The Role of Affected Communities in Delivering HIV Prevention, Testing and Treatment

Pangaea
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The Pangaea Global AIDS Foundation

Founded in 2001, the Pangaea Global AIDS Foundation is a leading international nonprofit technical cooperation and policy development organization based in Oakland, California. Our mission is to build partnerships to improve the lives of people living with and at risk of HIV through equitable global access to HIV prevention, testing, treatment and care. Pangaea's approach is to:

- Assist countries to devise and sustain innovative & cost-effective HIV strategies, linking testing, prevention and treatment, with a focus on community leadership
- Document and promote lessons learned in these countries to drive global policy and funding, and to inform international guidelines
- Forge linkages between HIV and other key health priorities, partucularly women's health issues

We currently have partnerships in China, the Dominican Republic, Nigeria, Tanzania and Zimbabwe as well as the United States. For more information, visit our website at www.pgaf.org.

An Evolving Approach

The worldwide response to the AIDS epidemic began over thirty years ago, led by those communities most affected by the terrifying new virus. From San Francisco and New York to Kampala and Bangkok, the people most affected by or most at risk of contracting HIV — men who had sex with men (MSM), poor women, people who used drugs and sex workers — were marginalized and persecuted by their governments and health care providers, and left to fend for themselves. People living with and at risk of HIV, along with their allies and caregivers, laid the foundation for the global response to AIDS that we know and take for granted today. They sought out information on prevention and treatment, cared for community members living with HIV, and advocated a public health response that was rooted in respect for human rights and informed by evidence – not fanned by fear and ignorance.

In the second decade of the 21st century, renewed attention is being focused on the role of local communities to expand and sustain access to HIV treatment. This has happened in part as frontline service providers and advocates have demanded recognition for their critical role in fighting the epidemic. In addition, the global economic downturn continues to squeeze national and international budgets, highlighting the urgent need for sustainable, locally based responses to the disease. At the same time, new international agreements call for scaling up HIV treatment dramatically and reaching ambitious new targets — such as the 2011 United Nations General Assembly Declaration on HIV, which aims to expand the number of people being treated for HIV from 8 million currently to 15 million by 2015. Most important, a growing body of evidence shows the effectiveness of community-based approaches at increasing the demand for and ensuring sustained retention of HIV health and social services.

HIV Treatment Optimization Consultations on Strengthening Community HIV Services

Since 2011, with funding from the Bill and Melinda Gates Foundation, Pangaea has supported the World Health Organization (WHO) and UNAIDS to make effective and efficient use of the best available HIV treatment tools – drugs, diagnostic tests and healthcare delivery systems. Part of our contribution to this effort has been to return to our collective history and reaffirm the central leadership of affected communities in responding effectively to AIDS. Pangaea provided logistic and substantive support to WHO and the Zimbabwe Ministry of Health in March 2012, when it organized a consultation in Harare, Zimbabwe to identify the most effective components of community-oriented treatment services in generalized epidemics. In September 2013, Pangaea collaborated with the Asia Pacific Network of People Living with HIV (APN+), in partnership with WHO and UNAIDS, to conduct a similar consultation, this time focused on concentrated epidemics. Over 100 participants from more than 30 countries participated in these two consultations.

The recommendations that emerged from these meetings were primarily intended to inform WHO as it prepares new consolidated HIV treatment guidelines in 2013. However, they also serve as important education and advocacy tools for policy makers, program managers and others around the world, especially because they include promising models for community treatment services that may be adapted in other settings.

We have summarized the recommendations from both consultations in this document. The full reports can be found on Pangaea's website, www.pgaf.org, and at www.HIVtreatmentoptimization.org, a site created especially for the Global HIV Treatment Optimization Initiative.

Interventions Community-Based HIV Care Providers Are Uniquely Placed to Deliver

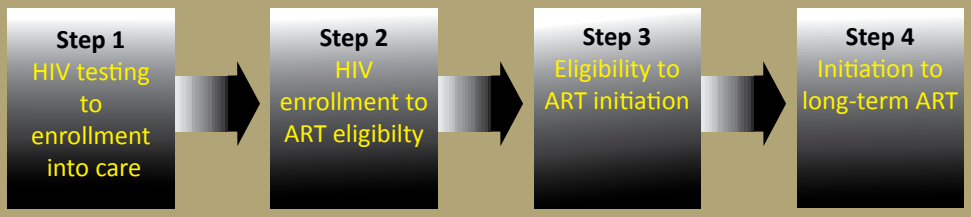
In 2011, the International Treatment Preparedness Coalition (ITPC), a worldwide network of HIV treatment activists, organized a series of community consultations to support the Treatment 2.0 Initiative. ITPC's consultations produced a comprehensive list of services and activities that community-based providers are uniquely placed to deliver (see below). Building on ITPC's work, the consultations in Harare and Bangkok examined effective models of some of these services and activities to expand the knowledge base on the roles of community in treatment optimization.

