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**Lessons from the Past, Challenges for the Future:
An Overview of HIV/AIDS in Africa**

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Happy New Year! My task this morning is to set the stage for the day's discussions on AIDS in Africa. A grim topic to focus on early in the year – but one that we should be focusing on much more, particularly in the way suggested by this conference, by focusing on what works.

Let me begin with the devastating numbers that represent the magnitude of the problem in Africa. The numbers are so large that they are difficult to comprehend and absorb – and therefore easy to deny. The reality is that sub-Saharan Africa is now facing a severe development crisis because of the AIDS epidemic. The human and socioeconomic toll is massive and will continue to be massive for many generations to come. Why? Because the region is now home to 29.4 million people living with HIV/AIDS, of which more than half are women, 10 million are young people between the ages of 15-24, and almost 3 million are children under 15. In 2001, of all young women aged 15-24, an estimated 6-11 percent were living with HIV/AIDS, compared to 3-6 percent of young men and there were 13.4 million orphans. National HIV prevalence rates are staggeringly high, particularly in southern Africa: 38 percent in Botswana and 33 percent in Zimbabwe and Swaziland. And the worst news – the news that makes me aware of a sinking feeling in the pit of my stomach -- is that prevalence rates have not peaked yet.

Those are the numbers – they are for real and they are very important. By focusing on the numbers it is easy to forget that HIV/AIDS is a

problem with a solution. There is no cure but there are proven ways to prevent infection, prolong life, treat secondary illnesses and infections, and provide care and support. Yet, Africa is caught in the grips of a deadly epidemic. We, the international community have not paid enough attention and even when we have, our response has been slow, delayed, and inadequate.

We have had the epidemic now in our midst for over two decades and it has taught us some important lessons. And that is the purpose of this conference to focus on what we know works, on the insights gained, the successes and how we can multiply them. The panels that follow will share with you the experiences gained from programs that worked – that will give us some answers on how Uganda has managed to slow the spread of infection, how Senegal has kept prevalence rates low, how infection levels among women aged 15 to 24 attending antenatal clinics in Addis Ababa have dropped – these are the insights that give us hope and that show us that human intervention works. Without focusing on the specific programmatic lessons, in the time allotted to me, I will highlight five of the most important overarching lessons learned from the epidemic that we must draw upon as we move forward in responding to the epidemic in sub-Saharan Africa – and in doing so I will draw heavily from the work that ICRW has done or sponsored.

Lesson #1:

We have learned that prevention, treatment and care and support are mutually reinforcing elements of an effective response to the epidemic. It is not useful to pit prevention against treatment or treatment against care because each is an essential part of the required comprehensive approach that must be used to fight HIV/AIDS. For example, HIV prevention supports efforts to expand health care access by keeping the cost of future treatment demands from spiraling out of control. Similarly, availability of treatment helps promote effective prevention by encouraging early detection of one's HIV status. Treatment also has been known to reduce the stigma associated with the disease, thereby making prevention efforts more effective. Only a tiny fraction of Africans receive treatment because of the world's continuing failure – despite the progress of recent years – to mount a response that matches the scale and severity of the epidemic on the continent. And prevention efforts have been limited in scale and inadequately resourced. This is a complex disease that will always require multiple interventions, simultaneously implemented and available, that work in synergy to contain the epidemic. Even though AIDS is a problem with a solution, there is no single magic bullet. Even when we have an AIDS vaccine, which I hope will be soon, it will not serve as the single solution.

Lesson #2:

The disproportionate burden of HIV/AIDS on women has long been evident to those of us working to reverse its spread. The physical vulnerability of young girls, the difficulties women face in accessing information and services necessary to protect themselves from infection, the near impossibility of obtaining treatment in most developing countries, and the extraordinary burden of care assumed by women, as governments watch and wax eloquent about the wonders of home-based care – all these factors combine to make HIV a virus that hits women – especially young women – the hardest. We now know, through research conducted by ICRW from 1990 to 1997, that gender inequality plays a key role in increasing women’s vulnerability. Through that research we learned that the way in which societies construct the roles and responsibilities of women and men – what women can or cannot do as compared to men – greatly affects the way in which they can protect themselves from infection, cope with illness once infected, or care for those who are infected. We know through many, many years of research on women’s roles in development, that gender norms, and the policies based on those norms, greatly restrict women’s access to productive resources (such as land, income, education, and credit), creating an economic and social imbalance in power between women and men, an imbalance that favors men. The economic vulnerability and dependency that results makes it more likely that women will sell or exchange sex for money, goods or favors, less likely that they will be able to negotiate safer sex with their partners; less likely that they will leave relationships that they perceive to be risky; less likely that they will be able to cope once infected; and less likely that they will be able to care for loved ones who are infected without great cost to themselves and their families. To make matters worse, far too many women have to deal with the most disturbing form of male power – gender based violence. Physical violence, the threat of violence, and the fear of abandonment and destitution act as significant barriers for women who are infected or are caring for others who are infected. Population based surveys from around the world estimate that anywhere from 10 to 50 percent of women report having experienced physical violence at the hands of an intimate partner. We have fought for many years as the international development community towards the freedom from hunger and disease – but somehow we forgot that what many women desperately need is the freedom from fear. Fear of violence and abuse regulates the behavioral choices of more women that we care to know and the costs of violence of borne by women themselves and their children, as well as the communities and economies in which they live.

