Stronger together

From health and community systems
to systems for health

Contents

Integrating community responses to HIV in national AIDS plans

A community response to HIV is the collective of community-led activities in response to HIV. These activities include: (1) advocacy, campaigning and participation of civil society in decision-making, monitoring and reporting on progress made in delivering HIV responses; (2) direct participation in service delivery; (3) participatory community-based research; and (4) community financing. (3)

This report is intended as a guide to governments, in particular ministers of health and finance, in making decisions on the integration of community responses to HIV in national AIDS plans, including budget allocations. Resilient systems for health that integrate community responses will be key to ending the AIDS epidemic by 2030.

Reducing HIV incidence and mortality by drawing on the expertise of communities

The world now has the ability to end AIDS as a public health threat by 2030. Doing so, however, will require a Fast-Track approach over the next five years, followed by sustained action until 2030 *(1)*.

Leadership by governments can make ending the AIDS epidemic their legacy, but important decisions must be made soon. One essential step towards ending the epidemic is establishing and maintaining comprehensive and resilient public health systems that include the public and private sectors and community-based services. Community-based services are particularly crucial, because they can support health systems, reach populations left behind, and achieve scale and quality and concrete health outcomes.

Accelerated and more equitable scale-up is necessary

Between 2001 and 2014, globally the number of new HIV infections dropped by 35%, the number of people accessing treatment increased from fewer than 1 million to more than 15 million and the number of AIDS-related deaths declined from 1.7 million to 1.2 million per year. The dramatic successes of the AIDS response over these past 15 years can be attributed to collaboration and partnership between diverse stakeholders, and mobilization of political will and community

involvement *(2)*. Civil society organizations and community networks have provided tireless and courageous work at the local, national and international levels. They were the first responders, and they remain the very core of the response *(3)*.

Despite these successes, there still is a long way to go. Of the 37 million people living with HIV in the world, 19 million do not know that they are HIV-positive, and 22 million people living with HIV are still not accessing antiretroviral therapy (this includes 68% of the children living with HIV). Furthermore, only 66% of people who initiate treatment remain on treatment after three years *(4)*.

An estimated 40–50% of the adults infected with HIV in 2014 are associated with key populations: gay men and other men who have sex with men, sex workers, people who inject drugs, prisoners and transgender people and their partners *(5)*. Many other groups also have been left behind in the AIDS response: children, people with disabilities, ageing populations, indigenous groups, displaced people, migrants and other mobile populations do not have the same access to health services and thus may be at higher risk of HIV.

Community-based responses deliver result

Impactful
The World Bank found that investments in communities have improved knowledge, increased service uptake and decreased HIV incidence *(6, 7)*.

Achieve scale
The AIDS Service Organisation (TASO) has provided services for more than 200 000 people living with HIV.

Deliver quality services
The application of models by Médecins Sans Frontières of community-based antiretroviral

therapy delivery demonstrate improved adherence to treatment regimens, resulting in fewer treatment failures and increased access *(8)*.

Have unique reach
In many settings, community-based responses may be the only way to reach key population.

Flexible
Community-based responses can directly support public health systems or provide stand-alone services.

Cost-effective
World Bank and other studies show the cost effectiveness of community-based responses *(6, 7)*.

What are communities?

The term "communities" covers a wide range of people, groups and organizations. It is a collection of different interests, opinions, capacities, resources and priorities. Communities refers to *(9)*:

- People living with HIV, their groups and networks.
- Community networks and community-based organizations, including those that are run by and/or for key populations.
- Local, national and international nongovernmental organizations (NGOs).
- AIDS service organizations.
- Faith-based organizations.

These groups may focus on HIV or they may focus on related areas. Examples of related areas include sexual and reproductive health, maternal and child health, women's health, human rights, economic development and harm reduction for people who use drugs.

