

# The Culture of Science and the Feminization of HIV/AIDS

Since the mid-1980s, researchers and grass-roots organizers have been calling attention to the social and political context of AIDS and to the specific situation of women struggling to protect themselves, but with scant effect (Bond et al. 1997; Farmer et al. 1993; Long and Ankrah 1996; Stein and Flam 1986; Susser and Gonzalez 1992; Dlamini-Zuma, Nkosazana 1988??a/b). The sharp critiques of the early period could be repeated and expanded today with no loss of cogency or point (Epstein 2007; Hunter 2003). Even as this book was delivered to the publisher in February 2008, a *New York Times* editorial lamented a new surge in AIDS infections among young men in New York City (New York Times 2008), while a letter-writer asked pointedly why only teenage boys were discussed: 48 percent of the increase was in teenage girls (Lieberman 2008). Why are women so invisible?

In discussing plans for sessions on gender at the 2008 Mexico City International AIDS Society Conference, some planners contended that men who have sex with men (MSMs) were the most important risk group for Latin America and themselves highly stigmatized. Women's issues, it was said, would get the attention they needed. However, at the same time, HIV-positive women in Mexico City were struggling for representation on the planning panels. One of the problems raised by organizers was that most of the women did not speak English. Among the positive men in Latin America, English-speaking professionals could represent the concerns of MSMs. But most positive women were poorer and less educated than the men.<sup>1</sup> The problem was addressed in constructive ways. One plenary paper was allotted to review the issues of gender and the vulnerability of women and girls. Later, a special request was added to the call for abstracts asking researchers to specify whether their data was broken down by gender. Still, the controversies concerning the representation of gender and the voices of positive women highlighted the ongoing struggles, even in the most enlightened precincts, for women and girls to combat erasure of their needs for prevention, treatment, fertility, and sexuality with respect to HIV/AIDS.

In the following chapters, we examine the ways in which ideologies of gender and everyday practices of subordination interact with political and economic forces to reproduce inequality. Working to address ideologies embedded in everyday practice has required continuous, and frequently controversial, efforts by public health practitioners, activists and grass-roots movements. This chapter briefly outlines the inclusions and exclusions of women in the history of research and scientific perspectives on AIDS.

As noted above, from the 1980s some researchers have grasped the necessity for a social, political, and economic perspective on AIDS transmission and prevention. As might be expected from a discipline that emphasizes holistic, qualitative approaches, anthropologists were a significant presence among this group (Baer et al. 2003; Bond et al. 1997; Farmer 1992; Schoepf 2001). Public health researchers, too, recognized that “because the social context determines to an enormous extent the lived realities of women, men, and children, social barriers to prevention must be recognized, understood, and directly addressed” (Mann and Tarantola 1996: xxxiii). And the Director of the HIV Center for Clinical and Behavioral Sciences at Columbia University writing in 1987 could outline a women’s agenda for AIDS as follows:

The epidemic will shake the very foundations of our society . . . any prevention and intervention program aimed at changing behavior must be designed with careful attention to the realities of women’s lives. These include ethnic, cultural, and religious standard, gender roles and the legal and economic conditions of women (Ehrhardt and Exner 1987:38).

However, 2003 brings a similar call for such considerations not yet fully taken into account:

A common thread in most of the reviews of the HIV prevention literature previously cited [those on women] is a call for more prevention initiatives that attempt to tackle the larger systemic barriers . . . that undermine attempts to decrease sexual risk behavior (Exner et al. 2003:129).

In the late 1980s, Elizabeth Reid, who led the effort to bring AIDS policy to the United Nations Development Program, called not only for attention to the context of women’s lives but also for a recognition of the power of women’s collective action with respect to AIDS. “While women individually may feel and be powerless to change men’s behavior, women collectively can effect extraordinary changes. There is a need to look for models of women’s collective action which have changed men’s HIV-related behavior” (Reid 1997:163).

In fact, in 1992, women sex workers in Calcutta were already organizing the Sonagachi Project to protect themselves from HIV infection. This project emerging as it did from the demands of a heavily marginalized community in conjunction with health activists and international donors, has become a model for women’s collective action (Cornish 2007; Jana et al. 2004).<sup>2</sup> But we find again that researchers

are just beginning to recognize the importance of collective approaches in 2007!<sup>3</sup>

Not only was women's collective action not widely acknowledged or supported, but women's particular vulnerability to AIDS worldwide frequently went unrecognized. One major reason often given for overlooking the situation of women was that men were at the center of the Western epidemic. In the United States, initial estimates suggested that positive men outnumbered women by about 10:1 (Sabatier 1989:40). However, while all members of minority groups in the United States were three times more likely to have AIDS than Whites, women of color were even more at risk than men. A Black woman was 13 times more likely to have AIDS than a White woman and a Latino woman was 9 times more likely (Sabatier 1989:40). Thus, the neglect of women points to a potent combination of racism and sexism in the United States.

Distressingly, among African Americans, fear of being stigmatized made many people reluctant to discuss AIDS. The Minority Task Force on AIDS and several other activist groups concerned with women and minorities were founded in the 1980s. However, in the course of fieldwork, I learned that as late as 2001, an African American woman editor of a major US women's magazine, who had been working with the United Nations representatives to highlight gender subordination as a central facilitator of AIDS transmission, decided not to run an article on women and AIDS. She was told that any such discussion would simply further stigmatize people of color.

Initial research in Africa in the 1980s showed women infected equally with men. However, some researchers argued that the epidemic in the United States and Europe was different and that women were not at risk. In fact, in 1988, the US Secretary of Health and Human Services announced, "We do not expect any explosion into the heterosexual population" (Sabatier 1989:38). We have to assume here that the Secretary of Health was referring to White women.

Public perceptions were dramatically evidenced by Michael Fumento's much-publicized book entitled *The Myth of Heterosexual AIDS* (1990, reissued to great acclaim in 1993). Major foundations such as the American Foundation for AIDS Research (AmFar) and Gay Men's Health Crisis turned down proposals for research among women. This was most likely because gay activists had raised donations for these foundations and fought hard for federal funds. In the United States, the plight of men who have sex with men loomed so urgent, so controversial, and so neglected by the federal government that only this research seemed to merit support. Nonetheless, this approach resulted in the neglect of research about women worldwide. What is now recognized as a classic article outlining the need for research on preventive methods for women and introducing the concept of microbicides (Stein 1990) was turned down by three journals before it was finally accepted by the editor of the *American Journal of Public Health* after a second submission and still over the objections of reviewers.

It was not until the 1990s that many researchers and funders began to accept that women were at risk from heterosexual sex (Corea 1992).<sup>4</sup> As Long and Ankrah

argued, “by taking women’s and girls’ experiences seriously, both men and women will be able to do a better job of preventing HIV/AIDS” (1996:2). By that time, according to estimates, over 11 million women had become infected worldwide, as well as over 3 million children and more than 15 million men (Mann ?? and Tarantola 1996:11).

Even when the idea of heterosexual transmission was accepted in the US, women were chiefly conceived as vectors of the disease for men and infants more than victims themselves and sometimes this emphasis remains the focus of research (Exner et al. 2003). Back in 1993, as we might have expected, researchers calculated that two-thirds of US federal research funding for women was spent on children (Long and Ankrah 1996:2). However, even at the 2007 Sydney International AIDS Society meetings on HIV pathogenesis, treatment, and prevention, a survey of abstracts submitted or accepted found that less than 20 percent addressed women’s issues and many of these were focused on mother–child transmission of AIDS rather than women themselves (Collins 2008).

