Action Group for Health, Human Rights and HIV/AIDS (AGHA) Uganda
AIDS Information Centre (AIC) Uganda • Civil Society Coalition on Human Rights and Constitutional Law
Coalition for Health Promotion and Social Development (HEPS) Uganda • Health Global Access Project (Health GAP) • Health Rights Action Group (HAG) • International Community of Women Living with HIV/AIDS (ICW) Eastern Africa • International HIV/AIDS Alliance Uganda • National Community of Women Living with HIV/AIDS (NACWOLA) • National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) • The AIDS Support Organisation (TASO) Uganda • Uganda Network on Law, Ethics and HIV/AIDS (UGANET) • Uganda Health and Science Press Association (UHSPA)
Uganda Network of AIDS Service Organisations (UNASO)

THE CHANGE WE NEED TO END AIDS IN UGANDA

A civil society analysis of the state of Uganda's AIDS response
and a 10-point plan to halt new infections, save lives, and ensure leadership

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Uganda's challenge: an end to "business as usual"

For years Uganda has been lauded as a global HIV success story, due to pronounced declines in HIV prevalence from the 1980s-90s. Some experts believe this decline was due to successful HIV prevention efforts; others argue that widespread AIDS deaths were probably the main cause of prevalence reductions. Alarmingly, those declines—no matter the cause—appear to be a thing of the past.

Now Uganda is one of a small minority of countries with generalized, mature HIV epidemics that are reporting rising HIV prevalence.[1] In Uganda, prevalence has risen from 6.4 to 7.3% between 2006 and 2012 and incidence is also estimated by Ministry of Health to have increased between 2005 and 2011. Importantly, Uganda is the only PEPFAR "Focus Country" reporting rising HIV incidence[2]—all other PEPFAR focus countries have consistently reported declines in incidence as well as prevalence in recent years.

A failing response to AIDS?

These troubling trends, recently reported in Uganda's 2011 AIDS Indicator Survey, signal serious shortcomings in the national response to HIV.[3] Some are blaming "complacency" among Ugandans—antiretroviral treatment (ART) availability has made people less worried about HIV, according to this argument. However, if that were true, similar trends would be expected in other countries with similar epidemic patterns with scaled up ART access—but these countries have reported the opposite trends. **Instead, assessing current data provides an evidence-based picture as to what is causing this alarming lack of progress in the fight against HIV:**

• HIV treatment saves lives and is one of the most powerful prevention tools available—groundbreaking new research shows that earlier treatment of HIV positive people—at levels greater than CD4 350—results in 96% reduction in the risk of HIV transmission through sex with an uninfected partner,[4] is highly cost effective,[5] and provides significant clinical benefit.[6] Access to treatment regardless of CD4 count ("Option B+") for pregnant women also holds the promise of elimination of HIV transmission through pregnancy, labor and breastfeeding while providing clinical benefits for the woman and prevention benefit for any HIV negative sex partner. However, ART coverage in Uganda is low—at 57% of currently eligible people with HIV,[7] and the pace of scale up has been slow, particularly when contrasted with other countries in the region such as Tanzania and Kenya (see Table 1). In 2009, providers in Uganda began turning new patients away from treatment despite clinical need do to a widely criticized policy of "capping" new treatment slots. By June 2010, these caps were stopped and 36,000 additional treatment slots were added—after intense public civil society pressure.

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[1] Angola, Mozambique, Uganda are the only countries in this category. See WHO: Global HIV/AIDS Response, Epidemic Update and Health Sector Progress Towards Universal Access, Progress Report, 2011. p. 12-17.

[2] PEPFAR Focus Countries have received the highest levels of US government prevention, care and treatment funding since PEPFAR was started in 2003. They are: Botswana, Côte d'Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Vietnam, and Zambia.

[3] Some policymakers have argued that rising HIV prevalence in Uganda might be caused by people with HIV living longer due to access to ART. However, this argument is not consistent with the overwhelming trend in other countries in the region that have been scaling up access to treatment faster than Uganda—which is one of *declining* HIV prevalence as well as *longer* lifespans for people with HIV. Uganda's population is also growing at one of the fastest rates in the world, a factor that would be assumed to affect trends inprevalence.

