclusion of communities in the design and implementation of HIV services has been critical to increasing the number of people who access pre-exposure prophylaxis (PrEP). In Thailand, HIV services, including prevention, testing and treatment, are covered by the universal health coverage system, and certified community-led organizations are reimbursed for providing services.

Governments across the world made a commitment through the 2021 Political Declaration on HIV and AIDS to prioritize community leadership. They pledged to strengthen and scale up community- and peer-led interventions. They pledged to invest in community-led service delivery, including through social contracting. And they agreed to support community-led monitoring and research.

Some have fulfilled these promises. They are succeeding. But it is urgent that these promises are fulfilled everywhere!

This year, HIV response stakeholders in the Asia and Pacific region gave feedback on the financing landscape for community-led responses in the region. These were the top three concerns:

- There are too many legal, policy and bureaucratic barriers to community-led service delivery.
- Community-led advocacy is severely underfunded.
- There is limited engagement with the policy-makers who make spending decisions, particularly at subnational levels.

Countries need to create a more enabling environment for the equitable financing of community-led HIV responses. They can build on positive examples from across the continent:

- The Indian Corporate Social Responsibility Law prescribes that 2% of company profits must go to charity.
- A 2022 Indonesian Health Ministry regulation outlines the role that communities play in HIV service delivery, and specifically enables community-led HIV self-testing.
- The 2019 Philippine Universal Health Care Act makes community-based health care organizations eligible for reimbursements.

The Seven Alliance, a consortium of seven networks of people from key populations and people living with HIV in the Asia and Pacific region, supported by UNAIDS, is working with governments, donors and other partners to strengthen implementation of community-led monitoring. Part of the challenge is to raise the level of resources to be commensurate with the level of need and the plans we have agreed together.

Community leadership is how the required results are achieved. This proven, smart investment needs to be assured of scaled-up, multiyear, predictable financing. It is essential work. And it should be compensated and financed as such. The lesson for governments and decision-makers across the world should be clear. No one should think of our contribution as volunteerism. To support us, invest in us.



Credit: The Global Fund/Brian Otieno

Much of the funding currently available to communities is project-driven. To effectively deliver on these projects and to ensure their long-term sustainability, community-led organizations require financing for basic infrastructure and systems. Operational support is seldom available for most community organizations.

This poses considerable challenges for underfunded community-led organizations. In addition to scrambling for limited grant funding, community-led organizations must satisfy monitoring and reporting requirements that differ between donors. Without robust and reliable investments in community systems, many community-led organizations have to choose between meeting project deliverables and answering the often-voluminous requests of donor or government agencies. The fact that resources for community-led responses and systems are so limited can place overburdened and underresourced organizations in competition with each other.

**Expecting  
community  
members to work  
without pay is  
neither fair nor  
sustainable.**

Global and regional HIV declarations acknowledge the essential role that communities play, but the reality is that the HIV response has often obtained the benefits of community-led responses on the cheap. Specifically, governments and international donors have continued to rely heavily on the willingness of community members to work for little or no pay. Studies have consistently found that women comprise the large majority of unpaid HIV caregivers (88). HIV is not alone in its reliance on uncompensated services, as the COVID-19 pandemic resulted in a surge in unpaid care, with women bearing a disproportionate burden (89, 90).

Expecting community members to work without pay is neither fair nor sustainable. Community workers, many of whom are already on low incomes, are often forced to leave HIV work in order to put food on their table. Unpaid or poorly paid work contributes to burnout, another source of turnover in community-led programmes, and a host of mental health issues (91). Given the vital role that community-led responses play in accelerating progress towards ending AIDS, it is essential that national governments and donors provide adequate compensation to strengthen and sustain community programmes.

## ROBERT CARR FUND: SUPPORTING THE SUSTAINABILITY OF COMMUNITY-LED RESPONSES

An exception to the lack of operational support for community-led organizations is the Robert Carr Fund, which provides flexible core funding for regional and global networks led by inadequately served populations, including people living with HIV and people from key populations. The Fund has raised US\$ 120 million to date. In 2019–2021, the Fund provided US\$ 7.9 million in support to community networks, with 60% provided in the form of core funding (92).

The Robert Carr Fund was named in honour of a tireless advocate for the leadership and engagement of civil society and communities affected by HIV. Using pooled funding from multiple donors, the Fund provides the kind of flexible, multiyear funding needed to address the HIV and human rights needs of inadequately served populations.

Networks receiving funding from the Robert Carr Fund allocate 88% of core funding to implementation of programmatic activities, including paying the salaries of trained staff responsible for implementation. As advocacy is a core function of community-led responses that is seldom funded by donors, the second most prominent use of the Robert Carr Fund by networks is to support advocacy. Funding enables community-led networks to undertake initiatives and cover costs that otherwise go uncovered by other funders.

The value of the Robert Carr Fund model became especially apparent during the COVID-19 pandemic. Through a special fund, it strengthened community action to leverage new technology for knowledge-sharing on human rights protections, adapt service models to preserve service action during national and local lockdowns, and move to cloud-based financial systems and remote working arrangements to sustain community infrastructure.

Credit: UNAIDS



## WOMEN'S CENTRAL LEADERSHIP ROLE IN EFFORTS TO END AIDS AS A PUBLIC HEALTH THREAT

Women living with HIV have played leading roles in propelling the HIV response forward and ensuring it meets the needs of women and girls in all their diversity. A key early milestone for women's HIV leadership was the founding more than 30 years ago of ICW. The ICW network now includes 10 regional networks, providing HIV leadership across the world.

Women-led networks have advocated tirelessly and effectively to raise key issues of concern to women living with HIV, including respect for the intersectional identities of women in all their diversity, sexual and reproductive health and rights, psychosocial support, gender-based violence, development of treatments that work for women (including ensuring compatibility with contraceptives and hormones), the specific needs of women from key populations, and raising awareness of the links between HIV, health and other aspects of the lives of women and girls (93).

UNAIDS has supported the creation and sustaining of platforms for the meaningful engagement of women and girls living with HIV in all aspects of HIV responses at regional and national levels. For example, in partnership with Women4GlobalFund, UNAIDS supported the engagement of women's organizations in the implementation of the Global AIDS Strategy and its alignment to the Global Fund 2023–2028 Strategy.

The critical contributions made by women's networks to the HIV response are multifaceted. Networks of women living with HIV have successfully supported litigation to prohibit the forcible sterilization of women living with HIV—including in Namibia, where ICW and the Namibian Women's Health Network led the Stop Forced Sterilization Campaign, which led to a landmark victory in 2022 in the national Supreme Court—and contributed to the development of consolidated WHO guidelines on the sexual and reproductive health and rights of women living with HIV (94).

After years in which progress in reducing new HIV infections among children stalled, women living with HIV exerted leadership to transform approaches, unblocking progress and putting the world on the road to eliminate new HIV infections among children (95).

