

THE MESSAGE FROM UGANDA AIDS COMMISSION FOR THE WORLD AIDS DAY – 1ST DECEMBER, 2011

Uganda's HIV/AIDS Epidemic: the Way Forward

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A lot is being discussed in the media concerning the dynamics of our HIV epidemic. This is healthy because through public debate the people get to know current status of our epidemic and the role each one of us should play in our continuing struggle to contain it. I would like to add my voice to this debate. I do so to make a contribution on three distinct phases of our struggle and what lessons we can draw that will help us move forward in a strategic way. I wish to draw attention to the early phase of our struggle; then examine the current dynamics of our epidemic; and to then chart out the way forward, based on lessons learned from previous efforts re-enforced by emerging scientific evidence.

The Early Phase of our Epidemic

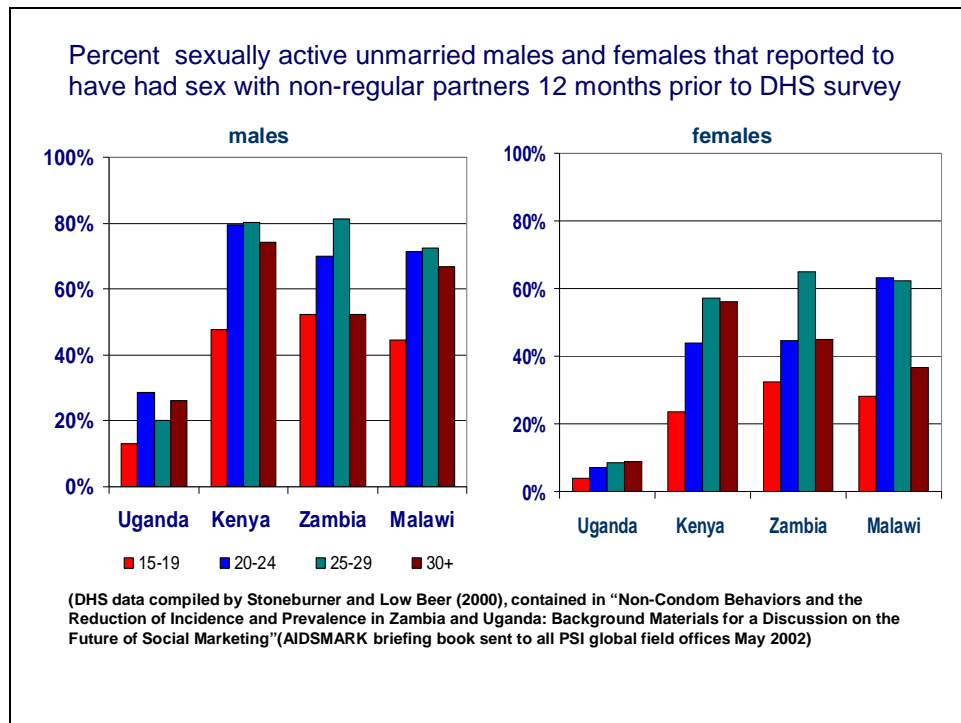
We scored impressive success when the whole nation got together in solidarity to fight the epidemic in its early phase. We succeeded in bringing down the prevalence rates together with the rate of new infections. The weighted averages of surveillance data for women attending antenatal services at 15 sentinel sites, suggest that national HIV/AIDS prevalence rates peaked around 15% (with some as high as 30%) in 1991 and fell to 5% as at 2001. Similar trends of decline were observed among other population groups such as military conscripts, blood donors, secondary school children, and clients attending clinics for sexually transmitted infections. More importantly, the rate of new infections also subsided. Based on data for 15-19 year-old pregnant women, believed to be a proxy indicator of new infections, the numbers fell sharply from the early 1990s, when data were first collected, until 1995 or 1996, and remained low. Indeed we also know that Uganda was one of the few countries that set up sentinel sites to monitor the rates of new infections in a community. The data from one of the sentinel sites in Masaka District, the epicenter of the epidemic in Uganda, shows that the rate of new infections fell from 7.6 per thousand in 1990 to 3.2 per thousand per year by 1998. The decline was most pronounced among younger populations (age 20-34 years), but with a greater reduction overall among men with a 75% decrease, compared to 33% among women.