[4] M. Cohen et al (2011). Prevention of HIV-1 Infection with Early Antiretroviral Therapy. The New England Journal of Medicine 365:493-505

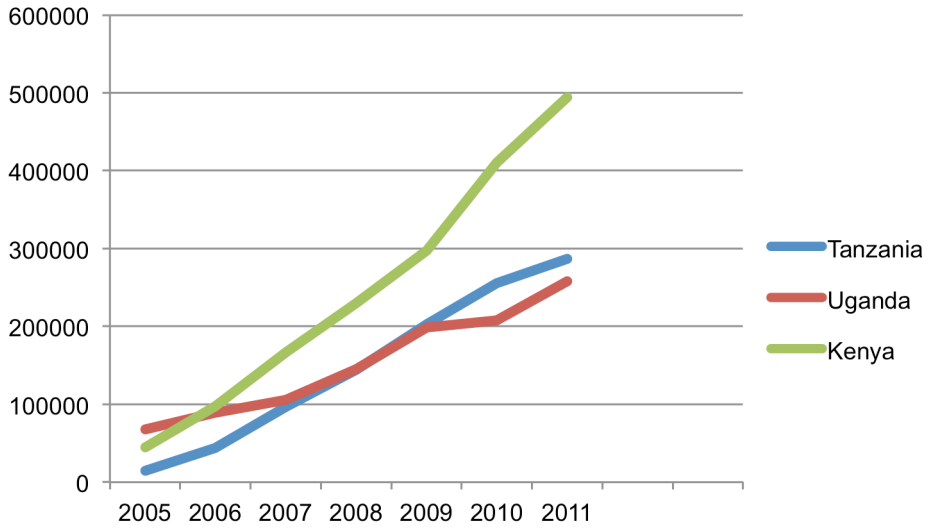
[5] K. Freedberg et al. The cost-effectiveness of treatment as prevention: analysis of the HPTN 052 trial. FRLBC01 - Oral Abstract. http://pag.aids2012.org/abstracts.aspx?aid=21242

[6] B. Grinsztejn et al. Effect of early versus delayed initiation of antiretroviral therapy (ART) on clinical outcomes in the HPTN 052 randomized clinical trial. THLBB05 - Oral Abstract. http://pag.aids2012.org/Abstracts.aspx?SID=16&AID=21278

[7] Annual Performance Review of the National Strategic Plan for HIV/AIDS 2010/11-2014/15. Financial year 2011/12.

Importantly, the World Health Organisation (WHO), which currently recommends HIV treatment be initiated for all people with CD4<350 or with clinical conditions that indicate immune system decline, will modify its guidelines about when to start ART in the first quarter of 2013, based on overwhelming evidence of the cost effectiveness, clinical and prevention benefits of earlier initiation of treatment. When WHO recommends earlier initiation of HIV treatment in early 2013, Uganda's coverage levels will fall even further behind.

Table A. PEFPAR directly supported ART scale up in Kenya, Tanzania and Uganda
source: PEPFAR Annual Country Progress Reports 2005-2011



• **In 2011, the Government of Uganda withdrew outreach clinics based outside of formal health facilities** that provided free comprehensive services in 54 sites around the country—including treatment and prevention of opportunistic infections, community based treatment monitoring, and prescription refills. Instead of using "outreaches" patients who miss an appointment are now not routinely followed up, and anecdotal reports indicate a negative impact on patient outcomes.[8] Scientific research indicates that successful HIV treatment programs *require* a component of non-facility based health services—including home based visits, psychosocial counseling, and adherence support. In fact, Uganda's patient outcomes have been markedly better than other cohorts *because* of these community based components[9]—which have now been eliminated.

