7. “It’s Not Fair:” AIDS, Gender and Human Rights

The title of my paper is based on a conversation my daughter and I had in 1992. (To believe that this really happened you should know that my daughter is like the kid in a popular cartoon, where an older kid says to a younger one: “I found a condom on the patio” and the younger kid says: “What’s a patio?” That younger one, that’s my kid!) She was seven years old then, and this conversation was what made me realize for the first time that my work on women and AIDS was work on human rights, not just on health.

Driving home from school one day, she asked me with considerable fear and apprehension how adults who had sex could protect themselves from HIV. (Apparently she had learned that day from a friend in school that AIDS is fatal.) In response, I began, as mothers are apt to do, with a long lecture on the value of abstinence and uncompromising fidelity, only to be interrupted with, “Yes, yes, all that is fine, but when I am grown up and want to have sex, what should I do?” So, I reluctantly described condoms and their use. “But that is what men use, right? What do women do?” she said. Almost without a second thought, I said, “Convince the man to use one.” To which she burst into tears and said with great anguish, “But that’s not fair, Ma! I want to live—it’s not fair! What if I can’t convince the man?” So, I entitled my talk today, “It’s not fair” to honor my daughter’s insight.

“Unfreedoms”

In his recent book Development as Freedom, Dr. Amartya Sen, an ex-Board member of ICRW, who is also known for having won the Nobel Prize for Economics in 1998, analyzes the nature of economic development from the perspective of human rights. He defines development as “a process of expanding the real freedoms that people enjoy.” Development, therefore, he argues, requires “the removal of major sources of unfreedom.” I would like to paraphrase Dr. Sen and say that health and well-being—critical indicators of economic development—require the removal of major sources of unfreedom. As Dr. Sen points out there are many sources of unfreedom—poverty, malnutrition, lack of access to education and health services—but the one form of unfreedom that I am going to talk about today is inequality between women and men, which I will show is experienced by women because of many of the other sources of unfreedom that Dr. Sen lists—such as lack of access to education, health services and employment. More importantly, I will demonstrate how this basic unfreedom—inequality between

women and men—fuels the AIDS epidemic by increasing women's vulnerability to infection, denying them equality in care, and burdening them with a disproportionate share of the responsibility of caring for others who are infected. Second, I will talk briefly about the challenges posed by the new, available and affordable anti-retroviral regimens for preventing the transmission of HIV from pregnant women to their infants, and the way in which inequality and discrimination stand in the way of the success of this medical intervention. And I will conclude with some recommendations for action.

More HIV+ Women and Children

The statistics on HIV/AIDS recently released by UNAIDS show us that despite new treatments and information campaigns, HIV/AIDS is rising rapidly around the world, still largely through heterosexual transmission. There are now 36.1 million people living with HIV/AIDS and more people have died from AIDS since the epidemic began (two decades ago) than the cumulative total of all those who died in all the deadly wars of the 20th century. We have now heard repeatedly about the damaging consequences of this deadly epidemic—life expectancy in the most hard-hit countries is likely to drop by about 12-15 years; the gains made in child survival are similarly affected; and companies doing business in Africa are hurting because of frequent illness and death among their workers. The new information also shows that 12 to 13 African women are currently infected for every 10 African men, and that over 90 percent of the children infected with HIV were born to HIV-positive women and acquired the virus at birth or through their mother's breast milk. Biological factors, e.g., greater vulnerability of the vaginal tract to infection, leading to greater efficiency in the transmission of HIV from man to woman than from woman to man, account for some of the emerging imbalance in the sex ratio of HIV infections, but women's gender also contributes to their vulnerability to infection.

Gender and Vulnerability

What is gender? It is a word frequently used but often misunderstood. Gender refers to the social construction of male and female roles—the widely held beliefs and expectations of the roles, responsibilities and obligations associated with being a woman or man. It is a culture-specific concept—what women can or cannot do in one culture differs greatly from what they can or cannot do in another. But what is consistent across cultures is that there is a distinct difference between women's and men's spheres of functioning. Typically, men are seen as being responsible for productive activities outside the home and women are responsible for productive and reproductive activities within the home. And we now know that women have less access than men to productive resources such as
income, land, credit and education. While the extent of this difference varies considerably from one culture to the next, it almost always persists.