As the result of our success, the whole world looked to Uganda for leadership in the fight against HIV/AIDS. The idea of setting up national AIDS councils (the equivalent of Uganda AIDS Commission) in every country to coordinate national response was taken from Uganda; the multi-sector approach was learnt from Uganda; the concept of placement of the coordination function in the highest office in the land was learned from Uganda; high level political engagement and leadership as an important factor for success was copied from the role played by our President; even the campaign strategy of 3 interventions; Abstain from risky sex encounters (A), Be mutually faithful to your partner (B) and use of a condom (C) where you are tempted beyond retreat – all of which came to be known as the ABC approach- was modeled on Uganda's pragmatic approach.

But how did we do this?

How it all happened in Uganda remains a subject of intense conjecture, with a long list of factors advanced to explain the decline. This author has analyzed the long list of factors in a book titled *“Turning off the Tap”* which is to be published soon. In this author’s opinion, the long list of presumed causative factors for the decline probably reflects a blurred understanding of the key drivers of success. Indeed, analysis of the sequence of events following the introduction of various interventions into Uganda’s HIV/AIDS national response does not show a direct link between onset of the decline of the epidemic and the time many of these interventions were first introduced.

Together with a colleague, Dr. Ted Green, at Harvard School of Public Health, we conducted a desk study funded by the USAID to analyze characteristics of the response in three countries that had experienced a decline in HIV prevalence and compared the results to three other countries with no signs of decline at all at that time. We found that the extent of evolution of primary sex behavior change was the single most important change that occurred in countries that had experienced the decline. The decline in sex with multiple sex partners was the key behavior change observed. The decline in this behavior, as the figure below shows, was observed in all the age groups and among both men and women.



Underlying this change in behavior was the keen sense of togetherness and solidarity among the communities, or what the sociologists describe as social capital. This sense of togetherness in the face of a common enemy, HIV/AIDS epidemic, communicated from one to another through informal interactions is vital for changing behavior. Indeed we observed that in countries with declining rates of infection both males and females, more so the females, acquired information

about HIV/AIDS through informal channels of communication, something in the style of what we know in Luganda as “Buli awulide abulire munne.” Translated into English it literally means “whoever has heard the news should share it with the neighbour.”

There is a school of thought that does not believe in the role of behavior change in controlling the spread of HIV infections. They argue that there is no scientific evidence. To them evidence is scientific only if it is from “case-controlled, double-blind” studies, to use the jargon. This has been given credence by the discourse global circles which has distorted the “ABC” approach implemented in Uganda. What we now have out there is pitching of the “A” strategy against “C.” In this distortion the “C” component is ferociously portrayed as a strategy for promoting promiscuity. On the other hand, the opponents of “A” view it as a political ideology of the extreme right supported by religious fundamentalists wishing to force a prescription of their own values of chastity for life on everybody. It is unfortunate that this distortion is beginning to find its way in our country. Yet both sides have missed the point.

We in Uganda need to stand firm and desist from this distraction as we face our own epidemic. The communities in Uganda perceived “A”, or abstinence, as a logical thing to do in certain situations where you did not know the status of the potential partner. It was to say “please be careful” as you take the decision, but should you choose to proceed despite the risk, then be sure to use a condom. The communities also saw delayed age at first sex as giving young people time to acquire life skills so as to be able to make informed choices about safe sex when they are ready for it. Young people, particularly young girls, are especially vulnerable due to many social and physiological circumstances. Moreover, early sexual debut tends to lead to multiple lifetime sex partners, which itself carries higher risk of infection. In an article in the *British Medical Journal* **328**: 891-893 titled “Partner reduction is crucial for balanced “ABC” approach to HIV prevention” we make a case that the battle between “A” and “C” is diversionary, and it sidelines sex partner reduction like a neglected middle child of the ABC approach.

