

Invest in Communities Now!

And live up to the
globally agreed
targets for the
community
response to HIV



 aidsfonds

Why does Aidsfonds urge to invest in the community response to HIV?



It is undisputed that communities have been at the forefront of the response to HIV since the start of the epidemic more than three decades ago. They deliver services that can reach everyone in need, including key populations, children and adolescent girls and young women; they advocate for fulfillment of the needs and human rights of people living with and affected by HIV; and they are critical to the sustainability of the HIV response. Research and decades of experience demonstrate that in countries where health systems are supported by civil society and communities, remarkable progress can be achieved in both HIV and broader health.¹ Success of reaching the UNAIDS 90-90-90 fast track targets by 2020 and ultimately the target of ending AIDS by 2030 included in the Sustainable Development Goals² depends on community and civil society action. We can only stop the spread of HIV and reverse its impact through a relentless focus on and inclusion of the communities that are most affected.

While we have made significant progress in some areas of the world to decrease new HIV infections, progress is uneven across and within countries. People at greatest risk of HIV and people who are the most marginalized, continue to face huge barriers to accessing quality and affordable HIV prevention, treatment, care and support. According to recent UNAIDS estimates, outside of sub-Saharan Africa, key populations³ and their sexual partners accounted for 80% of new HIV infections in 2016 and even in sub-Saharan Africa, key populations accounted for 25% of new HIV infections.⁴

The last mile

However, despite ample evidence that community responses result in positive health outcomes and improved quality of life for individuals and communities at large⁵, community responses are not sufficiently supported, funded and integrated in national HIV responses and health programmes. This has to change if we ever want to cross that last mile to end AIDS.

WHAT DO WE MEAN WITH 'COMMUNITY RESPONSES TO HIV'?

There is no single definition, term or universally shared understanding when we talk about the community response to HIV. In addition to "community response", many other terms are used to refer to a similar or slightly different idea. For example, we hear people referring to community action, community mobilization, community-based or community-led service delivery, or community empowerment, just to name a few. Also, there are many different types of community responses, from informal to formal and at different levels, from local to national, regional and global.⁶ Volunteers, peer educators, religious leaders, activists, caretakers at the household level, networks of people living with HIV and key populations, networks of key populations and people living with HIV, registered community-based organisations, local NGOs and (in)formally organised groups of women or young people are all part of **"the collective of community-led activities in response to HIV"**.⁷

From the perspective of Aidsfonds, positive change always starts with the people and communities affected. We work directly with people most vulnerable to HIV and most affected by stigma and discrimination. We support community-led and -based organisations and networks at the national, regional and global level through funding and expertise, and providing access to platforms and key stakeholders, guided by the principles of community demand and meaningful involvement.

From global consensus and commitments to implementation?

There is a global consensus that the important work carried out by communities must be supported and governments across the world agree that investments in communities must be increased. Many national HIV/AIDS strategies explicitly recognise the role of communities, and key global donors and technical agencies, such as the Global Fund to Fight AIDS, TB and Malaria, UNAIDS, WHO and PEPFAR, have guidelines and policies promoting meaningful community engagement in the design, delivery and monitoring of HIV programmes.

In addition, the 2016 United Nations Political Declaration on HIV and AIDS actually includes two globally agreed targets for funding the community response to HIV.

THE 2016 POLITICAL DECLARATION ON HIV AND AIDS

The Political Declaration on HIV and AIDS: On the Fast Track to Accelerating the Fight against HIV and to Ending the AIDS Epidemic by 2030, that was adopted by the UN General Assembly on 8 June 2016, states the following:

60 (d). Commit to building people-centered systems for health by strengthening health and social systems, including for populations that epidemiological evidence shows are at higher risk of infection, by expanding community-led service delivery to cover **at least 30 per cent** of all service delivery by 2030.

64 (a). Call for increased and sustained investment in the advocacy and leadership role, involvement and empowerment of people living with, at risk of and affected by HIV, women, children, bearing in mind the roles and responsibilities of parents, young people, especially young women and girls, local leaders, community-based organizations, indigenous communities and civil society more generally, as part of a broader effort to ensure that **at least 6 per cent of all global AIDS resources** are allocated for social enablers such as advocacy, community and political mobilization, community monitoring.

