

The leadership of communities in HIV service delivery

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HIV treatment and prevention strategies are life-long endeavours, requiring not only comprehensive, high-quality, consistent and equitable medical services but also appropriate political and cultural milieus to be effective. Communities directly affected by HIV offer a unique expertise and understanding in developing services to meet the needs of people seeking out and utilizing HIV treatment, prevention and support services. Through their organizations and networks, and through partnerships with health systems, these communities provide leadership, services and advocacy to ensure the delivery of high-quality, comprehensive services to meet the needs of diverse populations affected by HIV. This article describes integrated approaches to service delivery in which affected communities play a key role in the development and implementation of HIV programmes. Further scale-up of these approaches to care can improve overall quality, reduce stigma and discrimination, increase demand for services and improve retention in care.

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Introduction

In 2003, the WHO called for an ambitious goal of providing antiretroviral therapy (ART) to three million people by 2005. Just over a decade later, almost 14 million individuals have accessed and initiated ART. New HIV infections have fallen 38% since 2003, and death rates from AIDS have fallen an estimated 35% since their peak in 2005 [1]. At the core of this success are individuals and communities directly affected by HIV, for whom HIV treatment and prevention strategies are life-long endeavours, requiring not only comprehensive, high-quality, consistent and equitable medical services but also appropriate political and cultural milieus to be effective.

The vast majority of people living with and at-risk for HIV are poor [2]. Many have families to support. Many are too young to support themselves. Many live in areas of political unrest and are forced to migrate. Sex-based violence and inequity severely limit the choices and ability of some women to obtain and utilize HIV treatment and prevention services. For some members of

key populations, such as MSM, people who use drugs and sex workers, merely seeking out HIV services may pose a greater immediate risk of death than AIDS itself [3]. All demographic groups, regardless of education or economic status, face challenges with treatment adherence and sustained engagement in care [4]. Maintaining HIV health is time-consuming, expensive, risky and often not the primary crisis in a person's life. It is, therefore, necessary to understand the needs and experiences of communities directly affected by HIV in order to structure and implement service delivery programmes that allow people to best utilize those services effectively over the course of their complex lives.

There are multiple ways to define an HIV-affected community. A community can share a cultural or demographic identity, such as people living with HIV, MSM and sex workers. Or community can be the sharing of a geographic sense of place. For example, in Kenya, the National AIDS/STD Programme, Ministry of Medical Services defines a community as a collection of household units brought together by common interests and/or made

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up of at least 5000 people (or 100 households) living in the same geographical area [5].

Since the beginning of the AIDS pandemic, communities affected by HIV have played an integral role in developing effective approaches to treatment, prevention, care and support [6]. Examples include the development of safer sex and harm reduction strategies, buddy systems and support groups, opportunistic infection prophylaxis, voluntary and confidential HIV testing and counselling, and treatment literacy programmes. Peer-based service delivery has been an important component of HIV care since 1981 [7]. The inclusion of people living with HIV in research development and implementation has led to improved participation in studies and more accurate results. HIV-affected communities have built networks and organizations that work at local, national, regional and global levels, whose advocacy has increased the levels of investments in HIV, reduced HIV-related human rights violations, stigma and discrimination, lowered drug prices and scaled up access to treatment and prevention worldwide.

In 2013, WHO revised its HIV treatment guidelines to recommend earlier initiation of ART [8]. These guidelines include recommendations for the use of community-based service delivery approaches to provide HIV prevention, testing and treatment support. In 2014, UNAIDS promoted revised HIV treatment and prevention targets that call for more than doubling the number of people initiating ART over the next 5 years, along with an increased emphasis on maintaining viral suppression through improved retention in care [9]. The further

development and scale-up of community-based services is needed in order to meet these goals.

In 2012, the World Bank published the results of a series of studies examining the impact of community responses to HIV and AIDS. These included country studies in Burkina Faso, India, Kenya, Lesotho, Nigeria, Senegal, South Africa and Zimbabwe over a 3-year period. Using a mixed-method approach, the evaluation investigated the impact of the community responses on knowledge and behaviour, use of services, social transformation and HIV incidence. This evaluation found that investments in communities have produced significant results, including improved knowledge and behaviour, increased use of health services, and, importantly, decreased HIV incidence [10].