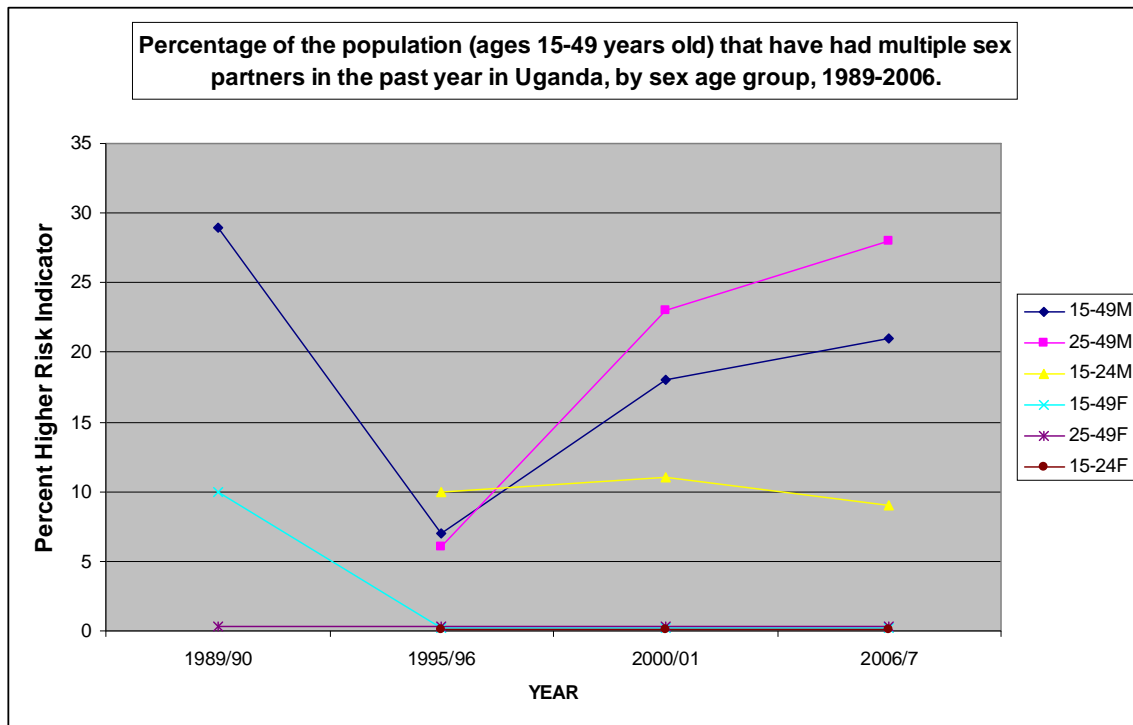
What do we know about our epidemic today?

We know that the epidemic is still raging in our country. Approximately 1.2 million Ugandans are currently infected and living with HIV. Moreover, we know that less than half of those who need to go on antiretroviral treatment are able to get the treatment. We know also that the epidemic is virtually heterosexually transmitted, with mother-to-child transmission as the only other major mode of transmission, which itself is a consequence of parental sex behavior. Our concern as a nation is that the situation is not getting better. The prevalence rate has stagnated between 6.1% and 6.5%, and the number of new infections is rising alongside our growing population. In 2007 we had an estimated 105,000 new infections, rising to 110,000 in 2008, 124,000 in 2009 and 129,000 in 2010. The truth is that we do not know what the actual situation is since the survey data for 2010 are not yet out. What all this means is that if we are to achieve our vision of a generation of Ugandans free of HIV and its effects, we have to more than double our efforts, since even a single new infection would be one too many.

The Danger of Complacency

Complacency has hit us as exemplified by deterioration in our sexual behaviours. The remarkable decline in the practice of multiple sex partnerships which was the single most important driver for the decline in HIV infections is no more. There has been a reversal in sex

behavior, more so among adults; and among the adults the reversal is most pronounced among males. As shown in the Figure below sex with multiple sex partners among adult males is back to where it was at the beginning of our epidemic, much as we know that this was the most important contributor to our earlier success. Consequently, up to 43% of new infections in adults (age 15-49) in 2008 were among people claiming to live in “monogamous relationships”, while 46% were among persons reporting multiple sex partnerships together with their partners. Commercial sex workers, their clients and partners of clients contributed 10% of the new infections.



Pleasantly, multiple sex partnership has remained low among women. However, this does not protect them because evidently they are getting infected by their “trusted” male partners who must be picking up the infection from unprotected sex with outside partners.