The effect of this gender difference and inequity on poverty and economic development has been discussed for over two decades, but its implication for the spread of HIV was not discussed until the early 1990s. I would like to share with you some of the research findings that contributed to this discussion. These are findings from the Women and AIDS Research Program, a grants program conducted by ICRW from 1990 to 1997, with funding from USAID. There were two phases to the program, which supported a total of 25 studies in 15 different countries. The findings from the studies gave us important insights into women's sexual experience, which we have since labeled as the four P's of sexuality:

♦ Practices
♦ Partners
♦ Pleasure
♦ Procreation.

The first two refer to aspects of behavior and the second two to underlying motives. What we learned is that there are gender differences in how each of these is experienced. We learned that there are many women and girls who enjoy sex and can express their sexual desires and needs. But far more overwhelming in the data were descriptions that showed that women have much less control over sexual interactions than men—much less control over when, how, where and with whom they have sex. Women experience and report the double standard of sexuality that dictates that women have to be virgins before marriage and consistently faithful afterwards, while men are not men if they do not have multiple partners.

For many women, sex is a burden to be accepted quietly, or a functional necessity to have children or a commodity to be sold to ensure survival or protection. And for far too many women, sexuality is associated with lack of control, abuse and resounding silence. Overall, the data showed us that in their sexual lives, far too many women worldwide are denied their right to basic human dignity and bodily integrity. We also gained some insights into male sexuality: the belief that men need sexual release at all costs, that men and boys are the ones who are supposed to be in charge of sexual interactions and even to be the sexual teachers. This is so even though they often have very little accurate information since most of what they know is picked up on the street. We learned that there is an immense pressure on men to live up to an image of being in control, to make new sexual conquests as proof of manhood and above all to do everything to ensure that they are not perceived as homosexual.

From all of this we inferred that there is a fifth P of sexuality—power, which is fundamental to how the other P's are interpreted and experienced. The findings also showed us very clearly that women have less power than men in sexual...
interactions and why women have less power than men do. Women know very little about their bodies and sex; there is much misinformation because in cultures in many parts of the world, female ignorance of sexual matters is a sign of purity. For this reason, women are denied their right to free and accurate information about their bodies. This lack of knowledge greatly contributes to their inability to protect themselves from infection, increases women’s fears about condom use and limits their ability to identify abnormal gynecological symptoms.

The culture of silence surrounding sex affects women more than men, because we were told that women who talk about sex are presumed to be of easy virtue. We found that the powerful norm of virginity for unmarried women that exists in many societies increases young women’s risk of infection—because they cannot ask for information out of fear that they will be thought to be sexually active. In high-prevalence countries, virginity also puts young girls at risk of rape and sexual coercion because they are presumed to be free of HIV infection and because of a widespread belief that sex with a virgin can cleanse a man of infection.

The data showed that violence is a daily reality in the lives of many women and that fear of violence and abandonment act as significant barriers to women’s ability to demand fidelity from their partners or negotiate condom use. Clearly, for many women worldwide, denial of the right to safety from violence or the threat of violence contributes greatly to their vulnerability to infection.

We learned that women are economically vulnerable because their access to economic resources, such as land, income, employment and credit, is restricted. The majority of women in the labor force are confined to the informal sector, which is characterized by low wages, income insecurity and poor conditions of work. We also know that women constitute the majority of the absolute poor—70 percent of those who earn less than a dollar a day are women. The data showed that women’s economic vulnerability makes it more likely that women will exchange sex for money or favors, less likely that they will succeed in negotiating protection and less likely that they will leave relationships that they perceive to be risky.

In sum, the findings showed us that gender-related discrimination and a denial of women’s economic, social and cultural rights contribute to women’s vulnerability to HIV infection. Or in the terms used by Dr. Sen, the sources of unfreedom that must be addressed in order to guarantee women health and protection from HIV are women’s social and economic vulnerability and the imbalance in power between women and men that constitutes gender inequality. We have since learned that women’s social and economic vulnerability and gender inequality also lie at the root of women’s painful experiences in coping with the stigma and discrimination associated with HIV infection.
HIV+ Women—Extra Burdens and Hard Choices

They are infected and they are women. In the words of one woman in Africa: “Yes, it’s my responsibility to tell my partner, but it’s hard to tell. If the wife knows she’s positive, she won’t tell her husband, because she will be afraid of being told she is the one who brought it. As a woman, to tell your partner is impossible.”