One of the World Bank studies, conducted in 28 communities in Nigeria, assessed the effects of the engagement of community-based organizations (CBOs) on a set of outcomes related to HIV/AIDS knowledge, attitudes, beliefs, and practices, stigma, service availability and utilization and social capital [11]. The results show that CBO engagement adds value to the national response to HIV/AIDS by increasing the awareness, availability and utilization of HIV/AIDS-related services, especially in the areas of prevention, care and support. Communities with a stronger CBO engagement were more likely to be aware of any HIV/AIDS-related services, report that prevention and care services were available in their communities and have used HIV/AIDS prevention and care-related services than people in communities wherein CBO engagement was weaker. In another study in Kenya, individuals in communities with higher CBO

Table 1. HIV services and activities that community-based providers are uniquely placed to deliver.

Treatment	Prevention	Advocacy
Adherence support	Prevention of vertical transmission	Monitoring and accountability (health systems, government responses, rights abuses, quality of services)
Testing and counselling	Harm reduction services (syringe exchange, opioid substitution therapy (OST) and so on)	Quality assurance of health services
Treatment literacy	Sexuality education	Antistigma, antidiscrimination and decriminalization efforts (legal support, law reform, lobbying)
Linkage to care/support services	Sexual and reproductive health and rights awareness	Policy analysis around access to and development of essential medicines
Linkages to harm reduction services	Condom distribution	Ensuring the meaningful involvement of people living with HIV in policy and programme development
Management of health and psychosocial needs following testing	PrEP (preexposure prophylaxis) education	
Disclosure support	Education on TB infection control	
Treatment delivery (a treatment extension role for community organisations)	Contact tracing/partner notification support	
Case management	Client negotiation, collectivization, peer outreach skills for sex workers	
Nutritional support	Promotion of male circumcision Postexposure prophylaxis (PEP) for sexual assault survivors	

TB, tuberculosis.

engagement were significantly more likely to have reported consistent condom use [12].

Services that are well integrated within communities, often provided by CBOs or through peer-based programmes situated within health systems, can offer a more inclusive approach to meeting patient needs, as well as relieve overburdened health systems. These approaches include not only healthcare services but also services that address psychosocial, transportation, childcare and legal protection needs. Table 1 provides a list of services and activities that are or can be provided through community-based approaches, which we assert are a critical component of high-quality HIV/AIDS services.

Examples of community-based service delivery approaches being implemented for and by different populations around the world are described below. Despite varied geographic and demographic targets, each of these programmes emphasizes the importance of direct involvement of people living with and at-risk for HIV in programme development and implementation as well as the incorporation of health and social service delivery with advocacy and monitoring.

Emphasizing a client-centred approach to service delivery

To be effective, HIV services must be tailored to meet the needs of very diverse populations. Examples of this diversity include people who are asymptomatic and stable on ART, people with acute HIV opportunistic infections and/or coinfections such as tuberculosis (TB), human papilloma virus (HPV) or hepatitis C, people requiring access to HIV services that are well integrated with sexual and reproductive health services, key populations such as sex workers, MSM and people who use drugs, as well as vulnerable populations such as young girls, migrants and the incarcerated, and both urban and rural populations (Table 2).

With increasing access to HIV testing and counselling services, people initiating and using ART will increasingly be asymptomatic, may have never felt ill from HIV disease and will often not want to be characterized as patients. For many, medication side effects may be the first time they have felt physically ill due to HIV. Their successful

and ongoing engagement in HIV care may depend most on the consistent availability of drug regimens that are easy to take and that have little to no side effects. Equally important are the ability to obtain medication and diagnostic tests without having to wait for hours or travel long distances, and the integration of HIV services into other areas of healthcare delivery and social services.

Several approaches to simplified and expedited drug delivery have been reported. The AIDS Support Organization (TASO) in Uganda is a major provider of HIV services; by 2013, the organization supported care and treatment for over 90 000 people living with HIV including 65 000 on ART. Initially, TASO observed high rates of death and loss to follow-up. In a cohort of 22 315 clients enrolled between 2000 and 2009, deaths were documented in 1498 clients (6.7%) and 1433 (6.4%) were lost to follow-up. In response, TASO developed a model using Community Drug Distribution Points (CDDPs) in which TASO delivers medication to a location within a local village or town that is chosen by clients, making it significantly easier for them to refill prescriptions without traveling long distances to the clinic. Counsellors and expert patients manage the programme, with the oversight of trained clinicians. A retrospective study compared retention in care and adherence to treatment in CDDP clients versus clients who picked up medication at a healthcare facility, and found that loss to follow up was significantly higher (16.5%) in the facility arm than in the CDDP arm (4.3%) [13].

