



UNAIDS AND STOP AIDS ALLIANCE 2015 | REFERENCE

COMMUNITIES DELIVER

THE CRITICAL ROLE OF COMMUNITIES IN REACHING GLOBAL TARGETS
TO END THE AIDS EPIDEMIC



CONTENTS

Executive summary	4
Introduction and overview	6
The impact of community responses to HIV	10
Community responses to HIV: four main components	17
Advocacy, campaigning and participation in accountability	19
Illustrative examples of community-based advocacy, campaigning and participation in accountability	20
Community-based service delivery	27
HIV and other health service delivery	29
Service provision for key populations	39
Service provision by faith-based organizations	45
Services for orphans and other children made vulnerable due to AIDS	48
Services to address gender-based violence and inequalities	51
Services to address self-stigma among people living with HIV	55
Community-based research	57
Illustrative examples of community-based research	59
Community-based financing	65
Illustrative examples of community-based financing	66
Recommendations for future directions in community-based HIV responses	71
Investing in community responses	73
References	74
Abbreviations	78

EXECUTIVE SUMMARY

Communities were the first responders to HIV three decades ago, and they remain essential in advocating for a robust response to the epidemic, delivering services that can reach everyone in need and tackling HIV-related stigma and discrimination. Working alongside public health and other systems, community responses are critical to the success and sustainability of the global response to HIV.

There is now wide recognition that community responses must play an increasing role in addressing the epidemic in the years ahead. The Strategic Investment Framework, published in 2011, identifies community responses as a “critical enabler” of service delivery. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has estimated that to achieve bold HIV treatment and prevention targets set in 2014, investments in community mobilization and services must increase more than threefold between 2015 and 2020 (1).

Much of the critically important work in making progress in the response to HIV and implementing a Fast-Track approach that lies ahead—including broadening the reach of services, supporting retention in care, increasing demand, monitoring quality, advancing human rights and combatting stigma and discrimination—can only be achieved with a strong community voice and presence.

This report draws on multiple sources to document the many ways in which communities are advancing the response to AIDS, and the evidence for the effectiveness of these responses. Core areas of community-based activities include advocacy, service provision, community-based research and financing; each of these areas is illustrated by examples of community-based actions.

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 and represent substantial value relative to financial investment in the sector (2). Studies 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. 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. They often support public health systems by filling critical gaps: they work effectively with marginalized populations, provide supportive services that buttress clinic-based care or extend the reach of health services into the community. There are also many examples of community-based services achieving substantial scale in service delivery on their own. For example, in Uganda, The AIDS Support Organization (TASO) has reached over 200 000 people with HIV treatment and other services (3).

Like every sector involved in the response to the AIDS epidemic, the role of the community is evolving with developments in research, and with changing trends in funding and the social and political context. While the core functions of the community response remain essential, community systems are being challenged to adapt to changing service models and demands from funders. Too many once-vibrant community-based organizations (CBOs) are now struggling with severe financial challenges, and many have already closed their doors.

New opportunities for supporting community responses are emerging through the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and other funders, but there remains a critical need for strategic investment in the community sector donors and implementing country governments. Beyond increased funding for essential services, greater investments in community systems strengthening (CSS) are needed to establish stable and sustainable responses for the years ahead.

Whether they are advocates, providers, clients, participants in research or researchers themselves, community members remain the foundation of the AIDS response. The goal of ending the AIDS epidemic as a public health threat by 2030 depends on transformed health systems that include significantly scaled-up community responses and the funding and sustained support to make these responses possible.

INTRODUCTION AND OVERVIEW

Communities have been at the forefront of responses to HIV since the start of the epidemic. Over 30 years of action have resulted in substantial achievement—communities have played a crucial role in reaching people with treatment, prevention, care and support, advancing human rights and reducing gender inequalities.

Successes and remaining challenges in the global response

The AIDS epidemic is being addressed successfully in many countries. We are now seeing declines in new HIV infection rates and AIDS-related deaths, and people living with HIV are living longer and have better quality of life. Community mobilization has been key to achieving this substantial scale-up and improvement.

Yet many challenges remain. While there have been significant successes during more than 30 years of action, epidemics are increasing in some countries, and there are substantial disparities in prevalence, scale of national responses and access among different population groups. Furthermore, human rights violations and harmful gender norms continue to limit the effectiveness of responses to HIV.

Greater access to treatment, prevention, care and support is not available or accessible to all population groups, and it has not reached the same levels of scale-up in all countries and regions (4). Also, not all services have been equally scaled up. For example, harm reduction programmes remain unavailable in some countries where unsafe injecting practices play a key role in the local HIV epidemic: only 80 of the 158 countries reporting injecting drug use indicate that they offer opioid substitution therapy (5). As of March 2015, only 15 million people were accessing antiretroviral therapy (ART), while the estimated number of people living with HIV by the end of 2015 was 36.9 million.

The quality, scale and availability of sustainable funding for services are not the only remaining challenges. For example, gender inequalities faced by young women in sub-Saharan Africa—and stigma and discrimination faced by people living with HIV in other key populations¹ globally—remain key in denying access to or deterring people from seeking vital services. Accessibility of available services is particularly difficult when faced with discrimination within the community or from those who provide services. In addition, legal and sociopolitical environments such as punitive laws² or abusive law enforcement continue to obstruct effective access to and delivery of services that leave no one behind.

¹ Key populations, or key populations at higher risk, are groups of people who are more likely to be exposed to HIV or to transmit it, and whose engagement is critical to a successful HIV response. In all countries, key populations include people living with HIV. In most settings, men who have sex with men, transgender people, people who inject drugs and sex workers and their clients are at higher risk of exposure to HIV than other groups. However, each country should define the specific populations that are key to their epidemic and response, based on the epidemiological and social context.

² Laws providing for overly broad criminalization of HIV non-disclosure, exposure and transmission, or punitive laws related to key populations (particularly men who have sex with men, sex workers and people who use drugs).

To end the AIDS epidemic community responses to HIV must be integral to the global response

Social and biomedical advances have yielded remarkable results: we have better, improved tools for screening, diagnostics and treatment monitoring. There also are more and better prevention options, including clarity and guidance on the strategic use of antiretroviral therapy. We have the necessary tools and we know what works and what doesn't. We know that criminalizing, excluding, violating rights and discriminating against communities or groups of individuals does not help the HIV response; in fact it hinders it. We also know that responses to HIV can be entry points for responding to broader issues of health and development—for example, health systems strengthening (HSS), addressing human rights, providing sexual and reproductive health and rights, challenging social norms regarding gender equality and changing societal attitudes towards marginalized population groups.

Overcoming the challenges to achieve full scale of key services that reach everyone and leave no one behind can only be realized with resourced community responses to HIV that are integrated into national and global plans and actions.

To end the AIDS epidemic by 2030, we need transformative action that identifies and scales up responses that:

- are rights-based, of good quality and equitable;
- transform prohibitive legal, political and societal environments into enabling contexts that empower individuals and communities, do not discriminate and leave no one behind;
- strengthen health and community systems to deliver a sustainable response to HIV and other health and social justice and development issues; and
- prove to be evidence-informed, effective and appropriate to the communities they aim to reach.

We know that community responses to HIV are the cornerstone of effective, equitable and sustainable programmes. They mobilize communities to demand services and exercise their rights; they also deliver services, support health systems and reach those most vulnerable to HIV where state facilities cannot. Moreover, communities act as barometers in their watchdog role, tracking what works and what does not with a local, contextualized perspective. In other words, communities give a voice to those who need services, provide feedback as to whether policies and programmes are working and suggest how they can be improved.

It is essential that community responses are integrated into the overall response—linking effectively with health-care systems and embedding community activities into a wider context—to transform the AIDS response in the post-2015 development agenda.

We need to learn from what works in the community responses to HIV and scale them up. We also need to resource these activities and create a long-term strategy for sustaining them.

Purpose of this report

This report synthesizes published findings to date that demonstrate that community-based responses to AIDS:

- generate positive health and development outcomes—in some cases more positive outcomes than those responses delivered by states or other facilities. In many contexts, community-based responses have also been shown to be key in strengthening health systems;
- work to safeguard the rights of those they reach and serve;

- mobilize communities, including marginalized, socially excluded and criminalized population groups—groups that often are not the primary focus of government or private sector provision, or who may be poorly reached;
- improve the quality, equity and scale of national responses through their participation in accountability and coordination mechanisms;
- mobilize communities and service providers, building on a sense of shared responsibility and solidarity around issues of health and social justice;
- bring programmes to scale when there are sufficient investments both in the programmes themselves and the capacity to build and sustain them; and
- pioneer innovative approaches that build ownership and leadership in communities.

Governments, civil society organizations, development agencies and other stakeholders can use this report to:

- support the better inclusion of community responses in national planning and funding, including Concept Notes to the New Funding Model of the Global Fund;
- make the investment case that community responses to HIV must be well-resourced and understood as being core to domestic and international funding;
- make the case that transformative community responses are needed to end the AIDS epidemic by 2030.

This report is the first in a series on community-based responses planned by UNAIDS and its partners. The series will include:

- practical tools, such as mapping of community-based service delivery;
- thematic reports on good policy and practice, such as community-based HIV testing and counselling, service delivery by and for key populations, and successful community advocacy strategies;
- synthesis of evidence and lessons learned, such as trends in investments for civil society at the national level through national plans and Global Fund grants.

Limitations of this report

This report describes the elements and impact of community responses to HIV, illustrated through some examples of community action. It is not intended to be an exhaustive compilation of all community responses, but simply to articulate briefly the main components of the community response through some real life examples.

This report distinguishes between: (1) community (system) responses, (2) community systems, and (3) community systems strengthening (CSS). UNAIDS recognizes that CSS merits further work, and it will collaborate with partners in the future to address this need for guidance and documentation.

DEFINITIONS

Community response

In the context of HIV, a community response 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.

Community systems

There is no singular understanding of community systems. In this report, community systems are defined as community-led structures and mechanisms used by communities that enable community members and CBOs and groups to interact, coordinate and deliver their responses to the challenges and needs affecting their communities. Community systems be from informal and small in scale, or they can be extensive networks of organizations. Community systems should not exist in isolation; rather they should serve as a critical component of the overall system that aims to protect and promote health and human rights. These broader systems include government or public health systems (such as, public health facilities, regulatory and governance bodies, and state-employed health-care professionals).

Community systems strengthening

CSS promotes the development of informed, capable and coordinated communities and CBOs, groups and structures. In other words, it is the capacity building needed to ensure that “community responses” can be delivered through “community systems”. It should reach a broad range of community actors and enable them to contribute to the long-term sustainability of health and other interventions at the community level, including the creation of an enabling and responsive environment in which these contributions can be effective.

THE IMPACT OF COMMUNITY RESPONSES TO HIV

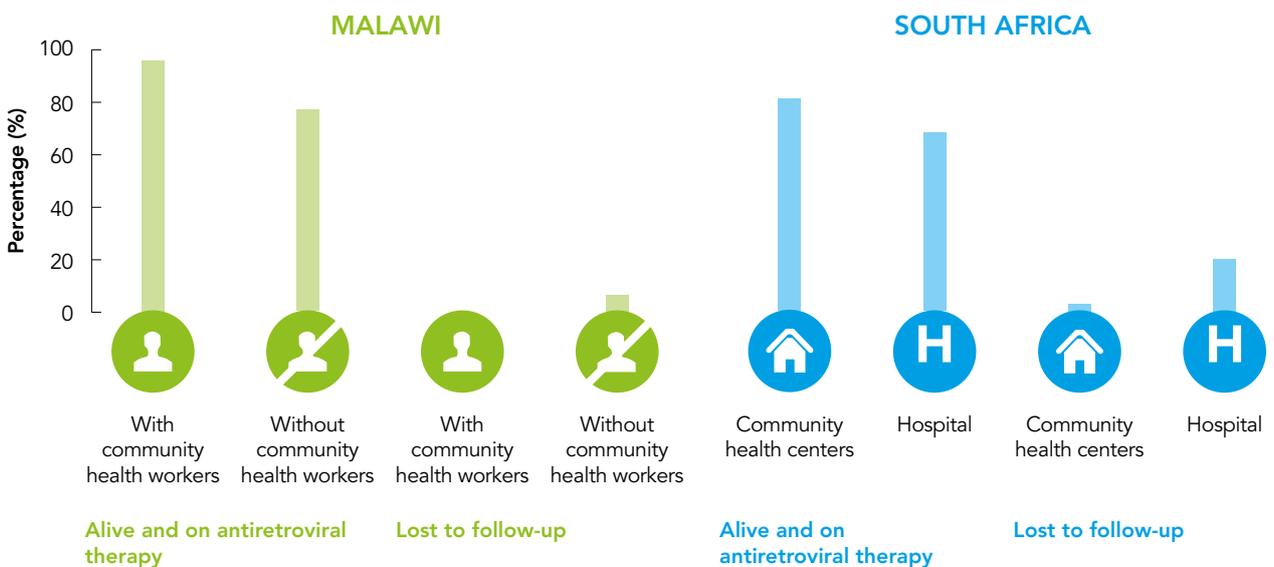
Evidence for the effectiveness of community responses

Community action translates into results. It can achieve improved health outcomes, mobilize demand for services, support health systems strengthening, mobilize political leadership, change social attitudes and norms, and create an enabling environment that promotes equal access (Figures 1 and 2).

In the response to HIV, like any other response to a development or health challenge, the evidence base is critical. One challenge often stated is that community responses and community mobilization are not easily measurable (6, 7). This is especially challenging now that there is such a strong emphasis on having evidence of effectiveness in order to prioritize limited resources and scale-up community responses with the greatest impact (8, 2). However, this report and numerous other recent research papers highlight how, despite the fact that there is always a need for further evidence, we now have enough evidence to make the investment case for scaling up and speeding up community responses to HIV. Community responses are effective.