The fact that AIDS would continue to press inexorably forward along fault lines of inequality had been clearly spelled out in the initial years of the epidemic (Bond et al. 1997; Mann and Tarantola 1996). Panos characterized AIDS as “a misery-seeking missile” (Sabatier 1989:ii). Accordingly, through the 1990s, the drama of rising rates of HIV/AIDS moved from men and women in Africa to families selling blood in destitute Chinese provinces to young unemployed drug users in the depressed cities of eastern Europe (Baer et al. 2003).

However, in spite of the general recognition that subordination and vulnerability had emerged as the driving forces of the epidemic and in spite of the inequality of women’s situation in most countries of the world, the idea that, over time, more women than men would become infected (UNIFEM et al. 2004) was far from generally anticipated. There was still “a *zeitgeist* that, at best, minimized women’s needs and perspectives” (Exner 2003:119).

One major change occurred at the first United Nations General Assembly Special Session (UNGASS) on HIV/AIDS meetings in New York City, June 2001. Noeleen Heyzer from UNIFEM and her deputy Stephanie Urdang, led the discussion of gender and AIDS. Heyzer’s closing speech documented the new recognition of the centrality of gender to the epidemic:

If the strong gender perspective that has been incorporated into this joint commitment is reflected in all policies, resource allocation and actions from this point forward, we can truly turn the tide of the HIV/AIDS pandemic.<sup>5</sup>

Other international spokespeople such as Peter Piot (2001), Executive Director of UNAIDS, and Kofi Annan (Annan 2002), Secretary General of the UN, also began to recognize that the worldwide epidemic was driven by gender subordination. However, even at the 2006 Toronto International AIDS Society Conference, HIV-positive women and women health activists felt compelled to organize a “Women and Girls’ Rally.” Speakers from “fourth world” women in Canada,



**Figure 1.1** “Survival,” 2003 an installation by Fiona Kirkwood (South Africa): 24’ × 4’11”, male and female condoms, resin, Perspex. The first artwork created from the female condom

women in poor countries, women prisoners, and women drug users highlighted the gender challenges they faced. Well-known international representatives such as Stephen Lewis, former UN Special Envoy for HIV/AIDS in Africa, and Mary Robinson, UN High Commissioner for Human Rights 1997–2002, also decried the continuing lack of attention to the problems of women and AIDS (Susser 2007).

### History of Diagnosis: AIDS Symptoms Among Women and Populations of the Global South

From the first signs of the disease, race, class, and gender shaped the scientific and cultural understandings of AIDS. Ironically, gender may even have played a role in the patterns of scientific recognition for basic research on the HI virus. In 1983, Françoise Barre-Sinoussi at the Pasteur Institute in Paris isolated the HIV-1 strain of the virus. Barre-Sinoussi, a woman researcher in Luc Montagnier’s laboratory, was listed as first author on publication in *Science*.<sup>6</sup> However, two men, Luc Montagnier, the director of the research team at the Pasteur Institute, and Robert C. Gallo, then the director of a research team at the National Cancer Institute, have competed for public credit for this discovery (Crewdson 2002).

The common misconception that HIV/AIDS was exclusively a gay men’s disease, began with the identification of the disease in 1981. The Centers for Disease Control (CDC) published an early warning about a new phenomenon found among patients at several hospitals, including Mount Sinai in New York City (Centers for Disease Control 1981). The cases identified by the CDC were all men, mostly with access

to good medical care. The CDC were alerted by doctors concerned about the strange disease that was killing young middle-class men who could, in most circumstances, expect to be extremely healthy (Shilts 1987). Even hemophiliacs who contracted AIDS through infected blood were only men, although a few early documented cases included women.<sup>7</sup>

Once alerted by the cases among middle-class men, researchers soon discovered similar symptoms among migrant sugar cane cutters in Florida. There, men and women workers from Haiti, living in a fenced enclosure while they worked for US agricultural business, displayed the characteristic rashes and other symptoms which had already been identified with the mysterious new disease. Within a year, poor and minority men and women in New York City were also found to be infected (Baer et al. 2003).

Later researchers demonstrated that since the 1970s there had been an increase in deaths among poor drug users in the United States which could be attributable to HIV/AIDS misdiagnosed as tuberculosis and pneumonia (Freidman et al. 1990).

Although migrant farm workers and poor Black and Latino/Latina New Yorkers had been dying of the new disease, their cases had not precipitated a medical alert. Either their deaths did not appear out of the ordinary or they did not seek care as often or, when they did seek medical help, their cases were not as carefully documented as the men in private care. The fact that both men and women in these poor and vulnerable populations were infected did little to change the public and scientific discourse, which, as noted above, continued to concentrate on men (Ehrhardt and Exner 1987).

By 1985, with a viral test available, men and women living with HIV/AIDS had been tested in Zambia, Kenya, and what was then Zaire, and in each case the ratio of men to women infected was approximately equal. Evidence of AIDS infection in Central Africa was later traced back to 1975, which was approximately as long as in the United States and western Europe (Iliffe 2006; Sabatier 1989). However, in Africa, as among poor people in the US and the Caribbean, the disease caused by the virus was not identified among African populations until the symptoms had been described in the United States and researchers were attempting to map its spread. Thus, the epidemic had been missed until Western, middle-income, predominantly White men began to die.

From early on, researchers understood that since the main characteristic of HIV/AIDS was that it destroyed the immune system, the actual manifestation and symptoms of the disease might vary in relation to the surrounding environment. Clearly the opportunistic diseases to which a person with HIV/AIDS might be exposed in any particular setting would differ dramatically in sub-Saharan Africa, Europe or the United States. As a result the symptoms or manifestations of HIV/AIDS would vary with culture and geography. Nevertheless, since Western research framed the cultural constructs, scientific understandings, and economic investments in treatment, the models developed with respect to gay middle-class men became the basis for diagnosis of HIV among both men and women internationally.

As Panos noted, "Typical symptoms" are "based largely on North American and European experience; the syndrome varies considerably from one part of the world to another and less clinical research is available on AIDS patients in developing countries" (Sabatier 1989:6). Diagnosis did not originally include the opportunistic diseases that were most common in sub-Saharan Africa.

Thus, the original Western criteria limited the possibility that either men or women in many parts of Africa could recognize that they had the virus. Kaposi's Sarcoma (KS), a skin lesion almost never seen before in the United States, was used as a diagnostic criterion of AIDS by the Centers for Disease Control. However, Kaposi's Sarcoma, which seldom occurred in women, was endemic in many African countries and therefore not immediately or usefully a symptom of AIDS in that region.

Among middle-class gay men in the West, unusual forms of tuberculosis were an immediate flag that AIDS might be present. However, among poor women and men in the US, as well as in most regions of Africa, Latin America, and even Russia and eastern Europe, there is much untreated tuberculosis. Drug-resistant forms can be found apart from AIDS and are thus not a good indicator of AIDS infection.<sup>8</sup>

Just as diagnoses based on the symptoms of gay Western men with AIDS made AIDS diagnosis difficult in other parts of the world, early diagnostic criteria also made it difficult to diagnose AIDS in women, even in the US (Marte 1996:230). In fact, the Panos report, generally one of the most enlightened of its time, does not even mention women's symptoms, although, as noted above, it was careful to point out the lack of research on the symptoms of Third World AIDS. Oral thrush (oral candidiasis), a yeast infection in the throat, was identified early among Western men with HIV. However, for many years, vaginal yeast infection (vaginal candidiasis), associated with HIV in women, was not officially identified with AIDS. The difficulty in assigning a diagnosis of AIDS to women in the United States limited their access to medical benefits, treatment, and disability assistance. Because of the definition of symptoms for AIDS, many poor women died before they were allowed the official AIDS label, which would have made them eligible for financial assistance (Marte 1996). As a result of women's protests, in 1994 the Centers for Disease Control broadened the diagnostic criteria for AIDS to include vaginal candidiasis and other symptoms more common in women.