Women are catalysing progress in addressing the diverse needs of women and girls living with or affected by HIV. In Mozambique, more than 200 women activists work for Kuyakana, a national network of women living with HIV consisting of 27 autonomous member organizations across the country. Supported solely by the contributions of Kuyakana activists, Kuyakana works to empower women and girls, raising awareness about HIV prevention, treatment reintegration and adherence support. Kuyakana operates within health-care facilities across the country, supporting treatment adherence by addressing the barriers that confront women living with HIV. Kuyakana has created a dedicated programme for adolescents in six districts, in which teen activists establish informal support groups to support adolescent girls living with HIV. An expanded programme for adolescent boys provides similar support to teenage boys living with HIV while promoting respect for teenage girls.

The Global AIDS Strategy recognizes the need for intensified support for women's continued leadership in the HIV response. The Strategy calls for 80% of services for women to be delivered by community-led organizations that are women-led.

## **COMMUNITY HEALTH WORKER PROGRAMMES—DIFFERENT FROM COMMUNITY-LED PROGRAMMING, BUT AN IMPORTANT PART OF THE RESPONSE THAT SHOULD BE BOOSTED AND HELPED TO BECOME MORE COMMUNITY-LED**

Community health workers are a discrete component of the health workforce and an important way in which communities are leading efforts to end AIDS as a public health threat and achieve universal health coverage (96). Community health worker programmes are distinct from community-led responses. Although some community-led organizations employ community health workers, most such workers are employed by governments.

Drawn from the very communities they serve, trained community health workers provide a high quality of care, improve service access and outcomes, drive innovation in service delivery, enhance adherence, and increase the efficiency of health service delivery (97). Studies have found that investments in community health workers yield economic and health returns that substantially exceed programme costs (98–100).

Although few, if any, health and development tools match the potential of community health workers to drive progress across the Agenda for Sustainable Development (97, 101), the world is largely failing to invest in this transformative workforce strategy.

Among 193 United Nations Member States, only 34 have formal community health worker programmes that include training, a minimum wage and accreditation. Most donor-financed programmes fail to budget for the services provided by community health workers. Globally, an estimated 86% of community health workers are unpaid, and those who are compensated are typically paid very low wages (102).

The expectation that community health workers will work for little or nothing forces many workers to leave the field, even when they are deeply invested in the important work they are doing. As the vast majority of community health workers are women, the failure to effectively resource and validate these programmes deepens gender inequalities.

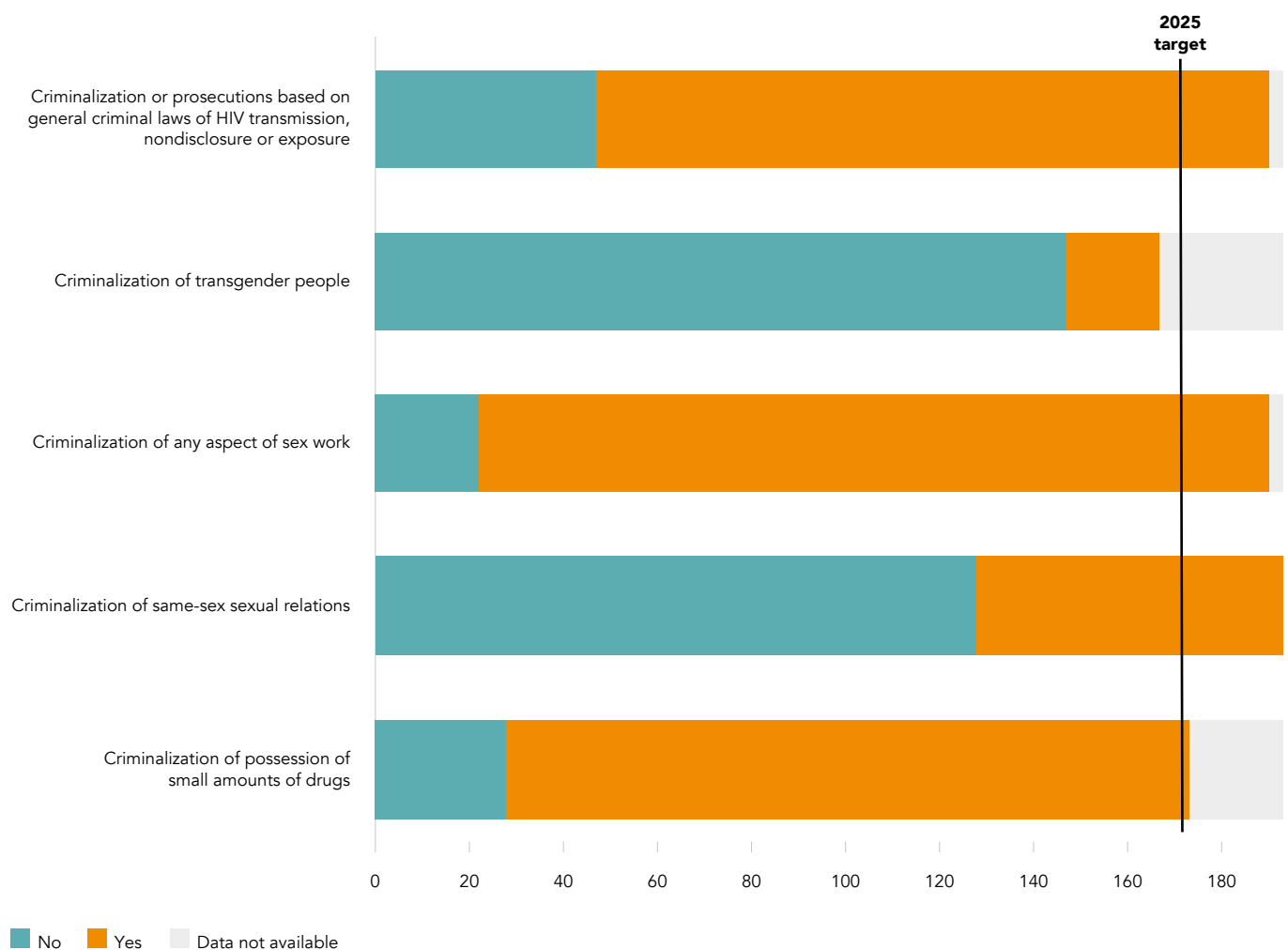
As services for HIV are increasingly delivered through primary health care, decent work in the health sector must include gender-sensitive employment free from violence, discrimination and harassment; manageable workloads; adequate remuneration and incentives; and occupational health and safety (103). Health systems must address stigma and discrimination towards health workers, including health workers living with HIV and health workers from key or vulnerable populations. Health systems must ensure the equal treatment of all health workers and ensure all health workers, including community health workers and lay providers, are protected from HIV with necessary protective equipment, including access to post-exposure prophylaxis, and the means to implement universal precautions.