The World Bank conducted a multi-study evaluation of community responses to HIV from 2010 to 2012 in order to provide robust evidence of community-level results (2). The study involved communities in research, engaged national researchers and AIDS authorities in demonstrating results, and worked closely with civil society to ensure that findings were relevant. The main finding from the study was that the community response is a cornerstone of the response to HIV and that it creates substantial value relative to the initial investment.

Figure 1. Community-based services achieve results, examples from Malawi and South Africa



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

Community responses work with and complement public systems

Community responses to HIV do not exist in isolation from health and social protection systems. Community-based interventions can simultaneously provide the support that community members need and linking them to the health system. The interventions can work in synergy with the health system to meet demand, especially where the health system does not have capacity (or is unable) to reach populations. These linkages augment community services within the health system, and they provide a social, protective and empowering role, ensuring that a community's rights to health are advanced.

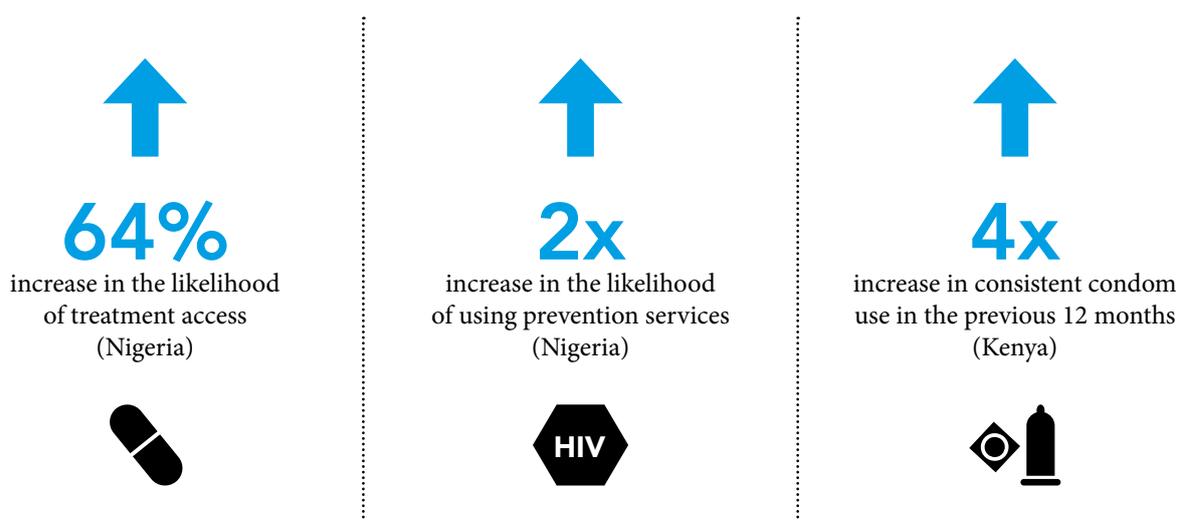
Community health-care workers work both within and with health-care systems. Task-shifting and task-sharing, for example, are now a fundamental part of HIV testing and treatment programmes, involving communities in treatment literacy, adherence and even distribution programmes. Community health workers provide services to their communities and act as the link between health systems and communities on health issues such as HIV, sexual and reproductive health and rights, and many others.

Evidence from a recent review documenting the role of community health workers demonstrated the wide range of services provided (9). These included patient support (counselling, home-based care, health education, adherence and livelihood support) and health services (screening, referrals and surveillance). Evidence shows that community health workers enhance the reach, uptake and quality of HIV services, as well as the dignity, quality of life and retention in care of people living with HIV. The presence of community health workers in clinics was reported to reduce waiting times, streamline patient flow and workload. Community health workers can be employed by the state health service or by nongovernmental organizations (NGOs), and they provide critical linkages between state-run health systems and community responses.

Evidence also shows that integrating legal literacy and legal services into health care is an effective strategy for empowering vulnerable population groups and addressing underlying determinants of health. Legal empowerment programmes have the potential to enhance access to health services, promote accountability, reduce stigma and discrimination, and contribute to altering unjust structures and systems (10-12).

Figure 2. **Community engagement leads to greater access to treatment and prevention**

(Increase for each community-based organization created per 100 000 people, Nigeria and Kenya)



Source: Rodriguez-Garcia R, Bonnel R, Wilson D, N'Jie N. Investing in communities achieves results: findings from an evaluation of community responses to HIV and AIDS. Washington DC: World Bank; 2013.

Community responses to HIV promote human rights, equity and quality of services

HIV is not just a health issue. HIV touches on all aspects of life—it is a social, cultural, political, economic, rights, health and development issue. The synergy between the HIV response and social development is crucial, and community responses to HIV encompass both issues. Community actions are fundamental to combatting stigma, discrimination and raising awareness of HIV and human rights, and for delivering programmes for prevention, treatment, care and support.

Community responses achieve scale

Community responses span the range of interventions that are needed to respond to HIV, and they can be credited with saving millions of lives worldwide. They can achieve scale by reaching a significant proportion of the communities they serve and by providing a considerable number of services available within a country (Table 1).

HIV has disproportionately affected those who are most marginalized, vulnerable and (often) criminalized. The centrality of the community-driven response and efforts to address systemic barriers and institutionalized forms of discrimination are at the heart of the extraordinary nature of the response to HIV. Community responses have demonstrated how they can reach those living at the margins of society, including the criminalized, the oppressed and the stateless.

Organic and semi-formal community responses are often better attuned to the needs of diverse communities; by their very nature and composition, these responses are carried out by people who have an intrinsic understanding of community experiences and needs. This allows for a focus on a range of vulnerabilities experienced by communities; ranging from very practical concerns (such as legal aid and welfare support), to advocacy for human rights (including sexual and reproductive health and rights, legal and policy reform), and addressing the longer-term concerns of impact mitigation.

Many people affected by HIV and other key affected populations are vulnerable to violence and punitive legal environments. Communities provide consultation and representation services, legal aid services and run rights literacy programmes for people living with HIV and key populations to address discrimination and infringement of their human rights. In many low and middle-income countries where there is no pro bono provision of legal aid by public institutions, these community-based services are often the only legal services available to key populations. Engaging communities in the capacity strengthening of law makers, law enforcement and health-care personnel to redress human rights violations have proven to be effective (13–15).

Community responses lead to better policies for greater treatment access

The early phases of AIDS activism were marked by campaigns to develop antiretroviral therapy and Fast-Track approval for effective therapies. This energy translated into the successful mobilization of global, regional and national community organizations in a coordinated push for scaling up access to treatments and reducing prices, including pressing for the use of flexibility within the World Trade Organization (WTO) agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS), which helped to make HIV medications affordable in developing countries. The success of community treatment advocacy had a huge impact, including accelerating the availability of generic formulations of HIV medicines, which enhanced competition within the pharmaceutical sector and reduced the cost of treatment in relation to branded medication.

Table 1. Examples of community responses to HIV that reach significant proportion of the communities they serve

<p>THE CHURCHES HEALTH ASSOCIATION OF ZAMBIA (CHAZ), ZAMBIA</p>	<ul style="list-style-type: none"> ■ The second largest provider of health services in the country. ■ Provides more than 50% of health services in rural areas. ■ Over 86 000 people living with HIV provided with antiretroviral therapy between 2005 and 2014.
<p>KHANA, CAMBODIA</p>	<ul style="list-style-type: none"> ■ In 2013, 16 775 adults and children living with HIV reached. ■ Identified 589 pregnant women living with HIV, 93% of whom were supported to access services to prevent mother-to-child transmission in 2012 and 2013. ■ Identified 1753 sero-discordant couples and provided them with a package of services in 2012 and 2013. ■ Only six infants were born with HIV during that period, among pregnant women living with HIV receiving services to prevent mother-to-child transmission (< 1%).
<p>MOTHERS2MOTHERS, SOUTH AFRICA</p>	<ul style="list-style-type: none"> ■ Reached 1.2 million women living with HIV in nine countries. ■ Frequently implementing the model through existing community-based and faith-based organizations. ■ Trains, empowers and employs thousands of mothers living with HIV as Mentor Mothers. ■ Mentor Mothers advise and support pregnant women living with HIV and accompany them through the process of accessing prevention of mother-to-child transmission services.
<p>THE AIDS SUPPORT ORGANIZATION (TASO), UGANDA</p>	<ul style="list-style-type: none"> ■ Direct support to over 200 000 people from key affected populations, in particular people living with HIV, since its inception (3, 16). ■ The largest community-based, NGO providing HIV services in Africa. ■ Over 23 000 clients provided with antiretroviral therapy since June 2004. ■ A thousand children provided with antiretroviral therapy since June 2004. ■ Demonstrates the important role of communities in health systems, from education and awareness to direct service provision, and monitoring and holding governments accountable (17).
<p>TOPS, MYANMAR</p>	<ul style="list-style-type: none"> ■ Provided clinical services to 10 900 sex workers and 7100 gay and other men who have sex with men in 2011.

Community responses ensure that limited resource allocations reach those in need

Community systems ensure that funds reach grass-roots programmes through on-granting to smaller effective organizations and provide back up and support to expand capacity (Figure 3). They also hold governments, donors and others to account for their financial promises and commitments to communities. The resourcefulness of communities in obtaining funding has often translated into the ability to stretch modest budgets to fulfil a range of needs that not only provides value for money, but also added value for donors and governments.

Community responses provide the evidence base

Within the HIV response, communities have moved from being the objects of research to being the researchers themselves. Community-driven evidence has informed—and continues to inform—the development of effective policies and services. Peer-led studies ensure that results reflect actual experience that enhances the quality of data.

Figure 3. **CBOs mobilize more resources when there is a higher concentration of CBOs per 100 000 inhabitants**



Source: Rodriguez-Garcia R, Bonnel R, Wilson D, N'Jie N. Investing in communities achieves results: findings from an evaluation of community responses to HIV and AIDS. Washington DC: World Bank; 2013.



A POP-UP HIV TESTING CLINIC IN CHISAMBA, ZAMBIA



COMMUNITY-BASED HARM REDUCTION PROJECT IN UKRAINE

COMMUNITY RESPONSES TO HIV: FOUR MAIN COMPONENTS

There are many ways to categorize community-based responses. After a review of categorization methods used by other organizations, UNAIDS chose to use the categories shown in Table 2 (below). This choice does not imply that there is only one typology, but offers one simple way among many of categorizing the comprehensive and multisectoral community-based responses to HIV.

In the following pages, each component is individually described in greater detail. Examples of current or recent community responses follow each description to illustrate the type of community actions that can fall under each component.

Table 2. **Four components of community responses to HIV**





ADVOCATES IN BOTSWANA RAISING AWARENESS OF TUBERCULOSIS ISSUES

COMPONENT 1: ADVOCACY, CAMPAIGNING AND PARTICIPATION IN ACCOUNTABILITY

The most successful advocacy is that which originates in and is driven by those communities that are most affected.

Community-based advocacy, campaigning and participation in accountability have changed the landscape of the AIDS response worldwide, and they continue to deliver key changes that enhance the well-being of individuals and their communities. They demonstrate examples of the innovative efforts of communities to negotiate the complex social and political landscapes that define the AIDS response.

Community-based advocacy and campaigning have: mobilized millions of individuals; influenced policies and laws; improved access to treatment, care, support, HIV testing and other services; challenged stigma and addressed discrimination; enhanced prevention interventions; and created more enabling environments. These changes have in turn supported the achievement of better health outcomes and human rights.

Attention to context is key to successful advocacy, campaigning and participation in accountability, as is a clear focus on the change that is intended and an understanding of what steps are necessary to achieve the desired outcome. Also key to advocacy success is founding actions and leveraging the expertise and knowledge of people in communities most affected.

TABLE 3. COMMUNITY-BASED ADVOCACY, CAMPAIGNING AND PARTICIPATION IN ACCOUNTABILITY

Participation in decision-making and monitoring mechanisms

- Resource tracking and monitoring.
- Meaningful engagement in National AIDS Councils, Country Coordinating Mechanisms, and other monitoring and coordination bodies.
- Participation in the design, implementation, monitoring and evaluation of policies and programmes, including enforcement and impact of laws.
- Securing accountability and fulfilling a watchdog role.

Advocacy and campaigning on HIV-specific issues

- Advocacy and campaigning to improve access to services, reduce cost of treatment, overturning restrictive laws and secure funding for HIV services.

Advocacy and campaigning on broader human rights

- Advocacy and campaigning to protect and advance gender equality, the right to health for all, and the rights of key populations, children and young people.

Campaigning across society

- Campaigning to change attitudes, combat stigma and improve levels of HIV-related knowledge and rights literacy.

ORGANIZATION

Positive Vibes and national civil society partners

ADVOCACY AND PARTICIPATION IN ACCOUNTABILITY

COUNTRY

Namibia

Coordinated advocacy by civil society results in greater investments for the community responses in the country

Namibia has reached upper-middle income status and key donors are phasing out their financial support for HIV. The United States President's Emergency Plan for AIDS Relief (PEPFAR), USAID and Global Fund contributions, which account for about 90% of donor contributions to HIV and AIDS, may decrease by more than 80% in the coming years. While sustainability measures have been taken, without adequate resources to replace those that currently come from international sources, civil society organizations will not be able to continue their critical work.

Positive Vibes and eight like-minded civil society organizations used the Strategic Investment Framework to engage in dialogue with the government and demonstrate areas of comparative advantage of civil society in the HIV response, where investments need to go.

In August 2012, Positive Vibes organized a workshop on the strategic investment framework for 27 civil society organizations in Namibia. Following the workshop, participants formed a network and a steering group committee to coordinate their engagement with the government. The network developed a civil society position paper that outlined how, using the strategic investment approach, civil society can act as a key government partner in the design and delivery of an effective HIV response. This paper served as the basis for securing and developing a dialogue platform with the government, as well as supporting a coordinated action by civil society on investments for community responses to HIV.