After the isolation of the virus in 1983, research on treatment became possible. For the first decade, many Western middle-class men, in desperate straits and also becoming extremely well organized, had early access to treatment through experimental drug trials. Women were not included in these trials, partly because AIDS was seen as a predominantly men's disease, partly too because most of the women were poorer, less educated, and less well organized, and partly because women were routinely excluded from drug trials in the United States (Farmer et al. 1996; Heise and Elias 1995; Susser 2002). To join possibly dangerous experimental drug trials, men and women sign away their rights to legal recourse in the event of toxicity. However, this agreement does not cancel the legal rights of the fetus. Legally, the problems of an infant can be traced much more easily to a mother's exposure than

to the father and for this reason, among others, the pharmaceutical industry has historically been wary of including women in trials. Even today, this remains a major obstacle in trials of microbicides, which would involve an invisible vaginal gel to protect women from the virus. Women who are or become pregnant have to be excluded from the trials to protect the fetus. Some current trials re-admit women after the birth of their babies.

Exclusion from early access to experimental drugs, much contested by the women's health movement, had even more profound ramifications. The US Food and Drug Administration (FDA) regularly insisted that new medications be licensed only to the age and sex groups included in the trials, which meant that women had less access to treatments once drugs were tested. The exclusion of women from trials and therefore neglect of treatment possibilities for women and infants was particularly damaging for poorer countries where many more women were infected and where the majority of cases of transmission of the virus from mother to child became concentrated.

Since 2000 and the advent of microbicide trials, vaccines, and research on mother-to-child transmission, contrasting problems of the ethics of experimental research among poor populations of the global South have become a central concern (Craddock 2005). With the highest prevalence of AIDS now occurring in poorer countries, trials must be conducted there. The trials need a large at-risk population in order to measure whether the intervention has shown any preventive effect. Such trials have raised difficult ethical questions. A major issue concerns the equivalence and continuity of care ethically required for people engaged in such trials. A subsidiary but quite thorny issue involves the lack of high-quality or continuing care for mothers who participate in trials of drugs that will reduce AIDS transmission to their infants but not necessarily help the women themselves. A second ongoing challenge, to be discussed later, involves the dubious advocacy of replacement feeding in situations where breastfeeding has for many decades proved the most healthy approach (Coovadia et al. 2007).

In 1996 when effective anti-retroviral medications were discovered, they became life-saving for middle-class people all over the world. However, most men and women in poor countries were completely excluded from access to the new and expensive treatments. Over time, this economic discrimination, with its deadly consequences, became the focus of a continuing worldwide campaign. Conditions have shifted dramatically. In Brazil, Argentina, and other countries of Latin America, highly active anti-retroviral treatment (HAART) is now distributed through national health services. Assisted by funding from the Bill and Melinda Gates Foundation and elsewhere, Botswana is committed to providing universal access to HAART. By the time this book is published, some affordable treatment is likely to have become available in South Africa, Uganda, and other regions of Africa as a result of powerful social demands.

The Women's Interagency HIV Study, initiated in response to women's demands and established in 1993, was set up specifically to fill the gender gap left by the original research on men. Federal funding did not permit comparison between men

and women through the selection of a similar men's group. However, since its inception the Women in Health publications have printed over 340 articles on the experiences of women in treatment for AIDS (Gollub 2008) and with respect to such issues as cancer of the cervix (Harris et al. 2005).

Nevertheless, the history of women's exclusion from drug trials and medications has had a cumulative effect. The data gathered for men in the global North over many years of taking the medications was not available for women, mostly from the global South. Positive women say that, even now, although some data exists, they have less access to networks with information about how women respond to AIDS medications (personal communication, members of International Committee of Women (ICW) living with AIDS).<sup>9</sup>

As I write, in 2008, women are receiving an estimated 59 percent of the HIV care.<sup>10</sup> Although more treatment for AIDS is available today than anyone imagined possible ten years ago,<sup>11</sup> the ways in which the availability and types of treatment will be distributed by income and gender is open to debate.

A recent United Nations Development Program study from India found that, as we might expect, "a significant proportion of new infections are found in women in monogamous relationships but have been infected by husbands or partners who have taken multiple sex partners." However, they also found that, since women are overrepresented among care providers, they find it difficult to seek treatment. "There are significant gender differences in the percentages of untreated opportunistic infections . . . Not only is the percentage of women's illnesses which go untreated higher than that of men, but in the case of women, financial constraints turn out to be an important reason for not seeking treatment."<sup>12</sup> In India, once widowed by AIDS, women often find it easier to go for treatment than when their husbands were alive. Freed from the burden of care and the domination of their partners, widows in India have begun to form strong activist networks (Anandi Yuvaraj, personal communication).

Many people access health insurance through their work. A few capital-intensive, strongly unionized industries, such as the Anglo-American Mining Company and Coca-Cola Company in South Africa, are currently the only industries to offer HAART. Since women tend to predominate in low-capitalized, non-union waged work or in the informal sector without any benefits, it remains to be seen whether the trend toward treating more women than men will continue. With women continuing to suffer from subordination and oppression internationally, the dearth of women-controlled preventive measures has not yet been fully addressed.

Worldwide, women and men are becoming infected faster than treatment is being implemented. In 2007, for every one person who received anti-retroviral treatment, six more were infected (AIDS Vaccine Advocacy Coalition 2007). In fact, estimates suggest that the rate of infection actually escalated worldwide between 2005 and 2007. Thus, clearly, in concert with treatment, technological preventions, and the socially effective distribution of condoms, we need to consider broader social transformations with respect to gender inequality.

## **Gender Inequality Increases Childhood Mortality**

As noted above, since doctors, women, and pharmaceutical companies were initially concerned that anti-retroviral treatments would harm the fetus. It was not until about 15 years into the epidemic that physicians in the US were permitted to try treatments for pregnant women. Only then was it discovered that, in fact, drug treatments during pregnancy and labor reduced the number of children who would test HIV positive after the first year.

Drug treatment during labor and early infancy has become one of the leading tools of prevention for children in the battle against the virus. As a consequence, in the United States and western Europe, the problem of infants who develop HIV/AIDS almost disappeared in the late 1990s. However, in sub-Saharan Africa, anti-retroviral programs for mothers and infants have only been extensively implemented since the turn of the millennium. By the time such preventive treatments became available, 500,000 infants in sub-Saharan Africa had already been infected at birth (UNAIDS 2000).

Typically, in poor clinics in which there is a program to protect the newborn child, the mother herself still has not been treated. As a result, the infants may be saved to become orphans. In a welcome contrast, newer programs are offering anti-retroviral treatment to infants, mothers, and other positive members of the household (Bassett 2001; ICAP 2007; Rosenfield 2002).<sup>13</sup> So far, this policy initiative is in operation in certain areas but has been delayed by the shortage of clinics, trained personnel, and government commitment in many parts of the world (UNAIDS 2006a). Children have suffered inordinately as the result of the neglect of women's health concerns. Although clearly noted among women researchers in the 1980s (Reid 1997), the significance of the mother-child dyad and the importance of the mother's survival in saving the child was little examined and even now is little emphasized.