We have also learned that power is fundamental to sexual interactions just as it is fundamental in gender relations. The unequal power balance in gender relations that favors men, translates into an unequal power balance

in heterosexual interactions, in which male pleasure supercedes female pleasure and men have greater control over when, how, where, and with whom sex takes place. The definition of male and female sexuality in society greatly affects both women's and men's vulnerability to HIV infection. For example, for women in many societies and communities, societal norms often dictate that "good" women must be ignorant about sex and passive in sexual interactions, making it difficult for them to be proactive in negotiating safer sex options. Conversely, prevailing norms of masculinity that expect men to be all-knowing and experienced about sex, put men, particularly young men at risk because they prevent them from seeking information and coerce them into experimenting with sex in unsafe ways, and at a young age, to prove their manhood. Research has also shown that in several parts of Africa, a strong norm of virginity for unmarried girls, can paradoxically increase young women's risk of infection, because it can restrict their ability to ask for information about sex, out of fear that they will be thought to be sexually active. Strong norms of virginity also put young girls at risk of rape and sexual coercion in high prevalence countries in the continent because of the erroneous belief that sex with a virgin can cleanse a man of infection and because of the erotic imagery that surrounds the innocence and passivity associated with virginity. Men, on the other hand, are expected to have multiple partners because of the belief that variety in sexual partners is essential to men's nature as men and that men need sexual release at all costs (the hydraulic model of male sexuality), and that sexual domination over women is the defining characteristic of male sexuality. These ideals of male sexuality seriously challenge AIDS prevention messages that call for partner cooperation, fidelity in relationships, or a reduction in the number of sexual partners, and contribute to homophobia and the stigmatization of men who have sex with men.

Thus, gender in combination with sexuality fuels this epidemic. Today we are faced with an incontrovertible fact: gender inequality is fatal. It is killing African women and men in their most productive years and leaving behind more orphans than the mind can comprehend.

Women's economic vulnerability and its links to the spread of this epidemic are just one illustration of how the HIV/AIDS epidemic is not just a public health crisis but a development one that needs a multisectoral response. What needs to be done today in Africa is what should have been done decades ago under the rubric of good development practice. Today AIDS feeds on our past mistakes, on the fault lines that inequality and poverty create in societies. Gender inequality and poverty are the primary factors exacerbating the AIDS epidemic and the epidemic's impact on women is what now is greatly exacerbating the spread of the famine in southern and central Africa. Women are central to household food security.

Burdened with the responsibility of caring for the sick and dying, or raising multiple orphans, women, both young and old, are unable to adapt as they once did to conditions of drought or to put in the extra effort needed to coax from the land food for their families.

An effective response to the epidemic must, therefore, pay attention to and address gender inequality through measures to improve women's economic status and educational opportunities. In Africa we must do this by ensuring that women have equal access to primary and secondary schools, that they have equal property and inheritance rights, that they have access to credit, and that they have access to agricultural technologies and the know-how to enable them to grow food crops that have shorter cropping cycles, generate a higher yield, are more nutritious, but are not labor intensive. All of these are HIV/AIDS interventions – even though they are often not recognized as such.

Lesson #3:

Effective scientific research is the only way forward. When faced with an epidemic that relentlessly rages on, it is particularly maddening to be slowed down to do the research to answer the questions that need to be answered to run effective programs. Yet, there is no option because we have made some very expensive mistakes that could have been avoided and in the long term that slight delay may have saved more lives.

Remember when the world went ahead with the distribution of a low-cost version of an antiretroviral regimen to prevent the transmission of infection from infected mothers to their unborn babies? The clinical trials had concluded that the intervention could substantially reduce the rate of transmission even though it was a shorter course of antiretrovirals than the ideal that is offered in the West. Understandably the demand and pressure from national governments, international agencies, and the communities most affected was great but left very little time to know how best to provide this intervention. Not surprisingly, the bad news came in fairly quickly after the intervention was introduced – there were very few takers – there were very low rates of uptake – we had a service but women were reluctant to use it. Loads of antiretroviral donated by GlaxoSmithKline lay languishing in warehouses.