As a result of civil society advocacy, the strategic investment approach is now completely integrated into the review process of the National Strategic Framework, and it is considered to be one of the concepts underpinning the process..

In addition, civil society organizations developed a successful Rolling Continuation Channel (RCC) Phase 2 proposal to the Global Fund, using the Strategic Investment Framework; civil society organizations will receive approximately one third of the resulting RCC Phase 2 grant.

ORGANIZATION

National networks of people living with HIV and civil society organizations in 10 countries

Supported by Global Network of People Living with HIV (GNP+) and World AIDS Campaign International

PROGRAMME

Leadership through accountability

COUNTRIES

Cameroon, Ethiopia, Kenya, Malawi, Nigeria, the Republic of Moldova, Senegal, South Africa, the United Republic of Tanzania and Zambia

ADVOCACY AND PARTICIPATION IN ACCOUNTABILITY

Evidence-informed and coordinated civil society advocacy centred on and meaningfully engaging people living with HIV

For more information: hivleadership.org

The Leadership through Accountability programme ran for five years (2009 to 2013) in 10 countries, funded by the Department for International Development of the United Kingdom of Great Britain and Northern Ireland. The programme was spear-headed by the Global Network of People Living with HIV (GNP+) and World AIDS Campaign International. The two organizations worked together with local partners to implement an evidence-informed, community participatory advocacy model that did the following:

- National networks of people living with HIV implemented participatory, community-based research by and for people living with HIV. The evidence from that research formed the basis for evidence-informed advocacy by the networks.
- Civil society partners were supported to get together and identify their priorities, and to coordinate joint advocacy strategies. The evidence from (and meaningful participation of) people living with HIV networks was central to these national civil society advocacy platforms.

The national networks of people living with HIV implemented five evidence-gathering methodologies: the People Living with HIV Stigma Index, Human Rights Count!, Criminalisation Scan, GIPA Report Card, and Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV.

The programme enabled national networks of people living with HIV to build a solid evidence base about why it is crucial to achieve universal access and how this can happen in practice through the meaningful participation of people living with HIV. The evidence generated was used to inform national-level priorities and the delivery of HIV programmes with a focus on key issues that were based on the real experiences of people living with HIV. Moreover, the evidence was used to assist governments to deliver coordinated and effective responses to HIV and AIDS.

The programme also highlighted the added value of a resourced, well-coordinated civil society that is working with governments to plan, implement, monitor and evaluate programmes that contribute to realizing targets for expanding access to HIV prevention, treatment, care and support without discrimination.

ORGANIZATION

Southern African AIDS Trust (SAT), the Zimbabwe AIDS Network (ZAN) and AIDS Accountability International (AAI)

ADVOCACY AND PARTICIPATION IN ACCOUNTABILITY

PROGRAMME

Leadership through accountability

COUNTRY

Zimbabwe

The Zimbabwe civil society priorities charter results in greater inclusion of community responses in the country's Global Fund Concept Note

Source: Zimbabwe civil society priorities charter: an advocacy roadmap for the Global Fund to fight AIDS, Tuberculosis and Malaria New Funding Model. AIDS Accountability and the Ford Foundations; 2014 (<http://www.aidsaccountability.org/wp-content/uploads/2014/03/Zimbabwe-Civil-Society-Priorities-Charter.pdf>, accessed 27 July 2015)

As an early applicant for the HIV grant to the Global Fund New Funding Model in 2013, Zimbabwe had experienced challenges in the meaningful and inclusive engagement of civil society in the Concept Note development process, particularly in the engagement of organizations representing the needs of key affected populations (such as women, young girls and the lesbian, bisexual, gay and transgender (LGBT) community).

In March 2013, SAT, ZAN and AAI held together a workshop that brought together 65 participants from 50 different partner organizations in Zimbabwe. Delegates representing a diverse set of constituents travelled from all geographical regions of the country in order to participate. Particular efforts were made to ensure the participation of LGBT communities, people living with HIV, people with disabilities, young women and other key affected populations. This workshop led to the development of the Zimbabwe civil society priorities charter, an advocacy roadmap for the Global Fund (March 2014). The Priorities Charter represents a landmark consensus among civil society on priorities for the national response to tuberculosis. These priorities include community needs and recommendations on community actions and CSS.

The Charter was used by civil society as an advocacy tool to hold the government and the Global Fund Country Coordinating Mechanism accountable during the Concept Note development process. As a result of the coordinated advocacy by civil society that was led by ZAN, the submitted Concept Note lists CSS as central to the proposed activities, and one of its main objectives is to “expand the scope of civil society organizations... supporting community tuberculosis activities beyond the current two organizations, to include 1 National and 11 Provincial [civil society organizations]”

ORGANIZATION

East Europe and Central Asia Union of People Living with HIV (ECUO)

ADVOCACY AND PARTICIPATION IN ACCOUNTABILITY

PROGRAMME

Regional Advocacy Strategy on access to antiretroviral therapy in eastern Europe and central Asia

REGION

Eastern Europe and central Asia

Successful advocacy to reach universal access to antiretroviral therapy

In 2012, Eastern Europe and Central Asia Union of People Living with HIV (ECUO) designed a Regional Advocacy Strategy on access to treatment for everyone who needs it. The goal of the Strategy is 100% state-financed antiretroviral therapy for those who need it in all eastern Europe and central Asia countries by 2020.

The Regional Advocacy Strategy was translated to the national level (and adapted to each country's context) through National Advocacy Action Plans to amend laws and make governments responsible for public funding for antiretroviral therapy.

Between April 2013 and June 2014, a series of press conferences, round tables with officials, petitions, direct advocacy and street actions were run in the following countries: Armenia, Azerbaijan, Belarus, Georgia, the Republic of Moldova, the Russian Federation and Ukraine. Actions were coordinated across countries using the same slogans. ECUO initiated the "Thank You for Cooperation" award to enlist authorities' support on the issue of ensuring antiretroviral therapy for people living with HIV through state budgets, and it lobbied with the Global Fund for to include governmental responsibility for funding antiretroviral therapy.

Through this multi-country and multi-level (national, regional and global), coordinated advocacy actions, ECUO's advocacy efforts contributed to the following successes:

- In Azerbaijan, the 2014 national budget anticipates 100% antiretroviral therapy coverage, including procurement of antiretroviral medicines.
- In Armenia, the National AIDS programme budget for 2014 has been increased by 14%; in 2013, antiretroviral medicines were included in the list of essential medicines, which in turn ensured that the state needed to ensure in-country availability and accessibility for all citizens living with HIV. By the order of the Minister of Health of Armenia, 13 May 2013, 17 antiretroviral medicines should be registered for the state budget.
- In Georgia, the transition plan was developed and approved by the country coordinating mechanism (CCM) to see the transition of provision from Global Fund grant to domestic funding. People living with HIV community representatives became members of the Country Coordinating Mechanism and the Country Coordinating Mechanism Overseeing Committee.

ORGANIZATION

Atlatl

PROGRAMME

Life with Dignity (Vida Digna)

ADVOCACY AND
PARTICIPATION IN
ACCOUNTABILITY

COUNTRIES

El Salvador, expanded to Mexico and central America

Ensuring dignity of communities

The involvement and leadership of key populations is essential for lasting change in the central America region. Vida Digna employs the methodology of Participatory Community Assessment, along with activities that encourage participants to examine stigma and discrimination at all levels, from the individual to the national. They help participants connect with human rights issues and provide tools to tackle stigma and discrimination through official channels.

For example, in one activity, sex workers surveyed members of the public at a local shopping centre about their perceptions of sex work. They then produced a report on the stigma and discrimination they face and used this to inform their advocacy strategies. The participatory assessment for Vida Digna signalled a clear need to support and empower sex workers, people living with HIV, gay men and other men who have sex with men, transgender people and people who inject drugs.

The programme has now been successfully implemented in El Salvador by Atlatl, and it has reached more than 8000 people. Through Vida Digna, Atlatl has increased its legitimacy regionally and nationally by engaging more deeply with key populations. It has also developed an accredited diploma programme on HIV, stigma and discrimination. Two Vida Digna partner organizations participated in the drafting of a new law on sexual and reproductive health rights to ensure that the rights of transgender women were addressed in El Salvador. Due to the efforts of these organizations, the draft law now refers to issues such as hormone regimes and transgender women's rights to see specialist doctors—an important step in encouraging the state to address gender identity issues formally.

Colectivo Sol continued to use the Participatory Community Assessment and Vida Digna approach beyond the end of the programme to train more than 60 organizations as part of an HIV prevention community of practice in Mexico. The Vida Digna model is now being further expanded in central America through a US\$ 12 million grant implemented by two regional networks, RedTraSex for sex workers and REDLACTRANS for transgender women, with support from Positive Action and the International HIV/AIDS Alliance.

ORGANIZATION

RedTraSex—the Latin America and the Hispanic Caribbean network of sex workers

ADVOCACY AND PARTICIPATION IN ACCOUNTABILITY

COUNTRIES

14 countries in Latin America and the Caribbean

Good practice guide for health systems

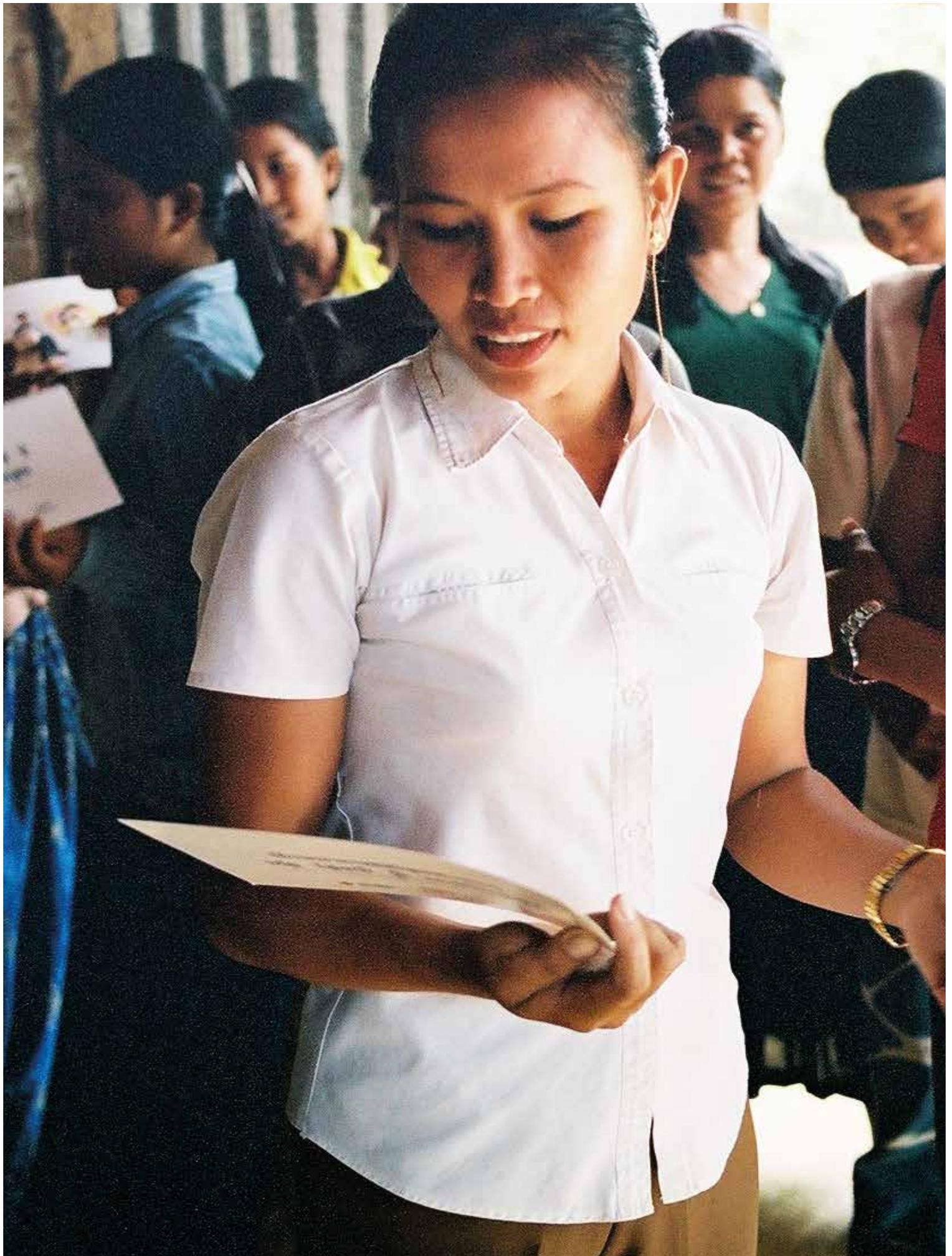
RedTraSex is a network operating in 15 Latin American and Caribbean countries, consisting of local and national sex worker organizations. Human rights violations against sex workers, the lack of policies and legal frameworks to protect them from violations, widespread stigma and discrimination, and capacity gaps (including in institutional capacities) make this population vulnerable to HIV, violence and other health issues.

In February 2012, RedTraSex started a programme to prevent HIV among female sex workers through national and regional advocacy interventions. Three main activities were implemented:

- advocacy capacities for sex worker rights were built and access to quality health services was promoted (including within policy design, legal framework review and the participation of sex workers in national and regional policy debates to fight against stigma and discrimination);
- activities aimed at reducing violence, stigma and discrimination were launched; and
- institutional capacities were developed.

