Women, AIDS, and Invisibility in the United States

Using Feminist Theory to Understand Sources and Consequences of Definitions

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Abstract

The practical project of this thesis is to create a critical account of the experiences of women in the AIDS crisis in the United States. The theoretical project is *to refine a concept of invisibility* of various kinds of problems and obstacles women have been confronted with. The question that both parts of this project seek to answer is roughly the following:
"What is it that we can learn about improving the lives of women by looking at the AIDS crisis as a lens into American social conditions at the end of the Twentieth Century?"
Feminist theories provide a basis for this inquiry as well as the theoretical work on a concept of invisibility.

Résumé

Sur le plan pratique, l'objet de cette thèse est d'offrir un récit critique narrant les expériences vécues par les femmes dans le cadre de la crise du SIDA aux Etats Unis. Sur le plan théorique, il s'agit de raffiner un concept d'invisibilité portant sur différentes problèmes et obstacles confrontant les femmes. La question à laquelle les deux parties de ce projet tentent de répondre pourrait être formuler comme suit:

"Que peut-on apprendre dans le but d'améliorer l'existence des femmes en prenant la crise du SIDA comme point de mire des conditions sociales aux Etats Unis en cette fin du vingtième siècle?"

Les théories féministes offrent un point d'appui à cette quête, de même que les travaux théoriques sur le concept d'invisibilité.

Table of Contents

"Can women get this disease?"
"No."
"How do you know?" they pressed.
"No one has looked," he replied. (Corea 1992)

Introduction

The purpose of this thesis is to provide an analysis of questions of definition and invisibility in the AIDS crisis in the United States. The theoretical goal of this work is to produce a more sophisticated and constructive approach to 'invisible' problems. I would like to show the importance of 'invisibility' for making sense of AIDS as a social crisis.

I do not suggest that the perspective I have chosen, namely of exploring invisibility in the experiences of women and by considering the potential analytical contributions of feminist theories, provides a privileged or exclusive possibility of interpretation. Although I have chosen the gender-sex connection as my primary perspective on the epidemic, I engage with other perspectives motivated more directly by questions of poverty, race, class, drugs and sexual orientation. Raising the questions of gender-sex leads to such perspectives and issues. Consider the examples of the connections drawn in the following quotes:

> 1) **Housing**: "As a result of this ineffectual health care system, many people with HIV-related illness are unable to work. Some lose their jobs when it is discovered that they are HIV-positive. Some three million people in the US are homeless. At least 35,000 Americans are homeless people with AIDS. While the homeless continue to swell in numbers, formally middle class individuals becoming symptomatic are faced with insurance that dries up in short order, an inadequate public health care system, and the likelihood of joining the ranks of the homeless. About 13,00 homeless people in New York City have AIDS. It is a holocaust that is happening before our eyes-eyes jaded by the daily sight of starving, sick and dying people." (Carter)

2) **Prison**: "In New York State, incarcerated women diagnosed with AIDS live approximately half as long as their male counterparts. The average survival time for women from AIDS diagnosis to time of death is between five and six months. Given the lack of proper medical treatment in prison, entering prison is a virtual death sentence for many women PWAs with felony convictions." (Women, AIDS and Activism 1990, 139)

3) **Health and Race**: "The Latino community does have people who are quite capable, but they have been providing services on a very limited basis because they don't have the resources. We need more than stop gap services that are not adequately addressing our community's needs. We have to develop a strategy for the entire health crisis, including prenatal and well-baby care to address the high infant mortality rate, geriatric care for our elderly, and more low-income housing. There cannot be a commitment to addressing HIV infection without a commitment to health." (Women, AIDS and Activism 1990, 101)

4) **Violence**: "Talk of protecting the community from the threat posed by Helen Cover permeated the Court proceedings.[1] The phrase "the community" sounded solid, sacred even. Yet the "community" that was being protected was the community of men. More specifically, it was the community of johns.

