

COMMUNITY-LED RESPONSES

IV

The activism, mobilization and on-the-ground work of community-led organizations have defined the HIV response and saved countless lives.

Community-led organizations drive HIV responses in numerous ways. They demand that HIV programmes uphold people's rights and dignity, advocate for legal and policy changes, and demand affordable access to medicines and services. In many locations, they provide a variety of HIV services directly to community members, and they boost facility-centred programmes by making services more accessible, bringing community insights to planning and implementation, and using grass-roots monitoring to strengthen surveillance and accountability (1).

THE ADAPTABILITY OF COMMUNITY-LED SERVICES PROVED ESPECIALLY CRUCIAL DURING THE FIRST YEAR OF THE COVID-19 PANDEMIC

Community- and key population-led organizations operate at the global, regional, national and local levels, and HIV responses work optimally when everyone is able to demand accountability from decision-making bodies at those different levels.

Studies show that community-led interventions can improve people's HIV-related knowledge and attitudes, increase service access, and enhance prevention, treatment and care outcomes. They do that by providing services that are more convenient and relevant, building trust and respect among providers and patients, and reducing discriminatory practices (1, 2). Those services can be more effective than standard health facility-based platforms for reaching marginalized and under-served populations, particularly when they are underpinned by capacity development (1, 3). Community-led interventions have helped reduce HIV and sexually transmitted infection (STI) incidence among sex workers (as seen in India and the United Republic of Tanzania), empowered sex workers (many of them indigenous or women of colour) in Vancouver, Canada, to take advantage of health services, and enabled adolescents to stay on HIV treatment in Zimbabwe by meeting their psychosocial needs (4–7).

The adaptability of community-led services proved especially crucial during the first year of the COVID-19 pandemic, when community-led organizations set up medicine and food pick-up schemes and sites, arranged home deliveries and shifted outreach work to virtual platforms (8–10).

United Nations (UN) Member States have committed to increase the proportion of HIV services delivered by community-led organizations to 30% of HIV testing and treatment services, 80% of HIV prevention services for high-risk populations and 60% of programmes to achieve societally enabling environments, all by the year 2025 (11). To reach those targets and realize the full potential of community-led HIV interventions, governments and other stakeholders must uphold the GIPA (Greater Involvement of People living with HIV/AIDS) principle and make concerted efforts to ensure the full involvement of people living with HIV and key populations—including women, adolescent girls and young people—early and in all stages of the HIV response. Much more needs to be done to understand community as an organizational concept to ensure the full voice and participation of those traditionally left behind—including all key populations and people living with HIV, as well as adolescent girls and boys, women, people with disabilities, migrants and refugees affected by HIV (12, 13).

Stakeholders should turn political commitment into action and integrate community-led interventions into the existing health sector responses for planning, implementation and monitoring at all levels. Obstructive laws and policies should be changed and more support should be available for communities. New policies, guidance and models are needed to scale up community-led responses, and more consistent and easily accessible funding and capacity-building support should be made available to enable key populations, women and young people to assume leadership roles in the HIV response.

HIV SERVICES THAT REACH AND WORK FOR PEOPLE

People living with HIV and key populations are often reluctant to seek the services they need because of the discriminatory attitudes they encounter at health facilities. Because health processes frequently fail to account for vulnerability and marginalization, many of the communities most affected by HIV are excluded from the design, planning and monitoring of HIV services, which directly affects their ability to effectively access or use these services. In particular, the lack of gender and key population expertise results in systematic exclusion from interventions, particularly of women living with HIV, women members of key populations and adolescent girls.

Compared to HIV services that are delivered in a top-down fashion, services that involve strong community engagement have been shown to provide greater understanding and respect for marginalized community members without compromising quality. In Nigeria, for example, sex workers, people who inject drugs, and gay men and other men who have sex with men who were served in peer-led facilities in four states said that services were more affordable at these facilities, that their concerns were taken seriously, and that their privacy and confidentiality were respected (14).

Studies show that the quality of community-led services for marginalized populations, particularly key populations and young people, can exceed what is offered at clinics and hospitals. A recent review of 48 studies of community-led HIV interventions, most of them in low- and middle-income countries and many involving youth, found positive outcomes in the areas of improved HIV-related knowledge, risk behaviours, health literacy, HIV prevention and treatment adherence, and viral suppression (1).¹

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As evidence of their impact grows, community-led services are more frequently being integrated into national HIV programmes. In Viet Nam, key population self-help groups transformed themselves into community-led organizations and social enterprises that provide HIV testing (including self-testing), pre-exposure prophylaxis (PrEP) and other health services. They performed well enough to prompt a decision from the Ministry of Health in 2020 to roll out community-led testing and PrEP services in almost half of the country's 63 provinces. Key population-led services have now been integrated into the country's national HIV response plan (15).² However, community-led services are still relatively scarce worldwide due to restrictive legal and policy contexts and financing constraints that can limit development of their technical capacity.