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

TREATMENT	PREVENTION	ADVOCACY
• Adherence support • Testing and counseling • Treatment literacy • Linkage to care/support services • Linkages to harm reduction services • Management of health and psychosocial needs following testing • Disclosure support • Treatment delivery (a treatment extension role for community organizations) • Case management • Nutritional support	• Prevention of vertical transmission • Harm reduction services (syringe exchange, opioid substitution therapy [OST], etc.) • Sexuality education • Sexual and reproductive health and rights awareness • Condom distribution • PrEP (pre-exposure prophylaxis) education • Education on TB infection control • Contact tracing/partner notification support • Client negotiation, collectivization, peer outreach skills for sex workers • Promotion of male circumcision • Post exposure prophylaxis (PEP) for sexual assault survivors	• Monitoring and accountability (health systems, government responses, rights abuses, quality of services) • Quality assurance of health services • Anti-stigma, anti-discrimination, and decriminalization efforts (legal support, law reform, lobbying) • Policy analysis around access to and development of essential medicines • Ensuring the meaningful involvement of people living with HIV in policy and program development

The HIV Treatment Cascade

To improve HIV health outcomes and reduce infection rates, interventions need to increase demand for HIV testing and counseling, link people from HIV testing and counseling to HIV treatment and prevention services, enroll people living with HIV (PLHIV) into care, initiate treatment in a timely manner and ensure life-long effective utilization of antiretroviral therapy (ART) and other health services. This continuum of care and services is often referred to as the "HIV Treatment Cascade". While there are a number of models that outline different HIV prevention and treatment components, Pangaea uses the outline below to frame recommendations and discussion:



Key Overarching Recommendations from the Harare and Bangkok Consultations

- Directly involve affected populations in the design, implementation and evaluation of service programs.
- Scale up testing and treatment simultaneously to ensure people have access to treatment, care and support.
- Integrate HIV testing and treatment with screening and treatment for TB, hepatitis C (HCV), sexually transmitted Infections (STIs), human papilloma virus (HPV), and harm reduction services.
- Tailor interventions to the specific needs, lifestyles and behaviors of key affected populations.
- Support communities to develop treatment literacy modules that are easy to understand, and in community-appropriate language.
- Ensure that psychosocial, legal and nutritional support programs — as well as advocacy and human rights training efforts — are considered integral to treatment optimization.
- Treatment optimization for key affected populations requires enabling environments in which the rights of sex workers, transgender people, MSM, people who use drugs, migrants, prisoners and women are protected and promoted.
- Service delivery strategies, innovations, and models developed and implemented by key affected populations should be recognized, resourced, evaluated and documented. Successful approaches should be scaled up at every step of the HIV treatment cascade.

Integrating Community and Health Systems

- Roles and responsibilities of actors in health and community systems need to be clearly defined as HIV care is integrated into generalized health systems.
- Integration of HIV programming into primary and sexual and reproductive health care is a priority for a more effective HIV response. However, HIV organizations' unique experience and expertise must be preserved — and their funding secure — to integrate their work into broader health strategies.
- Community and health systems integration needs to be balanced against the continued need for community-based services for key affected populations, who often still face stigma, discrimination and neglect in government health systems.

Shifting Responsibility to Community Organizations

- Affected populations are often unable to access equitable and high-quality services due to stigma and discrimination within health care settings.
- Community-based organizations are often better equipped to support these populations and provide an important bridge to health services.
- For efforts to be sustainable, workers within community-based settings — including community health workers, peer counselors and home-based care providers — require adequate training and compensation for their work.
- Community-based service delivery should not be seen as a way for governments to abdicate responsibility for providing citizens with equitable and consistent health care.

Examples of Community Leadership in Delivering HIV Prevention, Testing and Treatment

Listed below are some examples of local community approaches to delivering HIV related services that were presented at the two consultations in Harare and Bangkok.

Liverpool VCT, Care & Treatment: Home-based Counseling and Testing, Kenya

www.lvct.org

Home-based HIV testing and counseling for increased access for couples, families and first-time testers.

Achievements include: stigma reduction, supported disclosure, easy-to-track referrals and fewer patients lost to follow-up. Community health workers and lay counselors, including people living with HIV (PLHIV), perform HIV testing and counseling.

Integrated services include:

- Alcohol screening
- Reproductive health and family planning
- TB screening
- Referrals and linkage to care
- Support groups
- Counselor-supported disclosure

Over 100,000 reached. High rates of positive test results, and 89% of HIV-positive patients linked to health-care and support services.

AIDS Care China: Better Clinic in Guangxi Province, China

www.aidscarechina.org

The "Better Clinic" is a non-profit health center for poor and key affected populations. Services combine testing, treatment of opportunistic infections, long-term housing support for people with TB and nutritional health care support.

Achievements

- Over 200 patients treated since 2011.
- 61% of them present with CD4 below 30.
- A comparative analysis showed that the cost per patient at the Better Clinic is 10-15% lower than the cost per patient at a government clinic.
- Two additional clinics in other cities are now being planned.

South Sudan Network of People Living with HIV (SSNeP+)

An umbrella membership organization of 33 PLHIV associations with 9,912 individual members who are openly HIV-positive.