Transforming service delivery: linking health and community systems

Research and experience in many countries where there is strong collaboration between health systems, NGOs and members of civil society shows that there has been a reduction in HIV incidence and mortality and an increase in reaching groups that have been left behind with quality services. This requires transformation and innovation of how HIV prevention and treatment services are delivered.

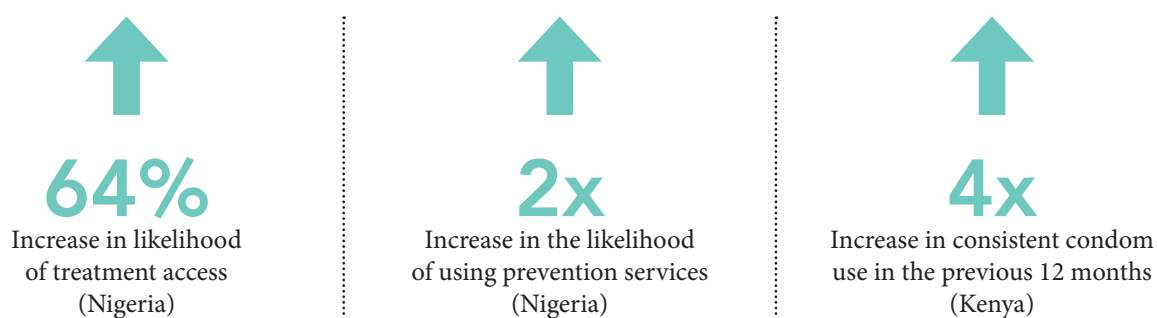## To end the AIDS epidemic a new approach is needed

Ending the AIDS epidemic as a public health threat is defined as a 90% decline in new infections and an 80% decline in AIDS-related deaths by 2030 (compared to 2010). To achieve this, the Fast-Track approach builds on current successes and uses a strategic combination of prevention and treatment programmes that are adapted to country context. Specific targets have been established to guide this Fast-Track approach and indicators to monitor and measure progress (1, 10).

A key component of the Fast-Track approach is the 90–90–90 treatment target, whereby 90% of people living with HIV know their HIV status, 90% of people who know their HIV-positive status are accessing

Figure 1

Community engagement leads to greater access to treatment and prevention

For an increase of one community-based organization per 100 000 people

64%
Increase in likelihood
of treatment access
(Nigeria)

2x
Increase in the likelihood
of using prevention services
(Nigeria)

4x
Increase in consistent condom
use in the previous 12 months
(Kenya)

Source: Rodriguez-Garcia R, Bonnel R, Wilson D, N'Jie N. Investing in communities achieves results: World Bank; 2013.

treatment and 90% of people on treatment have suppressed viral loads. These targets are a radical new way of both saving the lives of people living with HIV and reducing the number of new HIV infections.

Countries are adopting and adapting the 90–90–90 treatment target to their national continuum of care and treatment cascades.

Communities also have a major role in scaling up prevention services. The UNAIDS Strategy for 2016-2021 includes targets to reach 90% of people in key population groups, young people and those in high-prevalence settings, with HIV combination prevention services, and to achieve zero infections among children.

To end the AIDS epidemic, responses to HIV need to achieve treatment targets as well as prevention

targets for reducing new HIV infections, and targets for eliminating discrimination, as outlined in the UNAIDS 2016–2021 Strategy *(10)*.

To reach any target the role of and support to community-based responses must be increased *(9)*.

Recent World Health Organization (WHO) guidance calls for expanding community responses for HIV testing and antiretroviral therapy delivery *(11)*. Implementing the recommendations of these guidelines will require leadership to shift the paradigm in service delivery and bring communities and health systems together.

Changing the paradigm to achieve targets and use resources effectively

Until now, many countries have relied primarily on centralized hospital and clinic facilities for the

delivery of prevention, HIV testing and treatment services. These systems are overburdened in many places, and some population groups find facility-based services difficult to access and/or face stigma and discrimination from health-care professionals.