What is the cause of this complacency? One major factor is the advent of anti-retroviral therapy. Complacency was expected to occur following the introduction of antiretroviral therapy. It was observed early in the epidemic in the New York studies of men who have sex with men. The author predicted in article presented at the International AIDS Conference in Barcelona as far back as 2002 that complacency would occur also in generalized heterosexually transmitted epidemics like ours if we are not careful in the way we market new interventions. I have observed reactions in the media about male circumcision. If we market it carelessly, the public could perceive it as being 100% protective and this will exacerbate complacency in sex behaviours. The other new intervention to watch out for is the pre-exposure prophylaxis. Already it has been sensationalized in the media as a panacea and there are voices calling for the immediate roll-out of this intervention countrywide. We must be careful not to excite the public prematurely. There are no magic bullets in science. Recent evidence now shows that this approach has no protection. The FEM-PrEP HIV trial has been stopped early because of failure

of the oral combination of tenofovir and emtricitabine (*Truvada*, Gilead) to show efficacy as pre-exposure prophylaxis (PrEP) for male-to-female HIV infection. This is from the findings of a phase 3 clinical trial being conducted in Kenya, South Africa, and Tanzania. The internationally well respected implementing agency, *Family Health International*, prematurely halted the FEM-PrEP study after an independent monitoring committee concluded that current data did not support the effectiveness of the combination treatment in preventing male-to-female HIV transmission.

What then is the Way Forward?

Today we live at a time different from the situation prevailing at the beginning of the epidemic. For a start, we should all take the test so that one knows one's HIV status. In our country only 2 out of every 10 Ugandans know their status. This is unfortunate because it is very important that each and every one of us should know their HIV status. I certainly know mine. I urge you, too, to know yours. Testing is not for the sake of testing. Testing has a purpose. It serves as an entry for you to a package of services appropriate to whether you test negative or positive.

If you test negative, you can gain access to a package of information and services to enable you to remain negative. This is an important population sub-group, representing up to 95% of our population. We must by all means protect this population. The package of services for them includes information about appropriate sex behaviours to protect oneself from the predisposing factors. The package also includes for males advice on safe medical circumcision to reduce risk although it must be stressed that protection by circumcision is not absolute. You can still get infected if you ignore sex behaviour. Information and provision of condoms for consistent use is part of the service. I must stress here too that condom use has to be consistent and not to use today and tomorrow you don't because you think you have gained trust in that partner. Attention to predisposing cultural norms and gender based violence are included in the package. Our new National HIV Prevention Strategy soon to be launched will spell out all these services.

Should you test positive, there is also a package of services to keep you in good health even without need for antiretroviral drugs. Positive living, as a concept and a principle is critical in the management of HIV care and treatment. The message here is one of hope. Hope because all is not lost after you get infected. You can live and pursue your career once you accept your status. It is not easy, I know. But it is possible. We know very many people who have succeeded in doing so and are with us today. It is also a message of prevention because it is indeed within the power of the individual to also protect oneself from acquiring new strains of the virus and to protect others by not transmitting infection to others. Again we know very many people who practice this. Importantly the package of services for the positive individuals includes access to health services for management of opportunistic infections; access to antiretroviral therapy as and when needed; access to care and social support; access to interventions to protect your unborn child against acquiring HIV infection at birth or during breast feeding. The package also includes reproductive health services.

Please note that the package for protecting the newborn infant is not about protecting the infant **alone** while ignoring the health and welfare of the parents. The package includes care and support services to enable both parents to live long enough to nurture their HIV-negative, newborn child. This package too is well elaborated in the new National HIV Prevention Strategy

to be launched soon. I have one comment to add on this issue of mother-to-child transmission. This is a biologically correct nomenclature for the mode of transmission. But it tends to exonerate the part played by the father of the child in this mode of transmission. We need to stress this because we the men are increasingly distancing ourselves from responsibilities aimed at protecting our newborn infants. Men must begin to accept our part and to participate without apportioning blame to the mother in this imperative to protect our innocent newborn infants.