The big question is whether governments are **actually living up to these commitments** and are making sufficient progress towards achieving these targets. While it is difficult to describe precisely how much of the global resources allocated for HIV is going to communities,⁸ it is clear that it is not enough. According to the most recent UNAIDS estimates, investments in community mobilisation (including community-led ART provision and HIV testing and counselling) must triple by 2020 (from 1% to 3.6% of global AIDS resources) if we are ever to end the epidemic.⁹

Evidence shows that nearly all of the funding received by community-based organisations, other than those located in Western Europe or North America, is received from non-domestic sources, such as bilateral donors (United States and European countries mainly), multilateral organizations and private foundations based in the Global North.¹⁰ In addition, this funding is too often channeled through large international and national NGOs and do not sufficiently reach communities, in particular key populations, youth and women's organizations.

Funding under pressure

Overall, we actually see a general **decrease in available funding from international donors, resulting in many community-based organisations facing severe financial challenges.**¹¹ It is especially worrying that these trends are most obvious in countries where donors are "transitioning" away from providing HIV support to low-income and lower-middle income countries. Many countries do not have the political will or the proper mechanisms in place to replace donor money with domestic resources for communities. Most of the available domestic resources go to HIV treatment provision delivered through the public health system. From the 42 of the 72 countries reporting as part of the 2018 UNAIDS Global AIDS Monitoring (GAM) cycle, only 10 countries reported spending 6% or above on social enablers.¹² Only 1% of total global AIDS resources currently go to community-led ART provision and HIV testing and counselling.

Finally, even when funding is available, communities face challenges in accessing these funds. These challenges are for example related to certain conditions of donor funding, such as lack of transparent procedures, complicated application mechanisms, unrealistic reporting requirements, and donor priorities that don't match realities on the ground. Stigma, discrimination, and an overall repressive legal and political environment in a large number of countries pose additional barriers for communities to access funds and provide services to key populations and other marginalized and stigmatized groups.

How Aidsfonds invests in community responses:

Aidsfonds has always played a pioneering role in directly supporting communities that are at the highest risk of HIV infection. Through programmes and funding mechanisms such as PITCH,¹³ Bridging the Gaps,¹⁴ GUSO,¹⁵ TAFU,¹⁶ MaxART,¹⁷ and the Robbert Carr Fund,¹⁸ Aidsfonds invests in long lasting change and the sustainability of the HIV response through supporting community-based service delivery, linking community systems with health systems, community led human rights advocacy, capacity-building, linking and learning of community-based organisations and national, regional and global community-led organisations and enabling them to take risks and initiate new and innovative things.

HOW MUCH DOES AIDSFONDS INVEST IN COMMUNITY RESPONSES?

Of a total budget of €50,4 million in 2018, €38,5 will be spent on community responses, which equals 76% of the budget.

Investing in key populations

HIV programming is most effective when key populations are involved at all levels of decision-making, as confirmed by the World Health Organization in its 'Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations'. That's why key population communities are in the driver's seat of the Bridging the Gaps programme. They are involved at all levels, from governance to implementation.



In Kyrgyzstan, sex worker organisation Tais Plus responds to the lack of coverage of sex workers by HIV prevention services provided by the government by combining traditional and innovative approaches to provide quality HIV and STI services and testing to sex workers. The organisation's mobile clinic goes to places agreed with and convenient for sex

workers, based on where and when it is safe in the increasingly hostile work environment with increased emergence of police violence. In addition to their mobile health clinic, Aidsfonds partner Tais Plus also runs a traditional clinic, and during 2017, the clinics were visited 1,284 times by 857 sex workers. If an infection is found after testing at the mobile clinic, a social worker and medical staff support follow up and treatment support in the traditional clinic. Tais Plus also trained health service providers in the NGO sector to provide quality and non-discriminatory services to sex workers.