• **Rates of condom use in Uganda have declined sharply between 2005-2011,** particularly during sex with non-cohabitating sex partners. For example, among women and men, reported condom use during sex with a non-cohabitating partner declined significantly between 2005 and 2011 from 47% to 29% and from 53% to 38%, respectively.[10]

• **Uganda's prevention funding is not matched to drivers of the epidemic** according to Uganda's 2011 National Prevention Strategy. Effective, evidence-based HIV prevention targeting vulnerable populations such as

[8] "PEPFAR: Snatching Defeat from the Jaws of Victory? Gains generated by Uganda's community HIV prevention, and treatment programs under threat." International HIV/AIDS Alliance Uganda, NAFOPHANU and Health GAP. September 2012.
[9] O. Koole et al. 19th International AIDS Conference Oral Abstract: MOAC0305 Retention and risk factors for attrition among adults in antiretroviral treatment (ART) programs in Tanzania, Uganda and Zambia.
[10] Uganda AIDS Indicator Survey 2011. Ministry of Health. Kampala. August 2012.

serodiscordant couples, fishing communities, sex workers, men who have sex with men,[11] migrant populations and prisoners not receiving proportionate funding for proven interventions.[12]

• **Uganda has also consistently spent more on "abstinence and being faithful" ("AB")** programming than other countries in the region that have declining incidence—those have invested more heavily in comprehensive, evidence-based approaches. There is no evidence that AB programs, focusing solely on behavior change, have had success in actually reducing the spread of HIV and increasing protection among communities at risk of infection.

• **Condom access has been undermined by the Government of Uganda's bureaucratic post-shipment testing requirements.** Condoms are an evidence based and cost effective means of preventing sexual transmission of HIV. Condoms also routinely run out of stock in Uganda,[13] and there has been an absolute reduction in condom procurement since 2010.[14] Condom use has also been stigmatized as a result of claims by government officials that evidence based interventions such as condom use and medical male circumcision do not prevent the spread of HIV.[15] New taxes, which have been widely criticized, have also been introduced on essential health commodities, including Mama's Kits and family planning methods.

• **Scale up of medical male circumcision—a critical element of combination HIV prevention—is slow and has been undermined by lack of government support.** Government has shown unwillingness to scale up safe medical male circumcision (SMC) since data from Uganda and South Africa in 2007 showed male circumcision results in a significant decline in the risk of HIV acquisition among men. Instead, the US government is funding and driving virtually 100% of program scale up, with no indication that the Government of Uganda will sustain these efforts. In a recent WHO and PEPFAR-convened review of country progress in SMC roll-out, Uganda was one of two out of the 14 priority countries without a designated SMC focal person.[16] The country's national SMC plan lacks a budget, annual targets or concrete plans for scale-up.[17] The national SMC task force, which is to have quarterly meetings, met only once in 2012.[18] In fact, there is persistent contradiction among officials about whether SMC even has a role in the response to HIV in Uganda.[19]

• **Freedom from stigma and discrimination are human rights of HIV positive people as well as core components of an effective response.** But persistent, stigmatizing comments by high level religious leaders, government officials, and other policy makers that people who have HIV have "gone looking" for infection, have most likely undermined the response in Uganda by creating exclusion and stigma in communities. A driver of effective responses in other countries has been active support for openly positive people in leading calls for behavior change and disclosure, and fighting discrimination and bigotry against people with HIV. Uganda's political and legal environment is also undermining the response—the proposed HIV/AIDS Prevention and Control Bill and Anti Homosexuality Bill would criminalize HIV, further exclude vulnerable populations, will curtail efforts to ensure positive health, dignity and prevention.

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[11] Some policymakers cite that unprotected sex between men who have sex with men is responsible for less than 1% of new HIV infections in Uganda—however, this estimate, recorded in Uganda's 2009 Modes of Transmission Analysis, is based only on one expert opinion and extrapolation from population estimates from Kenya—*not* on evidence from Uganda. By contrast, the 2010 Crane Survey reports HIV prevalence among a group of self identified men who have sex with men in Kampala is about twice the national average—14%.

[12] cf "The National Prevention Strategy for Uganda: 2011-15. Expanding and Doing Prevention Better." July 2011, p. 6.

[13] cf 29 June 2012. "Uganda: Public irritated by yet another condom shortage," PlusNews. http://www.plusnews.org/Report/89667/UGANDA-Public-irritated-by-yet-another-condom-shortage

[14] Annual Performance Review of the National Strategic Plan for HIV/AIDS 2010/11-2014/15. Financial year 2011/12.