Novel approaches are needed for reaching people who have been left behind. This can be done through decentralization of health services and by community- and faith-based organizations that complement state-run health systems. New approaches for linking ongoing community-based services to overall systems for health are also required.

Community-based responses are an important component of the wider delivery of HIV services. Community systems strengthening *is* health systems strengthening *(9)*.

Evidence shows that community-led services provide a greater impact in terms of better access and wider coverage than do other types of service provision. For example, evidence from the application of community-based antiretroviral therapy delivery models in Malawi shows increased HIV testing, retention and adherence to treatment regimens *(12)*.

Evidence also shows that community-based service delivery results in improved health outcomes and can lead to rapid scale-up of programmes through demand creation. For example, effective integration and linkages between community and health system activities in the MaxART project in Swaziland has enabled the project to reach more than 80% of eligible people living with HIV with antiretroviral therapy, with more than 85% retention in care *(13)*.

NGOs can deliver quality and stigma-free services, and they can accelerate and maximize how other

As well as encouraging community-led service provision, the Global Fund also encourages applicants to include community system strengthening components in concept notes. Community systems strengthening is an approach that promotes the development of informed, capable and coordinated communities and community-based organizations, groups and structures. (15)

partners deliver services. Similarly, community actions can ensure that services are acceptable, available, affordable and appropriate; communities also can focus on improving the environment for vulnerable populations by addressing stigma, discrimination and potential human rights abuses *(14)*.

HIV has continued to affect members of populations who are marginalized, vulnerable and criminalized. That is why a community-driven response that addresses systemic barriers and institutionalized forms of discrimination is at the heart of a successful response to HIV. Community actions can include legal literacy and legal aid services, training for police officers, facilitation of dialogue between law enforcement and key populations, collaboration with health-care providers to measure discrimination in health-care settings and the

development of evidence-informed responses. Community responses to advance human rights can strengthen health systems and support governments to achieve equity across all sectors.

WHO urges integration of community services into comprehensive systems for health

Community-based models of antiretroviral therapy delivery can benefit people living with HIV and reduce overcrowding in facilities in settings with a high burden of HIV infection.

There is no one-size-fits-all approach to community models of antiretroviral therapy delivery. The context in which they operate is important, and models need to be flexible and responsive to the needs of people living with HIV.

A conducive national policy and regulatory framework around providing antiretroviral medicines is essential to the success of community-based antiretroviral therapy delivery.

"Community-based HIV testing services include a number of approaches—door-to-door/home-based testing and mobile outreach campaigns and testing in workplaces, parks, bars, places of worship and educational establishments. It is an important approach for increasing early diagnosis, reaching first-time testers and people who seldom use clinical services, including men and adolescents in high prevalence settings and people from key populations in all settings … Community-based HIV testing services are now widespread, with 93 of 124 countries reporting in 2014 that their national policies support community-based HIV testing services." *(11)*.

A crucial role in prevention services

Communities also play an essential role in delivering prevention services, including harm reduction, services to key populations, prevention of mother-to-child programmes, and behavioral interventions. For example, since 2006 49 civil society organizations in Malaysia have worked together to roll-out a needle and syringe programme.

Investments to end the epidemic will yield a large pay-off

Since 2011, UNAIDS and partners have promoted a strategic investment approach for the effective funding of the AIDS response. This ensures that programmes use the most effective prevention and treatment initiatives, but also provide maximum return on investment *(16)*.

The strategic investment approach includes both proven initiatives and new approaches, such as starting people on treatment as soon as they are found to be living with HIV and using pre-exposure prophylaxis (PrEP) for selected populations to prevent HIV-negative people from acquiring HIV.

The investment approach has been continually refined since it was first introduced, in part because of the recognition that civil society linkages to community-based services needed support *(17, 18)*.