In the global South, concerns for children were the leading edge of prenatal prevention. Paying attention to both the mother and the child did not emerge for another ten years. Recently, it has become clear that in many African countries, exclusive breastfeeding, avoiding the pollution of water and bottles, and allowing the mother's immune responses and hormones to be transmitted to the baby has saved more babies over time than the provision of formula (Coovadia et al. 2007; Kuhn 2007). In addition, when the mother is receiving effective anti-retroviral treatment, her breast milk hardly transmits the virus.

It has taken 25 years for research on breastfeeding to develop and the subject is still highly marginal among medical researchers in AIDS. Breastfeeding was not mentioned at the plenaries of the 2006 Toronto International AIDS Society Conference. A panel on breastfeeding was organized as an independent satellite, and no other breastfeeding research was presented at the meetings, despite a plenary presentation on nutrition.

In May 2006, the World Association for Breastfeeding Action (WABA) organized a pre-conference meeting ahead of the 2006 Toronto IAS Conference to address the

issues of breastfeeding and AIDS. The event itself, like many other AIDS events, had taken several years to organize from both sides. Women and AIDS activists were concerned about WABA's focus on the infant rather than the woman. WABA activists did not all see AIDS prevention as an appropriate issue for their organization. However, members of several feminist NGOs from the Athena Network as well as members of Blueprint, the Canadian Positive Women's network, were invited to the WABA pre-conference in Toronto in 2006. As a result of this pre-conference and other women's organizing efforts, including such advocacy groups as International Committee of Women Living with AIDS, Athena, Change, Blueprint, and others, a member of WABA was included in the 2008 Mexico City IAS Conference and the category "Nutrition, infant feeding, and food security" was added for abstract submission.

Although, the significance of the mother-child dyad to child survival was established by Dr. Cicely Williams in the 1950s,<sup>14</sup> in the AIDS literature this is often recognized only implicitly in the gender-specific definition of orphans as those whose mothers have died or who have lost both parents (Barnett and Whiteside 2002:9). However, the failure to address women's concerns with respect to HIV has also dramatically increased the tragedy for children. Even foster-care providers for orphaned children are usually female relatives, who are forced to take on extra responsibility in the face of the epidemic and, as women, are themselves at greater risk of infection (Botswana 2000; Kalipeni et al. 2004). Anthropological studies have described a broad network of kin who have taken care of children in the past (Etienne 1997; Gluckman 1965). In many cases, the concept of kinship obligations extends far beyond any biological relationships (Lee 2003). However, in the face of the ravages of the AIDS epidemic, children without mothers and orphans in general have lost social supports (Hunter and Williamson 1997).

An approach to treatment and prevention which always counseled and treated the woman, pregnant or not, would save the mother as well as the child. The mother could breastfeed, adding to the child's chances of survival. Care providers would survive. Such an approach still has the potential to transform the face of the epidemic in southern Africa.

## Unequal Prevention

In spite of the millions of dollars spent over the past decade on the search for a preventative microbicide or a vaccine, only two proven methods prevent the spread of the virus through sex: the man's condom and the woman's condom. In conventional terms, "condom" usually refers only to the man's condom, but, in fact, a female condom has been available for over 15 years. Both the male and the female condom, if used correctly, have been shown to prevent the spread of the HIV virus at least 90 percent of the time. In addition, the woman's condom is made of an

extremely strong form of polyurethane and is less likely to break than the male condom.

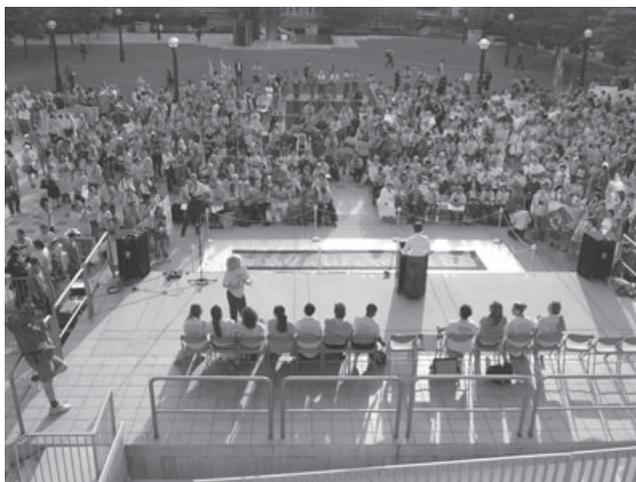
A man's condom, whether provided by the man or the woman, is clearly under the control of the man. It has to be put on at the moment of intercourse and requires that the man have an erection. A woman's condom, designed to fit into the vagina, can be inserted by the woman, even several hours before sex. Although, once inserted, the edges of the female condom can be seen by the man, it is under the control of the woman and can be perceived, like the diaphragm, as part of the woman's effort for reproductive health (Mantell et al. 2006; Mantell et al. 2008; Susser 2001; Susser 2002; Susser 2007; Susser and Stein 2000).

In Southern Africa today, most of the women becoming infected with HIV/AIDS are in fact married, and many of them have already become accustomed to taking responsibility for family planning (Piot 2001; Sinding 2005). Family planning measures, such as Depo-Provera, provide no protection against HIV/AIDS. It is in this context that the woman's condom may prove most useful to HIV prevention.

However, there has been a worldwide disparity in the provision of the woman's condom as opposed to the man's. The man's condom was made available practically as soon as the sexual transmission of AIDS was understood. In the 1980s and 1990s, it was provided in great quantities, free of charge, by the US government and international agencies both in the United States and in many other countries around the world. No requirement was instituted for testing the man's condom to see if it prevented HIV infection before it was distributed universally in the campaign to halt the AIDS epidemic. When men did not like the male condom and did not use it, it was not withdrawn from the market. Until recent policy reversals by the Bush administration discussed in Chapter 2, extensive education and social marketing campaigns were introduced, using film and rock stars on education videos. New colors, aromas, and flavors were used with some success to sell the male condom and make it more appealing. Men who had sex with men had never before used condoms and became a target population of the new "sexy" condom marketing.

The fate of strategies for women to protect themselves from the virus has been different. At least three styles of women's condom were developed in the 1980s in response to the AIDS epidemic. Seeking greater erotic appeal, a European company developed what was known as the "bikini style." It tied around the hips and evoked the sexiness of thong underwear before thongs were as fashionable as they are now. All three female condom styles were subjected to extensive testing and bureaucratic regulation. Only one company survived the ordeal financially. In 1992, after seven years of trials and legislative hurdles, the Reality Female Condom was approved by the US Food and Drug Administration. In 1993, the Reality brand was also approved by the US Medicaid system to be available at reduced costs to women eligible for Medicaid.

However, 15 years later, in 2007, while 11 billion male condoms were distributed worldwide, only 26 million female condoms were circulated (Female Health Company 2007; UNFPA 2007).<sup>15</sup> Little effort or funding from either US or African



**Figure 1.2** Women and Girls' Rally, International AIDS Society Conference, Toronto 2006. "Survival," 2005, by Fiona Kirkwood (South Africa): 24' × 4'11" digital print onto polyester fabric

governments or international agencies have been used to promote this strategy – it is said that women will not use it, or that they already have the man's condom (see Mantell et al. 2006 for review of current literature). Why spend money on promoting a condom for women? A voluminous literature documents the usefulness, feasibility, and cost-effectiveness of the woman's condom (Aggleton et al. 1999; Gollub 2000; Mantell et al. 2006; Wellbourn 2006).