Through this approach, RedTraSex reached 17 306 female sex workers and sensitized 1259 health workers in 14 countries and developed the Good practice guide for health systems for sex workers. Sex workers increased their participation in parliamentary debates and presented a draft bill on sex work in Argentina.

The main changes that resulted from these interventions were increased visibility of sex worker issues (at national and regional level through their involvement on the Organization of American States), improved quality of health care for sex workers at health centres and agreements signed with formal health systems.



COMPONENT 2: COMMUNITY-BASED SERVICE DELIVERY

When coordinated and working in partnership with national health systems, community-based service provision plays a decisive role in scaling up HIV services by connecting clients, especially people who are marginalized, with services.

Community-based service delivery is an important component of the wider delivery of HIV services. Evidence shows that there is a greater impact, in terms of better access and wider coverage, with services that are community-led compared to other types of service provision (18). Evidence also shows that community-based service delivery has better health outcomes (19) and can lead to the rapid scale-up of interventions through demand creation (20).

Communities create the demand for services, but they also directly provide those services—whether they are medical interventions, social care or legal and human rights-related.

Community-based services also humanize the delivery of prevention, treatment, care and support. The actions of communities in providing HIV-related services are particularly noteworthy, as they bring knowledge of the complexities and specifics of lives, rights and needs, enabling access to (and trust from) highly marginalized communities.

Community-based services lend expert knowledge combined with lived experience from people living with HIV and key populations to inform and improve health systems service delivery. Given the high levels of stigma and discrimination experienced when accessing health services by people living with HIV and other key populations, the training and sensitization of health-care providers is a critical component of community-based service delivery (21–23).

Addressing health, social, psychological and economic issues, including impact mitigation, is the mainstay of most community-based services, and it is done through informal as well as formal services. Communities are diverse, and so are their needs; strong community action is defined, led, implemented and owned by communities with support from civil society, government and other stakeholders.

TABLE 4. COMMUNITY-BASED SERVICE DELIVERY

HIV prevention

- Distribution of prevention commodities.
- Delivery of behaviour change interventions.
- Prevention of mother-to-child transmission related-services (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 in accessing testing (including home testing) and counselling, and in coping with results.
- Different types of 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.
- Adherence support.

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

Community-based antiretroviral therapy delivery

Médecins sans Frontières (MSF) has been delivering medical services, including antiretroviral therapy for the past two decades. MSF applies the listed below models of care in six countries: the Democratic Republic of the Congo, Lesotho, Malawi, Mozambique, South Africa and Zimbabwe (24,25).

Adherence clubs

In facility-based antiretroviral therapy adherence clubs, groups of up to 30 people living with HIV meet every two months for less than an hour. Participation is open to any adult who has been on antiretroviral therapy for at least 12 months and who is considered clinically stable, with an undetectable viral load. The groups provide essential tasks, such as measuring weight and conducting symptom-based general health assessments. The results are recorded by a peer educator or lay counsellor who acts as the club facilitator. Since legislation may require that only staff with a dispensing licence can distribute medication, antiretroviral medicines are pre-packaged and labelled for each participant; they are then brought to the group by the club facilitator. Any person living with HIV reporting symptoms that suggest illness, adverse side effects or weight loss is referred back to the main clinic for prioritized assessment by a nurse. All club members see a nurse twice a year: once for blood tests, and then two months later for an annual clinical check-up. The club facilitator also is responsible for completing the club register.

- In Khayelitsha, South Africa, 97% of club patients remained in care over a period of 40 months. This is compared to 85% of those who qualified for clubs but remained in mainstream, clinic-based care. Club participation reduced loss to follow-up by two thirds and almost halved the proportion of people with a detectable viral load (compared with patients who remained in clinic-based care). A cost-effectiveness study showed the cost per patient year was US\$ 58 in the antiretroviral therapy club model, versus US\$ 109 in the mainstream model of care.

Community antiretroviral medicines distribution points

MSF works with local networks of people living with HIV to establish community antiretroviral medicines distribution points, bringing medication delivery closer to patients' homes free of charge. These distribution points are managed by people living with HIV who are trained to provide antiretroviral medicines refills, adherence support and follow up of basic support and health assessments. People living with HIV who have been on antiretroviral medicines for more than six months, have no active opportunistic infections and possess a CD4 count above 350 cells/ μ l are considered stable and eligible for participation in these community antiretroviral therapy distribution points.

Clients attend the distribution point every three months for antiretroviral therapy refills; they also report to the health service annually for clinical consultation and blood tests (for CD4 count testing). Referral to clinical care is done by lay workers from networks of people living with HIV, and clients who do not show up for their visits are traced by peer counsellors through phone calls or local support group networks. The distribution points also offer free HIV testing and counselling at the community level. Community distribution points require lay workers for staffing, secure spaces to store medication, and a means of transportation to bring medication from the health facility to the distribution posts.

- By July 2013 in the Democratic Republic of the Congo, 2162 patients had been down-referred from the facility-based HIV treatment centre to one of the three community antiretroviral therapy distribution points; this represents 43% of active patients on antiretroviral therapy. A cohort analysis shows that over 89% of patients were retained after 12 months post-transfer to the distribution points. Initial analyses found that the average cost in human resources expenditure per patient is significantly lower at community distribution points than at the clinic. Patients at the community antiretroviral therapy distribution points spend an average of 12 minutes collecting antiretroviral therapy refills—seven times less than patients receiving antiretroviral therapy at the hospital (85 minutes).

Community antiretroviral therapy Groups (CAGs)

Self-formed groups of six stable patients on antiretroviral therapy take turns collecting antiretroviral medication when they visit the clinic for their semi-annual appointments and blood tests (for CD4 count testing). These visits are scheduled in such a way that someone collects the medicines every month. Clients then organize delivery of the antiretroviral medicines to other group members in the community. Group members also provide adherence support and monitor treatment outcomes; if there are any problems, clients present themselves at the clinic, or they are referred by other CAG members. The CAG model has been transferred to other contexts through the adaptation and simplification of procedures, tools and visit schedules (such as 3 month medication refills and yearly clinical consultations with viral load monitoring).

- By September 2013, 3168 people were tested in Tete, Mozambique, with 273 (8.6%) testing positive for HIV. Of these people, 115 (42%) were eligible for antiretroviral therapy, and 102 (89%) started treatment.

Community mobilization at scale and reach

For more information: www.aidsalliance.org/our-impact

The International HIV/AIDS Alliance (the Alliance) is a unique alliance of independent, national civil society organizations dedicated to ending the AIDS epidemic through community action. The Alliance includes 40 organizations across four continents (known as linking organizations) receive technical and financial assistance from the Alliance's international secretariat based in the United Kingdom, regional Technical support hubs and each other. In turn, linking organizations support and develop thousands more nongovernmental and community-based organizations. Some linking organizations also provide HIV services. The Alliance has an accreditation system to ensure that linking organizations and the Alliance's international secretariat operate programmes that are of quality, effective and designed with the involvement of the communities they are trying to reach.

The Alliance has been at the front line of the epidemic for over twenty years. In 2014, it had a significant impact on reducing the effects of HIV epidemics worldwide. Results included:

- In one third of countries where the Alliance is present, Linking Organisations contributed 10% or more of the national coverage for HIV prevention, care or treatment;
- Over one million defined packages of HIV prevention services were provided to key populations;
- 919 000 people were enrolled in HIV care services;
- 483 000 people were supported with community-based access and adherence to antiretroviral therapy;
- 1.47 million people were reached with integrated HIV and sexual and reproductive health activities;
- 2316 CBOs received grants through the Alliance;
- 775 CBOs and networks were supported by the Alliance to monitor and report on human rights-related barriers to access services; and
- Global Fund Country CCMs in 28 countries received technical support through the Alliance regional technical support hubs.

COUNTRIES

**Kenya, Lesotho, Malawi, Rwanda, South Africa,
Swaziland, Uganda, the United Republic of Tanzania
and Zambia**

Mothers living with HIV change lives

For more information: www.aidsalliance.org/our-impact

Mothers2mothers (m2m) was established in 2001 in South Africa, and now runs programmes in Kenya, Lesotho, Malawi, Rwanda, Swaziland, Uganda, the United Republic of Tanzania and Zambia. m2m trains, employs and empowers Mentor Mothers—mothers living with HIV who have experienced services for the prevention of mother-to-child transmission—to work alongside doctors and nurses in understaffed health centres as members of the health-care team. In one-on-one and group sessions, Mentor Mothers provide essential health education and psychosocial support to other mothers living with HIV on how they can protect their babies from HIV infection and keep themselves and their families healthy. Mentor Mothers' ties to the community and their first-hand knowledge of HIV makes them highly effective and credible peer mentors.

Over the past five years, 1.2 million women living with HIV in nine countries have been reached by m2m, with substantial health benefits for the mothers and their babies. Women reached by Mentor Mothers are more likely to take antiretroviral medicines, both to prevent transmission of HIV to their infants and to protect their own health. Also, children born to mothers reached by m2m are also more likely to receive antiretroviral medicines to protect them from HIV, and to receive an early infant diagnosis test to determine their status (compared to infants born to mothers living with HIV).

Home visits to build treatment adherence

Since 2004, a community-based adherence support programme at Kheth'Impilo in South Africa has managed to improve antiretroviral therapy and tuberculosis treatment adherence and reduce loss to follow-up. This was achieved by addressing household socioeconomic problems impacting adherence. The programme involved providing home-based counselling regarding antiretroviral therapy or tuberculosis treatment adherence for children, assessing and addressing household socioeconomic and psychosocial factors that have been observed to reduce antiretroviral therapy adherence in children, and forming a link between the clinic and children on antiretroviral therapy.

As a result of the programme, 8000 children received adherence and psychosocial support from 896 trained community workers providing patient support. This has brought about a significant 61% reduction in mortality, a 43% reduction in attrition of children from clinics and a 60% improvement in viral suppression on antiretroviral therapy in children.

ORGANIZATION

Linda Clinic

HIV AND OTHER HEALTH SERVICE DELIVERY

COUNTRY

Estonia

Community-driven health services: “patients providing services”

Source: A community-based service delivery model to expand HIV prevention and treatment. GNP+ and the International Federation of the Red Cross and Red Crescent Societies (<http://www.ifrc.org/Global/Documents/Secretariat/AIDS%20conference/1281400-HIV-leaflet-LR.pdf>, accessed 27 July 2015)

The Linda Clinic was registered in June 2012 in Estonia by AIDS Healthcare Foundation and the Estonian Network of People Living with HIV. The clinic is operated by people living with HIV in Narva, situated on the Russian border. This model of patients providing services is starting to be accepted as a viable way of approaching a national response in the region.

Although the Linda Clinic is not yet able to provide antiretroviral therapy services on its own premises (this is being discussed with government), there is ample early evidence to show that the clinic is successful. It is currently supporting more than 200 people living with HIV, with a high retention in care, good patient satisfaction and well-established referral pathways. The clinic also collaborates with other medical institutions, especially those dealing with infections such as tuberculosis and hepatitis C. Linda Clinic staff focus on the adherence, retention and peer support areas of a client’s needs which other facilities are not equipped to provide. People living with HIV, together with staff from the clinic, are also combining outreach testing services with advocacy activities. Since 2013, these outreach activities have resulted in more than 1900 people being tested.

Holistic HIV treatment, prevention, care and support for people living with HIV

KHANA is the largest national NGO providing integrated HIV prevention, care and support services at the community level in Cambodia. Since 1997, KHANA has been providing an integrated care and prevention programme, mobilizing people living with HIV to become community support volunteers. The programme specifically reaches people living with HIV, orphans and other children made vulnerable due to AIDS and their families. Activities include supported referrals to health services, antiretroviral treatment adherence, prevention services, access to livelihood activities, nutritional assistance, support for school attendance and self-help group facilitation. The programme also includes volunteers who work with health centres and hospitals to ensure user-friendly services are available.

In 2013, 16 775 adults and children living with HIV were covered under the programme; of these, 98% were receiving the minimum package of support, including support for enrolment in antiretroviral therapy, maximized retention in care, and integrated services for sexual and reproductive health and family planning.

In 2012 and 2013, a total of 1753 sero-discordant couples were identified and supported by the programme and provided with a minimum package of services, including treatment literacy, distribution of condoms and lubricants, and referral support to health services (including HIV testing and counselling, antiretroviral therapy, sexual and reproductive health, and family planning). As a result of this intervention, HIV incidence in sero-discordant couples was low (0.7% or 13 of 1753 couples). During the same period, a total of 589 pregnant women living with HIV were identified, 93% of whom were supported to access prevention of mother-to-child transmission services. As a result of the intervention, only six infants were born with HIV (less than 1%).

A social return on investment study found that this programme delivered a cost to benefit ratio of 1:1.73—a 73% social return on investment (26).

Reaching key populations: an integrated approach of advocacy, service provision and research

The Malaysian AIDS Council is an umbrella body linking 49 civil society partner organizations that represent key populations across Malaysia, including people who inject drugs, sex workers, gay men and other men who have sex with men, and transgender people. It provides technical support and oversight to partner organizations to carry out HIV prevention programmes in Malaysia. Key services include needle and syringe programmes and sexual risk reduction.

The Malaysian AIDS Council operates within the context of a national approach, working in partnership with government and others. Their work is guided by the National Strategic Plan for HIV and AIDS (2011-15), which aims to sustain service coverage above 80% by 2015, with at least 60% of people covered consistently practicing behaviours safe from HIV infection.

