Eastern and Southern African Civil Society Position Paper on Universal Access to HIV and AIDS Prevention, Treatment, Care and Support

We, representatives of civil society groups responding to HIV and AIDS in eastern and southern Africa[1], met on 10 and 11 March 2011, to build consensus on progress, barriers and lessons learned, aimed at catalysing actions to ensure a trajectory towards zero new HIV infections, zero AIDS-related deaths and zero discrimination. The deliberations resulted in this position paper, which aims to contribute to discussions on achieving universal access to HIV and AIDS prevention, treatment, care and support as well as the Millennium Development Goals by 2015, including the African Union Ministers of Health Meeting in April 2011, in Windhoek, Namibia as well as the High Level Meeting on AIDS in New York in June 2011.

The main outcome of this consultation is a recognition that the gains made in the regional AIDS response over the past decade are under threat. Now more than ever, **political will and commitment** is needed to ensure the achievement of zero new HIV infections, zero AIDS-related deaths and zero discrimination through universal access, in the true sense of the word – an equitable, accessible, affordable, comprehensive, measurable and sustainable advance towards a higher level for the most effective interventions needed to manage the diverse epidemics across countries[2]– is achieved in the region.

Welcoming the considerable progress made in the response to HIV in eastern and Southern Africa, due to global solidarity and the political commitment of governments in the region, as captured in the 2006 Brazzaville *Commitment on Scaling Up Towards Universal Access to HIV and AIDS prevention, treatment, care and support in Africa by 2010*, and endorsed in the 2006 *Abuja Call for Accelerated Action Towards Universal Access to HIV and AIDS, Tuberculosis and Malaria Services in Africa*. Significant gains were made in the scale up of access to antiretroviral treatment with an estimated[3] 3.18 million people on treatment in the region in 2009, compared to only 255,600 in 2004. In addition, access to prevention of vertical transmission has expanded substantially across the region, where 68% of pregnant women living with HIV received antiretroviral medication to prevent vertical transmission of HIV in 2009 compared to only 15% in 2005. There were 32% fewer children under 15 newly infected — and 26% fewer AIDS-related deaths among children in southern Africa in 2009 compared with 2004. UNAIDS also reported a decline of more than 25% in HIV prevalence among youth in 9 of the 20 countries in the region over the last decade and several countries in the region have reported substantial declines or a stabilisation in HIV incidence – albeit at high rates;

Recalling that much of the impetus for the regional response to HIV has come from the mobilisation and activism of people living with HIV and an independent civil society in the region, through their meaningful involvement in HIV responses; holding governments and themselves accountable for their

[1] Participants of the meeting comprised networks of people living with HIV, AIDS service organisations, women's groups, youth groups, organizations of people living with disabilities, networks of sex workers, private sector, trade unions, academia, faith-based organizations, organizations of lesbian, gay, bi-sexual, transgender and intersex people, organizations working with children and young people, treatment access movements, legal assistance organizations, human rights organizations, and others working at the frontlines of the response to HIV and AIDS in the region.

[2] UNAIDS, 2009, What countries need: Investments needed for 2010 targets

[3] UNAIDS, 2010, UNAIDS Report on the Global AIDS Epidemic: 2010

commitments; and working tirelessly for rights-based national HIV responses, which protect the rights of those living with and at higher risk of HIV;

Recognising that people living with HIV are powerful advocates in the quest to achieving zero new HIV infections, zero AIDS-related deaths and zero discrimination. Placing the person living with HIV at the centre of managing their health and wellbeing, through the Positive Health, Dignity and Prevention approach, maintains their dignity and has a positive impact on that individual's physical, mental and sexual health, which in turn, amongst other benefits, creates an enabling environment that contributes to HIV prevention, treatment, care and support outcomes;

