Unlocking Solutions for HIV/AIDS Globally: Empowered Women Hold the Key

by

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Key Note Presentation at the
Annual Meeting of the
AIDS Foundation
Chicago

November 11, 2003

If Charles Dickens were alive today, and if he were asked to provide a social commentary on the situation of HIV/AIDS today as compared to even a decade ago, he would most certainly have described these times as “the best of times and the worst of times.”

Therapies and treatments are now available not just in countries in the North to substantially improve the quality of lives of those living with HIV and AIDS, but also in a few countries in the Southern hemisphere. And WHO’s new “3 by 5” campaign with the goal to provide antiretrovirals to three million people in the developing world by the year 2005, is a global commitment that did not exist before – a commitment that is most likely going to be funded at the country-level by the Global Fund for AIDS, TB, and Malaria, a source of funds that did not exist before. We now have a few countries to show as examples to prove that prevention strategies work. There are interesting private and public partnerships being created for the development of a vaccine and a growing advocacy and R&D movement to do the same for the development of female controlled methods of prevention. And we have a low-cost way to prevent the transmission of HIV from mothers to their infants. Compared to years past, all this certainly qualifies for the first part of the Dickens’ descriptor: “the best of times.”

Simultaneously, however, in most of the developing world, which bears the burden of 95 percent of the world’s HIV infection, the epidemic continues to rage on. Seventy percent
of the people living with HIV/AIDS globally reside in sub-Saharan Africa, which is home to only 11 percent of the world’s population (UNAIDS/UNICEF 2000). Southern Africa is the worst hit – some of the national HIV prevalence rates there are staggeringly high – 38 percent in Botswana, 33 percent in Zimbabwe and Swaziland – worse than our worst nightmares. And in India and China we could see an explosion of the epidemic if we do not dramatically expand access to HIV prevention today. Additionally, the total number of orphans in Africa is staggering, and life expectancy rates for all on that continent are expected to plummet in the coming years. And, despite all the media attention and the talk, inequality and poverty remain ubiquitous hurdles in prevention, as well as in access to treatment and care. All this makes it equally true, that these are also the worst of times.

Ironically, it is this dilemma, reconciling the best with the worst, recognizing that even the best is not good enough, that will perhaps in the long run provide us with some important lessons for the future. It will force us to pause briefly, despite the speed of the epidemic, to introspect on our policies and programs and examine each aspect of what we are doing.

As concerned Americans, it is particularly important that we pause at this stage because the President’s five-year $15 billion Emergency Plan for AIDS Relief could represent a historic turning point in the global response to this epidemic. Even though the Senate approved only $2.4 billion of this amount for the first year – not the $3 billion that we had all wanted, this Plan is a unique opportunity which could represent a turning point, if, and only if, it draws from the lessons of the past. It could represent a historic turning point in the global response to AIDS if it prioritizes public health and scientific imperatives over ideological positions. It offers an opportunity – an unprecedented one – for this Administration and Congress to show its true commitment to combating HIV/AIDS, not just through increased resources but also by setting priorities for the allocation of those resources for the kinds of prevention, treatment, care and support programs that we know through experience and evidence work. In this epidemic a wrong step is fatal – it costs lives, and in the countries that are hardest hit in Africa or in
countries that sit on the cusp of a raging epidemic like India or China, those that die because of mistaken priorities can number in the tens of millions.

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. Despite this we are still battling this disease. I would like to make the case today that part of the reason for this state of affairs is that we have not paid adequate attention to the many lessons that this epidemic has taught us over the past three decades.

Today, I will focus my remarks on five key lessons that this epidemic has taught us. Five lessons that are particularly important because women are now indisputably the face of the epidemic globally. Globally, 50 percent of all those infected are women. In Africa that percentage is 58 percent, such that in some countries in sub-Saharan Africa there are now 12-13 women infected with HIV for every 10 men. Even more tragic is the fact that young women are particularly vulnerable. 68 percent of all new infections on the African continent occur among young women between the ages of 15 to 24 years. Recent data from four African countries show that among adolescents between 15 to 19 years of age, the number of new infections is six times higher for girls than for boys.

So in this talk I would like to focus on five key lessons about prevention, care and treatment that we have learned from experience with this epidemic that can help us identify the challenges for the future that must be met if we are to address women’s, particularly young women’s, vulnerability, and if we are to make greater progress in containing the epidemic globally.

**Lesson #1:** We now know, through research conducted by ICRW and by many others over the last two decades that gender inequality plays a key role in increasing women’s vulnerability in the HIV/AIDS epidemic. 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 typically 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. The link between violence against women
(domestic violence, rape, sexual abuse) and HIV infection is increasingly evident.
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 are borne by women themselves and their children, as well as the communities
and economies in which they live.