Here I cite some of the most convincing and thorough studies, many of which have been available for over a decade. In Brazil, it was found that when the woman's condom was introduced by knowledgeable and supportive providers, many couples used it and unprotected sex decreased considerably more than when only the man's condom was made available to women (Barbosa et al. 2007). In Senegal and Mexico, UNAIDS experimental programs demonstrated that some women preferred the woman's condom and were more likely to use it than to be able to persuade their husbands to use a man's condom (Mane and Aggleton 2000). In South Africa, when UNAIDS made women's condoms available free to women sex workers in Mpumalanga Province, the workers reported that men offered to pay more for the woman's condom because they preferred it to the man's condom. In 1998, in Zimbabwe, 30,000 women signed a petition requesting that the woman's condom be made available. (For a review of the studies of the female condom in the United States and elsewhere see Aggleton et al. 1999; Gollub 2000; Mantell et al. 2006; Mantell et al. 2008).

In 2006, at the Toronto International AIDS Society conference, CHANGE (Center for Health and Gender Equity), led by Jodi Jacobson, launched a campaign to promote the female condom. Much unofficial effort was devoted by feminist health activists to the promotion of the female condom, including an art creation

by Fiona Kirkwood, "Survival," which was a textile poster composed of male and female condoms and placed in front of the podium at the Women and Girls' Rally.

The following year, 20 years after the female condom was first manufactured,<sup>16</sup> a major international initiative was funded through the United Nations Fund for Population Activities (UNFPA), also known as the Population Fund, to distribute the female condom. Perhaps as a result of all this activity, including pamphlets by the Society for Women and AIDS in Africa (Society of Women Against AIDS in Africa 2006) and the Program for Appropriate Technology in Health (PATH and UNFPA 2006),<sup>17</sup> the Bill and Melinda Gates Foundation, after years of lack of interest, also contributed to the female condom initiative.

Sadly, this new recognition of the female condom might be attributed to recent setbacks for the microbicide trial, the diaphragm and the vaccine trials, all in 2007 (AIDS Vaccine Advocacy Coalition 2007).

On November 13, 2007, the *New York Times* "Science" section finally published a spread that highlighted the usefulness of the female condom. However, even in this report the science writer once again highlighted the "yuk" factor as the reason female condoms had not been distributed up till now.<sup>18</sup> Notwithstanding any unesthetic factor for middle-class Americans, female condoms are now in use in 75 countries and since funding has become available for their distribution, many more women in sub-Saharan Africa and elsewhere are using them (PATH and UNFPA 2006; Society of Women Against AIDS in Africa 2006).

There has been extensive testing of vaginal microbicides, gels that would not be seen or felt in sexual interactions but would kill the virus, which would clearly be preferred by men and women around the world. However, it was announced in July 2000 in Durban that none of these had yet been successful. Seven years later, in January 2007, people were waiting with bated breath for results of further microbicide tests and again the results showed that using a microbicide might in fact raise the risk of HIV infection for women (AIDS Vaccine Advocacy Coalition 2007).

An invisible vaginal microbicide that would kill the virus but allow pregnancy is a powerful and important goal but one that is not yet under test, although at least one of the candidate microbicides could do this. Some microbicides now in testing stages would kill the sperm as well as the virus and even then are not expected to be more than 50 percent effective. The research on the diaphragm, which would also be invisible in intercourse, has not yet proven conclusively that the method is effective in the prevention of HIV infection although there are possible indications that it may be as good as the male condom (Padian et al. 2007).

The idea that women worldwide should wait for the microbicide option, without having access to the female condom in the interim, suggests an inflexible representation of sexuality for both men and women, at least among a professional elite. It would appear that many national governments, funding agencies, and global non-governmental organizations prefer to wait for an invisible method, possibly more conducive to "beauty" and sexual fantasy, than to promote access to any other

method that will save women's lives *now*, even if more clumsy and awkward (Susser 2001). Women are dying for lack of the immediate and secure option of the female condom.

It is sometimes the elision of biological difference, and at other times its emphasis, that contributes to the unequal access for women to strategies for HIV diagnosis, treatment, and prevention. For example, women were denied access to experimental drug trials because the medical community feared the impact of the drugs on pregnancy, a denial based on the biological differences between men and women. In contrast, in the distribution of the male condom, it was assumed that women were somehow equivalent to men. If women had access to male condoms, it was as if women themselves had them – inequality justified by ignoring biological difference.

Whether women are viewed as the same as or different from men, female needs have rarely been met and, as a result, the lives of children and men have been ravaged by the various forms of cultural blindness that continue to plague efforts to prevent disease.

### **Gender Inequality and the Relentless Inevitability of Infection**

The ongoing costs of gender and sexual inequality outlined here can be tracked again in the shifting demographics of HIV/AIDS worldwide. In the early 1980s in sub-Saharan Africa, HIV was found in a ratio of one man to one woman. In the same region by 2000 more women than men were infected, and while men were dying between the ages of 25 and 45, women were dying of HIV/AIDS between the ages of 15 and 25 (Botswana 2000; Piot 2001). By 2000, twice as many young girls as young boys, age 15–24, in Namibia, Botswana, and throughout southern Africa were living with AIDS. In Namibia, 20 percent of young girls aged 15–24 were living with AIDS and 9 percent of young boys. In Botswana, 34 percent of young girls between 15 and 24 were living with AIDS, as compared with 16 percent of young boys (UNICEF 2000). At that time, one community sero-prevalence study in Ndola, Zambia found four sero-positive girls age 14 for every one sero-positive boy of the same age (UNAIDS 2000). In 2007, clearly, if the growing gender disparity among youth is any indication, in which girls are living with AIDS at a rate three times that of boys in sub-Saharan Africa, the epidemic of the future bodes even worse for women (Physicians for Human Rights 2007). In southern Africa, it is powerfully driven by the search of older men for younger women, partly in an effort to find sexual partners who are free of HIV/AIDS.

As noted earlier, similar trends toward the greater infection of young women can be traced in the United States. Although proportionately few women were infected in the early 1980s, by 2006, 25 years into the epidemic, many more women had become infected. Black women were still particularly at risk:

During 2001–2004, in 35 areas with HIV reporting, 51 percent of all new HIV/AIDS diagnoses were among blacks, who account for approximately 13 percent of the US population. Of these, 11 percent (12,650) of HIV/AIDS diagnoses in men were in black men who were infected through heterosexual contact, and 54 percent (23,820) of HIV/AIDS diagnoses in women were in black women infected through heterosexual contact. In the US today, women account for approximately one quarter of all new HIV/AIDS diagnoses and, in 2002, HIV infection was the leading cause of death for black women aged 25–34 years (Centers for Disease Control: Fenton and Valdiserri 2006).

In the United States, HIV has even shifted regionally from its main concentration in the urban north. Poor young Black women in the rural south infected through heterosexual sex are a new and fast-growing population (Centers for Disease Control: Fenton and Valdiserri 2006). Clearly we are watching the interplay of inequality in race, class, and gender reflected in the medical and health experience.