Community health worker programmes can be supported to become more community-led, by strengthening accountability of programmes to service users and by recognizing affected community members involved in the work not only as deliverers of plans but as people who should be involved in shaping plans. In the words of one community organizer, “We have heads as well as hands.”

# Punitive laws and policies obstruct community-led responses

The world is not on track to ensure that less than 10% of countries have punitive legal and policy environments. In 2023, the overwhelming majority of countries criminalized the use or possession of small amounts of drugs; 168 criminalized some aspect of sex work; 67 criminalized consensual same-sex sexual relations; 20 criminalized transgender people; and 143 criminalized or otherwise prosecuted HIV exposure, nondisclosure or transmission (Figure 2). As yet another form of counterproductive policies, 106 of 148 countries with available data report requiring parental consent for adolescents to access HIV testing. Of the 120 countries that report having a national plan or strategy for condom programming in the National Commitments and Policy Instrument in 2017–2022, only 39 endorsed condom promotion in secondary schools and only 21 expressly allowed condom distribution in secondary schools (2).

**Figure 2.** Countries with discriminatory and punitive laws, global, 2023



Source: UNAIDS National Commitments and Policy Instrument 2017–2022 (see <http://lawsandpolicies.unaids.org/>).



Punitive legal frameworks obstruct communities' leadership in the HIV response. As United Nations Secretary-General António Guterres warned in his address to the General Assembly in September 2023, "Democracy is under threat. Authoritarianism is on the march. Inequalities are growing" (104). In 2021, 87% of the world's people resided in countries ranked by CIVICUS as closed or repressed (105).

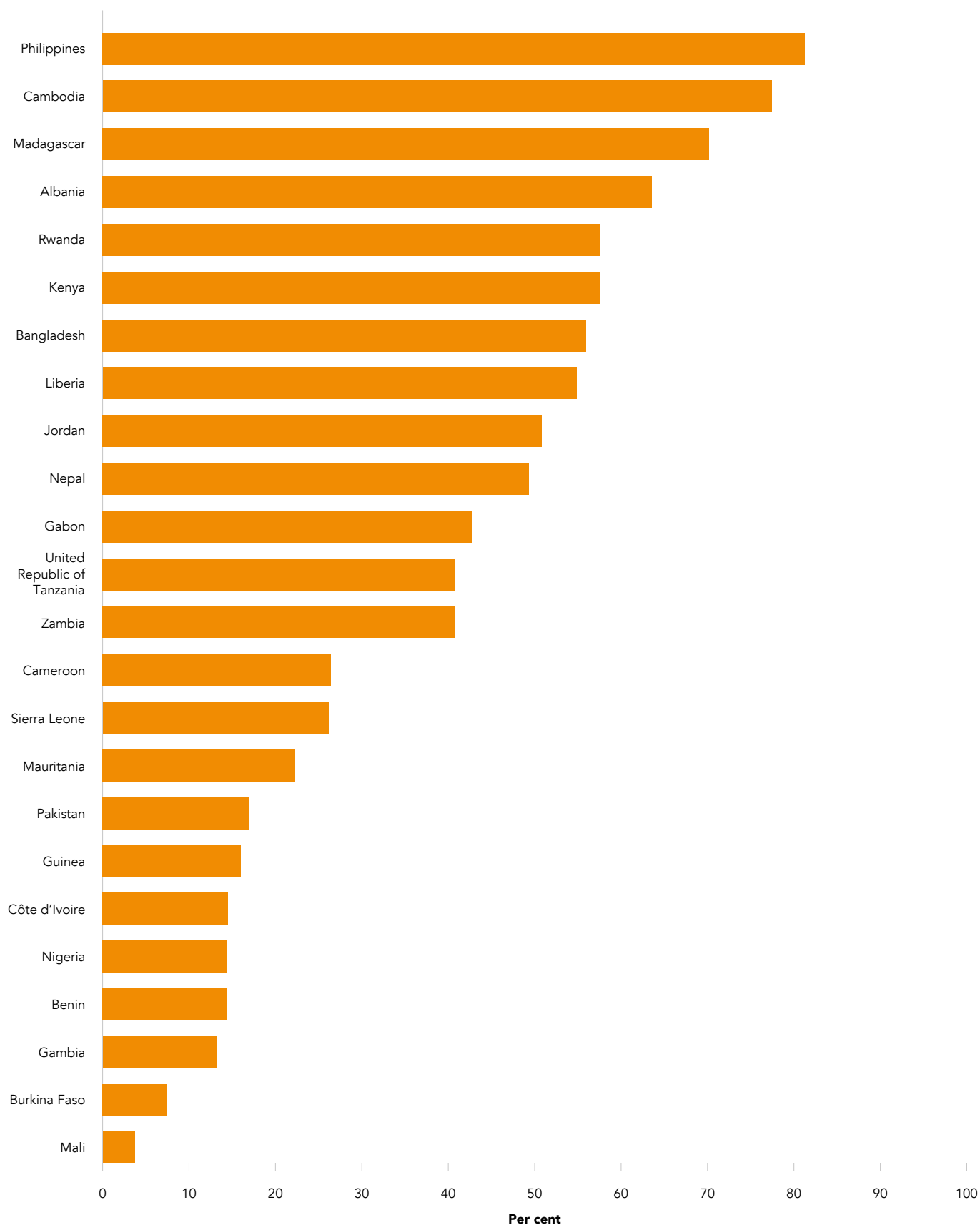
Growing restrictions on civil society constitute a key element of the global human rights retrenchment, as an increasing number of countries appear to view communities as threats rather than essential partners for health and development. According to multiple data sources, 63 of 194 countries had no provisions in place to enable the registration, operation and government funding of nongovernmental organizations or community service organizations (106). In countries where funding for civil society provision of HIV services is available, express or implied legal provisions often prevent civil society organizations from advocating for legal or policy change (107).

As part of de-democratization in many countries, there is a growing anti-rights backlash, including notable threats to sexual and reproductive health and rights (108–110). One effect of this backlash is to undermine efforts to promote the leadership of women in all their diversity and to strengthen community-led efforts to address the needs of adolescent girls and young women. In 14 of 18 countries with relevant data, more than 10% of ever-married or partnered women experienced violence in the last 12 months (Figure 3).

Credit: UNAIDS



**Figure 3.** Percentage of adolescent girls and young women aged 15–24 years who are currently married or in union who make their own informed decisions about sexual relations, contraceptive use and health care, countries with available data, 2018–2022



Source: Demographic and Health Surveys, 2018–2022.

