

Invest in advocacy

Community participation in accountability is key
to ending the AIDS epidemic



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What advocacy has achieved

AIDS activism and civil society remain crucial for the AIDS response. Activism constitutes a global public good, deserving investment commensurate with the part it plays in improving health outcomes. (3)

Advocacy by people living with and affected by HIV has been critical to the progress made the response to HIV since the beginning of the epidemic. Advocacy has sparked action in the face of denialism and indifference, mobilized unprecedented financial resources and enabled communities to participate in designing health services that meet their needs. When traditional policy-making processes stall due to bureaucracy, advocacy shines a light on the problem and leverages community power and political will to drive action and innovation. This is why AIDS advocates around the world remain a major force for an accelerated, more equitable scale-up of effective HIV and health programming.

Increased funding support for advocacy from private funders, multilateral organizations and governments is essential if the world is to meet ambitious Fast-Track Targets around treatment, prevention and human rights, and advance towards ending the AIDS epidemic as a public health threat by 2030.

Community-led AIDS advocacy can include community mobilization, policy analysis, litigation, public events, media campaigns, accountability scorecards and protests, and it utilizes international and national human rights commitments to uphold the right to health.

Getting funding to the response

In Brazil, mass mobilization by people living with and affected by HIV, human rights activists, doctors and health-care workers led to the creation of the first governmental AIDS programme—and eventually to government-funded access to antiretroviral treatment for all people living with HIV in Brazil (1, 2).

Facing an absence of services for people affected by HIV in Ukraine in 1999, the All-Ukrainian Network of

People Living with HIV/AIDS successfully used public actions, the media, lobbying and other means to demand access to treatment, care and support. As a result, thousands of people living with HIV are now able to access basic health-care services, and the network continues to advocate for non-discriminatory health policies at the national level (4).

In South Africa, civil society advocacy continuously informs the national response to HIV. The Treatment Action Campaign (TAC) used a combination of community mobilization, protests, litigation and shrewd communication to urge the South African Government to end AIDS denialism and provide funding for antiretroviral therapy and prevention. TAC advocates with local and national government agencies on access to quality, primary healthcare, including monitoring stock-outs of HIV medicines and supplies (5). The National Association of People living with AIDS (NAPWA), established in 1994, advocates for access to treatment and prevention for the poorest people living with HIV, including those in rural areas, townships and informal settlements. The Positive Women's Network (PWN) champions the meaningful involvement of women living with HIV and campaigns for gender equity and respect for human rights in national and international forums.

Getting medicines approved

Created in the early 1990s by members of the United States-based AIDS activist group ACT-UP, the Treatment Action Group (TAG) has become a recognized expert on HIV therapies. Through analysis, communication and lobbying, TAG has advocated with government scientists, pharmaceutical company researchers and officials from the United States Food and Drug Administration

*“Advocacy for us—people directly affected by an issue—is equal to fighting for our lives. Fund grassroots empowerment and human rights work led by people directly affected by the issue, **because we will never stop fighting, and we have the strongest commitment and the deepest community connections.** What we achieved in the AIDS epidemic, such as universal access to HIV treatment in Thailand, is a testament to our bravery and determination.”*

Paisan Suwannawong, Thai AIDS Treatment Action Group

to urge faster development of new HIV therapies and increased AIDS research funding for the United States National Institutes of Health (6).

Lowering medicine prices

In South Asia, litigation and protests by the Lawyers Collective, Asia Pacific Network of People Living with HIV and International Treatment Preparedness Coalition successfully challenged intellectual property laws that limited access to generic HIV medicines. As a result, treatment access has been

improved for many countries that procure their medicines from India (7).

Combating discrimination

In China, the Henan Women's Network Against AIDS was formed in response to high HIV prevalence in the province due to contaminated blood transfusions in the 1990s.

The network learned that more than 2000 people living with HIV annually who were undergoing surgery were being charged discriminatory hospital fees for "doctor protection." The network received a microgrant to support their advocacy. Working with the Women's Network Against AIDS/China and the International Labour Organization, they provided training to doctors and nurses and advocated with hospital management for policy change, and successfully persuaded the local hospital to end the "doctor protection" fee (8).

Persuading governments to adopt evidence-informed approaches

In the early 2000s, the Thai Drug Users Network (TDN) mobilized people who use drugs to draw global attention to Thailand's detention and extrajudicial execution of drug dealers and people who use drugs. Through human rights documentation, advocacy and the creation of the Mitsamphan Harm Reduction Center in Bangkok, TDN led the way in establishing harm reduction services in Thailand (9).

Overturning punitive laws and holding law enforcement accountable

In Argentina, India, Kenya, the Russian Federation, Uganda and many other countries, lawyers and community paralegals have trained people living with and affected by HIV to know their rights. Changes to law and policy, sometimes sparked by litigation, have increased access to health services by key populations, liberalized gender identity laws, decriminalized sex work, provided training in human rights and harm reduction for law enforcement officers and removed laws criminalizing HIV transmission. In Zambia and other countries, outspoken AIDS activists have been jailed for calling for access to treatment—and they have been released because nongovernmental organizations have advocated and litigated on their behalf. This work is ongoing: in Kenya, for instance, human rights lawyers have sued over the forced sterilization of women living with HIV and to overturn a presidential directive requiring public registration of children living with HIV (10).

Mobilizing leadership

In 2015, Health GAP and other advocates attending the International AIDS Society Conference in Vancouver, Canada, launched the Vancouver Consensus Statement, which calls for immediate and universal access to antiretroviral medicines as part of a comprehensive HIV response. The leaders of the United States President's Emergency Plan for AIDS Relief, the International AIDS Society, the Global Fund to Fight AIDS, Tuberculosis and Malaria, UNAIDS and other health experts endorsed the statement (11).