The Community Adherence Group (CAG) model, first developed in Mozambique by Médecins Sans Frontières (MSF), provides another approach to client-centred medication delivery. Patients volunteer to participate in CAGs, which are groups of six patients living in the same area. Each month, one group member travels to the health facility to report on the health of group members, pick up medications for all members and have his or her diagnostic tests performed. The following month, another group member travels to have blood work performed and pick up the group's medication and the test results of the previous member. In this way, each group member is able to have blood work performed twice a year, and travel for prescription refills is significantly reduced.

In the Tete district in Mozambique, more than 6000 patients have joined CAGs since 2008. A cohort analysis showed that retention in CAGs was 98% at 12 months

Table 2. Innovations in client-centred service delivery.

Organization	Countries	Innovation	Outcomes
The AIDS Support Organization (TASO) Médecins Sans Frontières (MSF)	Uganda Mozambique, Malawi, Lesotho	Community drug distribution points Community adherence groups	Improved retention in care Improved retention in care
The Academic Model for the Prevention and Treatment of HIV/AIDS (AMPATH)	Kenya	Home-based testing and counselling for HIV	Earlier linkage to care and treatment services

[14] and the level was maintained up to 92% at 48 months [15]. The CAG model has evolved over time on the basis of client inputs, improving both patient empowerment and treatment outcomes [16]. High retention rates were also achieved in sites wherein CAGs were newly implemented, ranging from 90% in Malawi ($N=299$) to 100% in Lesotho ($N=108$) at a median time in CAGs of 9 and 5 months, respectively [17,18].

The Academic Model for the Prevention and Treatment of HIV/AIDS (AMPATH) is a collaborative partnership between Kenya's Moi University School of Medicine, Moi Teaching and Referral Hospital, and a consortium of academic institutions in the United States led by the Indiana University School of Medicine. AMPATH provides HIV care and treatment for clients in eight counties in western Kenya, a catchment population of approximately 3.5 million people. In 2007, to improve HIV testing rates and enable earlier HIV diagnoses, AMPATH launched a home-based HIV counselling and testing programme (HBCT) utilizing community health workers. A comparison of HBCT and other HIV testing and counselling approaches – including voluntary testing and counselling (VCT) and provider-initiated counselling and testing (PITC) – showed that HBCT was more effective in reaching HIV-positive pregnant women, provided the highest percentage of individuals in discordant couples with effective linkage to care and identified patients with higher median $CD4^+$ cell counts. In addition, 86% of patients with early-stage disease (WHO stage I/II) came to care via HBCT, compared with other testing approaches. Overall, the study concluded that HBCT was effective in gaining patient acceptance for testing and linking patients to care earlier in the course of HIV disease [19].

Building on the success of the HBCT programme, AMPATH developed a new model called Perpetual Home-based Counselling and Testing (PHCT) to address other chronic healthcare needs through its HIV testing services. Rather than travel from town to town, PHCT counsellors are indefinitely assigned to a designated location, where they counsel and test for HIV, screen for TB, diabetes and elevated blood pressure, treat children for intestinal worms, provide information on safer sex practices and distribute condoms. They take responsibility for linking to care all those who might need it, including those who test positive for HIV. AMPATH also engages people living with HIV as care navigators, who provide support and linkage to comprehensive services at the clinic as well as actively seek out patients that have missed appointments.

Programmes such as those developed by TASO, MSF and AMPATH not only provide more efficient ways to access treatment but also place a high value on shared group accountability and the ability of people living with HIV within their communities as experts and counsellors. We

believe that an indirect result of client-centred service delivery is increased self-esteem among clients leading to improved engagement in care, as well as reduced stigma and discrimination against people living with HIV within their families, communities and healthcare facilities. This, in turn, can lead to greater demand for HIV and other healthcare services throughout the community. Measurement of this potential impact provides an important area for further research and evaluation.