In contrast, it was standard practice not to protect the community of women. When women appealed to police for protection from mates who battered them in the home, the police frequently left the women alone with their assailants. Although battery was the leading cause of injury to women in the late 1980s, only ten states legally mandate arrest for domestic violence." (Corea 1992, 175)

In these examples we see how issues of health, violence, race and housing are inextricable from AIDS. What underlies my approach to AIDS is the understanding that if AIDS is dealt with in the contexts of the lives women are living it will inevitably bring to the surface other circumstances of hardship, discrimination or adversity that may be somewhat distinct but *cannot be considered unconnected.* If we try to speak about AIDS in the lives of women we will simultaneously be speaking about education, employment, violence, racism, homophobia and homelessness. I support the view that an understanding of AIDS which places the concerns of women into a broader context of health and social justice will be more successful in the long run than one which insists on looking upon AIDS as just another obstacle for science to overcome.

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[1] Gena Corea tells the story of Helen Cover in order to illustrate the effects of the AIDS crisis on Cover's life.

The relevance of feminist thought in the context of my work here is quite easily explained. The feminist health movement has been a vital force in the United States, providing critical analysis of many of the same issues as I address By challenging the traditional medical discourse in which women were by nature ill and insane and providing an alternative to the sexist, racist and classist social mentalities that were being mingled with supposedly sound scientific advice. The feminist health movement revealed social dimensions of medicine as an institution, effectively politicizing relationships between doctors and female patients as well as the production and control of knowledge. Their are important insights available from this movement that apply to the AIDS crisis. There are still many problems "Our Bodies, Our Selves" raised in 1969 that deserve attention today. A social-scientific study of the AIDS crisis inevitably brings these problems into sharper focus.

Why sex? Why gender? I do not claim that sex or gender are the most important ways of approaching the epidemic for the many purposes of social science. Rather, I have chosen sex and gender as my starting points for this particular investigation of the epidemic on account of the strong sex-based and sexual-orientation definitions of AIDS as a disease in its initial period. The reverse of this qualification is also true: an analysis of the AIDS crisis that ignores the issues of sex and gender must necessarily remain inadequate and cannot claim any overarching validity.

I was motivated to examine the connection between women and AIDS because the social construction of the epidemic and the official definition of AIDS resulted in delays in research, policy and care. These delays have reduced the quality of life of women, shortened the length of their survival and made it generally impossible to ever know how many women have really died of AIDS in the United States. The urgency of my project stems from these circumstances.

A gender-sensitive analysis of the AIDS crisis is internally and externally justified. Internally, AIDS, as a medical phenomenon, has been gender differentiated by

categories of knowledge, and social policies have been based on this differentiation (women have on the basis of their bodies been defined out of eligibility for social security, for example). Externally, because more than two decades of feminist analysis have shown that in almost every class, culture and society, women's lives have been recognizably different from those of men. In the case of the United States, this has most definitely been true.

AIDS "in general" often simply means that the speaker is referring to "AIDS in men." This is not surprising given the background of a medical tradition that regards women's reproductive organs as an aberration of the standard male. Women's symptoms have long been *invisible* to those who were blind to organs not present in the male body. An impartial account of AIDS pares down the "details" that result from the particular perspective and creates a uniform definition applicable to all instances of AIDS. However, the tendency of the medical establishment, under the guise of supposed impartiality, to privilege studies involving the male body has created distortions and invisibilities *that are now visible* in the initial definition of AIDS, which was so narrow it practically excluded women by definition. There must be an ongoing watchfulness as to the construction of a body of information about the epidemic: What is visible? What is invisible?

The term invisibility is often loosely employed as a term to denote a problem that remains unrecognized or unappreciated as such. Often it is the very lack of recognition that constitutes the problem, but it is also the case that unrecognized and unaddressed problems tend to worsen over time. The longer they resist definition, the more they tend to fade into the vague and distorting fabric of the status quo What I would like to do in this thesis is to articulate possible conceptual formulations to specify what lurks behind the term 'invisibility' so as to facilitate recognition of such problems. Although I see invisibility as non-monolithic, flexible, and variable The very flexibility of the term

invisibility is, however, its danger. My project will be to make specific some forms of invisibility.