1 More than half reported improved prevention behaviours (including condom use), eight reported improved treatment adherence and viral suppression, and 10 reported improvements in access, use and quality of services. Increased community engagement and social cohesion was also reported. Nine of the studies reported mixed or no differences in outcomes between the intervention and comparison arms of studies.

2 For more details, see: Unequal, unprepared, under threat: why bold action against inequalities is needed to end AIDS, stop COVID-19 and prepare for future pandemics. World AIDS Day report. Geneva: UNAIDS; 2020.

Social contracting is one way to financially support expanding the coverage and improving the quality and relevance of services. National programmes and other partners also need to strengthen the technical and operational capacities of community-led organizations and allocate funding for their activities as an integral part of the implementation of national plans. In tapping the potential of community-led services, it will be important to have a sound understanding of the conditions in which these approaches work best and how they can most productively link with broader health systems and responses.

Equitable access to HIV and [hepatitis C] services for people who use drugs means our communities are able to enter, continue and exit programmes in the same ways that the general population does: of our own choice, agency and volition. We are able to access affordable, quality services and treatment, irrespective of our drug use status. We do not have to avoid seeking health services due to criminalization, fear of stigma and judgment, and [we] are provided with accurate health education and information. We are empowered to make informed decisions about our own bodies, which are taken seriously by health providers.

– Judy Chang, International Network of People who use Drugs (INPUD), presentation at the United Nations Office on Drugs and Crime (UNODC) Commission on Narcotics Drugs pre-conference, March 2022.

BRINGING NEW ENERGY TO THE HIV RESPONSE

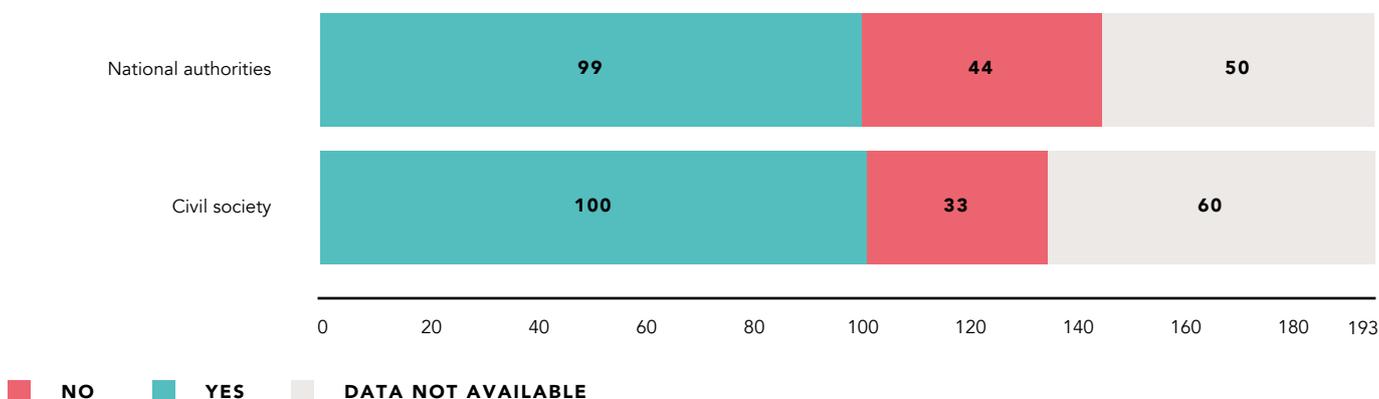
Young people (aged 15 to 24 years) accounted for more than one quarter (27%) of new HIV infections globally in 2021 and more than three in 10 (31%) new infections in sub-Saharan Africa. Despite this, youth-friendly services for HIV, sexual and reproductive health and harm reduction that reflect the diversity of young people and respond to the specific needs of young key populations are still not the norm. Too often, young people are judged, stigmatized or discriminated against for their sexual identity or for being sexually active or living with HIV.

Young people understand their own challenges and needs, and they have vital roles mobilizing around rights-based demands and making HIV-related services relevant and accessible. There are numerous examples of the insights and impact that young people bring to HIV programmes. They range from the Teenergizer project in eastern Europe and central Asia and YouthLEAD's extensive work with young key populations in Asia and the Pacific, to YouthRise's work with young people on harm reduction and drug policy reform and the support that Ground Up! provides to young people living with HIV in eastern and southern Africa (16–19). Peer-led HIV testing services are highly acceptable to young people—as seen, for example, among university students in the Democratic Republic of the Congo, South Africa and Zimbabwe, in the "Yathu, Yathu" project in Lusaka, Zambia, and in Nigeria (20–24). But those kinds of services are still uncommon, typically small in scale and short on funding. The #UPROOT Scorecard, a youth-led monitoring tool, for instance, still shows uneven participation, partnering and youth leadership in HIV responses (25).