Recognising also that, although the HIV response in eastern and southern Africa has experienced a significant increase in political commitment as well as financial and other resources over the past decade; the region remains the epicentre of the HIV and AIDS epidemic, with 16.1 million people living with HIV residing in the region, accounting for 48.3% of global HIV infections[4]. Of these, 1.6 million are children. In 2009, 3,200 people in the region became newly infected with HIV every day, while 890,000 deaths due to AIDS-related causes were reported - of these, 150, 000 were children;

Convinced that the realities and responses in eastern and southern Africa - the epicenter of the epidemic - should shape global thinking about how to achieve zero new HIV infections, zero AIDS-related deaths and zero discrimination as well as ways to roll back the socio- economic impact of HIV on communities, families, women, girls and children globally;

Noting that in most countries in the region heterosexual sex is the key driver of new infections – however, even in countries with generalised epidemics, there are concentrated epidemics among key populations at higher risk of HIV infection such as lesbian, gay, bisexual, transgender and intersex people; persons who inject drugs and sex workers, fuelled by punitive laws and rights violations against these populations, which drives them underground and away from services;

Greatly concerned that young people, women and girls in the region are disproportionately infected with and affected by HIV, due to biological and other vulnerabilities, the underlying causes of which include gender inequality; poverty; harmful cultural, social and gender norms and practices; gender-based violence and social marginalization, still prevailing in the region. About 40% of all adult women living with HIV globally live in southern Africa, where young women are at particularly high risk of HIV infection;

Concerned also that poverty, food insecurity and other development challenges contribute to and reinforce HIV infection and its impact on the individual, household and community levels, in a vicious cycle. Thus, HIV is intricately linked to all Millennium Development Goals and has contributed to the regression of development gains, leading to a severe negative socio-economic impact on all countries in the region. The impact of this has disproportionately been carried by women, children, the elderly, disabled people and key populations at higher risk of HIV in the region;

Alarmed that stigma, discrimination and homophobia remain key barriers to universal access to prevention, treatment, care and support services in the region; and contribute to rights violations targeted at people living with HIV, women, children, people living with disabilities, refugees, mobile populations, prisoners and key populations at higher risk of HIV infection such as sex workers; lesbian, gay, bisexual, transgender and intersex people; and people who inject drugs;

[4] UNAIDS, 2010, UNAIDS Report on the Global AIDS Epidemic: 2010

Alarmed also that many countries in the region still have laws, policies and regulations that create obstacles to effective HIV responses by failing to ensure access to services; protection against discrimination; and upholding the rights of people living with HIV; women; children; sex workers; lesbian, gay, bisexual, transgender and intersex people; people with disabilities; prisoners; youth; people who inject drugs and others with special needs and vulnerabilities. In settings where protective legal frameworks exist, implementation and enforcement is inconsistent;

Distressed that opportunistic infections, in particular tuberculosis (TB), are strongly associated with HIV infection and remain the biggest killer of people living with HIV. Cervical cancer, specifically, has emerged as the most common type of cancer among women living with HIV as more HIV positive women are infected with the Human Papiloma Virus (HPV) and the disease progresses faster within those with a compromised immune system to become the most frequent cause of cancer-related death among women living with HIV;

Concerned also that the lack of financial resources for HIV remain a serious threat to HIV responses in the region. Most governments in the region are yet to meet their 15% Abuja commitments to domestic funding for health or the World Health Organisation recommendation of ensuring that per capita income allocated to health is at least $40, while donors are not contributing their fair share to HIV and health responses. The under-funding of the Global Fund to Fight AIDS, Tuberculosis and Malaria and other bilateral and multilateral programmes threatens to halt or even reverse gains made in strengthening and expanding prevention, treatment, care and support programmes;

Gravely concerned that the gains made in the HIV response over the past decade are at great risk. In the region, only 1 in 10 people aware of their status and most people learn about their HIV status very late in the progression of the disease according to UNAIDS. In addition, for every 2 people going onto treatment programmes, another 3 are becoming newly infected with HIV;