The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) has incorporated investment cases into its New Funding Model *(19)*. Countries are encouraged to use the investment case approach whenever rigorous examination of the HIV response is required, especially in the development and review of their national strategic plans and investment cases for HIV.

The evidence for the impact of community services

When taken in the aggregate, this portfolio of 17 studies provides a robust body of evidence that supports the tenet that investing in communities achieves results that contribute to ameliorating the effects of and potentially halting the HIV epidemic. (7)
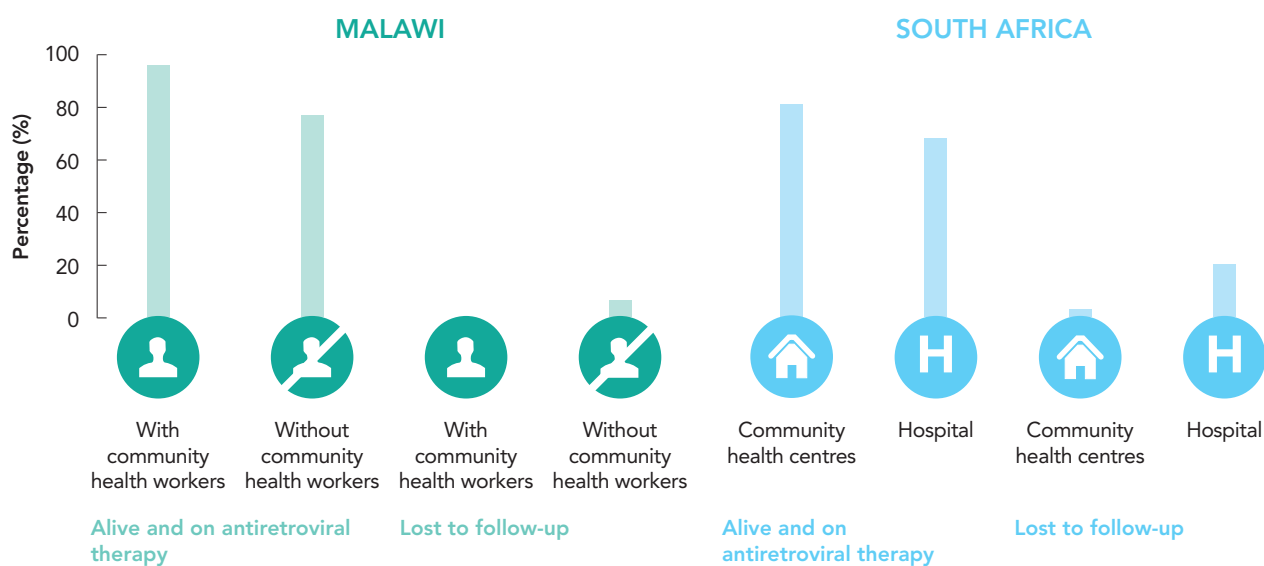
Over the past 15 years, organizations and programmes—including the Global Fund, Médecins Sans Frontières, UNAIDS, the United Nations Development Programme (UNDP), the United States President's Emergency Plan for AIDS Relief (PEPFAR), the World Bank and others—have generated a growing body of evidence that documents the value of communities in responding to the AIDS epidemic.

Numerous studies from around the world document the success of community health workers in enhancing the reach, uptake and quality of HIV services.

Community-based services play varying roles in different settings. For instance, they often support health systems by filling critical gaps, working effectively with marginalized populations, providing supportive services that buttress clinic-based care or extending the reach of health services into the community. There also are many examples of community-based services achieving substantial scale in service delivery on their own *(20)*.

Figure 2

Community-based services achieve results: examples from Malawi and South Africa

MALAWI   SOUTH AFRICA

Percentage (%)

| With community health workers | Without community health workers | With community health workers | Without community health workers | Community health centres | Hospital | Community health centres | Hospital |

Alive and on antiretroviral therapy   Lost to follow-up   Alive and on antiretroviral therapy   Lost to follow-up

Source: Zachariah et al. 2009. Task shifting in HIV/AIDS: opportunities, challenges and proposed actions for sub-Saharan Africa. Transactions of the Royal Society of Tropical Medicine and Hygiene. 2009;103:549–558.