Through community based research done by the center that I lead, we learned in a very low-cost way that there were good reasons that women were not showing – that the fact that this intervention would save the life of the unborn infant but do nothing to save the life of the mother was not the primary reason that women were reluctant to use the service. We learned that they were hesitant to be tested for the infection when they were

pregnant because they feared that if they positive their men would blame them because the first one detected to have HIV is the one who bears the burden of having brought the infection home. And pregnancy is when women need the most support from their families and communities. We learned of the low levels of information and knowledge about the perinatal transmission of infection in communities and the resentment that men felt that this service was shutting men out. Women, in turn told us they wanted their men informed to ease the way to using the service. And we learned that women refused to stop nursing their babies because the stigma associated with doing so resulted in immediate social ostracism – which was perceived as being much more expensive than the probability of the transmission of infection to the baby. We learned that in order for them to cope with the stigma, their men and elders needed to be educated about the intervention and that community advisory boards could help service providers modify the delivery of services in minor ways to suit the particular needs of communities. This is just one example but it teaches an important lesson though it is a tough one – I do not want to suggest that everything we do must be measured and documented – I am only too aware of the best and most effective responses to the epidemic coming from small community based NGOs who have developed interventions based on their very special knowledge of the communities they serve – but I am also a convert on the value of good community based research guiding the formulation and development of interventions, operations research guiding the implementation of interventions, and evaluation and monitoring research teaching us how to shift gears and keep being successful.

Lesson #4:

Stigma and discrimination against those infected with or affected by HIV/AIDS can undermine the success of AIDS prevention, testing, and care efforts. It is frustrating to be stymied by an abstract attitudinal barrier that fosters denial, shame, rejection, discrimination, isolation and even death. Stigma is the cause of gross human rights violations against those who are living with the infection, it impedes individuals from knowing they are at risk, creates barriers to testing, reduces access to treatments, hinders individuals' ability to negotiate protection, and worst of all, prevents individuals from providing loving and humane care to their family members and loved ones who are infected.

Through research conducted in Tanzania, Ethiopia, and Zambia, researchers at ICRW working in close collaboration with teams in each of these countries have learned that sex, morality, shame and blame are closely related to HIV-related stigma. The data show that much of the stigmatizing language and discriminatory behavior of individuals centers around the sexual transmission of HIV. Premarital sex, extramarital sex, and

multiple partners are viewed as immoral and as shameful and so those that are infected with HIV are thought to have engaged in these shameful behaviors – and therefore deserving of blame and discrimination.

An example of stigmatizing language in current US policy discussions that affects our responses in Africa is the reference to orphans and HIV infected children as “innocent victims.” Such language stigmatizes all those who live with HIV/AIDS by differentiating some from the others. We have learned the hard way that the costs of punishing others who are viewed as having transgressed are borne by us all – not just those who are infected – because we now know that stigma and discrimination fuels this epidemic, sets it on fire, ensures its unabated spread.

Lesson #5:

And finally, we have learned that the single most precious ingredient in successful national programs is political will and commitment from those in leadership positions. We need leaders at the local level and at the national and international levels who will be champions for the cause of AIDS prevention, treatment, care and support. Individuals who will be bold enough to stand up and speak openly about sex and sexuality and what public health research has taught us even if this is politically expensive and embarrassing to do. We have several examples of such leadership from Africa but we need much more both on the continent and in donor countries in the West. If this epidemic has taught us one thing it is that we must not perpetuate a culture of silence and shame about sex. Many countries in Africa and around the world have learned the hard way the cost of doing so – by losing lives. Warning preadolescents of the risks of early and unsafe sexual behavior and promoting abstinence and delayed sexual debut is the right thing to do but must be accompanied by full information on how they can protect themselves once they are sexually active. We must not let the misguided morality of our leaders, or a misinterpretation of religion, or for that matter politics, to stand in the way of public health imperatives. We know the value of information and we know through research that information on sexuality does not cause promiscuity, just as we know that marriage is no way to protect our daughters from infection. In fact, if anything, we have learned that young women have more leverage to negotiate protection before marriage than they do within in.

In conclusion, as we continue our discussions today let us remember that policies that foster gender inequality or support a culture of silence and shame around sex and AIDS are compromising the rights and freedoms of individuals and promoting a cycle of illness and death. This must stop. And let us remember that women, both young and old, are at the forefront of this epidemic – infected in increasingly large numbers and primary

caretakers of others who are infected. They are the glue that holds communities together in the face of this epidemic in Africa. They need all the support and resources we can provide them, and at a minimum they need our respect. There is a very powerful reason for change – the disempowerment of women is killing and incapacitating them and their households. This must change. I hope that each one of you will communicate that loudly and clearly without any caveats ifs or buts. Thank you.