The epidemic presents social scientists with a special opportunity in which AIDS as a lens opens up a view of many social and political issues not otherwise connected or brought into such sharp relief The cumulative disadvantages that different groups in society suffer are exacerbated by the impact of AIDS as a disease. The consequences that result from infection range from social and economic to the effects of institutions. Addressing AIDS in the social sciences means addressing the circumstances of different lives as they are determined not only by infection but also by the social and political realities of the United States. AIDS offers social scientists an occasion to inquire not merely about separate social and political institutions but to understand them as *inseparably connected* in the life of the individual. Looking at AIDS in this way presupposes a certain understanding of justice, one which takes seriously the implications of democracy and human dignity.

One of the most important sources for thinking about invisibility as a social crisis is the comparison of first person accounts with those of separate institutions. Thinking about this crisis in terms of *what it means to the lives of people* and what it can reveal about the positions in power relationships of these people is central to this thesis. What motivates this thesis is thus the search for issues in need of being addressed in order to improve the overall well-being of women in the United States in the long run.

The AIDS crisis is, so to speak, a fire in a building where fire alerts have not been practiced. The past years have revealed obstacles that different groups of women face: some doors are jammed, others locked and fire alarms are not in working order. These conditions are not so because of AIDS, it is AIDS that creates the stark situation that reveals them and facilitates their definition. I will explore some of these definitions in this thesis. The crisis revealed by AIDS is larger than AIDS and goes to the heart of

social and political organization in the United States. The scope here is narrow and, in as much as it attempts to articulate a theoretical concept, somewhat experimental

Much work remains to be done:

> AIDS is not a single issue crisis and it's not an issue that is only of concern to people with AIDS. It affects all of us and is informed by every type of oppression. There is no one oppression that needs to be combated in order to end the AIDS crisis. (Women, AIDS and Activism 1990, 243)

An important task is to make connections between different kinds of oppression and to explain how they are linked in the AIDS crisis. The AIDS crisis should be of interest to all people because it has revealed and problematized events of everyday life. The project of this thesis is to create connections between different kinds of oppressions (incidences of societal discrimination) that women encounter in the AIDS crisis by examining so-called problems of invisibility and determining what is at their root.

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Women and AIDS by the year, 1981-1993

The following history has been assembled from a variety of published sources. The purpose of this history is to create a framework of events of particular importance to women.

1981 The first case of an infected woman in the United States is reported to the Centers for Disease Control (CDC). Only one woman was *reported* as an AIDS case. But in fact, an unusual number of young women, particularly drug addicts, died that year. Deaths of young women from a variety of respiratory infectious diseases thought to be AIDS-related began to increase dramatically in 1981 in those areas with heavy concentrations of AIDS, as journalist Chris Norwood (The Network News, November/December 1988, "Women and the "hidden" AIDS epidemic") would later uncover. But the fatalities have never been counted as AIDS deaths. (Corea, 5)

1982 AIDS gets its current name.

According to CDC statistics, women constituted approximately seven percent of all persons with AIDS. (CDC 1983)

The first version of the official definition of AIDS is created. This definition will be the basis of statistics and reporting on AIDS. This first definition included no gynecological symptoms. The definition covered opportunistic infections that had been witnessed in a small number of white gay men. The conditions that were considered valid grounds for an AIDS diagnosis were PCP, Kaposi's sarcoma, cryptococcal meningitis, and certain

lymphomas. Twelve percent of the cases in women were thought to be heterosexually acquired, yet the CDC's procedures and definition failed to reflect this fact. The CDC did not add a category for heterosexual transmission to the system used for classifying AIDS cases. (Corea, 16-17)

1984 Isolation of the virus that was subsequently named HIV.

1985 NIAID (National Institute for Allergies and Infectious Diseases) released an HIV-antibody test but the test was not offered to individuals who wanted to find out whether they had been exposed to HIV. The test was first used for research purposes and eventually distributed to a small number of doctors.