Integration of service delivery and advocacy to support women's rights and health

Monitoring and advocacy are often required to address the obstacles that people face in accessing and using healthcare services that are consistent, high quality and respectful of human rights and values. The work of the Southern African Litigation Centre (SALC) provides a useful example of how such advocacy, when well integrated with service providers, is a critical enabling component that leads to improved health services. In Namibia, SALC worked with the Namibian Women's Health Network to challenge the coerced sterilization of HIV-positive women in court, after direct advocacy with government officials had failed. SALC learned about the sterilizations at a workshop with women living with HIV, who discussed their experiences receiving healthcare. In 2012, Namibia's High Court held that HIV-positive women had been subjected to coerced sterilization at public hospitals in violation of their fundamental rights, a decision that was upheld in 2014 [20]. As a result, women with HIV are more likely to access care without fear of mistreatment.

SALC has also studied barriers to access to cervical cancer screening in Southern Africa [21]. Although preventable and treatable, cervical cancer, with high rates among women living with HIV, is the leading cause of cancer death among women in southern Africa. The SALC report found a lack of awareness among policymakers about cervical cancer, its extent in their countries and the inexpensive means of stopping cervical cancer deaths. No country in the region was found to have comprehensive policies on cervical cancer prevention, screening or treatment. In partnership with SALC, CBOs led by and providing services to women living with HIV are now working with governments in Lesotho, Malawi, Mozambique, Namibia and Zimbabwe to develop comprehensive cervical cancer policies. These same organizations are now educating women in their communities about the need for early diagnosis and treatment.

Addressing the needs of key populations

MSM, people who use drugs, sex workers and transgender people are socially marginalized, often criminalized and

face a range of human rights abuses that increase their vulnerability to HIV [3]. Also at a heightened risk are prisoners, migrants and youth. In every nation that reliably collects and accurately reports surveillance data, these key populations have higher HIV risk, mortality and/or morbidity than the general population. Access to and uptake of relevant services is significantly lower for these populations than for other groups [2]. Community mobilization can be an effective approach to improve engagement in care. For example, a recent study examining the value of community mobilization for HIV prevention among sex workers, transgender women and MSM in India reported that individual involvement in community mobilization activities increased condom use and service utilization from government health facilities in each of the three populations [22].

Key populations, especially those who are criminalized, experience discrimination across a range of government services, including health. Service delivery for key populations must be provided in ways that gain the trust of people who may have little reason to trust government-administered services. CBOs play a primary role in identifying those at risk, gaining their trust, providing services such as HIV testing, linkage to care and ongoing support in ways that provide sustainable and well tolerated environments. Human rights advocacy and monitoring of the practices of governmental and other systems to ensure equitable and nondiscriminatory practices in healthcare delivery are also an integral part of service delivery for these populations. Four innovative service delivery programmes for HIV key populations are described below [23].

Targeted Outreach Programme, Myanmar

With 95% of its staff composed of sex workers and MSM, Targeted Outreach Programme (TOP) carries out integrated HIV prevention, treatment and advocacy programmes in 18 sites across the country. TOPs' approach to engaging communities in testing, treatment and life-long care includes:

- (1) Targeted outreach to sex workers and MSM in places where they gather and live, including condom and lube distribution, dissemination of prevention education and referrals to TOP-run drop-in centres.
- (2) Empowerment services in drop-in centres offering meals, spaces for bathing, peer support groups and English lessons.
- (3) Clinical services, including medical consultations, VCT provided by sex workers and MSM, and promotion of sexually transmitted infection (STI) and TB screening. Two of their centres have laboratories for CD4⁺ testing and provide ART. Another three have HIV testing facilities.
- (4) A home-based care programme to provide care and support services.

In 2011, through targeted outreach and drop-in centres, TOPS reached 206 729 sex workers and 222 830 MSM. In the same year, 10 904 sex workers and 7162 MSM received clinical services.

Timur Islamov Foundation (Russian federation)

Established in 2006, the Timur Islamov Foundation provides harm reduction services, case management, referrals for HIV treatment and care, rights training and advocacy with and for people who use drugs in the Tartarstan region. With only four staff members and six volunteers, the organization provides between 100 and 200 clean syringes and 10 vials of Naxalone per day, hygiene kits for women who use drugs living on the street and case management provided by a staff social worker. Case management services include facilitating referrals for HIV care, housing and other social services. They conduct four to eight trainings and meetings a month on topics that are central for advocacy for the rights of people who use drugs and provide a safe space for people who use drugs to access one-on-one group support through daily 'coffees' and lunch meetings every Saturday.