Achievements since 2007 include:

- 91 volunteers trained as community counselors and home-based care providers, providing psychosocial support, prevention education, palliative care and referrals for HIV care and treatment services.
- 6,940 people referred to HIV testing and counseling (HTC), 1,790 for antiretroviral therapy and opportunistic infection treatment, and 24 for prevention of mother to child transmission programs (PMTCT).

Volunteers create door-to-door awareness of HIV, TB, and STIs facilitating access to economic development opportunities including micro-credit schemes and agricultural inputs.

Community Adherence Support Groups (CAG): Médecins Sans Frontières Mozambique

www.msf.org

Each community action group (CAG) consists of six adult PLHIV on antiretroviral therapy. One member visits the clinic each month to report on the other five members, collect drug supplies for the entire group, submit his or her own blood sample for CD4 testing and retrieve CD4 results for the member who came the previous month. Thus each member need only attend a clinic once every six months, unless there are pressing clinical indications.

Results

- There are 4410 members in 1023 CAGs in Tete Province.
- Only 121 have transferred to other sites and 112 chose individual care.
- 96.8% of CAG members have remained in care, 3.1% have died and .1% was lost to follow-up.
- The government has now taken over the program and is piloting it in 20 health centers countrywide.

International Centre for AIDS Care and Treatment Programs (ICAP) Tanzania

www.columbia-icap.org

651 HIV-positive peer treatment navigators provide adherence support at 124 health facilities.

The goals of the project are to:

- Add to the evidence base regarding why adherence is a challenge.
- Track and re-engage patients who fall out of care & treatment.
- Reduce the burden on health care workers.
- Reduce stigma through the presence of HIV-positive educators and leaders in communities and health facilities.

Peer supporters link health facilities to communities through home visits, support group facilitation, patient escort through treatment and care and tracing patients who have defaulted on treatment. Through default tracing, peer supporters found 70% of the clients lost to follow-up.

ICAP will build capacity of community based organizations (CBOs) to take over these programs and advocate for increased donor support to sustain them.

Ashar Alo Society (AAS) (Light of Hope) – Bangladesh

www.aas.org.bd

People living with HIV operate an organization combining service delivery, capacity enhancement programs for CBOs, treatment advocacy, and HIV prevention programs for PLHIV, women at-risk of HIV and key affected populations.

Services include:

- Creating demand for testing through community mobilization.
- HTC with both individual and group counseling.
- Collecting antiretroviral therapy from government hospitals and private clinics and dispensing it to clients as a stigma reduction strategy.
- Adherence support through home visits, pill checks, referrals to support groups and a mobile phone reminder system.
- “Courtyard education meetings” on treatment literacy.
- Capacity building of local PLHIV groups in both treatment adherence and income generation strategies.

AAS started with 11 people in 2000 and now has 1,272 members, 634 of whom are on treatment. They facilitate testing for more people than any other government service or non-government organization in the country.

TOPS – Myanmar

A staff of sex workers and MSM provide prevention, treatment and advocacy programs in 18 sites.

Services include:

- Outreach to sex workers and MSM, condom and lube distribution, information dissemination, referrals to TOPS drop-in centers.
- Drop-in centers in each region offering spaces for hygiene, peer support groups and English lessons.
- Clinical services at drop-in centers including medical consultations, peer-run VCT, STIs and TB screening. Two drop-in centers provide CD4 testing and antiretroviral therapy. TOPS also refers clients to Population Services International (an international NGO) or government services.
- Trained “buddy” (home-based care) program.
- Facilitation of national networks of MSM and sex workers.

Achievements

- In 2011, TOPS reached 206,729 sex workers and 222,830 MSM; 10,904 sex workers and 7,162 MSM received clinical services.
- Myanmar’s national AIDS programme (NAP), recognized that TOPS’ peer counseling model increased the uptake of testing.
- NAP organized a weeklong training program resulting in 20 TOPS-trained sex worker and MSM counselors operating in government programs.

Estonia Network of People Living With HIV (HPV)

www.ehpv.ee

Services include:

- HIV testing and counseling: Rapid testing for MSM, people who use drugs and prisoners.
- Linkage to care: A linkage manager (a staff social worker) ensures that newly diagnosed clients reach HIV clinics for CD4 testing and ART initiation, provides individualized counseling to clients on available services and schedules clinic treatment opportunistic infection.
- Retention in care: On-site case management links clients to social services and to group and individual psychosocial counseling led by peers from sex work, drug users and MSM communities; this serves to prevent loss to follow-up.

Achievements

From July - August 2012:

- 687 members of key populations were tested — 55 were positive and 43 were linked to care.
- 603 clients received at least two individual counseling sessions, 268 received psychological counseling, 1662 received peer counseling support and 239 support group meetings were held.


" I KNOW MY HIV STATUS"
DO YOU ?
GET TESTED !

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For more information about HIV treatment optimization and strengthening community-oriented HIV service delivery, contact Pangaea at www.pgaf.org or visit the HIV treatment optimization website at www.HIVtreatmentoptimization.org