Convinced that political commitment and strong leadership by the governments of eastern and southern Africa is key to achieving zero new HIV infections, zero AIDS-related deaths and zero discrimination; as well as addressing the core drivers of HIV in the region, including gender inequalities; legal barriers; and the impact of poverty and other socio- economic challenges on communities;

Certain that HIV responses should be placed centrally within the broader development agenda and in relation to a paradigm of sexual and reproductive health and other public health and development threats such as poverty reduction, malaria and TB;

Reaffirming that civil society led advocacy, activism and action for government and donor accountability is key to accelerating gains made in prevention of new infections, treatment scale up and mitigation of socio-economic impact;

Also believing that enhanced collaboration between all sectors of the HIV response - and in particular between governments; donors, people living with HIV; civil society, particularly people living with and at higher risk of HIV; and the private sector is key to achieving universal access;

Convinced that universal and indivisible human rights must underpin all responses to the epidemic recognising that everyone, regardless of nationality, gender, sexual orientation, age, race, or socio-economic status, has the right to health;

We call on African governments, civil society, donors and the international community to ensure the following in order to achieve zero new HIV infections, zero AIDS-related deaths and zero discrimination and begin to reverse the HIV epidemic in eastern and southern Africa:

National ownership of the HIV epidemic

- *Governments in eastern and southern Africa*, from district and local government to national levels; people living with HIV; civil society - particularly indigenous groups at the community level; and other stakeholders should renew their commitment to universal access and undertake concrete actions to own and contribute to the multi-stakeholder national response to the HIV epidemic;
- *Governments in eastern and southern Africa* should incorporate their HIV response into all key national strategies and budgets and ensure that it is resourced adequately by, as a minimum, meeting the 15% of annual budget to health threshold as dictated by the Abuja Declaration or the World Health Organisation recommendation of ensuring that per capita income allocated to health is at least $40. This can be achieved by, amongst others, establishing a national fund for HIV and other high burden diseases, financed through innovative domestic financing mechanisms such as taxes, levies and the engagement of the private sector. Ownership of, and accountability for, the use of these resources rests with governments, civil society and private sector;
- *Governments in eastern and southern African, donors and the UN system* should support civil society groups, particularly indigenous organisations, to empower themselves to contribute to, and advocate for, rights-based HIV approaches, by ensuring an enabling environment, sustainable and robust funding, technical capacity for programme design, implementation and evaluation, as well as the development of organisational strategic plans that support national development and action plans and national HIV and health policies;
- *Donor governments and the international community* have an obligation to continue to respond fully to the epidemic, recognising that national ownership does not absolve international partners, including the G8, of their responsibility to ensure the realisation of the right to health; and
- *Donors, civil society and governments in eastern and southern African* should establish mechanisms to more effectively track the allocation of both external and domestic funds in order to monitor not only the progress but also the impact of interventions towards zero new HIv infection; zero AIDS-related deaths and zero discrimination in the context of HIV and AIDS. This should include regularly updated situation analyses on vulnerable populations, including children, women people with disabilities and young people; and populations at higher risk of HIV infection such sex workers, people who inject drugs, lesbian, gay, bisexual, transgender and intersex people. National monitoring and evaluation systems need to be reviewed, strengthened and supported in view of this, with a stronger emphasis on resource tracking and impact at the community level.

Zero New Infections: HIV prevention

- *Governments in eastern and southern African and donors* should renew leadership and increase financial commitment to deliver a comprehensive, robust and evidence informed HIV prevention response according to the UNAIDS approach of 'know your epidemic, know your response' and tailored to meet the unique and changing needs of the diverse groups living with, affected by and at higher risk of HIV, for which all stakeholders will be accountable;
- *Governments, civil society and donors in eastern and southern Africa* should recognise that the HIV prevention revolution in the region should clearly prioritise and resource interventions, which target the underlying causes of vulnerability to HIV infection, particularly of women and girls as a disproportionately affected group and be based on a comprehensive combination prevention

effort. This should include linkages between HIV-related services and a comprehensive package of sexual and reproductive health interventions, including screening and treatment of cervical cancer for women living with HIV and early access for all young women to the HPV vaccine; aimed at having a high impact on prevention outcomes for women, girls, young people, children and other key populations at higher risk of HIV. Efforts must also take into account and address the vulnerable position of women and girls in eastern and southern African societies, especially with regards to violence against women, and how this is central to fuelling the epidemic;