The global backtracking on human rights is happening at a time when strong leadership is needed to combat the persistent stigma and discrimination that undermine all aspects of the HIV response, including those led by communities. Among 54 countries with recent survey data, a median of 59% of respondents reported discriminatory attitudes towards people living with HIV—a level nearly six times higher than the 10% target for 2025—with more than 75% of respondents in 13 countries reporting discriminatory attitudes (2).

## In many countries, community-led responses are sidelined when important decisions are made

Neither governments nor community-led responses will be optimally effective if they work independently of each other. Instead, the goal must be a mutually respectful, collaborative partnership in which synergies are captured, diverse evidence is used to inform strategies, and the autonomy of communities is ensured.

The HIV response is globally recognized for its inclusion of communities in governance and decision-making. Communities are represented on the governing boards of a growing roster of global health initiatives. Communities are actively engaged in the Global Fund Country Coordinating Mechanisms (CCMs), in processes for developing regional and country operational plans for PEPFAR, and in many national AIDS coordinating bodies.

With respect to health governance, the HIV response has served as a pathfinder for the global health field, highlighting the feasibility and added value of incorporating communities in decision-making and prioritization processes. Inclusion of communities in health governance broadens support for HIV and other health services, helps ensure health programmes meet community needs, flags issues that are underprioritized (such as equity, gender and human rights), and encourages innovative approaches to reach people who are not well-served by existing systems (111).

Yet, although the HIV response is rightly proud of its elevation of community voices, there is still a long way to go to ensure communities are able to lead efforts to end AIDS as a public health threat. Among 92 countries reporting data, all but one involve people living with HIV in the development of policies, guidelines and strategies affecting their lives (112). Certain populations, however, including young people, LGBTQI people, people who use drugs, sex workers, women and girls, are often excluded or inadequately engaged in HIV decision-making in many settings. Sixty-two countries report no involvement of people who inject drugs in HIV decision-making, 46 exclude people currently or formerly in prisons or other closed settings, 44 do not engage transgender people, 34 have no participation by sex workers, and 25 lack engagement of gay men and other men who have sex with men (112).

**Punitive legal frameworks obstruct communities' leadership in the HIV response.**

# AFRICA'S YOUNG WOMEN ARE NOT JUST THE FUTURE—THEY ARE LEADERS OF TODAY

**Naadu Awuradwoa  
Addico**

**Ghana**  
Creator, ReproHealth Unfiltered



Efforts to prevent new HIV infections will succeed only if they succeed for Africa's adolescent girls and young women. When we have raised our voices to be heard, we have had support from allies who value us. But we African young women remain held back because of situations in which, instead of being listened to by decision-makers, we are talked to, talked about and talked over. We call this "age prejudice". It is the attitude that says "You are young and do not know—and we are old and wise, so we will decide for you."

Some decision-makers blame us and tell us what to wear or how to speak. Others feel sorry for us and want to "rescue" us. These attitudes put us at greater risk. To help Africa's adolescent girls and young women stay safe, let us lead.

I became a peer counsellor when I was a schoolgirl. I did not plan to be one. My classmates picked the role for me. I had been a very confident, sociable child when I was little—but when an experience and witness of abuse made me retreat into myself, I found solace and information that helped me in the library. I wanted to know about my body, so I went to find the biology textbook. I looked up the explanations for the things that we girls were not allowed to talk about to adults.

That is how my role as peer counsellor began. I became the person to ask. My classmates gave me the nickname Love Guru. Friends from school and from church came to me with questions about the health issues they faced and the relationships they were in, that they were too afraid to ask a parent, a doctor, a priest or a teacher. The biology I had read helped, but even more important was empathy. I learned from experience that the way to help my peers was to listen, never to judge and always to be there.

I got more and more involved in young women's groups, and eventually I became a youth leader fellow. What has given me strength throughout has been other young women. We look out for each other, and we look after each other, and we help each other grow. We respect differences and we understand that young women's needs are not all the same, because our lives are intersectional. For example, I work a lot with young women with disabilities, supporting them in advocating for their rights. Many decision-makers do not understand that the risks of sexual abuse and exploitation can be even greater for young women with disabilities. This is what authorities miss when they plan for people instead of supporting people to plan for themselves. And because young women with disabilities face a double prejudice—for being young women and for having disabilities—they get even less recognition of their contribution as leaders.

We African young women and adolescent girls are developing approaches for HIV programming that can reach our generation. Many of the official public health messages do not connect with young women, because they do not speak in ways that we relate to. So instead of long leaflets in formal medical English with cold statistics, I make short social media videos with clear graphics, using our patois.

Because young women seeking advice are often scared and ashamed, I use roleplaying, dancing, music and humour to help my peers be at ease. Learning needs to be fun, or there will be no learning! And because no one size fits all, my communications open a space for people to ask the questions that matter to them, and reassure them that there is nothing they should be afraid to ask. I do not plan any of these alone—everything is a collective process.

While we are proud of what we have achieved as young women, we are frustrated that our work is often not properly valued and supported. Frequently we are brought in to do tasks set by others, but only rarely are we recognized as leaders. We get looked down upon. When we work with older people, some of them talk to us as though we will do all the learning and they will do the teaching, and we are expected to continuously demonstrate respect but not receive respect. Speaking up and sharing important insights from our experiences often gets treated as causing trouble. When, despite all this, we manage to rise to positions of authority, the nastiest comments are made about how we are assumed to have reached there.

Young women's initiatives are often left to operate without funding support, or depend on one-off awards that do not ensure a sustainable future. Some older people ask "What can these young women do?" And yet despite so much being rigged against us, we are already doing a lot. With full support, we can do even more.

We are determined to help our fellow young women keep protecting themselves from HIV, and to ensure all young women living with HIV access treatment. We African young women can lead—not tomorrow, but today.





Credit: UNAIDS

Other factors obstruct the full involvement of communities in HIV governance. Unlike board representatives from national governments, donor agencies and large philanthropic organizations, many community representatives serving on governance bodies have few or no staff to support their work. Too often, documents are not translated into local languages or provided with enough time for proper community consultations and prioritization processes. Especially at the global level, the limited number of community seats on governing boards means that community representatives are often expected to reflect the needs, perspectives and priorities of broadly diverse communities spread across extended geographical areas, without sufficient funding for broad consultations or selection processes (111).

These factors underscore the importance of global and regional networks of people living with HIV and people from key populations, and broad-based community partners such as Frontline AIDS globally and national partnerships such as Alliance Côte d'Ivoire.

## Decision-makers do not always take community-collected data into account

It is often said that “what gets measured gets done”. The HIV response has proven the truth of this adage, developing and sustaining what may be the most comprehensive and detailed data system for any health problem.

What is measured, however, sometimes does not get done—for example, if decision-makers do not listen to the available data. Omission of community-generated data in national decision-making undermines the effectiveness of national responses. Community-led monitoring provides important added value to monitoring and evaluation systems, enabling data triangulation, highlighting issues of specific concern to communities that may not be fully captured by existing systems and providing insightful qualitative data to complement quantitative measures.