A word about stigma

The people who get infected do not do so out of choice. They are simply victims of accident and extenuating circumstances. Those people are part of us- parent and child; husband and wife; teacher and student; soldier and civilian; brother and sister etc. In otherwise any one of us could be in those shoes because we are all vulnerable. The minimum we can do is to show empathy and understanding. To deny anyone of them kindness, understanding, support and access to these services is to do so unto one's own; to deny employment opportunity or to dismiss an employee on the grounds of HIV status is to do injustice to one's own brother or sister yet it has been shown beyond any doubt that an infected individual can be as productive as anybody so long as he or she is accessing good social support and care, including treatment. You will not get infected because you shook hands or shared a joke with or embraced an infected individual. You will not get infected because you shared a plate or glass with an infected individual. We need them to make a contribution to the fight against the very epidemic and they can. In fact they have done a lot both locally and globally, and most significantly they were the force behind the drive to establish the Global Fund. Many of us do not know that.

At an individual level our HIV-positive citizens can do a lot. At the opening session of a very well attended, international conference in Kampala, presided over by none other than President Museveni, an internationally recognized and respected Ugandan HIV activist, Ms Milly Katana, had this to say: "Mr. President, it is not common that I get an opportunity to address you. Today is my chance. Mr. President, I got infected with HIV when I was a young girl and student at university, but I took the decision that I must not pass on the infection to anybody. I could have passed it on. But I decided I must not." So if we are to "Turn off the Tap" we must recognize and nurture this very important contribution that our HIV-positive citizens can make.

Let me also say something about sexual orientation. The services in the new HIV Prevention Strategy are for all Ugandans regardless of gender, age, tribe, race, social status or sexual orientation. Medical profession ethics forbids denying anybody access to health services. Social inclusion and social justice demand no less. So let us not allow ourselves to be side-tracked by the global debates about sexual orientation. To do so is to risk being led into vitriolic exchanges about sexual orientation, the kind we have witnessed in recent times. This does not help us at all in our efforts to bring down our epidemic.

Leadership for HIV Campaign

The last message I would like to share with you is on leadership. Philly Lutaaya acted as an individual to lead and give AIDS a human face. His heroic interpretations and messages through music are well documented. As an individual citizen he played his part. Notable contributions by the likes of Dr. Noreine Kaleeba and Professor Peter Mugenyi brought hope to many Ugandans afflicted by HIV/AIDS. You, too, have a role to play. But today, leadership in the fight against

HIV/AIDS has remarkably gone missing. Religious leaders are not talking about it in their sermons let alone urging prospective couples to establish their HIV status before they tie the knot; political leaders are not talking about it in their addresses urging people to beware of the fact that HIV epidemic is still with us; cultural leaders are not doing enough in advising their subjects; sex education in schools is no longer a big concern; the message of **zero grazing**, the most important message in the earlier campaign has completely gone off the radar on all the communication channels, only to be replaced by confusing, inaccurate and contradictory messages that make no sense to the public. We must seek to re-enforce quality assurance of HIV messages communicated to the public. Leadership at all levels critically needs to re-engage. For we know from our history that with the political commitment under the leadership of our President, communities rose up to offer care, support and social protection to those in need; individuals personalized the HIV risks and adopted safe sex behaviours. Let us do it again, enjoined by our development partners. But Ugandans must take the lead.

We also know that in Uganda, like everywhere else, women and young girls still bear the brunt of the HIV epidemic. They also contribute bigger percentages of the infected compared to male counterparts, and are more involved in the care giving yet. Worse still, they are not empowered enough to make independent decisions concerning their sexual lives. We need to develop and implement targeted interventions, including appropriate legal frameworks, for women and girls in order to overcome the effects of gender disparities.

Let me conclude then by once again raising the red flag- HIV epidemic is continuing to spread in our country. Prevention remains core in the control of the epidemic because increasing number of new infections is not at all an option. We must be ready to invest, first and foremost, our attention and commitment and then the resources. Above all, we all need to exercise our leadership roles at all levels. Let us re-engage and together share the challenge. I pray that after you read this message you will share the message therein with your peers and friends; with your wife or husband; your daughter or son; your boyfriend or girl friend; your congregations if you are a religious leader; your students if you are a teacher; your constituency if you are a political leader; and your neighbor in general. In short, I call upon all of us in our diverse capacities to join hands as we double our efforts to control the scourge so as to achieve our vision – a vision of a *generation free of HIV and its effects*.

This article is based on extracts from a book by the author, titled “*Turning off the Tap*” that is to be published soon