There is now an ever-increasing amount of data on the ways in which gender affects not
just prevention behavior, but also the way in which women and men experience and react
to this epidemic. For example, research has shown that there are distinct differences
between women’s and men’s use of VCT services and their patterns of disclosure of test
results – women find it more difficult to access such testing services and more difficult to
disclose their results. There are differences in perception of risk – women’s perception of
risk is lower than that of men; there are differences based on gender in caring for the sick, with women bearing a disproportionately higher share of the burden of care, and so on. These data, emerging at a fast pace from studies all over the world, highlight the important ways in which gender as a construct, and gender inequality, in particular, make women more vulnerable to infection and restrict their ability to cope with its impacts.

**Challenge #1:** The first challenge we must confront in the coming decade, therefore, is to implement measures to rectify gender inequality by improving women’s economic and social status in the developing world, and in poor communities here, in order to protect them from infection and to strengthen their ability to cope when infected or affected by HIV/AIDS. We must include these measures as essential components of every plan to prevent HIV/AIDS.

Specifically, I recommend that we must do this through five actions.

First, by expanding government and private sector investments in initiatives to improve economic opportunity in the poorer parts of this world – in our inner cities here in the U.S. and in the developing world, while simultaneously ensuring that women in these areas benefit equally from those economic opportunities by having equal access to jobs, earning equal pay for equal work, and not experiencing any of the gender-specific barriers to economic opportunity that are so rampant worldwide.

Second, we must increase women’s access to economic assets such as land and property – assets that are marketable and can serve as collateral – assets that can provide women with a source of livelihood and shelter – assets that can provide women with some leverage when forced to leave a risky relationship or negotiate protection with a long-term partner. Assets are also an important way to assure economic security for women and can protect them from the necessity of exchanging sex for income, food or shelter. Ownership and control over land and property signifies command over productive resources, which enables women to make choices regarding livelihoods, provides security against poverty, and promotes autonomy. There are many countries in which women still
do not have the right to own or inherit land and property – and even where such laws exist, most land and property is owned by men because of the poor enforcement of the laws. We need to push for the land reforms that incorporate specific provisions that give women equal land rights, protect their interests, and prevent their exclusion from access to and use of land.

Third, we must ensure that women have equal access to a quality education in primary and secondary schools and that the education curriculum in every school includes information on HIV prevention – abstinence and condom use. Barriers to schooling such as the cost of tuition or books or uniforms, distance, lack of hygienic surroundings, and safety within schools must be addressed if girls are to have equal access to education.

Fourth, we must do all that we can to end violence against women. We need judicial and legislative reform to ensure that women are protected and that perpetrators are penalized. But more importantly we need to put in place the systems and institutions that can enforce the legislation. We need training programs for judicial and law enforcement personnel to change the traditional attitudes that often stand in the way of proper enforcement. And we need an appropriate mix of legal, psychological, social, medical, and educational support services for women who experience violence. But most importantly we need to bring about a change in the threshold of acceptability of violence against women – much like we did to reduce the acceptability of smoking. For that we need leadership at the highest levels and a massive public education and media campaign targeted to the general public.

Fifth, we must support the needs of women caregivers, with particular attention to older women and adolescent heads of households. They provide the care and support to those who are sick, dying or orphaned, with little, if any, support, information, or resources. This has implications for the health and well being of those women and their families but as the famine in Southern Africa has shown us, it also has consequences for household well being and food security. Burdened with the responsibility of caring for the sick and dying, or raising multiple orphans, women 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. Helping them requires programs that provide access to information, services, and support, but also access to economic resources such as credit and agricultural technologies and know-how to grow food crops that have shorter cropping cycles, that generate a higher yield, are more nutritious and less labor intensive. These types of agricultural inputs are now AIDS care and support interventions and must be funded as such.

To conclude Lesson #1, 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. We must do all we can to rectify the economic and social disadvantage that they face.

**Lesson #2:** Sexuality, as it interacts with gender, is at the root of the epidemic. Sexuality is the social construction of a biological drive. An individual’s sexuality is defined by whom one has sex with, in what ways, why, under what circumstances and with what outcomes. Explicit and implicit rules imposed by society, as defined by one’s age, gender, economic status, ethnicity and other factors, influence an individual’s sexuality. Power is fundamental to sexual interactions just as it is fundamental to 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.
Similarly, in many societies, including ours here in the U.S., a norm of virginity for unmarried girls, can paradoxically increase their 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 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, in many societies are expected to have multiple partners because of the belief that variety in sexual partners is essential to men’s nature as men, that men need multiple partners for sexual release, 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.