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A significant number of countries still do not provide opportunities for young people to help develop national health policies (Figure 4.1).

FIGURE 4.1 Percentage of countries reporting young people aged 15 to 24 years participate in developing national policies, guidelines and strategies related to their health, global, 2017–2022



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

Governments and donors should be capitalizing on the knowledge and creativity that young people bring to HIV responses, and they should live up to the commitments that they made in the Global AIDS Strategy and the 2021 Political Declaration on AIDS. They can do that by meaningfully involving young people in the decisions and priority-setting that shape programmes for HIV, sexual and reproductive health, and harm reduction, and by supporting youth-led organizations through consistent funding and ongoing capacity development. This will ensure that young people can contribute fully to making HIV programmes work for themselves and their peers.

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Engagement of young people in Inanda, Durban, South Africa, February 2022. The National Association of Child Care Workers was contracted as part of a community project to support children and young people in Inanda, the largest township in eThekweni (Durban). The main objective was to reach children and young people with HIV services, ensuring that people living with HIV remain in care, and to address stigma in the community.



YOUNG PEOPLE STAND UP TO END HIV ONCE AND FOR ALL

If we hope to end AIDS by 2030, young people will need to lead the way. UNAIDS has played a key role in coordinating #GenEndIt, a coalition of youth-serving organizations funded in 2016 to support the leadership of young people from around the world in the HIV response.¹

The Global AIDS Strategy prioritizes partnerships as a central strategy for getting the HIV response on track to end AIDS as a public health threat, and the #GenEndIt initiative illustrates the critical importance of partnership for delivering on the Strategy's promises for young people. #GenEndIt is an especially strong example of a mechanism for ensuring sustainable investments in programmes to meet the needs of young people.

#GenEndIt, with support from the Oak Foundation and Restless Development, has recruited and trained 15 young leaders, known as "Ambassadors," from around the world to become advocates and campaigners for HIV responses that build on the engagement, leadership and solidarity of young people. It is also using youth-focused communications and community mobilization to increase young people's HIV knowledge and awareness. The coalition advocates for changes in cultural and religious practices that reduce young people's access to sexual and reproductive health and rights (SRHR) and comprehensive sexuality education. The coalition also works to combat stigma and discrimination, especially against young people living with HIV and young key populations.

#GenEndIt advocacy campaigns are designed and implemented by and for young people. The coalition has already reached 4457 young people in Fiji with youth-focused radio programming, generated more than 15 000 HIV-related social media engagements in Nigeria and reached 118 young people through community dialogues in Cameroon.

By centring young people as decision-makers and leaders and building their capacity to lead efforts to end AIDS, #GenEndIt offers a pathway for a sustainable HIV response. Through focused investment, #GenEndIt has expanded outreach for young people, especially for young key populations, by combining peer-led outreach with social media and other communications platforms.

¹ #GenEndIt is a collaborative initiative made up of Grassroot Soccer, the Elizabeth Taylor AIDS Foundation, the Elizabeth Glaser Pediatric AIDS Foundation, the Elton John AIDS Foundation, The PACT, the Charlize Theron Africa Outreach Project, Sentebale, Avert, MTV Staying Alive and UNAIDS.



"THE INCLUSION OF YOUTH POWER IN MEANINGFUL ENGAGEMENT AND LEADERSHIP IN HIV-RELATED PROCESSES AND DECISION-MAKING HAS BEEN OBSTRUCTED DUE TO MERE TOKENISM. MORE LOCAL AND GLOBAL SPACES FOR COLLABORATION AND ENGAGEMENT FOR YOUTHS SHOULD BE CREATED TO CREATE MORE OPPORTUNITIES AND PLATFORMS TO SUPPORT THEIR ADVOCACY AND INITIATIVES."

"I HAVE OFTEN SAID THIS TO YOUNG PEOPLE: 'IGNORANCE IS THE GREATEST INHIBITOR TO ANY PROGRESS WE MIGHT WANT TO MAKE, AND THEREFORE, LET US NOT BE PROUD OF NOT KNOWING WHAT IS HAPPENING AROUND US!' THERE IS STILL A BIG KNOWLEDGE GAP, AND IT IS VITAL TO USE THE PEER-PEER APPROACH TO TRAIN YOUTH ON HIV. I BELIEVE THAT WE NEED A BOTTOM-UP APPROACH, WHERE THERE IS COMPREHENSIVE SEXUAL EDUCATION FOR YOUNG PEOPLE AT EARLY STAGES IN THEIR LIVES. THAT WAY, THEY CAN COME UP WITH IDEAS AND CONTRIBUTE MEANINGFULLY TO THE HIV RESPONSE."