World Bank: community is a "cornerstone" of the response

A World Bank study of HIV service delivery from 2010 to 2012 found that community-based efforts are a "cornerstone" of the response to AIDS, representing substantial value relative to financial investment in the sector *(6)*.

Evidence from countries as diverse as Cambodia, South Africa, the United Republic of Tanzania and Zimbabwe point to the effectiveness and cost-efficiency of community-based HIV services. The study found that community-based organizations can have an impact on the uptake of services, which may increase service effectiveness. In particular, the evaluation found robust evidence of increases in service uptake (such as HIV testing or treatment adherence) in multiple countries *(7)*. It also found that community responses can be effective in responding to the HIV epidemic by improving knowledge, decreasing risk behaviour and increasing access to (and use of) health services. It also can contribute to social transformation and, in two cases, it decreased incidence of sexually transmitted infections *(7)*.

Evidence from Médecins Sans Frontières: models of effective programming

Evidence from the application of models by Médecins Sans Frontières on community-based treatment delivery has demonstrated significant reductions in burdens for patients and the health system, increased retention in care and lowered service provider costs (8).

Three service delivery models demonstrate impact:

- Adherence clubs meet at local health facilities and provide peer support for stable patients on antiretroviral therapy. In South Africa, for instance, adherence clubs showed a remarkable 97% retention in care after 40 months (21). Groups also are being established in other countries.

- Community antiretroviral therapy distribution points provide easier access to medication refills by bringing them closer to where people live. In the Democratic Republic of the Congo, these facilities contributed to 89% retention in care at 12 months follow-up.

- Community antiretroviral therapy groups are formed by (and within) affected communities. In these groups, members take turns collecting medicines at distribution points, providing adherence support and monitoring treatment outcomes for fellow members. At a model community antiretroviral therapy group in Tete, Mozambique, 95% of patients were retained in care after 20 months.

Evidence from AMPATH-Kenya: effective HIV testing and linkage to care

In Kenya, a consortium of partners launched a home-based HIV counselling and testing programme (HBCT) using community health workers. Comparisons with facility-based counselling and testing models showed that the HBCT programme was more effective in reaching pregnant women, identifying serodiscordant couples and linking people living with HIV to treatment programmes (22).

Evidence from faith-based organizations

Faith-based organizations provide a significant proportion of HIV-related health care, with impressive retention rates. HIV-related health care from faith-based organizations includes both institution-based and community-based health service delivery. This is complemented by a wide range of community-based activities, such as HIV prevention education, initiatives to reduce stigma and discrimination, income generation and microcredit programmes, legal aid, and widespread care and support. For example, AIDSRelief—a partnership of faith-based organizations that operated in 10 countries over nine years—reached more than 700 000 people with care services and approximately 400 000 people with antiretroviral therapy (23, 24).

Integrating community responses into sustainable systems for health

The world now needs a paradigm shift away from niche support for community systems to building comprehensive health and social support systems that provide seamless collaboration between public health, communities and the private sector.

The world now needs a paradigm shift away from niche support for community systems to building comprehensive health and social support systems that can provide seamless collaboration between communities and the public and private sector.

Under the Fast-Track approach, community-based service delivery of HIV testing, antiretroviral therapy and support will need to be scaled up, increasing from the 2013 global average of 5% of all service delivery to at least 30% by 2030 (4). Similarly, the proportion of global HIV resources allocated to community mobilization—including civil society advocacy and accountability work—will need to increase threefold to 3% by 2020 (1).

National government authorities in each country—in dialogue with community-based organizations and members of civil society—will need to decide on the percentage of the HIV budget that has to be allocated to support community-based services.