**Challenge #2:** Thus if this epidemic has taught us one thing it is this – we cannot hide behind a shroud of silence with regard to sex and sexuality and its role in the spread of this epidemic. In the coming decade, we owe it to the youth of this world, to our sons and daughters, to be open and honest about sex. Many countries have learned the hard way the cost of supporting a culture of silence and stigma surrounding sex – by losing lives. We must focus priority attention on the needs of preadolescents and adolescents within this epidemic. They have the fastest rate of new HIV infections and in the fourteen countries included in the President Bush’s Emergency Plan for AIDS there are more than 6 million young people between 15-24 years of age who are living with HIV. More than two thirds of those are women. Warning pre-adolescents of the risks of early and unsafe sexuality and promoting abstinence and delayed sexual debut during adolescence is the right thing to do but must be accompanied by full information about how to protect themselves once they are sexually active. The challenge we face is to not let our misguided morality, a misinterpretation of religion, or our politics, stand in the way of public health imperatives. We know the value of information and we know through
research that information on sexuality or access to reproductive health services does not cause promiscuity – so let us not waste any more precious time debating this point. As one young gentleman at International AIDS Conference in Barcelona put it: If we believe condoms cause promiscuity, we must believe that umbrellas cause rain! We know that condoms are not perfect – there are sometimes errors in their use. Condoms sometimes fail but let us not forget, so does abstinence! More importantly though, condoms are the most effective prevention tool we currently have and we have evidence to show that they successfully avert infections. Any information that contravenes this truth is unscientific and must not be tolerated – it is unethical and costs lives.

**Lesson #3:** We have learned from the family planning field that couples need multiple contraceptive options because their needs vary from one couple to the next and from one stage of a relationship to the next. Why is it then that we offer only one technological option – the male condom -- to couples for preventing HIV infection? The male condom is often not feasible or available for women because condoms are essentially a male-controlled technology. Many women face cultural barriers that prevent them from requiring their partners to use condoms, or are subject to violence when they attempt to insist on condom use. Ensuring greater accessibility of female barrier methods such as the female condom (by reducing its cost and increasing its availability), and investing in the research to establish the effectiveness of barrier methods such as the diaphragm are one way to ensure that women have more control over prevention. The other way is to ensure that there is an increase in resources for microbicides – topical substances that women can use intravaginally to protect themselves and their partners against HIV and other sexually transmitted pathogens. Women and couples need options – the condom while theoretically very effective is not used by many couples worldwide. Women need a prevention technology they can control and use. There are currently 60 potential microbicides in the pipeline, two or three of which will soon be ready to enter Phase 3 clinical trials to prove their effectiveness in humans. But clinical trials need resources and it is resources that are holding back the promise of microbicides for the many women who are losing their lives because of their inability to convince their male partners to use a condom.
**Challenge #3:** The challenge therefore is to obtain an increased investment of resources for the development of microbicides – a challenge that I know the AIDS Foundation has taken on as a priority for its work – for that I congratulate you! Many of the prevention goals described in the President’s Emergency Plan for AIDS Relief could be achieved if we had safe, effective, and accessible microbicides. Lack of public and private sector support for microbicide research has made it difficult to move promising candidates through the R&D pipeline. Experts in the microbicide field estimate that at least $1 billion more is needed to accelerate R&D efforts. You should be proud to know that because of the successful grass roots advocacy in the state of Illinois, spearheaded by all of you, three Congresswomen from this state will be soon introducing a new bill, The Microbicides Development Act, calling for a higher priority to be given to microbicides. Microbicides could change the course of the epidemic once available – all it needs now is strong leadership to ensure that resources are devoted to the necessary R&D.

**Lesson #4:** We have learned the hard way that the mere proof of efficacy of biomedical products and their availability is not sufficient to guarantee access to all. I know that this lesson will resonate with all of you as you struggle to ensure that everyone in the communities in which you work -- poor or not so poor, men or women, white, black, brown or any other color, young or old, gay or straight – that everyone gets full access to the care, treatment and prevention services that are available.

The lesson we have learned from the world of treatment is that unless we plan for it, there can be, and often is, a huge gap and time lag between the availability of a biomedical product and its accessibility and use by the people in poor communities who need it most. The barriers of poverty and economic, social and gender-related inequalities stand in the way. The seemingly intractable nature of these hurdles creates an understandably high level of frustration. It is maddening to know that we have potential solutions at hand and yet cannot guarantee results because of gender-related or socio-cultural or economic factors that cause inequities that affect an individual’s access to all resources, economic, social, or biomedical.
Addressing and taking account of these inequalities and contextual factors, I am convinced, will give us better long-term results, even though it may, in the short term, mean a slight slowing down in the introduction of a product or the implementation of a clinical trial. Short-sightedness and impatience have cost us dearly in the past and are expensive in the long run. Let me give you one example that we, as a community of scientists and practitioners working in the developing world, committed to stopping this epidemic, recently experienced.