The selected Ambassadors bring together youth activists from the HIV, SRHR, climate change and feminist movements. Here are some of their stories.

Bipana Dhakal brings to #GenEndIt five years of work on development initiatives, social action and leadership development. She is the founder of The Learning Fortress, an initiative for creating a nonformal teaching–learning environment in the rural communities of Nepal. In addition to her work as a #GenEndIt Youth Ambassador, she is a WEDU Rising Star 2021 and YouthxPolicyMakers Ambassador 2021.



Tanyaradzwa Makotore is a 22-year-old woman in Zimbabwe who is using social media as a tool to end AIDS by 2030. In 2020, she launched I Just Want To Be Heard, which promotes adolescent girls and young women to use their voices to end the social injustices they face. Tanyaradzwa is also an ambassador for the the DREAMS initiative, which is led by the United States President's Emergency Plan for AIDS Relief (PEPFAR), and she was selected in 2021 to be one of 20 global activists to attend the High-Level Meeting on AIDS to advocate for comprehensive education for all populations affected by HIV. SRHR Africa Trust named her a leading national sexual and reproductive health activist in 2021.



"STIGMA AND DISCRIMINATION HAVE BEEN ONE OF THE BIGGEST BARRIERS TO TACKLING HIV, AND ONE WAY WE CAN OVERCOME THIS IS BY PUSHING FOR AN ANTI-STIGMA LAW THAT PROTECTS THE RIGHTS OF YOUNG PEOPLE, ESPECIALLY THOSE LIVING WITH HIV IN ALL COUNTRIES. THERE IS A NEED FOR THOSE IN POWER TO BE ABLE TO RELINQUISH POWER TO THE YOUNG. THERE IS A NEED FOR PARTNERS TO TRUST YOUNG PEOPLE IN ALL THEY DO IF WE ARE TO END AIDS. THOSE IN POWER OR IN LEADERSHIP POSITIONS SHOULD STOP BEING SELF-CENTRED AND HOLD THEMSELVES ACCOUNTABLE FOR PUSHING OTHER YOUNG PEOPLE IN THE GLOBAL SPACE, NOT JUST AT THE NATIONAL LEVEL. THIS WILL GO A LONG WAY TO BRIDGE THE GAP."

"IN NIGERIA AND OTHER AFRICAN COUNTRIES, PUNITIVE LAWS REMAIN ONE OF THE MAJOR LIMITATIONS PREVENTING THE MEANINGFUL ENGAGEMENT OF YOUNG PEOPLE IN THE HIV-RELATED PROCESS. POLICY-MAKERS MUST ENSURE THAT THE LAWS OF THEIR STATE UPHOLD THE PRINCIPLES OF DIVERSITY, EQUALITY AND INCLUSION. EVERY NATION'S LAW SHOULD RECOGNIZE THE EQUALITY OF ALL PERSONS; THE HUMAN RIGHTS AND DIGNITY OF EVERYBODY SHOULD BE PROTECTED IRRESPECTIVE OF THEIR SEXUAL ORIENTATION, GENDER IDENTITY/EXPRESSION AND SEXUAL CHARACTERISTICS."

Faith Onu first volunteered at age 14, when she began working as a counsellor tester in Nigeria with the Youth Network on HIV and AIDS. She began volunteering at age 16 with the Institute of Human Virology to support and mentor adolescents and young people living with HIV. Faith is well known in Nigeria as an effective advocate for young people. She founded the Young People's Network for Sustainable Lifestyle and Health (YOUNPEN4SLAH), which advocates for attention for the health of young people in all their diversity. Faith's goal is to ensure that in every society, every young person is healthy and economically empowered.



Emmanuel Onwe is a Nigerian biomedical scientist and trained specialist in SRHR. As a firm believer in diversity, equality and inclusion, Emmanuel is dedicated to the advancement of the human rights and dignity of lesbian, gay, bisexual, transgender and intersex (LGBTI) Nigerians through strategic advocacy, lobbying and active engagement of policy-makers. In their work as a #GenEndIt Youth Ambassador, Emmanuel is: (a) leading advocacy for the decriminalization of HIV and people living with HIV; (b) addressing stigma and discrimination and legal support issues; and (c) championing advocacy on HIV treatment-as-prevention, test-and-treat, PrEP and equal HIV treatment access.



BRINGING HIV TESTING TO THOSE WHO NEED IT

Late diagnosis of HIV infections is a major stumbling block in the global HIV response. Rates of undiagnosed HIV are especially high among key populations, adolescents and men. Late diagnosis of infection compromises the health—and sometimes costs the lives—of people who only seek treatment after becoming critically ill. It also gives HIV ample time to spread to others.

There are many reasons for the uneven uptake of HIV testing.