HIV/AIDS affects women differently than men and worldwide affects as many, if not more, women than men. With respect to every aspect of HIV, transmission, diagnosis, treatment, access to care, care-giving, reproduction, and stigma, women have particular experiences and needs different than men. Historically, women were diagnosed later than men, and treated, if at all, later than men. Apart from (or, more accurately, in association with) the biological, women have different kin and household responsibilities and expectations, different demands at different points of the life cycle, and, of course, very different access to employment and resources.

I am not arguing here for an essentialist perspective on “woman” but rather for a holistic and practical vision which takes women’s lives in terms of class, inheritance patterns, gendered violence, and employment opportunities into account, along with obvious biological differences. This is the kind of vision that is being generated by Physicians for Human Rights in their studies of Botswana and Swaziland when they begin their Executive Summary with the statement:

HIV/AIDS interventions focused solely on individual behavior will not address the factors creating vulnerability to HIV for women and men in Botswana and Swaziland, nor protect the rights and assure the wellbeing of those living with HIV/AIDS. National leaders, with the assistance of foreign donors and others, are obligated under international law to change the unequal social, legal and economic conditions of women’s lives which facilitate HIV transmission and impede testing, care and treatment. Without these immediate and comprehensive reforms, they cannot hope to halt the deadly toll of HIV/AIDS on their populations (Physicians for Human Rights 2007:1).

### **Reconsidering Biology: Some Notes on the History of Public Health Terms**

The representation of women’s issues within public health and AIDS research was overdetermined in a number of ways. Clearly, Western funds and Western research

emphasis was initially on the first identified Western problem of the gay epidemic, as it was called early on. As the disease was recognized, the tragedies of early death among middle-class Western men led through denial to outrage (Shilts 1987). Both men and women, as represented most dramatically in the gay and lesbian cooperation in such important and effective protest groups as ACT UP, called for action (Brier forthcoming). They protested the lack of funds and research and demanded the speed-up of drug trials. In fighting the stigma of homosexuality and defining the human right to confidentiality, activists framed the AIDS debate in terms of what was most progressive and enlightened for the Western epidemic among gay men (Oppenheimer 1988; Oppenheimer and Bayer 2007).

However, as has been argued with respect to the general discourse on human rights and enlightenment values, rights must be framed within a situated understanding of poor people and women of color in the West and women in different contexts worldwide (Asad 2000; Nussbaum 1999). We need to also consider the situated rights and challenges of women with biological and socially different positions from the gay men who framed the important demands of the Western epidemic.

In the early 1990s some activists recognized the different problems of poor and minority people living with AIDS. For example, New York ACT UP worked to prevent evictions of people with AIDS. They blocked traffic with furniture and through a variety of strategies fought successfully for the rights of people with AIDS to government-subsidized housing (Eric Sawyer, personal communication, 2003). However, as mentioned earlier, in this period, most poor women did not survive to present the symptoms which would allow them to access that right.

The much-criticized public health focus on “risk groups” also led to a lack of understanding of women’s issues (Baer et al. 2003; Patton 1990). As discussed earlier, risk groups such as IV drug users, partners of IV drug users, and sex workers were singled out in the literature without attention to their lives as men or women in the social context of families or neighborhoods (Baer et al. 2003; Patton 1990). From early on, in the US, Uganda, and elsewhere, it was evident that married women, women civil service workers or even professionals were also contracting AIDS (Mann and Tarantola 1996). However, partially reflecting the power of the “risk group” characterization of women sex workers, even today, one speaker in 2006 at Toronto said, “We sex workers are never included in panels that are about ‘women’.”

A third issue that led to the misunderstanding of the epidemic among women stemmed from the epidemiological perspective that focuses on the modes of transmission. Here we return to terminology. The very terms that have been used to describe the women’s AIDS epidemic have sometimes obscured our understanding of the processes of transmission. “Heterosexual transmission” is the term most frequently used in the public health literature to index the problem of women contracting HIV through sex with men. Talking about and measuring “heterosexual transmission,” while appearing to construct a scientifically specific image, makes invisible the actual differences in behavior as well as minimizing the differences in risk of infection between men and women involved in a sexual encounter. Such an

apparently objective rendition of behavior as “heterosexual sex” erases gender differences and confuses scientific questions with respect to the transmission of HIV/AIDS: the biological, the cultural, and the social.

If we look at the research literature since 2000, we can see some of the confusing aspects. One review illustrates the problem:

Heterosexual intercourse is the most common mode of transmission of HIV in poor countries. In Africa slightly more than 80 percent of infections are acquired heterosexually, while mother-to-child transmission (5–15 percent) and transfusion of contaminated blood account for the remaining infections<sup>3</sup>. In Latin America most infections are acquired through men having sex with men and through misuse of injected drugs, but heterosexual transmission is rising. Heterosexual contact and injection of drugs are the main modes of HIV transmission in South and South-East Asia (Lamprey 2002:207).

When this writer says “heterosexual transmission is rising,” he means that more women are becoming infected. However, nowhere is the problem stated this way. In this paragraph the words “men”, “mother” and “child” are used, never “women.” We are never told whether the drug users are men or women, but implicitly “drug user” is coded as “men” and, as we shall see later, the consequent heterosexual transmission referred to in the article is to partners of drug users almost universally read as “women.” In the rest of the article, the differences between men and women’s experiences are reduced to a general concern with “women’s vulnerability.” In the literature, transmission of the virus to men through female sex workers is stressed, but sexual differences in the behavior of women, in general, are seldom raised. Often, women, 50 percent of the human population, are classified as “vulnerable groups” and problems related to the infection and treatment of women are incorporated into general themes such as “culture.”

A detailed review of the 2006 Toronto Track categories and the proposed categories for 2008 reveals what tended to make invisible the differences between men and women. In Toronto, categories such as “culture” and “vulnerable groups” became the general terminologies under which issues of women’s subordination or women’s different opportunities might be classed. The problems of women as a whole – biological challenges and opportunities, social and economic inequalities, and cultural subordination – were rarely highlighted.

Firstly, of course, only women contract HIV/AIDS through the vagina, though, of course, heterosexual relations for women can be vaginal or anal. Anal sex may be even more risky for women than vaginal sex (Exner et al. 2008). Since women are much more subject to gender-based violence (Jewkes et al. 2004), it can be assumed that women are more likely to have participated or been forced to participate in anal sex than men. In regions such as Puerto Rico, with its long history of Catholicism and emphasis on virginity, extremely high rates of anal sex between male and female young college students have been documented. These particularly high rates of anal sex might suggest that the women are trying to avoid pregnancy

and the “violation” of their virginity while acquiescing to their male partner’s demands (Cunningham 1994).

Overall, since the measures of “heterosexual transmission” do not in themselves imply the differences in cultural, economic, age, or physical power between the two groups, the “men” and “women” incorporated indiscriminately in the term “heterosexual” are in fact apples and oranges. Such confounding of categories makes it difficult to sort out the social and cultural pathways of risk and vulnerability. Although there is much speculation and some evidence that women are more likely to be infected through sex with men than men are infected through sex with women, 30 years into the epidemic, definitive data on this question is still not available. Just as there has been extensive discussion in the social science literature of the ways in which blindness to racial difference does not address racial discrimination (Baker 2001; Harrison 1995), so an insistence on terms such as “heterosexual” and even “gender” serve in many ways to erase important differences in the experiences of women and men.