The Malaysian AIDS Council has pioneered needle and syringe programmes roll-out since its implementation in 2006. In 2013, community-based needle and syringe programmes reached a total of 71 827 people who inject drugs through 39 civil society organizations and 573 outreach points. The sexual risk reduction programme targeted sex workers, gay men and other men who have sex with men, and transgender communities. In 2013, a total of 6507 clients were reached with comprehensive HIV testing and counselling, condom provision and safer sex education. Integrated bio-behavioural surveillance (IBBS) conducted in 2012 showed that 86.5% of people who inject drugs have been reached by needle and syringe programmes. Through the intervention, 97.5% of the people who injected drugs were using sterile injecting equipment, and this resulted in a 50% reduction in new HIV infections in the past decade (from 73% in 2002 to 38% in 2012). This is indicative of the Malaysian AIDS Council's success in implementing needle and syringe programmes. It is now attempting to replicate its success with its sexual risk reduction programme, which includes improving HIV testing and counselling uptake.

Context-specific solutions for food and nutrition insecurity

Source: World Food Programme (WFP) Ethiopia's Support to an HIV Community Volunteer Network, WFP Regional Bureau for East and Central Africa

In Ethiopia, communities are involved to provide a comprehensive package of care to people living with HIV receiving antiretroviral therapy, women accessing prevention of mother-to-child transmission services, and orphans and other children made vulnerable due to AIDS. Through World Food Programme (WFP) support, a Community Volunteer Network was established to create context-specific solutions for issues of food and nutrition insecurity and how they relate to HIV-related care and support. The Network's members are people living with HIV who are on antiretroviral therapy, including women who are receiving services to prevent the mother-to-child transmission.

Once community volunteers are recruited through the local association of people living with HIV, they are trained and equipped with the necessary materials and resources. The community volunteers then provide support through home visits, during which they assess the health status of the beneficiaries and provide support. They also initiate referrals to other services and facilities. Monthly group discussions are used to map HIV-related community services, keep a referral directory, and share it with community networks and service providers to strengthen linkages with the health system.

The Community Volunteer Network is being applied in an HIV cash and voucher transfer scheme where WFP assists HIV-affected, food-insecure families in urban areas. It was initially piloted across 23 sites with around 50 volunteers being recruited to provide rapid feedback from beneficiaries on the new cash and voucher modality. Today the Community Volunteer Network is nationwide, covering 87 sites, and it has attracted 221 volunteers, including 107 women.

ORGANIZATION

**Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS),
The Swaziland National Network of People Living with HIV and AIDS (SWANNEPHA),
Global Network of People Living with HIV (GNP+), MaxART consortium**

PROGRAMME

Maximizing ART for Better Health Prevention and Zero New HIV Infections (MaxART)

COUNTRY

Swaziland

HIV AND OTHER
HEALTH SERVICE
DELIVERY

Ensuring quality and equity in treatment scale-up

Maximizing ART (antiretroviral therapy) for Better Health Prevention and Zero New HIV Infections (MaxART) implemented a number of health and community system interventions to dramatically scale up HIV testing to 250 000 people per year, to improve access to treatment and reach 90% of people eligible for treatment, and to reduce loss to follow-up of people on treatment from 22% to 10% by 2014. MaxART takes a rights-based approach to interventions and focuses on community-owned solutions.

The following community-based advocacy, services and participatory community research have been implemented as part of MaxART:

- trained 98 traditional and 12 political leaders to lead the response to HIV in their communities;
- organized 269 community dialogues to mobilize communities to create demand for HIV services;
- trained 5761 community-based volunteers and rural health motivators trained to implementing door-to-door visits for mobilizing community members to HIV testing and taking treatment and support retention.
- community teams implemented 35 Fast Track interventions aimed to mobilize men and young people for HIV testing and increase the uptake of ART;
- established 15 Teen Clubs and trained 115 adolescents as peer educators; and
- people living with HIV conducted Positive Health Dignity and Prevention research and monitor human rights.

Three years after MaxART's implementation, Swaziland is on track to reach national targets by the end of 2014. The country experienced the highest number of annual HIV tests in 2014, and 90% of the people currently eligible for treatment are on antiretroviral therapy, with improved retention rates. These results could not have been reached without the community work. The effective integration and linkages between community and health system activities was critical to achieve key outcomes. The collaboration between government, community-based organizations, networks of people living with HIV, civil society and research institutes in the MaxART project has been instrumental to the success of the programme.

ORGANIZATION

Heartland Alliance in Nigeria

SERVICE PROVISION FOR KEY POPULATIONS

COUNTRY

Nigeria

Community-based services overcome legal challenges to deliver health services for marginalized populations

Heartland Alliance in Nigeria is a partnership between five local key population organizations that works to ensure sustainable access to HIV services for key populations—particularly gay men and other men who have sex with men—in a legal environment where sexual orientation and gender identity may pose a barrier to access treatment, prevention, care and support.

Heartland Alliance in Nigeria is now a strong organization of 34 outreach staff and 255 peer educators who have been trained and employed in five states in Nigeria. Over 62 000 people have been reached through its integrated HIV prevention programme for gay men and other men who have sex with men, and at least 21 000 people from most-at-risk-populations and their partners have been provided with palliative care and support.

In collaboration with local hospitals and other partners, Heartland Alliance in Nigeria has established specialized clinics across the country to delivery HIV services in a safe environment to most-at-risk populations, in particular gay men and other men who have sex with men. Working at the intersection of health and human rights, Heartland Alliance in Nigeria also provides legal aid to those whose rights have been violated because of their sexual orientation and gender identity.

ORGANIZATION

Service Worker IN Group (SWING)

SERVICE PROVISION FOR KEY POPULATIONS

COUNTRY

Thailand

Integrated sexual health care

The Service Worker IN Group (SWING) is a Thai-based foundation that provides sexually transmitted infection (STI) diagnosis and treatment to male and transgender sex workers, including migrants. In order to address the prevalence of both syphilis and HIV, SWING offers syphilis screening with HIV testing and counselling services at its drop-in centre. If an infection is diagnosed, the case is referred for treatment at Bangrak Hospital (Bangkok) or Banglamung and the Queen Savang Vadhana Memorial Hospital (Pattaya).

SWING also collaborates with the Bangkok Metropolitan Administration Public Health Center to offer mobile clinics that provide primary screening and treatment at intervention sites. In addition, SWING provides educational opportunities, including English language classes and vocational training, and it serves as a drop-in centre where workers can eat, use the Internet, prepare for the evening, and take part in HIV-related information games and sessions. Besides treatment and prevention services, SWING also provides access to legal services.

Reaching migrant gay men, other men who have sex with men and transgender communities through community-based clinics

Since October 2013, Rainbow Sky of Thailand has been promoting HIV testing and counselling, STI screening, and care and support for Thai and migrant gay men, other men who have sex with men and transgender people by establishing a permanent community-based clinic. This clinic is one of the few places migrants can access HIV services in Thailand.

In the first four months of operation, the Rainbow Sky Clinic saw 123 clients, all of whom were referred by community peer-educators: 79% of these clients self-identified as gay men, 17% as transgender and 4% as heterosexual men. The majority (96.7%) were Thai, while the rest (3.3%) were from Myanmar. Of the 123 clients, 21.1% tested positive for HIV and were referred to treatment and care services.

The clinic has become popular with gay men, other men who have sex with men and transgender international migrants, especially those from Cambodia, the Lao People's Democratic Republic and Myanmar. As a result, the clinic is developing a multilingual system to cater to their needs. This will be the first community clinic in Thailand that provides friendly and specialized services for men who have sex with men and transgender international migrants.

ORGANIZATION

Red Crescent Society

SERVICE
PROVISION
FOR KEY
POPULATIONS

COUNTRY

Kazakhstan

Integrated tuberculosis and HIV programmes reach prisoners

The Kazakh Red Crescent Society's Prevention of Tuberculosis and HIV Programme in Kazakhstan started in 2003, and is designed to serve key populations in order to improve tuberculosis and HIV adherence to treatment, build capacities for rehabilitation and prevention, and provide HIV prevention services. The Society offers psychosocial, legal, advocacy and communication support, and it carries out information dissemination activities.

Since the Programme began, approximately 20 000 people from key populations (including prisoners) receive services each year. The advocacy and social mobilization tools offered also promote services while providing information. Significant changes have been observed, including HIV treatment adherence among 85% of people living with HIV, with 80% of the target group reporting behaviour change, and less than 5% of clients with HIV or tuberculosis failing to adhere to their treatment protocols. As a consequence, there has been strong continuity of HIV and tuberculosis treatment from the penitentiary system through to civil society.

Applying tools from the private sector to reach sex workers through community action

Inspired by the Sonagachi sex worker movement in Kolkata, India, Avahan (with substantial support from the Bill and Melinda Gates Foundation) mobilized communities at scale using tools developed in the private sector. This novel partnership between community and business created exceptional results, and it is an excellent and well-documented example of a comprehensive, holistic response that addresses the core structural drivers of HIV risk as well as individual behavioural interventions. Avahan gave local communities the creative imperative to design and tailor structural interventions to their needs. Services include peer-led outreach and education, treatment of STIs, referrals for HIV and tuberculosis testing and for HIV care, distribution of free condoms, needle and syringe programmes, and community mobilization initiatives to address structural and environmental barriers.

At the end of the first phase of the Avahan programme in 2009, 320 000 individuals at highest risk for HIV (which included female sex workers, men who have sex with men, transgendered people, and people who inject drugs) in six high HIV prevalence states in India were receiving a package of HIV prevention intervention services (7).

Part of the Sonagachi success came from the movement's ability to collectivize and to redress the balance of power in the community (27). Avahan mirrored this process in its programmes by enabling local communities to interact on a more equal footing with local government. By the time the programme transitioned to government control, Avahan had demonstrated evidence from independent evaluations—measured through increased condom use and lower prevalence of STIs—that community mobilization was cost effective and contributed to significant risk reduction. They also confirmed the linkages between sexual violence and health behaviour (28–32).

The effort to collect evidence on community mobilization at Avahan contributed to developing evaluation tools that set new standards for measuring community mobilization (6).

ORGANIZATION

Ashodaya Samithi

SERVICE
PROVISION
FOR KEY
POPULATIONS

COUNTRY

India

Empowering sex workers living with HIV: by and for sex workers

Source: India: community empowerment key to turning tide on HIV. In: The World Bank: news [website](worldbank.org/en/news/feature/2012/11/27/india-community-empowerment-key-to-turning-tide-on-hiv, accessed 27 July 2015)

Ashodaya Samithi is a community-based organization in Mysore, India, that was established in 2004. At the time the programme was established, HIV prevalence among sex workers was 25%, no HIV prevention programmes were in place in the city for sex workers, and there was only one HIV testing and counselling centre at the district hospital. Now, however, the group uses a social enterprise approach to mobilize its own resources through collective efforts. The organization runs a local restaurant, originally supported by the World Bank, as well as serviced apartments. Profits support a community care home for sex workers living with HIV.

Currently, Ashodaya Samithi more than 8000 female, male and transgender sex worker members who promote condom use, provide HIV testing and counselling, and link sex workers living with HIV to antiretroviral therapy services and care. Moreover, these members volunteer at local hospitals to ensure sex workers receive the services they need with dignity and without discrimination.

ORGANIZATION

Daughters of Charity

PROGRAMME

DREAM Center

SERVICE
PROVISION BY
FAITH-BASED
ORGANIZATIONS

COUNTRY

Nigeria

Faith communities deliver comprehensive health care and support

For more information: daughtersips.org/wp-content/uploads/2012/09/DREAM-HIV-AIDS-Case-Statement-8-1-20121.pdf (accessed 27 July 2015)

The DREAM Center clinic is organized and run by Daughters of Charity, a faith-based organization, in collaboration with the community of Sant'Egidio. DREAM stands for “drug resource enhancement against AIDS and Malnutrition.” The DREAM Center has been in operation since 2007 and delivers services for people living with HIV at St. Vincent’s Health Services Hospital in Abuja’s Kubwa district. DREAM focuses on HIV through an integrated services approach that also includes care for tuberculosis, malaria, coinfections and malnutrition. With dedicated outreach activities carried out in the community, the hospital has achieved a 90% adherence rate for people receiving antiretroviral therapy, with very few cases being lost to follow-up. DREAM also supports and hosts support groups by and for people living with HIV.

ORGANIZATION

AIDSRelief Consortium

PROGRAMME

Sanghan Metta project

SERVICE
PROVISION BY
FAITH-BASED
ORGANIZATIONS

COUNTRIES

Cambodia, China, the Lao People's Democratic Republic, Myanmar, Thailand and Viet Nam

Community-level HIV care and treatment

Source: Providing treatment, restoring hope. AIDSRelief final report. Catholic Relief Services; 2014 (<http://static1.1.sqspcdn.com/static/f/752898/24068845/1392128023880/aidsrelief-final-report.pdf?token=EsLNIIW2yk%2BwjiGqbbNGRWEwH8M%3D>), accessed 27 July 201

AIDSRelief is a consortium funded through PEPFAR. It consists of Catholic Relief Services as the prime grantee, the University of Maryland School of Medicine Institute of Human Virology as the technical lead for clinical care and treatment, the Futures Group as the lead agency for strategic information, the IMA World Health and Catholic Medical Mission Board as implementing partners, and the Children's AIDS Fund as a key sub-grantee supporting sites in three countries.

Since 2004, AIDSRelief has delivered high-quality HIV care and treatment to 707 000 people in 10 countries, including nearly 400 000 people on antiretroviral therapy. AIDSRelief has achieved this by integrating and leveraging community responses within an interdisciplinary and comprehensive health systems strengthening approach. One of its efforts was to engage communities to improve adherence.

The AIDSRelief Chikuni Mission Hospital in rural Zambia, for example, monitors loss to follow-up as a secondary measure to track patient adherence. In late 2008, loss to follow-up was at an impressively low 1.2%. Nonetheless, the staff developed a comprehensive, community-based strategy to reduce it further by re-engaging missing patients. Specific interventions included supporting groups at 21 outreach centres, running a community radio programme focused on HIV, conducting outreach programmes in schools and villages, providing education programmes for community leaders, and offering adherence counselling at all pharmacy pick-up appointments. Within eight months, loss to follow-up fell below 1%. The impact of these efforts is striking. In the seven AIDSRelief country programmes where viral load surveys were conducted, the average viral suppression proportion, the gold standard for treatment success, was 88.2%, a rate comparable to or better than those seen in industrialized countries.