There are many reasons for the uneven uptake of HIV testing. The presence of punitive laws, fear of being stigmatized, and concerns about privacy and confidentiality discourage people, especially members of key populations, from testing. HIV testing is also offered mostly in health-care facilities, which can be costly to attend, inconvenient and intimidating (25–29). Best practices show that HIV testing approaches that strongly engage community organizations, especially if they are also community-led, can sidestep many of those hindrances.

- A meta-analysis of seven controlled trials of peer-led testing services among gay men and other men who have sex with men found testing rates were significantly higher in the intervention groups where participants had access to peer-led services (30).
- Peer-led services tested as part of a trial in Zimbabwe performed more than twice as many HIV tests (2606 versus 1151) among female sex workers and almost doubled the number of HIV diagnoses (1052 versus 546) (31).
- In rural Malawi, seven-day self-testing campaigns among adolescents and men that were designed and carried out by community health groups showed a marked increase in HIV testing uptake. The percentage of diagnosed people who started antiretroviral therapy within three months of diagnosis was twice as high in the community-led arm of this randomized trial (32).
- Outreach testing and other activities run by the Technological Clinic, a community-led HIV service facility in Bangkok, have been successful at diagnosing transgender women and gay men and other men who have sex with men who do not know they are living with HIV. Convenience, flexible service hours, peer follow-up support and staff trust were the key factors (33).
- In three Nigerian states (Akwa Ibom, Cross River and Lagos), community-engaged partner testing was highly effective at diagnosing HIV infection among the sexual partners of people who inject drugs and among gay men and other men who have sex with men (34).

These examples, however, are not yet the norm: community-led organizations face formidable impediments, including hostile legal and operating conditions. The added advantages they can bring to HIV testing require removing those barriers and striking tactical partnerships with public and other health-care providers, not least to ensure that people diagnosed with HIV are efficiently linked to treatment and care. Adequate and diverse representation from within the community—in addition to inclusive health governance and coordination—is vital to make this work, as is technical and administrative skills-building for community-led service providers.



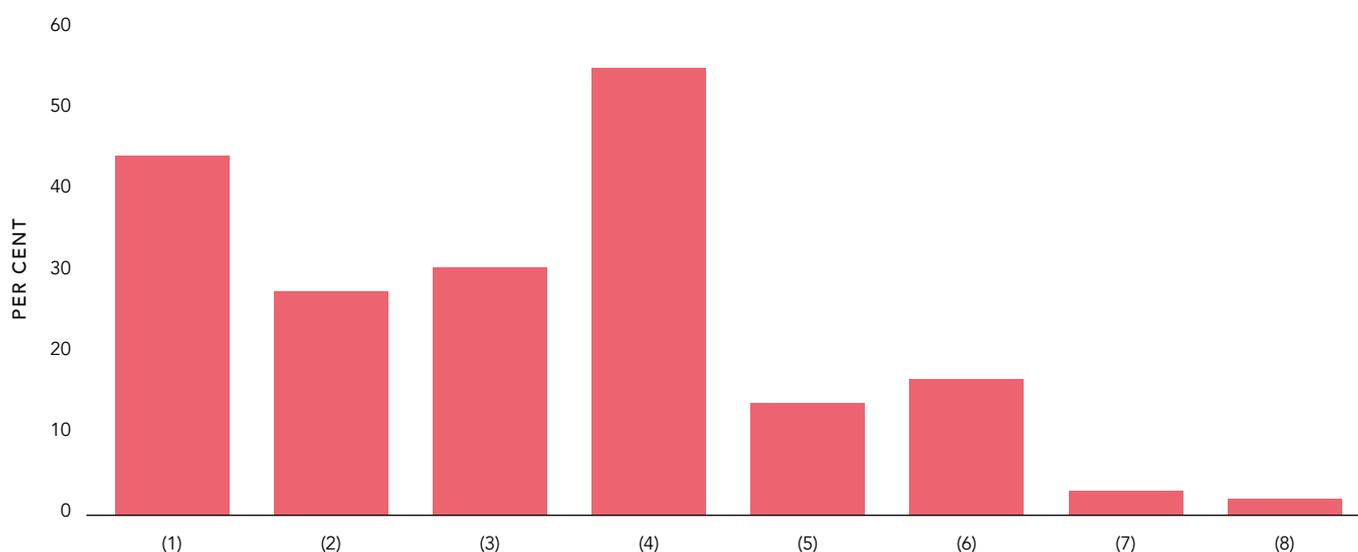
Community health-care worker at J.C Ménard Clinic in Port au Prince on 30 November, 2021. The SEROvie Foundation is a Haitian community organization that has been providing health services to Haitians for more than 20 years by offering free specialized sexual and reproductive health services, psychosocial support and family support services.

