



KENYA TREATMENT ACCESS MOVEMENT (KETAM)

African Civil-Society Recommendations on the Next Phase of U.S. Global AIDS Assistance *December 11, 2007*

On December 10-11, 2007, representatives of 21 civil-society organizations, including representatives of PLHA organizations as well as large PEPFAR AIDS treatment providers, met in Nairobi to provide feedback and recommendations on the future of U.S. global AIDS policy. The meeting was hosted by the Kenyan AIDS Treatment Access Movement, Global AIDS Alliance, and Health GAP. In light of the upcoming debates on PEPFAR reauthorization, we respectfully submit the following recommendations from people living with HIV/AIDS and working on the front lines of the AIDS pandemic. The following summarizes our prioritized recommendations, and a full report will be made available shortly.

1. Numbers on treatment versus measuring healthy patients: PEPFAR is doing a historic and important job of getting people on ARV treatment. However, counting a person who is receiving AIDS drugs is not the same as supporting health for people with HIV. The urgent and important work of attempting to meet treatment targets is not integrated with more comprehensive support for actual patient health. When patients are only provided *one part* of what we need to survive, however important, the end result is poor health outcomes, questionable accounting practices, and unacceptable loss to follow up.

- ◆ The second five years of U.S. global AIDS initiatives should measure longer-term patient health outcomes in addition to simple numbers of people on ARV treatment. This should be backed up by independent patient satisfaction surveys and spot audits of PEPFAR-supported medical facilities.

2. Opportunistic infection drugs are not available: Many programs provide free ARVs, which are urgently required and profoundly appreciated. However, efforts to scale up access to AIDS treatment is taking place without an eye toward actually increasing patient survival. While anti-AIDS medicines are almost always free, medicines to treat the **opportunistic infections** that accelerate our death are often unavailable from clinics and too costly for patients to purchase from pharmacies. Stock-outs at medical facilities and dispensaries are also common and very harmful to patient health.

- ◆ PEPFAR should provide free and accessible OI treatment and services at all health facilities.

3. Unequal standards of care: Powerful new antiretroviral drugs are transforming the lives of people with HIV in the United States, producing much more durable viral suppression, greatly reduced toxicity and side effects, and improved prospects for long-term adherence. With few exceptions, these new drugs are not available through PEPFAR-supported ART sites or other treatment support programs. We recognize that drug regimen decisions are largely made at the country level, but guidance from PEPFAR strongly influences treatment formularies.

- ◆ Support provision of **quality regimens** that are less toxic and more accessible, affordable, and manageable for people living with HIV/AIDS.
- ◆ The U.S. should work with countries, generic drug manufacturers, and PEPFAR recipient programs to ensure that there are equitable standards of medical care between the North and South.

4. Services for young adults: HIV prevalence is mostly impacting children and young people between the ages of 9 and 24.

- ◆ Funding and programs should specifically target **children and young people**, and meet the needs of the increasing number of orphans and other vulnerable children. The age bracket receiving support from the OVC earmark should be increased to include young adults, and the percentage of funding for orphans, vulnerable children, and youth should be increased.

5. Efforts to reach marginalized populations should be expanded: Programs should be designed and implemented with respect for the human rights of marginalized groups, such as people living with HIV/AIDS, orphans and other vulnerable children, women, prisoners, commercial sex workers, men who have sex with men, people with disabilities, migrants, people living in conflict or post-conflict situations, pastoralists, rural populations, ethnic minorities and the elderly. **PTMCT** services are the privilege of a few, and many poor mothers cannot afford recommended services, such as alternatives to breast milk. There is a new wave of **stigma** due to existing PEPFAR **prevention policies**, and current programs are insensitive to age, culture, and gender-specific needs. The abstinence-only earmark is a distraction from meaningful work to reduce rates of new infections in our countries.