Despite federal policies that criminalize harm reduction services in Russia, the Timur Islamov Foundation accessed office space from Chelny city administration, raised \$15 000 in support from the city government and successfully advocated that all health centres in Tartarstan have a peer counsellor on staff. Their advocacy resulted in acknowledgement by regional authorities that harm reduction services were central to successes in reducing HIV prevalence.

Caribbean Vulnerable Communities Coalition

Caribbean Vulnerable Communities Coalition (CVC) is a coalition of civil society organizations providing direct services to vulnerable groups. Operating out of hubs in Jamaica and the Dominican Republic, CVC brings together civil society experts in human rights based prevention, care and treatment to pursue social mobilization and advocacy on behalf of vulnerable groups; programming and capacity building with partners in the coalition to increase access to prevention, treatment and care; partnering with national AIDS programmes to scale-up services for vulnerable groups; and building the evidence base about risk factors and optimum service approaches for vulnerable groups in the region through participatory research. Grassroots CBOs are part of the service delivery package promoted by CVC, creating a community-rooted, sustainable base for services that are linked to government health centres.

From December to July 2012, CVC reached 703 sex workers in Jamaica and 1303 in the Dominican Republic. Of these, 32% were referred for an HIV test and 76%

were referred to other services, primarily provided by community partners.

Via Libre (Peru)

Via Libre works to increase access to comprehensive healthcare, with a focus on sexual health and HIV among lesbian, gay and transgender people, sex workers and people living with HIV. In addition to outreach services and advocacy activities, Via Libre runs a prevention centre for STI and HIV testing and an HIV clinic.

Begun in 2007, their Somos Project increases access to testing and linkage to care for individuals who were not accessing the formal healthcare system. The programme includes targeted outreach through mobile testing units, innovative videos targeting men at risk on social networking sites, a strengthened case management system and operational research. In 2012, HIV testing was provided to 7015 MSM. Prevalence rates among subpopulations within this group were as follows: 25.1% among transgender people, 14.5% among gay men, 4.9% among gay sex workers and 1.4% among heterosexual men. Further, 98% of clients accepted rapid tests, and 83% came back for western blot confirmation. The percentage of clients who accessed care in this programme was 81% compared with 28% in earlier programmes. Via Libre attributes this increase to community mobilization efforts including the use of mobile units and volunteer university students who helped clients navigate testing and service options.

Conclusion

The programmes described above represent a small sample of the thousands of similar programmes around the world that are a lifeline for people living with and at risk for HIV. Despite large differences in geography and demographics, these programmes share several core elements and values that increase the quality and sustainability of health services. These programmes all directly involve community members as service providers, counsellors and advocates. Second, they incorporate health services within a broader spectrum of social services that look to support the whole person and their community as a means of controlling HIV and improving health. Finally, they integrate advocacy and service delivery as a way to ensure that services are of high quality, equitable and rights-based. These are essential components to high-quality and comprehensive care, without which the challenges of accessing and remaining engaged in care can be overwhelming. Governments can work to support collaboration and partnerships to link community-based providers with health systems as a key way of scaling up their national HIV response, as well as incorporate community-oriented and peer-based approaches into their health system models.

The need and opportunities for further research in this area are many. Further research is needed to better understand how best to structure community-based service programmes for different populations and geographies, what kinds of training and supervision are most effective, the impact on stigma and discrimination from engaging people living with HIV as service providers and how to appropriately remunerate people for their efforts. Little information is available regarding the costs of these approaches, the level of resources being devoted towards them and how best to scale-up effective models. What is clear is that these service delivery approaches are underfunded and undervalued. Yet, the November 2014 UNAIDS Global Report states that investment in community mobilization will need to more than triple of the coming 5 years. The authors call on the Global Fund, PEPFAR and other donor agencies to strategically assess how they will meet this need and implement that strategy. Without this investment, the ambitious targets set by UNAIDS, WHO and national governments will remain only aspirations.

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Conflicts of interest

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