PUTTING SOCIAL CONTRACTING TO WORK

Reliable funding is a major challenge for community-led organizations, especially those that serve key populations: commitment and goodwill do not pay their bills. Social contracting is one way to fund these organizations and enable them to tap into their unique advantages for working with populations who are poorly served or missed by standard HIV services. Social contracting involves governments contracting and paying nongovernmental organizations to perform certain roles, such as service provision, research and monitoring.

The potential benefits are plentiful. Social contracting can extend the reach and relevance of programmes, foster pragmatic partnerships between community-led organizations and public health systems, and bring much-needed funding to the organizations, and by extension, the people who deliver the services to the ones who need them the most. Governments are increasingly establishing mechanisms to facilitate some form of social contracting, as are international donors (Figure 4.2). Of the 80 countries reporting these data in 2022, 45 allowed for domestic funding of service delivery by community-led organizations, 28 did so for monitoring and research, and 31 did so for advocacy led by communities.

FIGURE 4.2 Countries reporting having laws, policies or regulations that enable access to funding for community-led organizations, global, 2022



- (1) Social contracting or other mechanisms allowing for funding of service delivery by communities from domestic funding
- (2) Social contracting or other mechanisms allowing for funding of monitoring and research led by communities from domestic funding
- (3) Social contracting or other mechanisms allowing for funding of advocacy led by communities from domestic funding
- (4) From international donors
- (5) Require a certain percentage of government funding for community-led organizations
- (6) No laws enabling access to funding, but community-led organizations are able to access funding under general laws, policies or regulations
- (7) There are no laws, policies or regulations enabling access to funding for community-led organizations
- (8) Other

Source: UNAIDS National Commitments and Policy Instrument, 2017–2021 (<http://lawsandpolicies.unaids.org/>).

Note: Data included in this figure are from 68 countries. Data are not available for 125 countries.

Social contracting can be highly effective. An assessment in Viet Nam found that HIV prevention services delivered across four provinces by contracted community-based organizations had a significantly greater impact than facility-based services, while also costing less (35). They were estimated to have prevented almost double the number of HIV infections (238 vs 124) and averted almost twice as many disability-adjusted life years (1088 vs 577). Similarly, Guyana's national AIDS programme has contracted sex worker-led organizations to provide HIV prevention and testing HIV services to peers. In one pilot project, more than 1000 female sex workers in the Demerara-Mahaica region were provided with condoms and lubricants, HIV information, and mental health and violence screening over the course of six months, and the acceptance rate for HIV testing was close to 100% (36).

But work is needed to make these arrangements work. As with any HIV provider, funding for social contracting has to be dependable, and solid accountability mechanisms should be in place, as research from eastern Europe and Thailand has highlighted (37, 38). Appropriate regulatory frameworks and transparent contracting procedures are essential, as are mechanisms and clear procedures so that public financing reaches the community-led organizations that provide services, conduct monitoring and perform advocacy. Social contracting works best when the funder works in partnership with the community members who are most affected by the interventions, ensuring that the affected community is leading the setting of targets and goals and that it has adequate capacity support to deliver. Through its Technical Support Mechanism, UNAIDS is assisting countries to enter into social contracting arrangements, assess the associated costs and resolve legal issues (such as registration and regulatory compliance). This work is ongoing in 85 countries, such as the costing and integrating of community-led delivery in Thailand's Universal Health Coverage package.

Funding for social contracting has to be dependable and solid accountability mechanisms should be in place.

KEEPING WATCH AND HOLDING DUTY-BEARERS ACCOUNTABLE

It is crucial to quickly identify and fix barriers to HIV and other health-care and support services. However, reliable channels for reporting problems, expressing grievances, documenting and acting on human rights violations, and developing solutions are often absent. Monitoring performed or led by organizations of people living with HIV, networks of key populations or other affected groups can fill that gap and hold duty-bearers accountable (39).

Community-led monitoring entails several phases of work, starting with collecting information at facilities or in communities, analysing the data, advocating for practical or policy changes, and then monitoring implementation of the changes. The most successful models are collaborative, and they engage closely with service providers and decision-makers to advise improvements and monitor the outcomes (40). When integrated with effective advocacy activities, these projects have been shown to increase access to and use of services, reduce waiting times, prompt facility upgrades and improve relationships between communities and health-care providers (41). That, in turn, establishes a basis for more effective services for HIV and other health-care needs.