- *Eastern and southern African governments, in coordination with donors and global agencies,* must capitalise on the prevention benefits of affordable, accessible and sustainable access to uninterrupted quality antiretroviral treatment for people living with HIV; recognising that access to antiretroviral treatment not only diminishes morbidity and mortality, but has also been shown to benefit prevention efforts by reducing prevalence and incidence. Treatment is thus inextricably linked to prevention. Significant gains will only be made if access to early HIV testing is also encouraged;
- *Eastern and southern African governments and donors* must commit to ensuring that no African child is born with HIV, by annually scaling up prevention of vertical transmission efforts according to the updated WHO treatment guidelines, as well as ensuring that mothers are treated comprehensively for HIV, and not just in the context of vertical transmission;
- *Eastern and southern African governments and donors* must also invest in the discovery of new prevention technologies suitable for the region, along with universal access to existing prevention technologies, including male circumcision, male and female condoms; and
- *Eastern and southern African governments* must acknowledge the heavy burden that TB and cancer of the cervix places on the region, especially within high-HIV settings, by developing and funding interventions that ensure greater access to TB education and prevention programmes as well as screening and treatment of cancer of the cervix in women living with HIV.

Zero Deaths: Treatment

- *Eastern and southern African governments and donors* must commit to ambitious annual targets, increasing the number of people, including children, on equitable, affordable, acceptable, accessible, uninterrupted, and quality tuberculosis, HIV and AIDS treatment according to the 2010 WHO treatment guidelines, in order to reach the universal access target of at least 80% coverage of antiretroviral treatment and prevention of mother-to-child transmission programmes;
- *Eastern and southern African governments and donors* must allocate substantial financial and other resources to health, and measure this by assessing the annual increase in the number of public health facilities providing comprehensive and quality HIV and TB testing, antiretroviral treatment as well as proper pain and symptom management. Ambitious targets can in part be achieved by adopting the UNAIDS Treatment 2.0 approach to ensure continued and improved access to fixed dose combination generic drugs and a commitment to the development of innovative new drugs to be made available throughout the developing world. Treatment scale up should be driven by a commitment to decentralisation and community-driven treatment literacy programmes that promote HIV testing and a patient-centred approach to treatment adherence, as well as ensuring that there is a strong linkage between testing, treatment and care;
- *Eastern and southern African governments and donors* must address the high-burden of TB within the region, ensuring a scale-up in TB testing and treatment through a rights-based, patient-centred approach. This includes ensuring HIV-TB integration and encouraging the creation and implementation of better and cheaper region-specific diagnostics and treatment;

- *Eastern and southern African governments* must make use of TRIPS flexibilities and enact and use legislation and agreements that work to ensure increased and uninterrupted access to high-quality generic medicines; and
- *Eastern and southern African governments* must renew their commitment to attaining universal access targets for correct knowledge of HIV status for all citizens through enhanced testing technologies and strategies, premised on a rights-based approach and the availability of point of care diagnostics, to enhance proper treatment monitoring for adequate treatment adherence, thus avoiding treatment attrition brought on by, amongst others, the current centralised monitoring approaches.