Community empowerment supports stronger programming

AIDS-related advocacy has raised the profile of health care as a priority for national expenditure. (3)

A growing body of scientific research shows that community empowerment and advocacy programmes can lead to reduced HIV incidence among vulnerable populations. For example, mathematical modelling has shown the possibility of reducing HIV burden among sex workers as a result of empowerment and other cost-effective programmes that reduce violence, and it suggests that reforming laws that criminalize sex work could significantly lower HIV prevalence globally (12–14). The World Health Organization now recommends “supportive legislation, policy and financial commitment ... addressing stigma and discrimination ... community empowerment ... and addressing violence against people from key populations” as part of the comprehensive package of programmes to address HIV among key populations (15).

Funding effective advocacy

Like all aspects of the AIDS response, advocacy needs and deserves strategic financial support. Advocates and funders have specified a variety of issues that must be considered when reviewing advocacy funding proposals. They include the importance of an orientation grounded in international human rights standards, genuine roots in affected communities and real independence from government and other stakeholders. An effective advocacy proposal should have a clear analysis of how a given change by a decision-maker may affect HIV service access, and a realistic analysis of how this might be achieved.

Advocacy funders should look for organizations that have a clear vision, strong leadership and strong strategies, and then consider funding the organization rather than just a specific project in order to enable the organization to build its organizational capacities, governance and systems.

Advocacy outcomes can be measured

Monitoring and evaluation (M&E) for advocacy begins with strategic planning and the definition of clear, realistic and measurable outputs and outcomes. Monitoring of outputs (such as reports published, number of meetings with decision-makers or quantity of news articles, opinion pieces and blogs) should be combined with the evaluation of outcomes and longer-term impact (such as changes to laws and policies, and their implementation).

The following tools explore M&E approaches for advocacy in more detail:

- PATH: http://www.path.org/publications/files/TB_acsm_me_guide.pdf.
- FHI 360: http://www.fhi360.org/sites/default/files/webpages/se-toolkit/SE_Toolkit_and_Steps_PDF_files/Stakeholder_Engagement_Toolkit-Step_3.pdf.

Advocacy is a defining feature of the response to the AIDS epidemic, and it is a crucial factor in the levels of investment and political commitment dedicated to responding to AIDS. Looking forward, advocacy remains crucial to driving sufficient resources, addressing the needs of the people most affected, and holding governments and funders accountable for the concrete results that will lead to ending AIDS as a public health threat.

References

- 1 Galvao J. Access to antiretroviral drugs in Brazil. *The Lancet*. 2002;360/9348: 1862–65.
- 2 Berkman A et al. A critical analysis of the Brazilian response to HIV/AIDS: lessons learned for controlling and mitigating the epidemic in developing countries. *American Journal of Public Health*. 2005;95/7: 1162–72.
- 3 Peter Piot, et al. Defeating AIDS — advancing global health. *The Lancet*, Vol. 386, No. 9989, p171–218 (2015).
- 4 A nongovernmental organization's national response to HIV: the work of the All-Ukrainian Network of People Living with HIV. Geneva: UNAIDS; 2007 (http://www.unaids.org/sites/default/files/media_asset/jc1305_ukraine_full_en_0.pdf, accessed 19 November 2015).
- 5 Klugman B. The role of membership-based organisations in constitutional democracies: Lessons from the experience of the Treatment Action Campaign in organizing communities for social change. Atlantic Philanthropies / Treatment Action Campaign, Johannesburg, October 2015.
- 6 History. In: Treatment Action Group (TAG) [website] (<http://www.treatmentactiongroup.org/history>, accessed 19 November 2015).
- 7 Our Health Our Right. The roles and experiences of PLWHA networks in securing access to generic ARV medicines in Asia. Asia Pacific Network of People Living with HIV/AIDS (APN+).
- 8 Davis S. and Mohamed C. Human rights, capacity, and right-to-health advocacy in China. Paper presented to Modern China Seminar, Columbia University, 10 December, 2015.
- 9 Tanguy P. Civil society and harm reduction in Thailand: lessons not learned. 10 February 2015. In: Middle East Institute [website]. Washington, DC: Middle East Institute; 2015 (<http://www.mei.edu/content/map/civil-society-and-harm-reduction-thailand—lessons-not-learned>, accessed 19 November 2015).
- 10 Chan A. High Court of Kenya to address forced sterilization of HIV-positive women and collection of names of people living with HIV. In: Harvard Health and Human Rights Journal/Blog [website]. Cambridge, MA: Harvard; 2015 (<http://humanrights.harvard.edu/publications/high-court-kenya-address-forced-sterilization-hiv-positive-women>, accessed 19 November 2015).
- 11 International AIDS Society Conference 2015. The Vancouver Consensus. <http://vancouverconsensus.org>
- 12 Decker MR et al. Estimating the impact of reducing violence against female sex workers on HIV epidemics in Kenya and Ukraine: a policy modeling exercise. *American Journal of Reproductive Immunology*. 2013;69(Suppl 1): 122–32.
- 13 Shannon K et al. Global epidemiology of HIV among female sex workers: influence of structural determinants. *The Lancet*. 2015;385(9962): 55–71.
- 14 Vassall A et al. Community mobilisation and empowerment interventions as part of HIV prevention for female sex workers in Southern India: A cost-effectiveness analysis. *PLoS One*. 2014 Oct 21;9(10).
- 15 Policy brief: consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. Geneva: WHO; 2014.

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