Linking communities and health systems

Governments in countries have been working closely with communities for nearly 40 years—since the very beginning of the HIV epidemic. Ministries of health—working with Global Fund country coordinating mechanisms, national AIDS commissions and councils, and networks of people living with HIV—possess the structures and mechanisms to complementary work with community groups and organizations that will

provide decentralized services tailored to the needs of young people, women and girls, key populations and people living with HIV.

Supporting community-based organizations will have benefits beyond the AIDS response

Supporting community responses and communities will also have sector-wide effects that can affect health and other services. For example, it has been demonstrated that fully engaging and supporting communities can lead to increased success in family planning, immunization coverage and child survival programmes. WHO is currently exploring how to enhance the engagement of NGOs and civil society organizations in the implementation of its new End TB Strategy *(25)*.

Establishing these linkages and capacities also could have an impact on the future implementation of other health programmatic areas, including universal health coverage and noncommunicable diseases. Moreover, supporting community-based organizations will enhance access to social protection and result in greater participation of people in their communities, economies and society at large.

The way forward

Global leaders are now strongly recommending the increased use of community-based services to accelerate progress of the AIDS response. The recently published findings of the UNAIDS and Lancet Commission: Defeating AIDS—Advancing Global Health specifically noted that "strengthening and expansion of the space for community responses to HIV and new ways to meaningfully

involve affected populations in decision making on policy, implementation, and assessment are essential to increase the likelihood that national systems will develop in ways that are responsive to the needs of people living with and at risk of HIV" *(26)*.

Similarly WHO, UNAIDS, the Global Fund, PEPFAR and other major stakeholders are developing strategies and guidelines that specifically define increased support for community-based services.

UNAIDS support to guide financing community responses

Community responses should be seen as a strategic component of an overall health and development system. As such, the next challenge is to identify funding streams for community responses, as part of the overall national and donor approaches to deliver an effective AIDS response to everyone in need.

At the country level, UNAIDS staff are prepared to assist national governments and civil society in developing new thinking about the investment case approach. This will ensure that communities and public health systems become stronger partners in all aspects of the AIDS response.

For further information and additional resources on how to integrate community responses in national plans, please contact the local UNAIDS country office or regional support team or the Community Mobilization Division at UNAIDS headquarters.

Components of community-based service delivery

Community responses to HIV include programmes in advocacy, participation in accountability, delivery of health and other services, research and financing.

While all elements of a comprehensive community response to HIV are essential, below is a brief outline of the different components service delivery can take.

HIV prevention
- Distribution of prevention commodities.
- Delivery of behaviour change programmes.
- Prevention of mother-to-child HIV transmission related-services (antenatal care, linkage to care, adherence support, antiretroviral therapy delivery, home-based care).
- Services for key populations through specifically designed combination prevention services, including harm reduction and peer education.
- Integration of HIV prevention services into sexual and reproductive health and rights services.

Confidential and voluntary HIV testing and counselling
- Testing services at the community level for the general population.

- Testing, counselling and linkage to care services for key populations.

- Peer support for accessing testing (including home testing) and counselling.

HIV treatment
- Antiretroviral therapy and other medicine provision and delivery.

- Treatment education.

- Treatment services for key populations.

- Services addressing coinfections (including tuberculosis and hepatitis C) and co-morbidities.

- Adherence support and retention in care.

Demand creation and service uptake
- Raise awareness of available services.

- Mobilize communities for demand creation.

- Broker access and referrals to services.

Care and support
- Palliative care, including home-based care.

- Psychosocial support.

- Food and nutrition support.

- Care for children and families.

- Economic empowerment and income generation.

Rights and legal services
- Programmes to reduce stigma and discrimination.

- Services to address and end gender-based violence.

- Legal services.

- Legal and human rights literacy.

Task shifting and task sharing
- Community health workers.

Training and sensitization of service providers
- Including health-care personnel, lawmakers and law enforcement officials.

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