As mentioned earlier, the other category that usually designates women and somewhat vaguely overlaps with “heterosexual transmission” is the term “partners of IV drug users.” This term almost universally implies women who do not use IV drugs and became infected through sex with men: in other words, a specific form of “heterosexual transmission.” As we can see, women disappear from the scene as researchers write:

Three cases of pediatric AIDS in children born in 1977 provided the first evidence for HIV infection among drug users in New York . . . Their only known risk factor was that they were born to IV drug using mothers . . . The first 5 known cases among heterosexual IV drug users occurred in 1980 when there were an additional 3 cases with IV drug use and male homosexual activity as risk behaviors (Des Jarlais 1992:280).

Here, although obviously we know, we are not told that the drug-using mothers also took part in heterosexual sex. One might ask, was the cause drug use or sexual transmission? We are to assume it was drug-use, as this is the categorical hierarchy of the CDC. We do not know if the “5 heterosexual IV drug users” are women or men, only that the other three were men who had sex with men. If a woman uses drugs, she is assumed to have contracted HIV through drugs not sex. A man’s drug use and sex with men is classified as possible sexual transmission (Exner et al. 2003). This particular article, on the history of IV drug use and AIDS concludes with a call for more attention to drug users themselves, rather than to their transmission of the virus to women, heterosexual men, and children. However, it fails to discuss the differences between men and women drug users or men and women’s sexual experiences (Gollub 2008).

The superficially objective “behavioral” distinction “partners of IV drug users” blurs much of the most useful information for understanding the increasing transmission of HIV/AIDS to women and young girls. We read sentences like this con-

fusing quote taken from the recent AMSA report, *AIDS has a Woman's Face* (American Medical Student Association 2005). Speaking of eastern Europe and central Asia, the investigators write:

... Most of the IV drug users are young and sexually active, characteristics leading to an increasing prevalence of sexual transmission as a mode of transmission.

In each continent this publication shows that women and young girls are becoming the largest group infected with AIDS. Each time IV drug use is mentioned, the sexual consequences are noted in the same vague way, without any examination of which group is using the drugs and which group is subsequently receiving the infection through sexual intercourse.

Clearly, sexual behavior is changeable and culturally determined. However, the biological, social, and cultural differences between the experiences and behavior of men and women which are hidden in the terms "heterosexual transmission" and "partners of IV drug users" simply illustrate the challenges faced by women as well as possible programs for intervention and prevention. Such differences are far from captured in the passing addition of women to a list of "vulnerable" groups, often including "orphans" (as noted above, another term that elides its gendered implications often meaning boys and girls without *mothers*) and poor people in general.

Recent controversy surrounding male circumcision again reveals inattention to women. Male circumcision is discussed as a sexual modification but the possibly differing prevention effects for men and women have not been much considered (Berer 2007). We know from extensive data that male circumcision reduces infections among men, but we do not know whether it reduces or possibly increases the risk for transmission of the virus to women. In fact, following the patterns of leaving out women in previous research, of the three recent studies of male circumcision as a protection from HIV infection, only one included women partners. All three studies showed that an HIV-negative man was less likely to turn positive if he was circumcised. The one study that included the women partners of circumcised men did not include enough women to show whether women were protected or possibly put at risk by male circumcision (AIDS Vaccine Advocacy Coalition 2007).<sup>19</sup>

A demographic argument has been made that if male circumcision reduces men's likelihood of being infected by women, it will reduce the overall rate of infection. However, this will be less effective if men, feeling safer, simply increase their sexual activity without using condoms or if, as many men have done, they have sex before the wounds of the operation have healed (Berer 2007; AIDS Vaccine Advocacy Coalition 2007). Under these conditions, the rates of infection for women may in fact rise.

Women's experience differs dramatically from men's in many ways beyond the biology of sexual transmission. It becomes necessary to state the obvious: only women can become pregnant and in this way transmit the HIV virus to their children (Reid 1997). This crucial biological difference means that an HIV-positive baby can be directly traced to her positive mother. Thus, women generally find out

in a much more public way than their sexual partners that they are HIV positive (Reid 1997). A man can continue to deny an AIDS infection, but a woman with a sick baby cannot. As mothers all over the world have discovered, an infant with AIDS deprives its mother of the right to choose whether to be tested and in fact makes such a choice irrelevant. Many of the discussions of voluntary testing and counseling turn a blind eye to this issue which, again, has dramatically different implications for men and women.<sup>20</sup>

Equally, only women can transmit the virus to children through breastfeeding. Correspondingly, only pregnant or breastfeeding women can transmit protective or harmful medications through their bloodstream to infants. All of these differences have had profound consequences for the experience of HIV/AIDS for women. As will be seen in the discussion of poor women in southern Africa, when HIV/AIDS affects the very basis of social and biological reproduction, a woman's ability to bear a child and create a family, this carries very different implications for lifetime decisions than the possible transmission of HIV/AIDS from man to man, or even through female and male sex workers.

The human and emotional dilemmas for women in their role as partners and mothers are dramatized in the fact that many women sex workers require their clients to use condoms. Nevertheless, the same women cannot easily make the same demand of their boyfriends or lovers (Cleland et al. 2006). The conflicts facing women in the constitution of family life are particularly challenging in the era of HIV/AIDS.

Clearly, condom use is universally situational and men too will behave differently with sex workers or casual partners than with their wives. A man may wish for children in his relations with a woman and therefore refrain from condom use. However, as we have seen, it is the woman who is at most risk of infection from such a decision and, in many sexual situations, the woman is subordinate to the man and he defines the nature of the relationship. Of course, it is also the woman who will have to bear the infant and often take the responsibility for raising the child whether or not her partner, herself, the baby or other children in the family are subsequently living with HIV/AIDS.

Thus, before we even begin to outline the historical, social, and economic discrimination women have suffered, combined with the lack of access to equal inheritance, and education and employment today, we have to recognize that biology has framed the experience of women in this epidemic differently than for men.

In conclusion, in poorer countries, where sexual transmission between men and women is dominant, women are in a central and, from this perspective, powerful position with respect to the HIV epidemic. As the first diagnosed by dint of bearing an HIV-positive infant, they are regularly exposed to blame and victimization for their positive status. As mothers who can protect their infants from transmission of the virus breastfeed to promote child survival and, in maintaining their own health, prevent a child from becoming an orphan, they hold a potential key to limiting the devastation. Approaches to treatment and prevention may either coun-

teract or exacerbate existing patterns of inequality and discrimination by gender. As was first said in 1997, only by putting women in the center of thinking about the epidemiology of HIV/AIDS can we fully address the increasing rates of transmission throughout the world (Reid 1997).

### Social Context of AIDS Research

Paula Treichler, Shirley Lindenbaum, and others early on, drew our attention to the problem of the Western gaze on AIDS (Lindenbaum 1997; Patton 1990; Treichler 1992). Scientific theories were developed based on a medical paradigm which did not take the local realities or perceptions into account but drew rather on Western representations of, for example, “darkest Africa.” In particular, Treichler commented on the heavy reliance on statistics to deal with the unknown. When nothing is known, the way statistics are used can also lead to paradigms that fit stereotypic conceptions. She called for a diversity of voices in the attempt to introduce diversity into science (Treichler 1992). Although many of these problems persist, there is no doubt that, after a prolonged struggle, qualitative work and anthropological analyses have gained more credibility and funding in contemporary AIDS research (e.g. Farmer et al. 1996; Hirsch et al. 2007; Lee and Susser 2006; Parker et al. 2000).

Although incorporating history and political economy into our understandings of the HIV/AIDS epidemic has long been recognized as essential to an ethnographic analysis of AIDS (Barnett and Whiteside 2002; Bond et al. 1997; Parker 2001; Schoepf 2001), it is also crucial to examine the historically changing relations of men and women within this context and to sort out which generalizations apply to men and which to women (Morrell 2001; Schoepf 2004; Susser 2002).