Mobilizing communities in Swaziland

Another example is the Maximizing ART for Better Health and Zero New HIV Infections (*MaxART*) programme. With input of the Swaziland Network of People living with HIV/AIDS, community based organisations, and the Ministry of Health, *MaxART* was designed to address the remaining barriers to HIV testing, care and treatment in the national response. The programme supported a number of interventions aimed to dramatically scale up HIV-testing, improve access to treatment, and reduce loss-to-follow-up to prepare the ground to implement early access to ART for all, regardless of CD4-count. Within the multidisciplinary *MaxART* team, community-based and community-led organisations have mobilized communities, empowered community leaders and community health workers and supported human rights monitoring and advocacy.



The Robert Carr Fund for civil society

The Fund is the first international pooled funding mechanism which specifically aims to strengthen global and regional HIV civil society and community networks around the world. The Robert Carr Fund invests in global and regional civil society networks addressing critical factors in protecting the rights of inadequately served populations (ISPs); scaling up access to HIV prevention, treatment, care and support; and assuring that resources are mobilized and utilized appropriately to respond to the global HIV epidemic. The ultimate goal of the Fund is to contribute to improved health, inclusion and social wellbeing for ISPs. To reach this goal, the Robert Carr Fund provides core funding to strengthen the institutional and advocacy capacity of regional and global ISP and civil society networks and/or their consortia. The linkages across and within the collective of the Robert Carr Fund grantees – who are often consortia of global and regional networks – hold the potential for fostering, catalyzing and facilitating collaborations, learning and exchange of best practices and ideas needed to unite allies and build a movement and capacity towards sustainability of the HIV response. As technical, intellectual and emotional capital of communities is pooled through these networks for greater impact, so too are funding partners' financial resources pooled through the Fund. Aidsfonds is the Fund Management Agent of the Robert Carr Fund.

Results of our investment in community responses

With the Bridging the Gaps programme, Aidsfonds and its partners already reached **1,756,096 people** with HIV services, trained **9,835 healthcare workers** and **6,401 law enforcement officials**. **393 general health facilities** are offering services to key populations and in **all 15 countries**, key populations engage with the government on national strategies and policies that affect their health and rights.

25% of the networks supported by the Robert Carr Fund influenced changes in legal and policy environments to better respect and protect human rights of ISPs – including gender identity laws adopted or tabled for consideration in Armenia, El Salvador and two Mexican states; and significant revisions to a potentially harmful HIV law in Malawi. **33% of the networks** supported by the Robert Carr Fund influenced changes in access to or quality of services for ISPs – including increased access to routine viral load testing in parts of Latin America, increased access to harm reduction services in Lebanon, Jordan and Egypt; and reduction of stigma from service providers for transgender women in Latin America and migrants in Asia.

In *MaxART* phase 1 (2011-2014) multiple community interventions were implemented. For example, **98 traditional leaders and 12 political leaders** were trained to become actively engaged in stimulating the HIV response within their communities. Through Aidsfonds partner SafAIDS, 16 local Community based organisations working with Rural Health Motivators and Community Based Volunteers organized **269 Demand Creating Community Dialogues** in 220 communities. Community and health system interventions were continuously adjusted based on the findings of research, human rights monitoring and experiences of people living with HIV. By the end of the first phase in 2014, **Swaziland achieved the highest annual HIV testing rate ever** (more than 250,000 people being tested annually for HIV—up from just over 120,000 in 2011), near nationwide access to antiretroviral therapy (ART), and a decline in the number of patients that were lost to follow-up from 22% to 15%. *MaxART* was an important intervention contributing to this success.

End AIDS: Invest in communities now!

Call to action

How do we ensure donors and national governments alike live up to their commitments to increase investment in community responses and achieve the global targets on community-led service delivery and social enablers?

- 1.** Donors and governments **need to make it more transparent** how they spend their HIV resources, in particular the share that is labeled for the community response. This includes the need for a significant increase in the number of countries reporting in the UNAIDS GAM system, and a better quality of donor databases and country reports, including detailed disaggregation of how HIV funding is allocated in each country.
- 2.** Donors and governments should **increase their investments in community-based and -led responses at local, national, regional and global levels.** This includes removing key barriers at the country level which prohibit community-based and community-led organizations to access funds and deliver critical HIV services, in particular to key populations and adolescent girls and young women.
- 3.** Donors should adequately invest in community responses in countries with a high burden of HIV, as well as in countries with an emerging or growing epidemic. This includes continued investment in “transition countries” if governments of these countries do not support communities, and ensuring lifesaving services are not interrupted.