[15] cf, "NGOs have failed AIDS fight – Museveni." The Daily Monitor. Geoffrey Mutegeki Araali. 2 October 2012: "President Museveni has blamed the increasing HIV/Aids prevalence in the country on Non-Governmental Organisations (NGOs) that are promoting condom use and circumcision."

[16] Presentation by Dr. Buhle Ncube, October 15 2012, Joint WHO-PEPFAR Meeting on Accelerating the Scale-up of Voluntary Medical Male Circumcision (VMMC) for HIV Prevention in East and Southern Africa.

[17] Safe Male Circumcision Policy (2010) Government of Uganda Ministry of Health. Accessed October 15 2012 at http://malecircumcision.org/programs/documents/Uganda_MC_policy_JAN10.pdf

[18] Personal Communication, members of the Civil Society HIV Prevention Research Working Group.

[19] Supra note 15.

Missing the opportunity to end AIDS—while infections rise

Scientific experts indicate that the end of AIDS is possible if access to combination prevention and treatment for all becomes a reality. This extraordinary outcome can only be achieved through ambitious scale-up of testing, rapid linkage to ART and safe male circumcision, along with consistent, targeted provision of male and female condoms, and structural and behavioral interventions. No single strategy implemented in isolation will decisively alter trends in new infections. The evidence for combination prevention is striking. Ongoing research supports the finding that SMC provides a durable long-term direct benefit to HIV-negative men, as well as an indirect population-level benefit to women[20]. In particular, exciting newer research shows that earlier access to HIV treatment provides important clinical benefit, is highly cost effective, and protects serodiscordant sex partners from HIV infection. Accelerating treatment scale up and reaching more patients, faster in order to leverage the prevention as well as clinical benefit of antiretroviral treatment, presents gamechanging opportunities and important challenges.[21] These challenges must be overcome to realize and extraordinary opportunity to end AIDS.

Uganda's slow pace of adopting and scaling up evidence-based interventions is extremely troubling

While other countries in East Africa such as Kenya and Rwanda are modeling how to reach all HIV positive people with treatment, and exploring how vulnerable populations such as serodiscordant couples, sex workers and men who have sex with men can be reached, Uganda is equivocating in the face of overwhelming evidence—and proposing counterproductive and non-evidence based legislation. UNAIDS has recommended a "Strategic Investment Framework" ("SIF") approach to prioritizing high impact prevention and treatment interventions—to ensure budgeting, prioritization, and target setting is based on evidence of what works. Uganda has not yet adopted this approach.[22]

THE CHANGE WE NEED TO END AIDS IN UGANDA—a 10-point plan

Below are 10 of the highest priority actions the Government of Uganda must take to halt new infections, save lives, and ensure leadership:

HIV TREATMENT—EARLIER, FASTER, AND OWNED BY COMMUNITIES

1. Speed up HIV treatment scale up to save lives and halt new infections—initiation should be earlier, faster, and owned by communities. In light of evidence that treatment scale up is slower and treatment coverage is lower in Uganda than other neighboring countries, and that earlier HIV treatment is cost effective, has clinical benefit and prevents transmission through sex and during pregnancy, Uganda should urgently convene stakeholders to develop national guidelines to support earlier HIV treatment initiation for HIV positive people, particularly serodiscordant couples and other vulnerable groups, as is consistent with current WHO guidelines[23] and complements government's commitment to implementing PMTCT Option B+ as well as accelerated pediatric treatment. Treatment targets must be sufficient to absorb people with CD4<350 while identifying and enrolling people with higher CD4 counts. The cost benefit, and impact on HIV incidence of innovative approaches, such as testing and immediate linkage to treatment regardless of CD4 count for all patients, should be modeled and debated, in close collaboration with people living with HIV and global experts. While additional resources will be required initially to adopt this approach, the cost benefits are clear and overwhelming—as well as the public health benefit. Guidelines should take into consideration WHO's likely plan to recommend earlier initiation of HIV treatment as part of its global consolidated HIV guidelines, which have a planned release date of the first Quarter

[20] Njeuhmeli et al. (2011). Voluntary medical male circumcision: Modeling the impact and cost of expanding male circumcision for HIV prevention in Eastern and Southern Africa. PLoS Med 8:21001132.