Nevertheless, even in much of the sociologically informed literature on AIDS with respect to gender, the unmarked category tends to assume privilege and refer to men. For example, Barnett and Whiteside’s volume *AIDS in the Twenty-First Century* (2002) is written in terms of “sociological” categories such as “individuals,” “people,” “wage earners,” and “parents” without in-depth consideration of how men and women differ in ways they take on or experience such roles.

In discussions of the economic impact of AIDS, Barnett and Whiteside stress “households.” However, like the word “heterosexual,” the word “household” obscures more than it reveals. In addressing AIDS effectively, it seems important to consider further the implications of the exploitation of women’s labor in the household, documented in the development literature in many parts of the world (Kabeer 1997). As we have often been reminded, the global economy frames the possibilities for governments, women, and men in dealing with AIDS (Altman 2001; Parker 2001; Susser 2004). Thus, we need to understand the interplay of the ideologies of gender and race with local, national, and international politics.

### **Global Strategies: Women's Rights To Health**

The international recognition of the feminization of HIV/AIDS has been both temporary and erratic. Indeed, the current political climate leaves little assurance that women's demands for protection, care, and treatment will progress in any concerted fashion in the coming years. While much attention has been paid to maternal transmission of the virus, the protection of women from infection has been less considered.

In 1990 at the San Francisco International AIDS Society Conference, plenary speakers Mindy Fullilove and Helen Rodriguez-Trias both articulately raised the issues of women's subordination. The Women's Caucus of the HIV Association was formed at this meeting.<sup>21</sup> The 1992 International AIDS Conference was held in Amsterdam after people refused to accept a conference proposed for Boston due to US restrictions on allowing people living with HIV/AIDS to enter the US.<sup>22</sup> The decision was made rather late, which left little preparation time. Jonathan Mann, co-chair of the conference, was adamant that human rights and community participation – especially including people living with HIV/AIDS – would be a key theme of the conference.

At that time, a group of women living with HIV/AIDS in the Netherlands wanted to establish connections with other HIV-positive women around the world. The women's group of the HIV Association and members of ACT UP The Netherlands proposed holding a pre-conference meeting that would unite positive women and help prepare them for navigating the conference. Fifty-six women from 27 countries attended this initial event and over the years ICW came to represent an extremely central group of women activists.<sup>23</sup>

In Durban during 2000, at the International AIDS Conference, Geeta Rao Gupta (2000) gave a plenary speech concerned with women and AIDS. This was the first conference to be held in the global South. To enter the scientific conference required a hefty registration payment. Community-based women leaders and global advocates collaborated to create a forum parallel to the Durban conference that would be open to the public. "Women at Durban," as this initiative would come to be called, highlighted the need for open forums where community members could engage the International AIDS Conferences and led to the initiation of "Women at Barcelona" and "Mujeres Adelante" at the subsequent International AIDS Conference in Barcelona, Spain. "Women at Barcelona" was organized to bring together advocates and researchers on women and HIV at the conference. Organized by ICW in Barcelona, "Mujeres Adelante" was a parallel forum, open to the public, which focused on the engagement of local community women living with HIV. However, Mujeres Adelante staged a march at the closing ceremony to highlight their frustration with the neglect of issues important to HIV-positive women. The difficulties for women to be heard in the conference persisted.

Together, these initiatives set the stage for the International AIDS Society to incorporate a forum at the International AIDS Conferences that would be open and

available to local community members and conference delegates alike. The Global Village became institutionalized at the International AIDS Conference in Bangkok, Thailand where the Thai Women and AIDS Task Force set forth a feminist platform. Building from this history, the Athena Network, ICW, the Coalition for a Blueprint for Action on Women and Girls in Canada, and Voices of Positive Women joined to convene the inaugural Women's Networking Zone in the Global Village of the International AIDS Society Conference in Toronto.

The Women's Caucus of the International AIDS Society convened to draw up a set of principles for the health rights of women and girls, which became the Barcelona Bill of Rights. The Barcelona Bill of Rights, which included the controversial right to abortion among such issues as rights to land and inheritance, was reiterated and carried forward at the 2004 Bangkok International AIDS Society Conference. *Athena: Advancing Gender Equity and Human Rights in the Global Response to HIV/AIDS*<sup>24</sup> was formed after Bangkok to connect feminist, human rights, and AIDS networks in global activism. Since that time, a Women's Networking Zone has been designated at international AIDS meetings, and panels related to women's claims and women's marches have been organized (Susser 2007).

One of the many interventions that takes women's lives into account is a "one-stop shopping" clinic for women and girls that includes family planning, HIV/AIDS prevention and treatment, and prenatal care. Since the 1980s, some public health activists, recognizing the centrality of women's experience of reproduction to the spread of the HIV/AIDS epidemic, have recommended that family planning clinics integrate HIV/AIDS services into their routine interactions with women. As long as they included all services, from sex education for young girls, fertility planning for positive women, harm reduction programs to well-baby clinics, this would certainly be a significant intervention. Indeed, in 2000, this was adopted as one of the Millennial Goals of the United Nations. Mary Robinson, who was then the UN Commissioner for Human Rights, and many others have advocated for these goals on the international stage ever since.<sup>25</sup> However, such an obvious and seemingly logical, practical, and economical approach to HIV/AIDS prevention has seldom been put into practice. Since 2000, as we shall see in the next chapter, family planning itself has come under attack. For this reason, the comprehensive approach to family planning and AIDS visualized in one-stop shopping care and prevention programs seems like an even more remote possibility, though still eminently worth striving for.

In related developments crucial to protection from HIV/AIDS, the 1995 Beijing Conference on Women represented a pinnacle for the international recognition of women's sexual and reproductive rights. But significantly, while Beijing and the 1985 Conference on Women in Nairobi were pinnacles in women's rights and reproductive and sexual health, there was little link to HIV despite this parallel course. It has only been in the past few years that a tighter link between the reproductive and sexual health community or the women's rights community and HIV has been crafted.

Women's ability to negotiate care and prevention of HIV/AIDS has recently been constrained by newly initiated international contestation of sexual and reproductive

rights (Baer et al 2003; Petchesky 2003). In line with US support for global restrictions on women's reproductive health and sexual rights, the US funding constraints with respect to international policies including sex education and abortion and the encouragement of faith-based initiatives and abstinence are also limiting and shaping the global possibilities for AIDS prevention and care.

### **A Theoretical Reevaluation: The View Over Time**

Having thus reviewed both the exhilarations and frustrations of struggling with the issues of gender and AIDS in terms of public health interventions and social movements, in the following chapters I step back from the fray in order to develop a more comprehensive theoretical framework for understanding the culture and politics of gender with respect to AIDS. I have tried to explore the reasons why, in spite of high visibility in global and even national discourse, women's needs with respect to AIDS are still far from addressed. In this effort, I outline the particular historical processes that have shaped women's experiences on the ground as well as contemporary ideologies of gender. I describe public health professionals, political actors and activists, and grass-roots leaders as they frame public discourse at particular historical moments. Through multiple voices, attention to changing global and class relations, gender, and social movements, I examine how the tragedy of AIDS plays its part in the public sphere and frames the domestic lives of women. I explore how the ongoing politics of sexuality, gender, race, and class in South Africa, Namibia, and among the San of the Kalahari have shaped women and men's options as they continue to fight for a future of their own making.