UNAIDS recommends the integration of community-led monitoring in broader processes to evaluate service and ensure accountability for improvement, including investments by governments in community-led monitoring systems and regular engagement with community-led monitoring implementers (12, 113).

**The Global  
AIDS Strategy  
recognizes  
the need for  
intensified support  
for women's  
leadership.**





**THE BARRIERS HOLDING  
BACK COMMUNITIES'  
LEADERSHIP ROLES  
CAN BE REMOVED,  
UNLEASHING THE  
FULL POTENTIAL OF  
COMMUNITY-LED  
RESPONSES**





**This report has outlined the barriers obstructing community leadership—not to bring a counsel of despair, but to spur a call to action. These barriers can be removed. The time is now to match the commitments made to support community-led responses with the requisite action everywhere. Communities across the world have shown that they are ready, willing and able to lead—but this leadership needs to be supported if the world is to get to the end of AIDS.**

## Provide community-led responses with the resources they need

National governments, international donors, multilateral agencies, philanthropic partners and other HIV stakeholders need to join together to reverse the downward trend in funding for community-led HIV responses. Major new investments are required to achieve the 30–80–60 targets for community-led HIV services. A first step to achieve these targets is to bring the share of HIV funding channelled through civil society organizations back up to the 31% level seen in 2012 instead of the current 20%, and to place particular emphasis on providing funding for community-led organizations.

Efforts are being stepped up to ensure robust funding for community-led responses is included in all funding proposals to the Global Fund. Philanthropic organizations are also having important conversations about adapting how they fund to help shift power to community-led organizations.

A crucial aspect of resourcing that enables community leadership is not only increasing the amount of funding but also complementing the funding for discrete projects with a growing proportion of financing for building community systems, enabling communities to optimize their effectiveness and ensure long-term sustainability. The withdrawal of funding after the expiration of a grant often leaves community-led responses without systems in place to mobilize new resources or build on lessons learned from implementing the project. Reliable, long-term financial commitments to support communities in contributing to efforts to end AIDS as a public health threat, while building community-led infrastructure, are essential.

The comparatively small number of donors that fund community-led responses could strengthen collaboration to develop a joint, simplified mechanism for soliciting proposals, monitoring grants and reporting outputs, outcomes and impact.

Social contracting is a critical strategy to provide dependable, sustainable funding to community-led responses. Using formal contractual channels, social contracting funnels government resources to community-led organizations for the provision of services for prevention, testing, support and linkages to care (114). Sound social contracting mechanisms enable community-led organizations to address priorities that communities themselves identify.

Several countries have implemented or piloted social contracting in recent years for community-led HIV and other health services (115). In Viet Nam, social contracting supports community-led delivery of harm reduction, HIV testing, and referral for HIV treatment or methadone clinics (information provided by UNAIDS Regional Support Team for Asia and the Pacific, 2023). Social contracting has proven especially valuable in preserving and strengthening community-led responses in eastern Europe and central Asia, where many HIV responses have transitioned from donor financing to national ownership (87). In Niger, social contracting has enabled the nongovernmental organization SongES to operate in 19 health centres, providing testing services to nearly 5500 people from key populations in 2023 and diagnosing 204 new cases of HIV (information provided by the UNAIDS Country Office in Niger, 2023).

**Join together  
to reverse the  
downward trend  
in funding for  
community-led HIV  
responses.**

Social contracting, however, remains inadequately implemented in many settings, with 63 of 93 countries reporting having social contracting or other mechanisms that allow for funding of advocacy, service delivery, or monitoring and research led by communities (112).

Making social contracting a meaningful, broadly available avenue to increase sustainable domestic financing for community-led responses requires the creation of formal social contracting mechanisms, early engagement of community-led organizations in the establishment of these mechanisms, and increases in domestic funding for HIV and health (115). Donor countries have a key role to play in accelerating uptake of social contracting through focused financial and technical support for social contracting mechanisms and provision of meaningful debt relief to create fiscal space for domestic investments. Funding provided through social contracting should be robust and flexible, include core support required to build sustainable community systems, and should not restrict or impede community-led advocacy.

To generate the robust and sustainable funding that community-led responses need, urgent attention should be paid towards building a strong investment case for such funding. While evidence is already sufficient to justify stepped-up investments in community-led responses, resource mobilization efforts would be strengthened by the development, monitoring and reporting of agreed metrics to assess the impact of community-led responses. UNAIDS is currently working to develop clear metrics for monitoring the 30–80–60 targets.

## **CATALYSING SCALE-UP OF COMMUNITY-LED RESPONSES IN THAILAND**

Thailand has integrated HIV services into its universal health coverage scheme, enabling certified community-led organizations and lay HIV service providers to access domestic financial support within the national health infrastructure. In 2022, almost 140 000 people across the country received services from health services led by key populations and communities. The majority of people on PrEP (60%) were recruited by community organizations.

Communities of people living with HIV have rolled out a national community health worker certification programme for volunteers. The initiative uses a curriculum developed by the Thai Network of People Living with HIV/AIDS, with support from the Health Ministry Division of AIDS and STIs, the National Health Security Office, and the Ratchasuda College of the Mahidol University. PEPFAR and the United States Agency for International Development, via the III Unify Collaboration Programme and UNAIDS, provided technical and financial support. The curriculum, recognized by the National Health Security Office, is enabling the scale-up of community health workers within community-led organizations.

## WHY KEY DONORS INVEST IN COMMUNITY-LEADERSHIP RESPONSES

The leading providers of HIV assistance prioritize funding for community-led responses, recognizing that communities have a unique and pivotal role to play in accelerating progress towards ending AIDS.

In 2021–2023, the Global Fund invested US\$ 281.7 million in strengthening community systems. According to the Global Fund, “Community members’ unique expertise, perspectives and lived experiences inform many of the answers to [health service gaps]... [The] Global Fund has been supporting community and civil society participation in ongoing country dialogues, funding request development, grant-making and implementation oversight across the grant cycle” (116).

PEPFAR not only provides funding to community-led responses for service delivery but also allocates funding for community-led monitoring. As the former Head of PEPFAR advises: “PEPFAR has learned that there is no better watchdog than people from the community once implementation of an award has started. Clients themselves are the best judge of whether a site or a programme is doing what it is supposed to; they identify lapses in quality and coverage the fastest” (117).

## YOUTH LEADERSHIP ON HIV IN LATIN AMERICA AND THE CARIBBEAN

Juan de la Mar is an audiovisual artist, lawyer, human rights defender, HIV activist and coordinator of political influence for the integration of Bogotá City in the Fast-Track Cities initiative. Juan studied law at a conservative university in Colombia. In an early sign of their activism, Juan was an active supporter and participant in the Subversión Marica student movement a decade ago, which promoted respect for human rights, sexual diversity, and the power of art to change hearts and minds. Juan’s activism emphasizes the integral links between ending AIDS and broader efforts to promote and realize the human rights of all people, everywhere.