ORGANIZATION

Catholic Health Association of India

SERVICE PROVISION BY FAITH-BASED ORGANIZATIONS

COUNTRY

India

Comprehensive spiritual and practical support

The Catholic Health Association of India is one of the world's largest NGOs in the health sector and it has been active since 1943. It has a base of over 3410 member institutions across the country, including large, medium and small hospitals, health centres and diocesan social service societies. Of its member institutions, 84% operate in rural and remote areas. The Catholic Health Association of India upholds its commitment to bring "health for all" through an innovative approach of marrying spiritual and pastoral care with service delivery needs.

In 2007, the Catholic Health Association of India staff initiated community care centres through its member institutions to provide treatment, care and support to people living with HIV. community care centres provide treatment for opportunistic infections, offer psycho-social support services (including treatment adherence and outreach services, and provide nutritional food and educational support. To date, community care centres have seen: 603 526 people living with HIV receive inpatient care, 1 589 450 people living with HIV receive outpatient care and 1 207 052 people living with HIV and their families receive counselling, home-based care and education on antiretroviral therapy adherence.

Through its community care centres, people living with HIV can receive quality medical and comprehensive care without stigma and discrimination. This has reduced opportunistic infection rates, and has increased antiretroviral therapy adherence.

ORGANIZATION

Youth and Women Empowerment Foundation

SERVICES FOR
ORPHANS
AND OTHER
CHILDREN MADE
VULNERABLE DUE
TO AIDS

COUNTRY

Uganda

Shifting the focus of palliative care

Youth and Women Empowerment Foundation in Kabarole District in western Uganda is a local NGO of people living with HIV. Part of the service offered by the Foundation is palliative and respite care, which includes home-based care. The service intends to increase access to care and treatment services among community members living with HIV and enable the formation of peer support groups for women and men.

To keep the community at the centre of its services, the Foundation actively organizes activities that perform auxiliary services, such as psychosocial support for orphans, adolescents living with HIV and other vulnerable community members. Every Saturday is a psychosocial day for the youth at the Foundation, and activities like these not only help mobilize the community for a worthy cause, but also provide an important sense of community for those who are in long-term care.

ORGANIZATION

Gestos

SERVICES FOR
ORPHANS
AND OTHER
CHILDREN MADE
VULNERABLE DUE
TO AIDS

COUNTRY

Brazil

Supporting children to confront the changing face of HIV

Gestos in Brazil conducted a 10-year programme (2000–2010) for children living with or affected by HIV, who were under served in Brazil (despite its strong national AIDS policies). Initially, Gestos only supported women living with HIV who needed help looking after their children. In time, however, they realized the impact the epidemic had on children's lives and their family relationships. Thus, Gestos began activities to help children better face their situation of feeling abandoned, neglected or exposed to domestic violence, child labour and absenteeism in school. These tailor-made services were the only ones of their kind in northeastern of Brazil.

Gestos provided individual and group psychosocial support for children and their parents, conducted educational activities promoting citizenship, and took the children on cultural outings such as visiting bookstores, theatres, museums, cinemas and parks. The psychological support strengthened the self-esteem and self-confidence of the children, improved their relationships within their families, and increased their results in school. Support also included visits to the children's homes (on request) and regular meetings with parents. Educators at Gestos helped children improve their performance at school and educated them about their rights as Brazilian citizens. Gestos workshops for teachers trained them in dealing with children living with HIV and informed educators about HIV in general. As a result of this programme, children's self-esteem and performance in school has increased and levels of violence against children within families and communities have reduced.

ORGANIZATION

Handicap International

SERVICES FOR
ORPHANS
AND OTHER
CHILDREN MADE
VULNERABLE DUE
TO AIDS

COUNTRY

Mozambique

Meeting the basic needs of orphans and other children made vulnerable due to AIDS

Handicap International offers care and support for orphans and other children made vulnerable due to AIDS (OVCs), their families and people with disabilities in Manica and Sofala in Mozambique. The objective of the programme was to ensure OVCs and their foster families have their human rights and health care needs well articulated and subsequently met through a locally established community monitoring and support system. The system is designed to promote and support the coordination of local multi sectoral services and actors. The task of putting the monitoring mechanism in place has helped build local capacity and provide some support to local income-generating initiatives.

As a result of the programme, more than 10 000 OVCs have been reached, and more than 6000 of them have access to at least three basic services from a variety of service providers. More than 3000 OVCs who had faced malnutrition and extreme poverty have been supported by local CBOs to meet their economic needs. As knowledge about children's rights grew in communities, local authorities became more aware of the situations facing OVCs, and they subsequently have addressed issues by planning more appropriate and targeted public services. In the areas where the programme had been implemented, the nutritional well-being of OVCs and access to education has increased significantly.

ORGANIZATION

Raising Voices

PROGRAMME

SASA ("now" in Swahili)

SERVICES TO
ADDRESS
GENDER-BASED
VIOLENCE AND
INEQUALITIES

COUNTRY

Uganda

Preventing gender-based violence

The SASA community approach—developed by Raising Voices, a Kampala-based NGO—aims to prevent violence against women by focusing on the root causes of girls and women’s vulnerability, gender inequality and the power imbalance between women and men.

SASA, which means “now” in Kiswahili, aims to mobilize communities to assess and redress the cultural acceptability of violence and gender inequality, to recognize the links between HIV and these issues, to change their own relationships and power imbalances, and to support women living with HIV and women who have experienced violence.

A study of the SASA intervention that aimed to assess its impact found that (33):

- the intervention was associated with significantly lower social acceptance of intimate partner violence (IPV) among women and lower acceptance among men;
- significantly greater acceptance that a woman can refuse sex among women and men;
- 52% lower past year experience of physical IPV among women; and
- lower levels of past year experience of sexual IPV.

In addition, women experiencing violence in intervention communities were more likely to receive supportive community responses. Furthermore, reported past year sexual concurrency by men was significantly lower in intervention communities compared to control communities.

ORGANIZATION

Southern Africa HIV & AIDS Information Dissemination Service (SAfAIDS)

PROGRAMME

Men as Protector Programme

SERVICES TO ADDRESS GENDER-BASED VIOLENCE AND INEQUALITIES

COUNTRIES

Lesotho and Malawi

Reaching community gatekeepers to address gender-based violence

The Men as Protector Programme in Lesotho and Malawi challenged the cultural practices that encouraged domestic violence by working with men to change their attitudes through education and training. Between 2011 and 2014, 10 000 communities in Lesotho and Malawi have been reached to unite and support zero tolerance for domestic violence and zero new HIV infections in their communities through the formation of Men as Protector clubs.

By strengthening the capacity of 10 community- and faith-based organizations to apply a cultural approach to address harmful cultural practices that perpetuate violence against women and increase their risk to HIV, the programme targeted traditional leaders to champion prevention of domestic violence in their communities in Lesotho and Malawi. Forty-five community volunteers were trained on the mHealth reporting system, reporting domestic violence on a monthly basis using cell phones. This has had an impact on the local community, and traditional leaders and religious leaders have taken the lead to address the issue. This leadership has translated to empowerment for women and girls to report violence immediately.

Women's empowerment to address social determinants of health

El-Hayet, the first NGO for people living with HIV in the Middle East and North Africa region, addresses the social determinants of health directly Algeria's programme. This contributes to gender equality for women and girls through empowerment and multisupport mechanisms. The aim of the El-Hayet programme is to ensure women's empowerment through rights education, lifeskills education and access to economic support; this will help them be independent and manage their own lives, and the lives of their children.

Between October 2012 and December 2013, women and girls were educated in lifeskills through workshops for legal literacy and vocational training in different jobs. The programme also campaigned with the government and UNAIDS for sustainable support, the development of a mechanism to acquire microcredit, and training in micro-company management. Income generating activities were also put in place. A total of 177 women and girls were enrolled in training sessions through this programme, and more than half of them (89) subsequently obtained micro-credits and went on to have their own businesses.

The rest of the cohort moved to work for the private sector or became associated with projects run by their fellow cohort members. The women and girls in the programme reported that they now have better access to treatment and other services, because they know where to access these services and they have the financial resources to go by themselves to hospital. They also report that this has given them more optimism and new hope because they feel that they are contributing to society.

Transforming gender norms through training

Sources: Stepping stones (steppingstonesfeedback.org, accessed 27 July 2015)
Banda, A. *Strategies for safety in a time of AIDS. AIDS 2014: 20th International AIDS conference*
Seeking safety: stepping stones in Malawi, vimeo.com/69251113 (accessed 27 July 2015)

The Stepping Stones intervention on gender, HIV, communication and relationship skills has been the subject of a number of evaluations, including a systematic review in 2012 that looked at seven studies, with a total study sample of 14 630 participants from Angola, Ethiopia, Fiji, the Gambia, India, South Africa, the United Republic of Tanzania and Uganda (34).

Stepping Stones is a gender-transformative, community training programme designed for HIV-vulnerable communities in low-income countries. The original intervention consists of two community meetings, 13 three-hour sessions for four separate peer groups (based on gender and age to accommodate intergenerational relations) and three cross-peer group meetings. It addresses many different aspects, including traditions, money, alcohol, relationships, power imbalances between genders and generations, and decision-making. It has received widespread support and has been translated and adapted into more than 20 languages in more than 100 countries.

Findings from a randomised-control trial in South Africa (35, 36), showed that:

- people who had participated in Stepping Stones were less likely to acquire HSV-2 (herpes simplex virus);
- trends of increased condom use were seen in findings from two of the eight countries; and
- results were inconclusive when looking at other factors, such as reduction in alcohol use (seen in two studies in the three countries that looked at this variable and fewer multiple partners (seen in one of the two studies looking at this)).

Evidence from other evaluations showed that:

- communicating HIV information to partners, family or community improved in three of seven studies;
- gender inequity was reduced in India (one in five studies); and
- stigma was decreased in four studies.

These reviews confirmed that the Stepping Stones methodology has impact, but they also highlighted the challenges that evaluations tend to face, and the importance of outcome measurements being standardized between studies.

ORGANIZATION

Zimbabwe Network of People Living with HIV (ZNNP+), Trócaire (the official overseas development agency of the Catholic Church in Ireland) and Connect (Zimbabwe Institute of Systemic Therapy)

SERVICES TO ADDRESS SELF-STIGMA AMONG PEOPLE LIVING WITH HIV

COUNTRY

Zimbabwe

“We are the change”: dealing with self-stigma among men and women living with HIV through Inquiry-based stress reduction—the Work of Byron Katie

Source: Ferris France et al. An unspoken world of unspoken things: a study identifying and exploring core beliefs underlying self-stigma among people living with HIV and AIDS in Ireland. Swiss Med Wkly. 2015; 145:w14113

Recognizing the prevalence of self-stigma and the absence of a dedicated strategy to address it, an intervention was piloted in Zimbabwe in 2014 using a methodology called Inquiry-based Stress Reduction (IBSR— The Work of Byron Katie and was implemented in partnership with the Zimbabwe Network of People Living with HIV (ZNNP+) and 23 of its members.

Trócaire and ZNNP+ designed, implemented and evaluated a 12-week pilot programme using IBSR. Based on formative research, a curriculum was designed to support participants to work through self-stigmatizing beliefs (self-abasement, shame, guilt, disclosure, restricted agency, hopelessness, sexuality and death). Two ZNNP+ facilitators worked with internationally-certified facilitators to deliver the programme with two groups of 11 participants. Qualitative and quantitative data was collected at baseline, post-programme and the three-month follow-up. The Internalized AIDS-related Stigma Scale and the Quality of Life scale measuring mood, perceived stress and quality of life were used. For evaluation purposes, it was designed as an operations research study with the support of the Royal College of Surgeons in Ireland.

Results at the three-month follow-up show positive impact. Qualitatively, participants report profound shifts in their lives around living positively with HIV, improved communication with their families, lessened fears about disclosure, not feeling limited by HIV and increased peacefulness. Quantitatively, results show statistically significant improvements in a number of areas (% improved): self-stigma (61%), depression (78%), life satisfaction (52%), fears around disclosure (52%) and daily activity (70%).

The model and impact will be carefully measured and evaluated, and based on that, the programme will be scaled up across Zimbabwe.



Association des Services de Santé
(A. S. S. C.)



BURKINA FASO
2011

Fiche d'une séance d'animation

Animateur Bilboute Masceline
CSPS Mabaïa II village S

Thème _____
Technique d'animation _____
Objectif _____

Nombre de participants - Hommes _____
- Femmes _____
- Enfants _____
Total _____

Observation de _____
Difficultés rencontrées par _____

Oui Non

COMPONENT 3: COMMUNITY-BASED RESEARCH

Effective community-based research can drive successful advocacy campaigns, change the shape of programmes and policies, and ensure investment in the services and activities that will have the greatest impact.

Community-based research is essential for ensuring that policy-makers and programme planners are well informed as to: (1) the needs of the communities that their policies and programmes are aimed to reach; and (2) the real impact, availability, accessibility, affordability, acceptability, quality and effectiveness of the services and policies they currently are (or plan to be) delivering. Beyond informing others, community-based research is also an important source of information for communities to guide services, advocacy and actions. Moreover, community-based research empowers communities to play an active role in influencing policy dialogue.

Participatory community-based research is particularly impactful because it demonstrates the importance of understanding the context within which needs, rights and responses are analysed and understood. It is also a more ethical form of research since it affords communities the opportunity to participate in the research discourse, enabling them to be the subject as well as the object of enquiry.