[21] AVAC & amfAR (2012). An Action Agenda to End AIDS: Critical Actions from 2012-1026 to Begin to End the HIV/AIDS Pandemic. Accessed 15/10/2012: endingaids.org

[22] B. Schwartlander et al. (2011) "Towards an Improved Investment Approach for an Effective Response to HIV/AIDS." The Lancet 377(9782):2031-41.

[23] Guidance on couples HIV testing and counselling including antiretroviral therapy for treatment and prevention in serodiscordant couples. Recommendations for a public health approach. Geneva, World Health Organization, 2012 (http://www.who. int/hiv/pub/guidelines/9789241501972/en, accessed 2 July 2012).

of 2013. **The target of 80% adult treatment coverage in the National AIDS Strategy should be reassessed and increased in light of this urgent need to get ahead of the wave of new infections.**

FOCUS ON HIGH-IMPACT HIV PREVENTION

2. Sexual prevention funding must follow the evidence. Shaming people at high risk of infection is unacceptable and dangerous. Uganda is facing a public health emergency and there is no time to waste debating who has the moral high ground. Ugandans need access to effective prevention and treatment services—not stigma and exclusion—particularly for vulnerable populations including serodiscordant couples, men who have sex with men, fishing communities, sex workers, migrant populations, and prisoners. This means a balanced, evidence based and focused combination prevention strategy of ART, PMTCT, SMC and access to condoms. The UNAIDS "Strategic Investment Framework" approach to structuring high-impact investments in HIV programs clearly emphasizes the need to focus on evidence-based strategies that are targeted to the epidemic. The persistent absence of efficacy in most AB programs cannot be ignored. In a situation of rising infections, resources should be reprogrammed to aggressive expansion of access to combination prevention, in particular provision of male and female condoms, safe medical male circumcision, ART, Option B+ for PMTCT, and significant increase in testing strategies such as Provider Initiated Counseling and Testing (PICT) and community based house-to-house HIV testing with immediate linkage to care and treatment. **To support effective implementation of Option B+,** any facility that offers ANC services should be equipped to offer Option B+, as well as treatment for adults. Enhanced monitoring and evaluation is also needed as Option B+ is implemented to ensure it is being implemented effectively. While Option B+ expands, the core ART program must also expand, to ensure Option B+ does not displace treatment targets for any other population—all new treatment targets must increase together.

ENDORSE AND EXPAND SAFE MEDICAL MALE CIRCUMCISION

3. Government must commit to leadership and investment in scaling up male medical circumcision. A national SMC focal person must be appointed within the month. The National SMC task force must begin meeting on a quarterly basis with full involvement of civil society and all relevant stakeholder groups. Clear government ownership of the initiative should be demonstrated through communications campaigns and close collaboration with implementing partners. Political leaders should show support for the evidence, and stop disparaging MMC with misleading comments. MMC is a core part of effective, evidence-based combination prevention and the policy makers who ignore that are exposing their own lack of commitment to ending the epidemic and saving lives. Women must be involved at all levels of policy development and implementation, to ensure there is no misinformation or unintended consequences for women, who are not directly protected by this intervention.

EXPAND GOVERNMENT FUNDING—THROUGH AN "AIDS LEVY" AND THROUGH INCREASED FUNDING

4. Budgeting by government for the AIDS response must increase as a matter of urgency for Financial Year 2013-2014 and beyond, prioritizing recurrent costs such as health worker recruitment and retention and procurement of essential health commodities rather than trainings, workshops, and seminars. **Uganda has considered an "AIDS Levy,"** or a small tax to generate additional ringfenced revenue for HIV treatment and other high priority, high impact services. Uganda must work urgently during this financial year to introduce and to pass a new AIDS Levy to save lives. In addition, any levy of a tax by Uganda Revenue Authority on any essential health commodity whether a medicine, a Mama's Kit, or family planning commodities must stop.