Successful community-led monitoring can make valuable contributions to achieving equitable access to HIV and health services. In western and central Africa, for instance, community-led treatment observatories have helped increase rates of HIV testing among key populations, reduce drug stock-outs, improve retention in care and expand viral load testing capacity (42–45). In Ghana, Mali and Sierra Leone, they successfully advocated for shifting policies towards a focus on differentiated services for key populations, and they used monitoring data to ensure that the policies were implemented. They were also instrumental in the abandonment of user fees for HIV services and care in public health facilities in Cameroon (see the Cameroon feature story in Chapter 5). Similarly, the Ritshidze monitoring project in South Africa has been using its findings to successfully advocate for changes at numerous poorly performing clinics (43, 46).³

When community scorecards were used in Malawi, the involvement of men and youth in sexual and reproductive health services increased, and the quality of services for pregnant women and recent mothers improved (47).⁴ In Kenya, Peru and Zimbabwe, the introduction of health facility committees at clinics led to a 20% increase in the use of antenatal care services, with low-income residents benefiting the most after user fees were reduced (48).⁵

20%

INCREASE IN THE USE OF ANTENATAL CARE SERVICES IN KENYA, PERU AND ZIMBABWE WITH THE INTRODUCTION OF HEALTH FACILITY COMMITTEES AT CLINICS

3 For more, see: Unequal, unprepared, under threat: why bold action against inequalities is needed to end AIDS, stop COVID-19 and prepare for future pandemics. Geneva: UNAIDS; 2021.

4 Community score cards are used to track the performance of health systems by using indicators that are jointly developed by and agreed upon by community members and health-care providers. The results can then be used as a basis for action plans.

5 Health facility committees document patient grievances and then work with health-care providers to resolve them.



Anastasiia Yeva Domani is the Director of Cohort, an expert on the Working Group of Trans People on HIV and Health in Eastern Europe and Central Asia and a representative of the transgender community on the Ukrainian National Council on HIV/AIDS and Tuberculosis. Kyiv, Ukraine, 30 March 2022.

THE POWERFUL VOICE OF COMMUNITY-LED MONITORING IN UGANDA

Recent experience in Uganda underscores the powerful impact of community-led monitoring. For the last two years, the Coalition for Health Promotion and Social Development (HEPS-Uganda), the International Community of Women Living with HIV East Africa (ICWEA), and Sexual Minorities Uganda (SMUG) have conducted community-led monitoring activities to bring an independent community perspective, with technical support from amfAR and Health GAP to strengthen data collection and improve management, analysis and advocacy capacity.

Stakeholders in the national response attest to the concrete impact that community-led monitoring has had. “[The collaboration between the organizations is] really amazing; [it’s] super great when it comes to advocacy,” said one observer who participated in a Georgetown University evaluation of the monitoring programme. “When they speak, they really speak, and they’re really recognized.”

The community-led monitoring of organizations, which aims to ensure the accountability of PEPFAR and the Ministry of Health, monitors services in more than 300 health facilities across the country, generating quarterly data on programme weaknesses and strengths. Findings from community-led monitoring are then synthesized in an annual report, *The people’s voice Uganda*, which is disseminated broadly and shared with PEPFAR (49).

The community-led monitoring has documented a number of shortcomings in Uganda’s national HIV response and prevention programming. For instance, it found that the country’s lack of success in reaching the national target for PrEP scale-up was due in large measure to the failure to leverage community capacity to promote PrEP. Use of packaging that was unfriendly for key populations and adolescent girls and young women also slowed PrEP uptake. Similarly, monitoring detected that while progress had been made in scaling up HIV prevention programmes for key populations, inadequate support for key population-led service delivery has resulted in persistent service gaps. The community coalition also found that many health-care clinics remain congested, even after the roll-out of multmonth dispensing of antiretroviral therapy.

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Community-led monitoring interview at health clinic. Uganda, 2021.



Other gaps identified by community-led monitoring include low levels of treatment literacy, which highlight the need for treatment literacy programmes that are designed by people living with HIV. Management of HIV–tuberculosis coinfection also remains inadequate: only 61% of people living with HIV report having been screened for tuberculosis symptoms, and most clinics serving people living with HIV lack informational materials regarding tuberculosis prevention. Community health workers are underpaid and frequently experience months-long interruptions in remuneration, while antiretroviral stock-outs are common: one clinic lacked STI treatments for at least six months. Finally, many people in Uganda who are newly diagnosed with HIV are unaware that their participation in index testing is wholly voluntary.

These and other findings were used to develop a series of recommendations to PEPFAR to improve programme reach and outcomes. PEPFAR has substantially expanded its outreach to civil society—including the community-led monitoring coalition and civil society in general—during the development of the annual PEPFAR Country Operational Plan and other PEPFAR processes. This includes biweekly update meetings and an annual scientific summit.

The findings and recommendations from community-led monitoring are having a demonstrable impact on the national HIV response. As one stakeholder noted, “there have been drastic changes in our policies and adoption of good practices following their assessments.” According to another person who participated in the project evaluation, the process has changed “how community-led monitoring is viewed as a tool . . . or a model to increase dialogue between PEPFAR and the communities on service delivery.”