There are a range of effective approaches that have been used by communities, nearly all of which involve a participatory approach that allows for a process where the community validates results and outcomes.

The meaningful engagement of communities in research is crucial. It is well understood that engaging communities in research, including biomedical and clinical research, is essential for achieving deeper and more reliable results, including reaching a representative sample, determining the right questions to ask and ascertaining how to interpret the data. Any research that aims to investigate a community or develop new technology that will be used by a community should involve the community as a partner.

When it comes to research led by communities, however, there is still insufficient funding, especially for research by marginalized communities. Where community-based and community-led research has been supported, it has resulted in crucial and insightful evidence for communities, policy-makers and programme planners.

There is a vital need for community-based research in order to understand better the programmes and services that are in place and to assess the impact of investment in these Programmes. This will ensure that there is sufficient evidence for scaling up the most successful work.

In addition, more community-based research is needed to understand essential rights and needs of communities, and to understand the drivers of stigma and discrimination in particular for key populations, harmful gender norms and gender inequality. To better understand how the epidemics are developing—including real-time shifts in risk factors and what needs to happen to be effective—requires deeper research by and for communities themselves to “know your epidemic” and “know your response.”

TABLE 5. COMMUNITY-BASED RESEARCH

Research on human rights, stigma, and discrimination

- Research on stigma and discrimination faced by a community or a population group.
- Research on stigma and discrimination experienced in accessing services.
- Research on gender norms and gender equality.
- Monitoring, documenting and analysing human rights violations.

Improving “know your epidemic” and “know your response”

- Research on burden of disease and HIV-related vulnerabilities for population groups and communities.
- Research on vulnerability factors to HIV for different population groups or different geographical locations.
- Research on available programmes, including treatment and prevention (for whom and how), and gaps in and barriers of access (for whom and why).
- Needs assessments (including by key populations) on priority health and social care needs, and services.
- Policy framework analysis and how it affects ability to access equitable and quality treatment, prevention, care and support.

Research on new treatment and prevention technologies

- Participation in the research to test new technologies.
- Participation in Ethical Review Boards and in deciding what and how research should be conducted.

Research to reach key populations with community- and rights-based policies and programmes

- Population size estimates.
- Modes of transmission-related research.
- Research on gaps and barriers to access for services and human rights.
- Needs assessments for key populations.
- Evaluating policies and programmes aimed at reaching or affecting access by key populations.

Evaluation of programmes and services

ORGANIZATION

National networks of people living with HIV

Supported by the Global Network of People Living with HIV (GNP+), the International Community of Women with HIV/AIDS (ICW) and UNAIDS

PROGRAMME

People Living with HIV Stigma Index

COUNTRIES

Worldwide (more than 50 countries to date)

RESEARCH

Community participatory research by people living with HIV to inform change and mobilize communities to demand change

Source: *The people living with HIV stigma index [website] (stigmaindex.org, accessed 27 July 2015)*

The People Living with HIV Stigma Index is a unique research tool. It quantifies stigma and discrimination experienced by people living with HIV and its impact on their lives, in their workplaces and to their health. It is a tool of empowerment as much as one for data generation. People living with HIV are the researchers who empower others and the interviewees become agents of change through sharing their stories.

The People Living with HIV Stigma Index has two key aims:

- to increase the evidence base for policies and programmes to reduce HIV-related stigma and discrimination; and
- to ensure people living with HIV, their networks and their local communities are at the centre of the response to AIDS.

The Stigma Index was developed by UNAIDS, GNP+, ICW and the International Planned Parenthood Federation (IPPF). Conceptualized in 2005, the People Living with HIV Stigma Index went through vigorous testing and was piloted in Kenya, India, Lesotho, and Trinidad and Tobago. It was then launched in 2008, with the Dominican Republic being the first country to implement it. To date, the Stigma Index has been undertaken on every continent in more than 50 countries.

So far, over 40 000 people living with HIV have been interviewed, including approximately 13 000 key populations living with HIV. It has been used and reported in more than 50 countries. When aggregated globally, it is probably one of the largest samples for tracking stigma and discrimination experienced by key populations living with HIV.

The data from different countries have generated diverse, targeted evidence that has informed advocacy on a range of issues, including addressing discriminatory provisions within the law (the Dominican Republic, Fiji, Kenya, Malawi and Nigeria), programming on the sexual reproductive health choices for women living with HIV (El Salvador, Fiji, Malawi and Swaziland), layers of stigma experienced by key populations (India, Mexico and Ukraine) and policy for health care provision to people living with HIV (Argentina, Estonia, Pakistan and Swaziland). The evidence from the Stigma Index has become the go-to evidence for stigma and discrimination.

Research led by people living with HIV challenges and changes access to treatment

A quantitative survey of 897 gay men, other men who have sex with men and transgender people living with HIV to assess health care service provision, access and availability in the Asia Pacific region was conducted by the Asia Pacific Network of People Living with HIV (APN+) in six countries in 2008 (22): India (424 participants), Indonesia (128 participants), Malaysia (83 participants), Myanmar (44 participants), Nepal (168 participants) and, Singapore (50 participants). The methodology was based on a peer-led action-based study design by APN+ that aimed to develop an understanding of the nature and pattern of treatment access (23). The project was designed and implemented by people living with HIV.

There is a constant interplay between infrastructural barriers and the sociocultural environment in each country that impacts on individual health care options and treatment access for gay men, other men who have sex with men and transgender people living with HIV. Even where antiretroviral therapy is available for free, the costs of medical tests and transport to seek treatment can be prohibitive, and treatment centres often are in cities or capitals, making access difficult for those who do not live in urban areas.

Stigma and discrimination, particularly among health-care providers, was a major disincentive to seek treatment, with the unethical disclosure of sexuality and/or HIV status by health-care staff perpetuating distrust in the local health-care infrastructure. There were also strong cultural norms pertaining to sexuality that impeded the availability of accurate treatment information, created fear of disclosure, and increased the likelihood of social isolation and loss of social support. Gender-based discrimination makes treatment access an additional challenge for transgender people.

This study informed treatment access issues and was the foundation of advocacy to protect the availability of generic medications in Asia, including the successful community mobilization against Novartis' challenge to generic medication in the Indian High Court in 2012. To guide its overall work on research beyond the above project, APN+ established its own Ethics Committee and trained people in research.

Sex workers lead research resulting in better practice

For more information: nswp.org/research-sex-work

The Global Network of Sex Worker Projects (NSWP) and its partner regional and national sex work networks have conducted (and continue to conduct) research to document good practice in community-led interventions by and for sex workers. This research has informed the development of normative guidelines by the World Health Organization (WHO) and others, and it has supported the scale-up of sex worker-led advocacy, service delivery and community-based financing.

One example of research performed is the Global report: good practice in sex worker-Led HIV programming (37). In 2013, research was carried out in each of the five NSWP regions: Africa, Asia and the Pacific, Europe (encompassing eastern Europe and central Asia), Latin America, North America and the Caribbean. After consultation with the relevant regional advisory group, four sex worker-led HIV programmes were selected in each region to present examples of best practice for sex worker organizations. These are defined as organizations where current or former sex workers occupy 50% or more of the places on the decision-making body, 50% or more of the spokespeople, and at least a third of any paid staff. The research produced a summary of best practices to guide sex worker programming, and it found that it was essential to ensure that funding sources have the best interests of sex workers at heart, that programmes include all sex workers and are led by sex workers where possible. Best practice included the necessity of engaging with sex industry gatekeepers, government, law enforcement, health professionals and the media to demand justice and forge alliances. The resulting good practice guidelines have been used to unite, strategize and mobilize sex workers globally.

A result of NSWP research is the development of guidance by WHO in partnership with NSWP, UNFPA, UNAIDS and the Bank. Published in 2013, *Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions* covers a variety of topics, including approaches and principles to building programmes that are led by the sex worker community (such as community empowerment, addressing violence against sex workers and community-led services) (38). The guidance also contains information on how to implement the recommended condom and lubricant programming, as well as other crucial health-care interventions for HIV prevention, treatment and care, and it provides suggestions on how to manage programmes and build the capacity of sex worker organizations. The resource contains examples of good practice that NSWP has identified and documented as supporting efforts in planning programmes and services.

Researching human rights violations against transgender women in Latin America

Transgender women are the key population with the highest prevalence of HIV in Latin America. Globally, transgender women are 49 times more likely to be living with HIV than the general population of adult women. Transgender women experience violence, including physical violence, on many levels as a result of social exclusion and discrimination.

A qualitative study was conducted by REDLACTRANS in Latin America among transgender women in San Pedro Sula, El Progreso and Tegucigalpa (Honduras), Guatemala City (Guatemala), Cali (Colombia), Santiago (Chile), Buenos Aires (Argentina), Montevideo (Uruguay), Curitiba (Brazil) and Guadalajara (Mexico) over a 16-month period (between January 2012 and April 2013). The aim of the study was to document evidence of human rights violations experienced by transgender women, with the ultimate goal of creating political and legal environments that favour the true inclusion of transgender women in society.

The study found that human rights violations reported by transgender women in Latin America are far-reaching and include extrajudicial executions, torture (and other forms of cruel, inhuman and degrading treatment), arbitrary detention, threats and extortion.

This innovative project included the parallel process of community consultation for research on human rights violations occurring alongside national and international advocacy and campaigning among members of the REDLACTRANS national chapters, a regional community-based organization of both key populations and those from mainstream HIV organization (such as the Alliance). This combination of research and advocacy created intense interest and led to high-level engagements at the Inter-American Commission of Human Rights, with the governments of the United States of America and the United Kingdom, and with the Global Fund.

Putting transgender issues at the centre of research

La Asociación Silueta X and Gender DynamiX work with amfAR to improve access to treatment, and addressing a range of other HIV- and STI-related issues among gay men, other men who have sex with men and transgender people (39). Both elements of the collaborative programme have conducted innovative community-based research programmes that have informed both policy and programming.

La Asociación Silueta X is a trans organization in Guayaquil, Ecuador, that is working to improve the lives of transgender individuals through policy, advocacy and research. In 2012, the GMT Initiative funded the first transgender-specific health and human rights study in Ecuador. The objective of the study was to analyse factors that may influence HIV transmission among transgender women in Guayaquil and the greater coastal cities around Guayaquil using a series of focus group discussions, personal interviews and surveys of 767 transgender women.

Key findings show that 35% of respondents did not know their HIV status, 55% reported that frequent discrimination by health-care workers makes health centres inaccessible and 90% reported at least one experience of discrimination on the basis of gender identity. Following Silueta X's study, the Ecuadorian government reviewed the results and agreed to finance the same study on a national level and expand it to address the broader LGBT population. Silueta X led the design and implementation of the national study, which surveyed 2805 members of the LGBT community on topics including health care access, discrimination and education.

Gender DynamiX is a transgender organization that uses a human rights framework to support transgender individuals in exercising and advocating for their rights, and to increase awareness and visibility of transgender people in South Africa. Gender DynamiX designed and implemented a study of HIV knowledge, sexual behaviour and access to clinical services among 80 transgender women in South Africa called the Transgender and HIV Research and Education Project.

Key findings were that public health services for transgender women and men were generally unsatisfactory due to discrimination from health-care workers. Many respondents reported a negative experience when getting tested for HIV, citing degrading or moralistic remarks. This experience was also a reason for many not to get tested for HIV. Knowledge of sexual health was poor, which underlined the serious issues regarding the inaccessibility and inequality of health services in South Africa. Following this study, Gender DynamiX worked with an independent doctor to write two sets of targeted guidelines for transgender people and providers.



PEER OUTREACH WORKER IN BATTAMBANG, CAMBODIA

COMPONENT 4: COMMUNITY-BASED FINANCING

From the outset of the response to HIV communities have mobilized resources for their own work and for major institutions, most recently playing a fundamental role in advocating for increase investments through the Global Fund.

Community-based financing approaches can create favourable economies of scale and leverage additional funds from relatively small investments.

Many community organizations have long had vibrant fundraising elements, and many are also experienced in disbursing funds to ensure that the community organizations, in particular those working most closely with people living with HIV and marginalized populations, are not left behind.

Civil society organizations undertaking this financing role have been supported by their ability to reduce transaction costs; they also can evaluate and disburse funds more rapidly, with less weighty infrastructure and often better accountability than many other large and bureaucratic organizations. Several examples show how communities are working to ensure that funds reach those in greatest need, ensuring that valuable resources are not lost in excessive transaction costs.

Many CBOs have proven that they can responsibly account for funds of major donors, especially if given adequate capacity strengthening in financial management. They may also be able to provide added value in the form of technical assistance and other support services.

Community financing initiatives (such as health insurance schemes) are becoming an increasingly important part of the landscape, as are efforts to reach key populations. Where state-funded social protection schemes are unable to reach certain population groups, community-based financing initiatives have stepped in to fill that gap, whether it is because state-funded schemes do not have the capacity or because there are legal or policy barriers to access for certain key populations.

Community-based financing can take the form of:

- on-granting (forward granting);
- resource mobilization; and
- community financing initiatives.

Funding programmes to address social vulnerability

Comunità Volontari per il Mondo is an international NGO that provides community funding in Ethiopia and the United Republic of Tanzania. Its funding initiatives promote the capacity of communities or civil society organizations to realize the rights of marginalized people. The initiative started in 2011 and targets people living with HIV, sex workers, women and girls, young people, street children, orphans and children made vulnerable by AIDS, mobile workers and migrants. The aim of the programme is to foster a community-based response to HIV in key populations. Comunità Volontari per il Mondo coordinates and builds the capacity of existing institutions so they will have a bigger impact on HIV prevention and care, as well as on issues around gender.