TACKLE THE HEALTH SYSTEMS CHALLENGES THAT HOLD BACK THE RESPONSE

5. Uganda has a massive shortage of professional health workers that is particularly acute at Local Government levels. The Ministry of Health has defined this shortage as an emergency, and the Executive has pledged to support recruitment of an additional 6,172 professional health workers during the current financial year. But this is not enough—government and all partners must dramatically increase the target for accreditation of HCIIIs to provide HIV treatment, through scaling up funding for health workers, training, equipment and commodities needed to provide ART. Leadership and governance—core elements of strong health systems that deliver for people—must also dramatically improve, from Local to National levels.

PROMOTE AND REBUILD COMMUNITY SYSTEMS THAT DELIVER VITAL PREVENTION AND TREATMENT SERVICES AS WELL AS ADVOCACY

6. Delivery of HIV prevention and treatment services must be owned by the community and must extend beyond the health facility—rather than passively waiting for people to arrive for standards at crowded Health Centres where health workers and essential health commodities are in short supply at best. ART sites with community based outreaches in Uganda have significantly less attrition than those offering ART in the clinic alone.[24] Successful expansion of PMTCT Option B+ as well as treatment for adult and pediatric patients will only be possible with strong community systems—in particular community based adherence support, outreach, and follow up using trained and remunerated community health workers. Existing structures such as Village Health Teams (VHTs) are not sufficiently functional to provide this crucial service. Community systems are a vital complement to the formal health system and must be meaningfully strengthened. Funding must also be expanded to support independent advocacy by civil society to increase accountability and results. People living with HIV and other members of civil society play a critical, underappreciated role and Uganda will never "Get to Zero" unless advocacy is expanded, strengthened, and fully funded.

GET SERIOUS ABOUT DEFENDING AND PROTECTING THE RIGHTS OF WOMEN AND GIRLS

7. Lack of economic independence, access to quality, free education, and lack of protection from sexual coercion and sexual violence is fueling Uganda's epidemic of HIV in women and girls. The Government of Uganda must get serious about implementing programs that prioritize the needs of women and girls and advance their sexual and reproductive health and rights. Pregnant HIV positive women report alarming rates of abuse and stigma by health workers and as a result they fear accessing PMTCT services. Access to family planning services for HIV positive women must also be given the support and funding it urgently requires. Integration of vital sexual and reproductive health services alongside ANC and HIV services is long overdue. Young women and men also need comprehensive sexuality education for both in and out of school adolescents and youth—interventions supported by a vast majority of respondents in the Uganda AIDS Indicator Survey.

STRENGTHEN AND SCALE UP HIV TESTING AND COUNSELING

8. Communities should be saturated with HIV testing opportunities designed based on the best evidence of how to identify and link positive and negative people to services. This includes a mix of PITC and house-to-house community based testing programs, assuring immediate linkage to care, treatment and prevention. Testing campaigns must engage all stakeholders, including Local Government officials and religious and cultural leaders. Currently only 15 Districts have home based HIV testing—unsurprisingly, 55% identified as being HIV positive through the Uganda AIDS Indicator Survey reported being unaware of their HIV status (26% had never been tested and 29% had reported their last test result as HIV negative).

CLOSE THE DATA GAPS—AND ACCEPT EVIDENCE FROM COMMUNITIES

9. Data on the AIDS response are unreliable, incomplete, or simply unavailable. This must be urgently corrected to ensure proposed actions are based on an accurate diagnosis of the problem. Systems knowledge must be strengthened at all levels—investment in information hubs are critically important in order to fix data gaps and to ensure both service delivery and non-facility based sources of data are available to improve knowledge availability and management. Community evidence—such as evidence of the harmful impact of the sudden withdraw of outreach clinics—should be included formally as part of national reviews—even as anecdotal reports—such as the Joint Annual AIDS Review, rather than ignored.

END HARMFUL POLICIES THAT FURTHER MARGINALIZE VULNERABLE GROUPS

10. Uganda is currently considering harmful bills, such as the HIV/AIDS Prevention and Control Bill, and the Anti Homosexuality Bill, which would criminalize people with HIV, people at highest risk of infection, and criminalize efforts to provide evidence based education to communities. These bills should not be passed, and vulnerable populations should instead be prioritized in efforts to expand HIV service delivery.

[24] Supra note 9.