There are data to show that there is gender-based discrimination in the care that is offered to HIV+ women within households. This is not surprising given the fact that in many societies there is a significant gender difference in the timing and quality of health care that is provided to girls and women as compared to boys and men. We also know now that women—wives, daughters, sisters, mothers, and grandmothers—bear a disproportionate burden of caring for others who are infected.

In many societies, being socially ostracized, marginalized and even killed (as happened to a woman in South Africa in 1999) are very real potential consequences of exposing one’s HIV status. For women with limited economic resources, fear of violence, abandonment and potential destitution acts as a significant barrier to agreeing to an HIV test. Yet, HIV counseling and testing are critical ingredients of the new prevention intervention for reducing mother-to-child transmission of HIV. This intervention requires pregnant women to be tested so that those women who are positive can receive a dose of an anti-retroviral (AZT or nevirapine) during pregnancy and/or during labor. The protocol also requires HIV+ women not to breastfeed their infants. While the nuances and details of this intervention are still being worked out, some countries, overwhelmed with the onslaught of the epidemic, have already begun its implementation. This new medical intervention poses new ethical complexities and conundrums, many of which are related to those ubiquitous hurdles—inequality and poverty.

For pregnant women, determining their HIV status exposes them to stigma and discrimination at a time when they are most vulnerable and require the most protection. Faced with the prospect of protecting and caring for another life yet to begin, pregnant women may find the potential consequences of being HIV+ to be worse than death. It is also overwhelmingly tragic that the intervention provides treatment to save an infant’s life, but does nothing to save that infant’s primary nurturer and caretaker—the mother herself. Over the years, this epidemic has gained a reputation for the difficult ethical choices it poses. This is yet another one—our very own “Sophie’s choice.” The only way to protect the rights of mothers and their children is to ensure that anti-retrovirals are only one of the many prevention options available to women who seek to protect their children from infection.

The most significant option must continue to be primary prevention, because the best way to ensure that an infant is not infected is to protect the mother and father of that infant from infection. A significant component of primary prevention must be the empowerment of women—the protection of their rights—because fundamentally it is the imbalance in power between women and men and society’s disregard for women’s rights as human rights that restrict women’s ability to protect themselves from infection. The power imbalance also does not permit women to feel safe in determining their HIV status, to seek support and care when infected and to make choices for their own welfare, independent of others.

But how should women be empowered to increase their level of autonomy? The answer lies in addressing the sources of their unfreedom, or put more positively, enhancing the sources of power—information and education, skills, economic assets, technologies and services, and social support. This means we must:

♦ Educate women; give them the information they need about their bodies and sex. Information is power and it is their right to receive it.
♦ Give women the skills they need to use a male or female condom—make them condom literate. Provide skills training on communication about sex—foster inter-partner communication.
♦ Improve women’s economic status. Ensure that they have property and inheritance rights, have access to credit, receive equal pay for equal work, have the financial, marketing and business skills necessary to help their businesses grow, have access to the agricultural extension services to ensure the highest yield from their land, have access to the formal sector for employment and are protected in the informal sector.
♦ Ensure that adequate resources are available for the development, improvement and increased accessibility of prevention technologies, particularly female-controlled and female-initiated prevention technologies such as the female condom and microbicides—because these will protect both women and men (and ultimately children) from infection.
♦ Integrate services wherever possible and ensure that they are gender-sensitive.
♦ Increase social support for women who are struggling to change existing gender norms to protect themselves from infection; promote sexual and family responsibility among young boys and men and allow them opportunities to re-examine the damaging effects of prevalent notions of masculinity.
♦ Allow opportunities for women to meet in groups, visibly in communities, to derive some strength from numbers and to be able to draw solutions from each other.
Move the topic of violence against women from the private sphere to the public sphere. It is not a personal issue. It is a gross violation of women's human rights and it has significant negative implications for the health of communities and for economic development.

Let me conclude by urging us all to ensure that the term *empowerment of women* becomes more than just a linguistic icon whose meaning is inversely proportional to its use! Empowering women and guaranteeing them their economic, social and cultural rights is not optional. In the AIDS epidemic it prevents deaths. It ensures that one of the greatest sources of unfreedom or barriers to the health of populations and to economic development is eliminated—gender inequality. And I will say again, as I have said before: In the long run, empowering women is not a zero-sum game. Power is not a finite concept. Empowering women and guaranteeing their rights increases the power of women, men, households, communities and entire economies.