Launch of *The people's voice Uganda*, an annual report that synthesizes findings from community-led monitoring in Uganda, 2021. Credit: International Community of Women Living with HIV in East Africa (ICWEA)



A community-led focus group discussion with mothers in Kyenjojo, Uganda, 2021. Credit: International Community of Women Living with HIV in East Africa (ICWEA)

COMMUNITY ENGAGEMENT IN HIV RESEARCH

Community-led organizations can play vital roles in person-centred, HIV-related research. In Queensland, Australia, research on stigma led by sex worker organizations is being used to campaign for the removal of harmful and discriminatory sex work laws and achieve decriminalization of sex work (50). Drug user-led research documenting the roles, mechanisms, impacts and outcomes of peer involvement in harm reduction services served to push advocacy on the value of meaningfully involving people who use drugs in HIV prevention and treatment responses (51). The People Living with HIV Stigma Index is a long-standing community-led initiative that gathers and analyses data on the stigma and discrimination experienced by people living with HIV in their communities, workplaces and when accessing health and other public services. The results are then used for advocacy to end HIV-related stigma and discrimination (see Rights chapter).

Generally, community-led organizations do not have the resources to conduct research on a large scale (52). A recent review of published literature also found sporadic and very low rates of reporting of community engagement in high-impact HIV intervention studies, and none of the reviewed studies reported on community engagement through all stages of the research process. A shift is needed in how research projects are designed, implemented and reported. One recommendation is to introduce standardized reporting requirements and accountability mechanisms in the research sector to capture community engagement more accurately (53).

A shift is needed in how research projects are designed, implemented and reported.

PUSHING FOR FAIRNESS AND EQUALITY

Community-led advocacy and activism have shaped the HIV response since the earliest days of the pandemic. Organized communities have challenged and often overcome deep stigma, political indifference and institutional inertia. They have mobilized unprecedented financial support for HIV programmes, driven down the prices of HIV medicines and other products, brought human rights to the centre of the global HIV response and held decision-makers to account (54–58).

Community-led advocacy is as important as ever for driving progressive changes in policies and laws at the country level, upholding the human rights of communities that are ostracized and neglected, improving the availability, accessibility, affordability and quality of services, and doing away with stigma and discrimination. This is especially important for highly criminalized populations, such as people who use drugs and sex workers. Empowered communities also help make access to HIV services more equitable by holding health-care providers and bureaucrats accountable for their deeds and omissions.

Community advocacy can be particularly effective in extending the power of community responsibility and support to persons with disabilities who are systematically excluded from HIV services. This can include acknowledging compounded stigma, addressing attitudinal barriers, promoting participatory responses, building political will and generating high-quality evidence to drive the continuing response. For example, persons with disabilities in a multicountry qualitative research study across Kenya, Uganda and the United Republic of Tanzania expressed a desire for increased sensitization activities in the community to address issues related to both HIV and disability. These activities employed messages relevant for persons with and without disabilities, including the importance of sharing responsibility, promoting peer leadership, and increasing the active and visible participation of persons with disabilities in intervention activities (59).

In Côte d'Ivoire, user fees for health services were eliminated after evidence-informed advocacy that was developed from community-led monitoring conducted by the Community Treatment Observatory.

Community-led advocacy can take many forms, from community mobilization and public campaigning to national policy analysis, litigation and accountability procedures. Sex worker-led advocacy in Victoria, Australia, mobilized the support of politicians for a legal reform process that led to the decriminalization of sex work. In British Columbia, Canada, communities of people who use drugs were on the front lines of advocating for a province-wide exemption from federal drug criminalization laws, as well as for access to a safe supply of drugs to mitigate the damage of an overdose crisis (60). Similar efforts recently led to success in decriminalizing sex work in Belgium (see the Belgium feature story in Chapter 3). In Côte d'Ivoire, user fees for health services were eliminated after evidence-informed advocacy that was developed from community-led monitoring conducted by the Community Treatment Observatory (61).

At the grass-roots level, health advocates from community-led organizations educate communities about their rights, document grievances and work with health authorities to bring about improvements (62). In Mozambique, these local advocates instigated speedier service provision for HIV and tuberculosis patients, facility improvements, greater use of mobile clinics and more (63). In Kenya, a male sex worker-led organization has been sensitizing police officers in a bid to reduce harassment and discrimination (64).

Despite all of these successes, the value of community-led advocacy is under-appreciated among many policy-makers and planners. This is reflected in the lack of financial and political support from governments in many countries (Figure 4.2). To perform their roles to the fullest, community-led organizations and networks need resources, including funding, training and capacity-building. In western and central Africa, the Civil Society Institute for HIV and Health is a promising model that strengthens the voice and visibility of civil society organizations and provides them with assistance, including capacity development and resource mobilization support. The Institute sets the basis for increased community and civil society coordination across the region.

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