Care and support

- *Eastern and southern African governments* must review their existing national action plans for HIV and AIDS and orphans and vulnerable children with the view to linking and integrating these strategies into broader national development plans and to regional strategies. This must include more comprehensive definitions of and responses to care, support and vulnerability. Consultations to this end must include the most vulnerable groups, including children, and include consultation at community level;
- *Eastern and southern African governments, civil society, and care providers* must commit to a rights-based, patient-centred approach to HIV care and support that encourages treatment adherence by addressing individual and community needs and challenges including those of food security and nutrition;
- *Eastern and southern African governments* must urgently address civil registration challenges in their country. This includes, where relevant, legislation for free birth and death registration as well as adequate domestic resource allocation for programmes which can ensure equal access to civil registration; and
- *Donors and governments in Eastern and southern Africa* should allocate sustainable external and domestic funds to support the development and implementation of HIV, child-and women-sensitive national social protection programmes, which also address food insecurity and poverty.

Gender

- *Eastern and southern African governments* must ensure that HIV responses are informed by issues of gender, particularly those of women and girls, through deliberate focus and inclusion of women and girls in the design, implementation, resourcing and evaluation of HIV and AIDS interventions;
- *Donors, civil society and governments in eastern and southern African* should scale up interventions that focus on the economic (and other) empowerment of women and girls, particularly those at the community level, and the strengthening of programmatic linkages between HIV and sexual and reproductive health services for women, girls, young people, people with disabilities, migrant populations, refugees, prisoners and key populations at higher risk including sex workers, people who inject drugs and lesbian, gay, bisexual, transgender and intersex people. These interventions should include screening and treatment of cervical cancer for women living with HIV and early access for all young women to the HPV vaccine; and
- *Governments in eastern and southern Africa* should design and resource interventions, which engage men to address gender-based violence, gender inequality and other underlying causes of women's vulnerability to HIV, including harmful cultural, social and gender norms that put women, girls, children and young people at increased risk of HIV.

Zero Discrimination: Human rights

- *Governments* in *eastern and southern Africa* should commit to developing and fully resourcing rights-based HIV responses, which are evidence-informed and focused on the realisation and protection of the rights of those living with HIV as well as the needs of the most marginalised in communities such as women, girls, children, young people, prisoners, refugees, mobile populations and people living with disabilities and key populations at higher risk of HIV such as sex workers, injecting drug users and lesbian, gay, bisexual, transgender and intersex people by encouraging their participation, inclusion and rights-awareness;
- *Donors, civil society and governments in eastern and southern African* should prioritise anti-stigma and anti-homophobia interventions at the community level, designed and implemented with the meaningful involvement of people living with HIV according to the principles of Positive Health, Dignity and Prevention and key populations at higher risk of HIV such as sex workers, people who inject drugs and lesbian, gay, bisexual, transgender and intersex people;
- *Eastern and southern African governments* should develop and adequately resource the strengthening and enforcement of comprehensively protective legal frameworks including anti-discrimination legislation and the enforcement of the ILO standard on HIV in the workplace; the repeal of punitive laws against sex workers and lesbian, gay, bisexual, transgender and intersex people as well as laws that hinder the effective implementation of harm reduction and opioid substitution programmes;
- *Donors, governments in eastern and southern African as well as civil society* should develop and fully fund human rights programming for inclusion in all National AIDS strategies, including supporting HIV-related legal services; legal audits and/or law reform; legal literacy through 'Know your rights/laws' programmes; training and sensitization of health care workers lawyers, judicial officers,law enforcement officers and/or judges on HIV and human rights; ; stigma and discrimination reduction programmes; and programmes that seek to empower women by reducing harmful gender norms and gender-based violence and increasing equality in the economic, social and legal spheres;
- *Donors, governments in eastern and southern Africa and civil society groups* should ensure the full integration of patient protections into biomedical interventions, such as consent procedures in the context of HIV and TB counselling and testing, and non-discrimination policies in the provision of treatment; and
- *Governments in eastern and southern Africa*, donors and civil society in the region should also ensure that independent, indigenous and other non-governmental organisations have the political space in which to operate, as well as the capacity to effectively plan and implement human rights programs and to hold governments accountable for the realisation of rights as this is essential for a human rights approach to HIV.

The Participants
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