In 2013, the initiative trained 3944 government officials and community leaders on the vulnerability of key populations in the Amhara region of Ethiopia. The programme also mitigated the problem of children on the streets by reuniting 203 street children with their families and by supporting education of 2042 vulnerable children. The initiative also organized groups of orphans, bar workers, housemaids, widows and women living with HIV to provide them with economic support, training on social vulnerability, and discussion forums about how to mitigate challenges.

Moving funds from government to NGOs

In Ukraine, Light of Hope has been the intermediary that provides government funding from the state and local budgets to NGOs. Founded by people living with HIV in 1999, the organization works to improve the resources of HIV NGOs in Ukraine. Beyond funding needs, they also build NGO capacity in advocacy through training and workshops.

In 2013, Light of Hope trained more than 20 representatives, developed manuals that describe the mechanisms for implementing advocacy practices, and built a network of regional experts in advocacy. Through the efforts of the organization, more than nine buildings were secured with favourable lease terms for NGOs that now provide HIV-related services at a lower unit cost. Advocacy by Light of Hope has also ensured that some of the NGO's staff salaries and HIV medication used in HIV services are paid for by the state budget.

Investing in regional and global civil society networks: country impact through global and regional advocacy actions

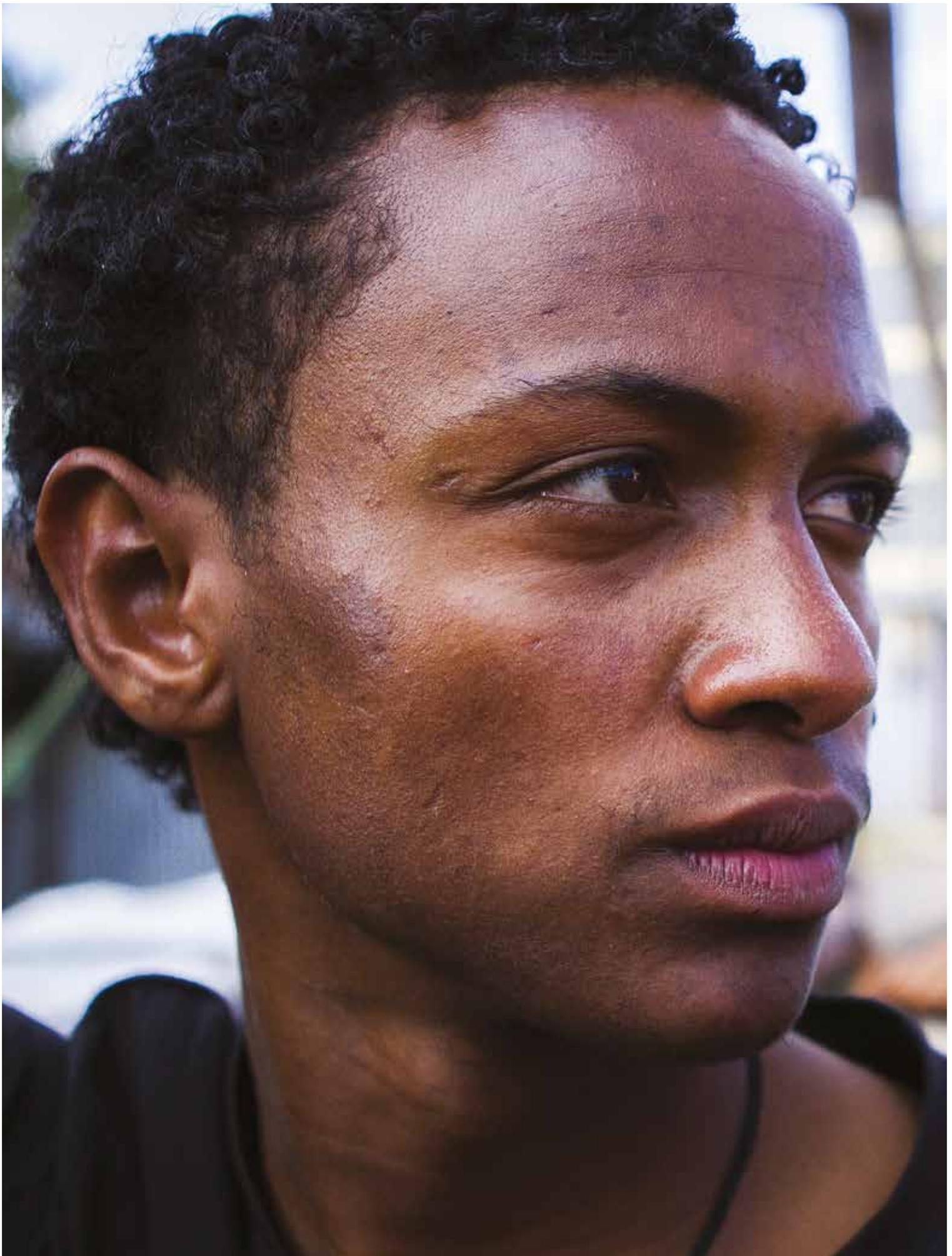
For more information: robertcarrfund.org

The Robert Carr civil society Networks Fund (RCNF) was launched in Washington DC in July 2012 and emerged from a multisectoral collaboration between regional and global civil society networks, potential donors and UNAIDS that had begun in 2010. RCNF responded to evidence of shifts in the donor environment that were endangering the ability of networks to sustain their activities and support their members. RCNF aims to support civil society networks in addressing critical factors for scaling up access to HIV prevention, treatment, care and support, and to protect the rights of inadequately served populations across the world.

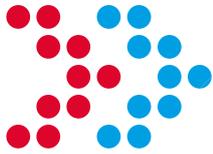
The International Steering Committee of RCNF decided to fund 24 networks (from 135 eligible proposals) in 2012, its inaugural year of operation. The funding selection reflects the attempt to balance global and regional issues with the needs of inadequately served populations.

In total, RCNF has made US\$ 5.4 million available in the first year of funding (40), with funding increasing to US\$ 12 million over two years, from 2013 (41). Funds were granted to 14 networks and consortia of networks working with women and men living with HIV, men who have sex with men, people who use drugs, sex workers and transgender people across the world.

Current donors to this pooled fund include the Norwegian Ministry of Foreign Affairs, the UK Department for International Development of the United Kingdom (DFID), the Bill & Melinda Gates Foundation and PEPFAR.



THE BEZA ANTI-AIDS YOUTH GROUP USES MUSIC AND DANCE TO GET MESSAGES ABOUT HIV PREVENTION ACROSS TO THE WIDER PUBLIC AND IN PARTICULAR TO YOUNG PEOPLE IN ETHIOPIA.



Fast-Track Targets

by 2020

90-90-90

HIV treatment

500 000

New HIV infections or fewer

ZERO

Discrimination

by 2030

95-95-95

HIV treatment

200 000

New HIV infections or fewer

ZERO

Discrimination

RECOMMENDATIONS FOR FUTURE DIRECTIONS IN COMMUNITY-BASED HIV RESPONSES

In order to meet the goal of ending the AIDS epidemic as a public health threat by 2030, the global response must not only maintain the current scale-up in delivering vital services, but it also must quicken the pace over the next five years.

To meet the 2020 and 2030 goals of the AIDS response, community-based services will be essential. These services must be resourced sufficiently and scaled up. Moreover, achieving scale will need more than just increased services: it will require a transformation of how community-based services are linked and work with health systems. Where health systems face a shortage of clinical staff and other capacity issues, community-based service delivery can share the load and improve efficiency through improved linkages and synergies. Scaling up community-based services requires support from governments, in supplying resources, providing an enabling policy environment and ensuring systemic linkages.

In order to leverage the benefits of community-based responses, communities need to balance advocacy with service delivery more effectively. This is a complex dynamic that needs addressing over time to ensure that the correct mix of responses are sustained in the long term and to maximize the impact of quality interventions that will reduce the epidemic.

Funding for community responses must be made available for advocacy, service delivery, research and community financing. Currently, more funding is available for service delivery than for other interventions (such as advocacy and research). It is important that all components of community response are resourced. Community-based advocacy and service delivery have a great impact on people who are more vulnerable, including key populations, people living with HIV, women and girls, migrants, and other population groups particularly vulnerable to HIV.

To secure a quality sustainable response to HIV, it is essential to look deeper at the structural and systemic inequities that have allowed the epidemic to grow and to understand them. This requires innovating approaches that combat stigma and discrimination, understanding which approaches are most successful and can be scaled up, advocating for the best possible responses and holding people to account.

More research is required to understand the impact of responses that are peer-led or community-based. In the shifting donor environment and sustainable development political landscape, programmes that are funded need to prove their impact. This is something that is generally more straightforward for biomedical and clinical interventions than for multifaceted community interventions. Community organizations are aware of the need for an evidence-based response. Documenting community-based actions and measuring the impact they have requires resources and support from research institutions that can provide guidance on appropriate methodologies and analyses.

Investments in and support for non-medical community interventions need to be scaled up and integrated. Biomedical interventions are not (and will not be) sufficient to end the AIDS epidemic. The response to AIDS has taught us that effective treatment and prevention requires addressing deep-rooted structural barriers; it requires a multisectoral approach that includes health, social care, justice, education, labour and all other sectors of society. It also requires investments in prevention. Community-based responses are best placed to design and deliver interventions to meet the non-medical needs of those most vulnerable to HIV.

Shifting community responses from emergency to long-term responses and integrating them in health systems requires supporting community-based service providers to make the transition.

As HIV becomes a chronically manageable condition with more people accessing treatment, community-based responses need to reflect on how to mitigate the effects of long-term care, including through addressing physical and psychological co-morbidities and socioeconomic welfare and needs. This necessitates capacity strengthening, which requires support and resources.

For community systems to deliver, CSS needs to be enabled and funded. In recent years, the concept of CSS has developed to highlight the importance of building a coherent approach to the structures that underpin the capacity of communities to respond effectively to HIV and create the sustainable infrastructure that is required. CSS has been highlighted by the Global Fund, which invites countries to apply for funds for implementation. However, it is important to emphasize that CSS is an approach that requires domestic and external partners to engage in systematic strengthening of community systems to ensure a comprehensive response: they must keep in mind an effective balance between state facilities and community systems. This is not the preserve of a single donor, but rather an approach that requires shifts in investment allocations from multiple partners.

The post-2015 development agenda must include the principle of Greater Involvement of People living with HIV and AIDS (GIPA) as a starting point for strengthening the participation of people living with HIV and key populations in measuring progress towards achieving Universal Health Care.



A COMMUNITY MOBILIZATION WORKER IN KENYA

Community responses to HIV—across the full spectrum of advocacy, service delivery, research and impact mitigation—must be included, costed and resourced in national strategic plans, Global Fund Concept Notes and other investment frameworks.

Investing in community responses

In all countries, inadequate sustainable financing for community responses now threatens the ongoing provision and scale-up of quality services, including services and action by the community. As a result of declining and inconsistent funding, many of the key community structures that have underpinned the community response are negatively impacted. And although domestic investment in the HIV response has gone up overall, increases in funding do not adequately reach the populations most affected.

The investments made in community responses to HIV are already yielding substantial benefits and showing results. HIV requires a sustained ongoing commitment, with investment following the most effective responses to amplify success to date and to ensure that quality services meet the needs of the most vulnerable, particularly people living with (and most profoundly affected by) HIV.

Community engagement, guidance and responses are the backbone of any AIDS response. As such, the Strategic Investment Framework and the UNAIDS Fast-Track approach identified community mobilization as a “critical enabler”—an essential component of responses that have an impact on HIV (42, 1). A systematic review found that community mobilization can have impact when there is a strong collective identity combined with efforts to address the wider sociopolitical context (43). It is this mobilization from the grass roots to national, regional and international levels that has underscored why investment in community mobilization is fundamental to scaling up effective responses to AIDS (42, 1).

Other guidance highlights the importance of investing in community responses, including the Community Systems Strengthening Framework initiated by the Global Fund (44) and UNAIDS guidance on how to apply Strategic Investment and Fast-Track approaches (1, 45, 46). These guidelines underscore the importance of both domestic and external financing for communities because investing in the community response is effective.

On its own, the concept of investing for impact is now fundamental to the HIV response, and the Strategic Investment approach is vital for guiding investments that are efficient and effective. Strategic Investment approaches therefore must include investments in community responses—from domestic state or municipal budgets, and from international funds. Investments in community-based responses to HIV must be part of transition financing plans where domestic financing needs to fill the gap as external resources diminish or come to an end.

On its own, the commitment of communities is not sustainable without the investment of necessary resources. Investment in the social capital of communities should be made based on the demonstrated added value that community responses bring to the HIV response and broader health and social justice issues. There is a lack of sufficient resources and, in some cases, investment in community-based responses is not only shrinking but under threat, with increased restrictions on both accepting and using foreign funds. This is of particular importance for community-based responses for key populations that receive more international funding than funding from domestic sources.

Community responses achieve impact, can reach scale, and deal with inequities and quality at a level and depth that cannot be approached by most health systems and state mechanisms. Because of these substantial qualities and their unique positioning, communities have been delivering even with inadequate investment.

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REDLACTRANS ON A MARCH THROUGH THE STREETS OF GUATEMALA TO DEMAND AN END TO TRANSPHOBIA IN LATIN AMERICA

ABBREVIATIONS

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
CBO	community-based organization
CCM	Country Coordinating Mechanism
CSS	community systems strengthening
GIPA	greater involvement of people living with HIV and AIDS
HIV	human immunodeficiency virus
HSS	health systems strengthening
IBBS	Integrated Bio-Behavioural Surveillance
NGO	nongovernmental organization
OVCs	orphans and other children made vulnerable due to AIDS
SRH	sexual and reproductive health
SRHR	sexual and reproductive health and rights
STI	sexually transmitted infection
TRIPS	Trade-Related Aspects of Intellectual Property Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United National Population Fund
WFP	World Food Programme
WHO	World Health Organization

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