“Six years ago, I was diagnosed with HIV,” Juan recalls. “I withdrew from LGBTQI+ activism for 2 years. I became very depressed. It was very difficult for me to receive the diagnosis. During this time, I began to study film in Bogotá and I made a documentary called Regresar Positive. In the documentary, I break the silence and the stigma that exists in Colombia to talk about HIV. It is autobiographical. During the film I talk about the diagnosis, I talk about my family, and I face—let’s say—those initial fears, the stigma and discrimination, especially the self-stigma that I had so internalized.”

The film has achieved substantial reach, helping change social attitudes about HIV and providing encouragement to other people living with HIV. It has been shown at 37 film festivals, including two international HIV conferences, and awarded 12 prizes in international film festivals.

## Remove legal and policy barriers to community leadership

To let communities lead the way to end AIDS as a public health threat, achieving the 10–10–10 targets is essential. Currently, the world is far short of these benchmarks. No country in the world has removed all forms of punitive and counterproductive laws and policies, and one in five countries has yet to enact laws providing enforceable penalties against gender-based violence (118). High levels of stigma and discrimination remain entrenched in many countries across the world (2).

Although progress remains mixed, recent experience shows it is possible to remove the legal and policy barriers that impede community-led responses. Several countries across diverse regions have removed punitive laws that criminalize same-sex relations, sex work, and HIV exposure, nondisclosure or transmission. Progress has been uneven, however, and alarming backsliding on punitive laws has been seen in a number of countries (119). Momentum towards legal reform now needs to accelerate, including through south–south sharing of perspectives between leaders of countries that have reformed their laws with those from countries that have yet to do so. INPUD has developed a toolkit to support community-led advocacy to achieve the 10–10–10 targets (120).

All countries must have legal frameworks that create and maintain a safe and enabling environment for community-led responses. This requires the removal of restrictions on the formation or registration of civil society organizations and networks, guarantees of freedom of expression and assembly, ensuring a political environment free of violence and arbitrary interference, clear avenues for civic participation, and long-term support for civil society (121). The 2021 Political Declaration underscored the need for actions to ensure a “safe, open and enabling environment” to support civil society efforts to achieve global AIDS targets (3).

Making space for civil society is not an option but a clear requirement of international law. As the United Nations High Commissioner for Human Rights has found, there is a compelling business and economic case for a robust civil society, as businesses and communities have a shared interest in the rule of law and access to information (121).

## Integrate, elevate and engage communities at all stages of HIV-related decision-making

Communities need to be supported to participate in decision-making processes—not only because it is their right and is core to democracy, but because inclusive outcomes depend on an inclusive process. All authorities, including national governments and donors, need to make good on commitments to the GIPA principle, ensuring nothing about communities is decided without them.

**Have legal frameworks that create and maintain a safe and enabling environment for community-led responses.**

# PARTNERSHIP, NOT PATERNALISM: PUT YOUR TRUST IN TRANS AND GENDER DIVERSE COMMUNITIES

**Erika Castellanos**

**Belize and the Netherlands**  
Executive Director, Global Action  
for Trans Equality (GATE)





As a trans woman living with HIV, the most important support I have ever received since my diagnosis in 1995 is from the trans community.

While medical advancements offer a beacon of hope for people living with HIV, the impact of medical advancements depends on people accessing them and being supported as they access them. That is why the success of the global HIV response is contingent on governments, donors and other stakeholders fully recognizing this and investing wholeheartedly in community-led responses.

My story, although unique in its specifics, echoes the lived realities of many people. I can attest to their unwavering spirit and potential. Each community has its distinct cultural, economic and social fabric. As the people in closest proximity to the challenge, communities understand the nuances of what works and what needs to change, and can craft interventions that resonate and make a difference.

The HIV work of the Global Action for Trans Equality (GATE) focuses on centring trans and gender diverse populations at the heart of the global HIV response, supporting them to engage at local and national levels in HIV advocacy, research and service delivery. Every project is led by and for the communities.

Trust is an essential asset. As someone living with HIV, I've found that people often respond better to peers who understand their journey because they too are on that journey. Communities can harness this trust to drive change, dismantle myths and rally people together. In this way, enabling community leadership is not only the right thing ethically—it is also central to the effectiveness of the HIV response.

Instead of ineffective paternalistic oversight approaches, we take the path that works in advancing health, placing our trust in trans and gender diverse-led community-based organizations to know their own needs, to serve their own communities, and to deliver advocacy at the local and national levels using their own strategies and tactics. This approach of mutual trust not only supports the trans and gender diverse populations but also serves the whole of society, by ensuring HIV advocacy, research, service delivery and policy are more effective because they are better designed.

Communities provide vital emotional support and play a pivotal role in linking people to essential health-care services, enabling them to access and stay connected to life-saving services. This is especially important where mainstream health care falls short—which for trans and gender diverse people happens often.

Because GATE initiatives are community-designed, its services meet intersecting needs. GATE funding and training help organizations deliver community outreach activities, including providing condoms and lubricants to trans sex workers; delivering rapid HIV testing to trans people who use drugs, trans sex workers, and other key vulnerable populations within trans and gender diverse communities; and delivering educational and informational

services directly to trans and gender diverse communities, such as conducting community-based research, monitoring, and increasing HIV service uptake and adherence. In addition, community-led programmes provide spaces for trans and gender diverse people to come together, eat food, share experiences, laugh and celebrate the simple fact of living and surviving in a world that often denies our very existence.

Governments should see that communities are deserving of recognition and are also the most powerful force for advancing progress. Some of the key outcomes of GATE projects in collaboration with local and national trans and gender diverse-led organizations have been inclusion in HIV national strategic plans, with specific funding allocated towards community-based and community-led service delivery; engagement of government health ministries and service providers with ongoing awareness and inclusivity training and informational materials led by trans and gender diverse communities; and successful advocacy for national government funding for HIV health-care services delivered by trans and gender diverse people.

Communities have the capability to make monumental differences—but to do so, they need to be met with support, not obstruction. Here is my appeal to governments, donors and stakeholders:

- Provide financial backing: passion fuels community-led initiatives, but they also need tangible resources. It is crucial for donors to invest in these grassroots movements, enabling them to amplify their efforts.
- Remove roadblocks: governments need to foster an environment where community-led efforts can thrive. This includes championing the rights of people from marginalized groups, ensuring inclusive policies, and protecting activists and community health workers.
- Strengthen bonds: the mission to end AIDS requires a united front. Collaborative efforts between governments, nongovernmental organizations, donors and communities are essential for effective strategies. Recognize communities as fellow experts, and recognize us as being on the same side.