- ◆ Services should be tailored to meet the needs of vulnerable populations and be accessible, affordable, and within reach.
- ◆ Prevention programs should invest in evidence-based preventive strategies that strengthen community-based and peer-led awareness creation and behavior change programs, placing vulnerable populations at the center of prevention responses, and addressing the social, economic, and cultural issues that drive new infections.
- ◆ Prevention program should be context-specific, include **prevention services for people living with HIV/AIDS**, and step up efforts to address AIDS-related stigma and gender-based violence.
- ◆ New efforts should be launched to support active outreach to underserved, high-risk groups such as prisoners and people in post-conflict areas.
- ◆ PMTCT services should be scaled up to provide nutritional support, alternative infant nutrition, and affordable Cesarean sections for pregnant HIV-positive women.
- ◆ PMTCT programs should be linked to AIDS treatment and sexual and reproductive health programs, including family planning, pre-, post- and antenatal services, and socioeconomic support for mothers.

6. Lack of medical equipment: Many health facilities—especially in rural areas—are poorly equipped in terms of equipment and supplies. In particular, countries urgently need CD4 machines and reagents as well as x-ray machines. People with HIV are required to show CD4 results or x-rays in order to medically qualify for AIDS or tuberculosis treatment and to monitor therapies. Too often, the machines are not available in any accessible medical facility, or the tests are prohibitively expensive.

- ◆ Procure and maintain medical equipment needed to provide AIDS care, including x-ray and CD4 machines and necessary reagents.

7. Shortages of trained health workers and facilities: There is a shortage of health care providers in our countries, and provision of primary health care suffers when PEPFAR-supported programs hire away scarce health professionals from public sector primary care facilities. Training of existing health professionals has not kept pace with the scale-up of AIDS programs at the country level, and improved quality assurance measures are necessary. Women and people with HIV serving as community health workers and home-based care providers bear the brunt of providing care and services to people living with HIV/AIDS, but are not recognized, supported, or paid. Additionally, access to functioning care facilities can be very difficult outside of urban centers, and too many rural clinics are understaffed, inadequately equipped, and inconsistently supplied.

- ◆ U.S. AIDS initiatives should invest to substantially increase the supply of health professionals, support pre- and ongoing in-service training of all cadres of new and existing health workers, and work with countries and professional associations to develop HIV care provider accreditation standards and monitoring.

- ◆ Much more should be done to retain existing health workers, including increased remuneration and improved working conditions.
- ◆ Community health workers should be trained, certified, equipped, and supported by a functioning referral systems and increased number of health professionals. Community health workers should be paid a wage sufficient to support a family and be integrated into the mainstream health system.
- ◆ More health facilities are needed in rural areas, as well as transportation support for patients.

8. PEPFAR country plans are not aligned with national plans or accountable to civil society: U.S. programs are too often operated as parallel systems—duplicating, undermining, or even weakening country-level capacity to respond effectively to health issues. While civil-society organizations have been at the forefront of the fight against AIDS, we are not consulted or meaningfully able to contribute to U.S. efforts, policies, plans, and priorities.

- ◆ Broader and transparent consultation is needed to ensure that PEPFAR programs are more responsive to country contexts, complement country plans and priorities, and strengthen the country ownership necessary to ensure sustainability.
- ◆ PEPFAR should prioritize integrating services into existing programs, especially in public-sector health facilities, rather than running parallel services. Parallel efforts such as the Supply Chain Management System (SCMS) should be required to work with in-country partners to transfer operations over time.
- ◆ PEPFAR programs should be developed in consultation with civil-society organizations, including networks of people living with HIV/AIDS and other vulnerable groups, to ensure community ownership, leadership, and sustainability. Future U.S. AIDS initiatives should adopt a bottom-up approach to empower communities to take leadership in policy design and implementation.

The following organizations developed these recommendations, and thank you for considering their inclusion as the U.S. global AIDS initiative is reauthorized, reformed, and renewed:

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Plus two additional individuals representing large AIDS treatment programs supported largely by PEPFAR, who wish to remain anonymous to protect their ability to offer candid assessments.

Sponsors:

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