- 1 Call to Action: the central role of community action in supporting the achievement of the Sustainable Development Goals, prepared by Stop AIDS Alliance with support from partners of the Free Space Process and PITCH, July 2017
- 2 See <https://www.un.org/sustainabledevelopment/sustainable-development-goals>
- 3 UNAIDS 2016. Key populations include men who have sex with men, people who use drugs, sex workers, transgender people, prisoners and other incarcerated people.
- 4 See www.unaids.org/en/topic/key-populations
- 5 See Communities Deliver: the critical role of communities in reaching global targets to end the AIDS epidemic, UNAIDS and Stop AIDS Alliance, 2015
- 6 According to the NGO Report to the 39th UNAIDS PCB, the most informal types of responses are at the level of households, families, and neighbourhoods. Other types include community leadership (such as political and religious leaders) and community initiatives (such as mutual care and support groups) that do not have any official status or formal recognition from governments. Formal responses include those that are “owned” or driven by officially recognized entities such as registered community-based organisations, local NGOs, networks of key populations, and social movement and rights-based organisations.
- 7 This definition is used in the report Communities Deliver: the critical role of communities in reaching global targets to end the AIDS epidemic, UNAIDS and Stop AIDS Alliance, 2015
- 8 According to the report An unlikely ending: ending AIDS by 2030 without sustainable funding for the community-led response, NGO report to the 39th UNAIDS Programme Coordinating Board (PCB), November 2016, “information on the direct and indirect funding for communities is not readily available from the donors’ centralized database as donors do not routinely disaggregate funding by implementing partners (e.g. government, civil society, international organisations) (paragraph 22)
- 9 Call to Action: the central role of community action in supporting the achievement of the Sustainable Development Goals
- 10 NGO Report to the 39th UNAIDS PCB, November 2016
- 11 In the survey mentioned in the previous footnote, 53% of the community respondents reported losing access to Global Fund support, 26% reported losing funds from the UN system, 24% reported losing investment from private donors, and 12% reported losing bilateral funding.
- 12 Report on feasible ways to monitor the achievement of the financial-related targets of the 2016 Political Declaration, 42nd UNAIDS PCB
- 13 PITCH, the Partnership to Inspire, Transform and Connect the HIV response is a 5 year advocacy capacity building programme (2015-2020), funded by the Dutch Ministry of Foreign Affairs and implemented by Aidsfonds and the International HIV/AIDS Alliance in Indonesia, Ukraine, Myanmar, Vietnam, Kenya, Uganda, Nigeria, Mozambique and Zimbabwe.
- 14 Bridging the Gaps is a strategic partnership with and funded by the Dutch Ministry of Foreign Affairs on health and rights for LGBT people, sex workers, and people who use drugs, implemented by Aidsfonds and a number of partners.
- 15 GUSO (Get up, Speak out) is developed and implemented by a consortium of partner organisations under the leadership of Rutgers and funded by the Dutch Ministry of Foreign Affairs. Other partners are Simavi, Dance4life, IPPF, and CHOICE.
- 16 Towards an AIDS-free generation in Uganda.
- 17 MaxART, Maximising ART for better health and zero new infections (2011-2017) initiated by Aidsfonds in collaboration with the Clinton Health Access Initiative and led by the Swaziland Ministry of Health, aimed at improving the lives of people living with HIV and prevent new HIV infections in Swaziland through regular testing, access to early ART and lifelong retention in care and treatment.
- 18 Aidsfonds is the Fund Management Agent for the Robert Carr Network Fund, which supports community networks in combatting AIDS and to advance human rights advocacy around the globe. It is funded by NORAD, UKAID, the Bill and Melinda Gates Foundation, PEPFAR and the Dutch Ministry of Foreign Affairs.