If authorities support grassroots movements and provide them with the robust support they merit, together we can bring about a brighter, AIDS-free future for all.



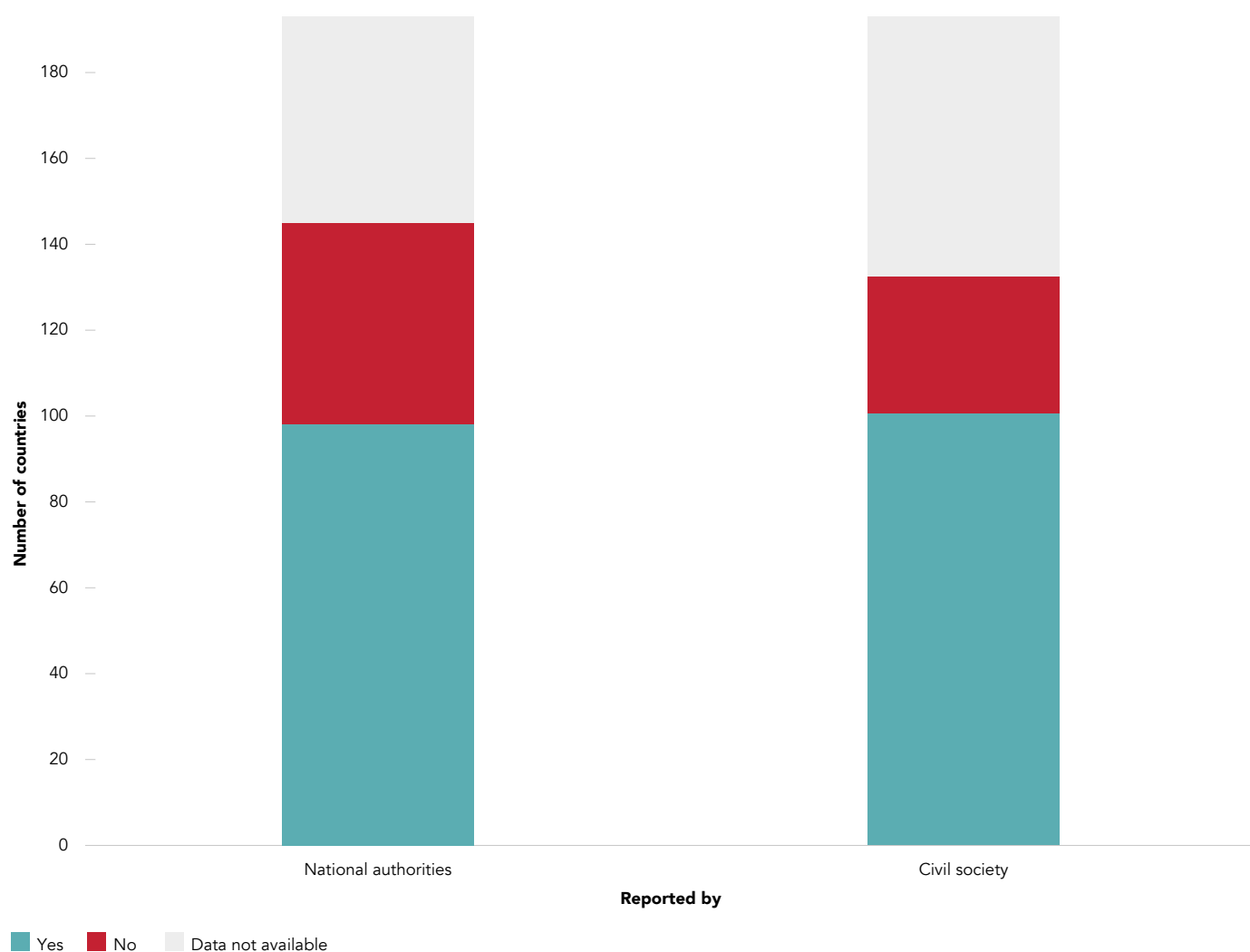


Credit: UNAIDS

The 2021 Political Declaration called for the provision of financial and technical support for the inclusion of communities in “HIV response decision-making, planning, implementing and monitoring” (3). Meaningful engagement requires not only reforms to technical consultative and decision-making processes but also provision of the means to engage, such as funding for transport for community members to attend meetings or support for community networks and fora to enable communities to meet and discuss their priorities.

Particular efforts are needed to engage communities that may be especially likely to be excluded from decision-making fora. For example, in 42 of 138 countries with available data, young people do not participate in the development of national policies, guidelines or strategies related to their health (Figure 4). To address this gap, the United Nations has issued concrete guidance on recommended steps for the meaningful engagement of young people in decision-making (122).

**Figure 4.** Countries reporting young people aged 15–24 years participating in developing national policies, guidelines and strategies related to their health, global, 2017–2023



Source: National Commitments and Policy Instrument, 2017–2023. Geneva: Joint United Nations Programme on HIV/AIDS (<http://lawsandpolicies.unaids.org/>).

## **BUILDING YOUTH LEADERSHIP TO END AIDS AS A PUBLIC HEALTH THREAT**

The Global Network of Young People Living with HIV (Y+ Global) is helping to lead global efforts to ensure the meaningful engagement of young people in all aspects of the HIV response. In 2022, Y+ Global made grants to 113 youth-led organizations from 41 countries. Its guidelines provide a roadmap for organizations to ethically and meaningfully engage with young people (123). The positive learning guideline developed by Y+ Global in concert with the United Nations Educational, Scientific and Cultural Organization (UNESCO) supports educational settings to engage young people in decision-making processes (124).

The READY to Care scorecard provides a platform for young people living with HIV to monitor and provide feedback on HIV services (125). The #UPROOT scorecard, administered by the PACT, UNAIDS and Y+ Global, enables young people to provide youth-centred information and insights on the drivers of the HIV epidemic, including discrimination, inequalities, violence and exclusion (126). In 2023, UNAIDS and Y+ Global developed guidance on key actions to strengthen sustainable youth-led responses, addressing priorities such as youth leadership and engagement, youth-led monitoring and research, youth-led service delivery, advocacy, campaigning and sustainable financing.

## **COMMUNITY-LED ENGAGEMENT IN GLOBAL FUND AND PEPFAR PROCESSES**

Engaging communities in decision-making processes is not only the right thing to do—“nothing about us without us”. It also leads to concrete, lasting improvements in national HIV responses.

In Haiti, for example, community participants have successfully encouraged greater attention to programming for key and other marginalized populations and for measures to ensure the long-term sustainability of national responses. During the process to develop the 2023–2024 PEPFAR country operational plan, civil society partners joined with other key stakeholders to analyse persisting inequities that undermine efforts to end AIDS as a public health threat. “The optimal participation of all HIV stakeholders is key to the process,” said Soeurette Policar, representative of the Forum of Civil Society for the Fight against HIV, TB and Malaria. “People living with HIV were represented in and contributed to all the thematic meetings during the week [of face-to-face discussions for development of the COP] and the exchanges were productive.” PEPFAR has pledged that its continued support for Haiti’s national HIV response will place communities at the centre.