You may remember how excited we were when a low-cost version of an antiretroviral regimen was found to be effective in preventing the transmission of infection from infected mothers to their unborn infants. It was, and in many countries still is, a concrete way to stop this infection on at least one front. Understandably, there was a great deal of pressure to immediately make it available to all populations, particularly in the poorer nations of the world. In an attempt to respond to this need a group of multilateral agencies announced that they would pilot test a model of MTCT prevention in a ten or so countries. The urgency of the epidemic forced them to move ahead quickly.

And then the bad news arrived – the intervention had been made available in several countries in prenatal clinic sites but there were very few takers. There were several papers presented at the Barcelona conference, for example, that cited the low rates of uptake in different settings. For example, in Zimbabwe, over the course of a two year study, of the 1,815 projected HIV positive women seen in a clinic, only 150 women or 8% actually agreed to receive antiretrovirals.

Results from research studies conducted by the Center that I lead and others have slowly begun to flow in – we now know, because women tell us, that they do not want to get tested, and many of those who do, do not return for their test results, because they are worried that if they test positive their men will blame them for bringing the infection home. There are anecdotes of women who are positive, who when given a three months supply of breast milk, leave the supplementation cans outside the door of the clinic because walking through the community with cans of powdered milk is like walking with
HIV positive written on your forehead. There is data on a drop in the rates of prenatal care service use -- women who typically would have used prenatal clinic services, we heard, are now reluctant to use the service out of fear that they will be tainted by the stigma associated with HIV/AIDS. Men, we have learned, feel resentful of MTCT prevention services because they are being left out since the service is offered in sites that women mainly use. And service providers complain about the burdensome workload created by the new intervention and the lack of adequate support given to them to take on their new role as counselors. The reports, one more dismal than the next, but all understandable from the perspective of the users and providers, keep pouring in. We are now doing what we should have done all along – we are finally talking to the experts: the users of the service and the providers of the service – to women, men and community members – to find out how they experience the intervention, how they would like to be provided this information and medicine, what they experience when they do not breastfeed their infants and so on. We have derived tremendous insights from what we have heard – and the communities we have spoken to understand better what we, as program managers, are seeking to do.

**Challenge # 4:** This lesson underscores the importance of investing in basic community-based research and in processes that facilitate community participation *prior* to the introduction and delivery of any new biomedical intervention. Let us apply this lesson as we call for the accelerated development of vaccines and microbicides, both of which would greatly increase women’s ability to protect themselves from infection. We must ensure that investments for the development of microbicides and vaccines are used not just to accelerate the development of safe and effective microbicides or vaccines but to accelerate their accessibility to and use by those who need it most.

It is important to remember that in order to ensure access we must listen with humility, to individuals who live in communities, who live the experience and therefore are often the best source of potential solutions. We have learned that helping women surmount gender constraints requires organizing women, providing them with the space to meet together, visibly in communities to gain strength from numbers and to support each other and share
solutions. We have also learned that reaching just women is not enough. Women’s lives are greatly influenced and controlled by the men and elders around them – we must include these significant others in our efforts and educate them on the need to support women.

**Lesson #5:** And finally, we have learned that stigma and discrimination against those infected with or affected by HIV/AIDS is currently the biggest barrier to 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 a barrier 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 and that women experience more severe stigma than men and are less able to cope with its consequences. We have also learned that incomplete knowledge and fear fuel stigma, and that stigma coexists with compassion and caring. The data show that much of the stigmatizing language and discriminatory behavior of individuals centers around the sexual transmission of HIV. Pre-marital sex, extramarital sex, multiple partners are viewed as immoral and as shameful and those infected with HIV are thought of as having engaged in these shameful behaviors and therefore deserving of blame and discrimination.

**Challenge #5:** A central challenge therefore is to reduce the stigma associated with HIV/AIDS by providing full information about this disease. The most urgent need is to ensure that the health care system and its providers do not stigmatize. From our research we have developed a tool-kit that can be used in any group setting to allow individuals to reflect upon their stigmatizing attitudes and its consequences. There is an urgent need to
develop and adapt such tools to learn and teach others that the costs of punishing those who are viewed as having transgressed are borne by all – not just those who are infected – because we now know that stigma and discrimination fuel this epidemic, set it on fire, ensure its unabated spread.

In conclusion, these five lessons that the epidemic has taught us have shown us that policies that foster gender inequality or that 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 worldwide. This must stop. Women need all the support and resources we can provide them, and at a minimum they need our respect. There is now a very powerful reason for change – the disempowerment of women is killing our young and women and men in their most productive years. This must change - - and the U.S., as the global leader in HIV/AIDS efforts worldwide, must communicate this message loudly and clearly, without any caveats, ifs, or buts.