Communities help shape and inform HIV programmes financed by the Global Fund through their extensive participation in CCMs. In Zimbabwe, five civil society dialogues informed development of the country’s funding proposal for Round 7 of the Global Fund (127). Key recommendations by community stakeholders—including development of a comprehensive service package for people most affected and intensified community-led monitoring of human rights barriers—were incorporated in the funding proposal approved by the CCM.

Engagement in funding processes by people from communities most at risk is also resulting in important advances in the availability of funding for targeted programming. Although key population programming has traditionally been included in countries’ “prioritized above allocation requests” to the Global Fund and subsequently unfunded, a 2023 survey by global key population networks found a notable increase in the incorporation of key population priorities in core funding requests for Round 7 of Global Fund grant-making (2023–2025) (128).

Governments also need to ensure that community-generated data are used to inform and improve national planning and implementation, to tailor responses to the needs of people living with HIV and those most at risk in all their diversity, making community data count.

## **Leverage community experience from the HIV response to accelerate progress towards sustainable health and development for all**

In the face of global economic headwinds, a debt crisis in low- and middle-income countries, accelerating climate change, and proliferating military and security crises, progress towards the SDGs is in jeopardy. United Nations Secretary-General António Guterres has advised that “Unless we act now, the 2030 Agenda will become an epitaph for a world that might have been” (129). Elevating and supporting communities to lead progress to end AIDS as a public health threat by 2030 will help unblock progress across the breadth of the SDGs.

The impact of ending AIDS through community leadership will be especially pronounced on progress towards the health targets of SDG 3 (good health and well-being for all, at all ages). As countries work to reimagine health systems to ensure they are fit for the purpose of achieving and sustaining universal health coverage, they should take on board lessons learned from the HIV response. As one of the central features of the HIV response, systematic engagement of communities should be mainstreamed across health practice (130). Indeed, there is already evidence that the legacy of community engagement in the HIV response is inspiring efforts to build on community leadership on other health issues, including addressing the toll from noncommunicable diseases (131).

Grounded first and foremost in the communities in which they live and work, community-led responses are guided by the needs of their constituents rather than a blinkered focus on a single disease. Already, community-led responses are paving the way for systems of health capable of delivering on the commitment to universal health coverage (127). In addition to strengthening the response to HIV and sexual and reproductive health and rights, investments in community-led HIV responses have supported interventions for nutrition, water and sanitation in the Democratic Republic of the Congo; integrated biomedical and mental health services in the Philippines; chronic disease care for migrants in Thailand; and hepatitis C prevention and treatment services in several countries (85).

**Ensure  
nothing about  
communities is  
decided without  
them.**

In the response to HIV, community-led efforts have shown how to address one of the central challenges of universal health coverage—reaching and engaging people who are not well-served by public-sector service systems. The people-centred spirit of innovation demonstrated by communities so powerfully in the context of HIV will be equally important in the historic push to ensure all people, regardless of where they live, have access to the good-quality, people-centred health services they need.

But the impact of ending AIDS would extend well beyond the health realm. Strengthening and accelerating the HIV response by placing communities at the centre will:

- Contribute towards the elimination of poverty (SDG 1) by preventing households affected by HIV from falling into or remaining in poverty.
- Support efforts to end hunger (SDG 2) through the integration of food and nutrition into community-led responses.
- Help scale up access to good-quality education (SDG 4) by supporting community-led initiatives to expand access to secondary education, especially for adolescent girls.
- Promote gender equality (SDG 5) by elevating the leadership of women and girls and implementing community-led initiatives to transform gender norms and practices.
- Advance decent work and economic growth (SDG 8) through community-led strategies to reduce social marginalization and exclusion and building entrepreneurial skills and opportunities for people living with or affected by HIV.
- Support sustainable cities and communities (SDG 11) through community-led action in Fast-Track Cities and other localities across the world.
- Contribute to peace, justice and strong institutions (SDG 16) through community-led efforts to address the exclusion, stigma, discrimination, human rights violations and violence that fuel the HIV pandemic.
- Promote partnerships for sustainable development (SDG 17), including through continued community leadership to ensure the affordability of and access to health technologies.

Letting communities lead is not doing them a favour—it is in the interests of the whole world.

# CONCLUSION

The evidence synthesized in this report demonstrates that the world cannot end AIDS as a public health threat without supporting communities in their leadership roles. Communities have long made and continue to make decisive contributions in driving progress to reduce numbers of new HIV infections and AIDS-related deaths, and to protect and promote the rights of all people living with or affected by HIV. The historic achievements the world has made in the HIV response have been possible only because of visionary, courageous leadership and action by communities. As the world strives to address the needs of marginalized people who have been left behind, facilitating community leadership is more important than ever.

Although the history of the HIV response is already one of unparalleled community leadership, much, much more can be done to facilitate the work of communities. Communities do not lack commitment, knowledge or insights, but they do lack the full, unstinting support they need to accelerate progress towards ending AIDS. Communities have not been provided with sufficient resources and are not yet optimally engaged in decision-making in many aspects of the response.

In too many countries, communities' leadership is compromised by a repressive legal environment and a restrictive space for civil society, which treats communities as a problem to be managed rather than understanding community leadership roles as essential to ending AIDS.

The guidance set out in this report is not guidance for communities. Rather, it is guidance gathered from communities and with communities, addressed to governments, donors and other stakeholders who need to act now, with boldness, to unleash the full potential of community leadership. Putting community leadership at the centre of the HIV response is not only the right thing to do—it is how to ensure we reach the goal of ending AIDS as a public health threat by 2030.

To this end, we must:

- Make communities' leadership roles central to the formulation, budgeting, implementation, monitoring and evaluation of all plans, policies and programmes that will affect them and that impact the HIV response.
- Provide urgent additional multiyear core resources for community-led HIV programmes so they can be scaled up, and the people implementing them can be properly supported and remunerated.
- Remove barriers to community leadership. The human rights of women, adolescent girls and people from key populations need to be upheld. Punitive laws that obstruct health access for LGBTQI people, sex workers, people who use drugs and people from other marginalized communities need to be removed. Clampdowns on civil society need to be dropped.

**Intensifying support to community-led HIV responses will yield dividends that extend well beyond HIV, helping advance all the Sustainable Development Goals.**



Intensifying support to community-led HIV responses will yield dividends that extend well beyond HIV, helping advance all the Sustainable Development Goals.

Communities are the guides the world needs to get on and stay on the path that ends AIDS. For the HIV response to succeed, let communities lead!

Credit: UNAIDS



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