On one hand, women still remain invisible in the epidemic even in the face of documented cases and reasonable grounds for concern; but, on the other hand, some women are suspected of being HIV-positive or having AIDS for absolutely ludicrous reasons (because they were mothers of gay men, because they lived near the gay village, because they couldn't explain why they were sick...). Since the test is not available, women cannot ascertain their serostatus. (Corea, 41)

1986 Creation of the famous SILENCE=DEATH[2] poster which became a symbol of AIDS activism, later associated with ACT UP (AIDS Coalition To Unleash Power). The poster inverts the pink triangle used to identify homosexuals in German labor and concentration camps in the Third Reich. The text in small print reads: "Why is Reagan silent about AIDS? What is really going on at the Center for Disease Control, the Federal Drug Administration, and the Vatican? Gays and lesbians are not

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[2]"The slogan SILENCE=DEATH refers to the complicity that permits events like the Holocaust of World War II to take place " (George M Carter, ACT UP The AIDS War&Activism. New Jersey: OPEN Magazine, Pamphlet Series, 1992).

expendable...Use your power...Vote ..Boycott...Defend yourselves. Turn anger, fear, grief into action." (AIDSDEMOGRAPHICS, 30/31). SILENCE=DEATH openly politicizes the AIDS crisis as a social injustice that is being tolerated because those most visibly affected are thought to be expendable by society and government.

1987 Awareness of women's vulnerability is indirectly stated in the concern about perinatal transmission. Tragically, concern is not yet directed at women themselves but rather at their potential to infect others. In some publications, the concern for women as vectors of disease exceeds the concern for women for their own sake, the example below exemplifies such treatment of women in publications.

> "As is the case with other sexually transmitted diseases, AIDS causes a disproportionately greater burden for infected women than for infected men. The major reason: women are child bearers and can transmit infections to their offspring during pregnancy or delivery." (Guinan 1987)

This quote says nothing about the specific burden to women; it indicates that women are a risk to their children. This quote is representative of an attitude towards women in the AIDS crisis that perpetuates the denial of their vulnerability by failing to provide a sharp focus on women themselves and only defining them in relation to possible partners or children. Given this approach, it is not surprising that there has been a large amount of misplaced paranoia about prostitutes, little attention for the situation of older women and no attention for the plight of lesbians in the crisis. Women of interest to AIDS research are predominantly "of reproductive age" and a central area of concern is perinatal transmission. Many publications fail to differentiate in any significant way between female infection and its consequences for women and in utero or related transmission. (Haddad 1992, 49)

ACT UP (AIDS COALITION TO UNLEASH POWER) is formed in New York City. Composed largely of gay men and lesbians, the group's stated goal is to transform

anger at the open neglect of AIDS into political action and protests. ACT UP protested "the near total neglect of AIDS by politicians, doctors and researchers, and their envelopment in a miasma of bureaucratic malaise The first action was undertaken on Wall Street to protest pharmaceutical giant Burroughs and Wellcome's profiteering from AIDS." (George M. Carter, ACT UP The AIDS War&Activism. New Jersey: OPEN Magazine, Pamphlet Series, 1992). ACT UP's activities create the possibilities for speaking of sexism and racism as well as homophobia by showing dynamics of societal discrimination that impede action to stop AIDS. ACT UP played a pivotal role in voicing the circumstances of social injustice at the heart of the AIDS crisis and demonstratively redefined AIDS as a social crisis rather than a scientific puzzle. The following quote from an ACT UP poster was intended to enrage readers and make them realize the inhumanity of the treatment of AIDS in the United States:

> "One million [People with AIDS] isn't a market that's exciting. Sure it's growing, but it's not asthma. -Patrick Gage, Hoffman-LaRoche, Inc." (AIDSDEMOGRAPHICS, 96).[3]

Advertisers and public health strategies tarted targeting women as responsible for heterosexual safe sex. The following commentary on a condom ad reflects the shift in responsibility for providing condoms in relationships from men to women:

> "In ads in major US. women's magazines in the spring of 1987, a beautiful woman praises a condom that sounds like a Greek god and looks like a container of yoghurt. It is said that AIDS has brought back the 1950s, but back then it wasn't women who bought the rubbers. DON'T GO OUT WITHOUT YOUR RUBBERS advises another ad for women, because, "if a woman doesn't look out for herself, how can she be sure anyone else will?"" (Paula Treichler in AIDS: The Burdens of History, 223)

Later on this strategy would be problematized on the grounds that women could not control their partner's condom use and that for some women the idea of initiating condom

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[3] Profitability of AIDS research was estimated to be lower than for asthma and therefore less of it could be expected

use with a partner was socially, culturally or religiously inconceivable. What followed were demands for a woman controlled barrier method of protection and more realistic assessments of heterosexual relationships.

1988 Risk categories are still limited and a number of female cases remain unaccounted for:

> "1,719 diagnosed cases of AIDS in Canada; 86 thereof adult women. Of these 86 women, one was an IV drug user, 28 came to Canada from geographic areas where HIV is found in a high percentage of the population; 28 had had sexual contact with a person "at risk," and 22 got sick as a result of a blood transfusion, prior to 1985. Seven women had no identified risk factors." (HEALTHSHARING FALL, 1988).

The most prominent example of mass media denial of women's vulnerability to HIV appeared in *Cosmopolitan* magazine in January. The January cover of *Cosmopolitan* reads "Reassuring News About AIDS: A Doctor Tells Why You May Not Be at Risk." Inside, non-MD.. Robert E. Gould assures women that "normal" sexual practices do not pose a risk to them. On January 15, ACT UP activists stage a large scale demonstration outside the *Cosmopolitan* offices as well as those of the Hearst company (the magazine's parent corporation) in New York. (see Women, AIDS and Activism, AIDSDEMOGRAPHICS and The Invisible Epidemic.) A video is created by activists: *Doctors, Liars, and Women: AIDS Activists Say No To Cosmo.*

Also connected to the protest against *Cosmopolitan*: The artist collective Gran Fury created a poster showing an abandoned, naked doll reading: "AIDS: 1 in 61. One in sixty-one babies in New York City is born with AIDS or born HIV antibody positive. So why is the media telling us that heterosexuals aren't at risk? Because these babies are black. These babies are Hispanic. Ignoring color ignores the facts of AIDS. STOP RACISM: FIGHT AIDS." On the lower part of the poster the message is repeated in

Spanish. (AIDSDEMOGRAPHICS, 42). Gran Fury also created a poster entitled 'Sexism Rears Its Ugly Head' depicting an erect penis cutting through the space of the poster in a hostile diagonal. The text reads: "Sexism rears its ugly head. Men: Use condoms or beat it. AIDS kills women." (AIDSDEMOGRAPHICS, 62).

Misleading ideas about how to prevent infection, who gets AIDS, and how you can tell remain common:

> "For our calculations, we estimate that the use of condoms reduces the infectivity of HIV by a factor of ten... The achievable effectiveness of condoms may be higher, especially if they are always used correctly with a spermicide, but this remains to be shown. On the other hand, the cumulative failure rate of condoms over several years may exceed 10%. Spermicides alone may also convey some protection, although this is not yet proved...*The single most important message for patients is to have sex only with partners who they know are at low risk of carrying HIV.*" (JAMA, Preventing the Heterosexual spread of AIDS, April 22/29,1988-Vol. 259, No.16) (italics)

It is misleading to recommend that people only have sex with people who they "know are at low risk for HIV." Guessing about someone's exposure is a risky undertaking at best. Recommending that such a guess be the basis of sexual decision making fails to acknowledge that AIDS is not confined to marginal risk groups. Such recommendations reflect the remnants of the belief that the "general population" is not at risk. In the conclusion, the quote fails to recommend safer sex explicitly and creates the illusion that proper partner selection is possible. Reconceptualizing AIDS has meant understanding that practices and not identities put people at risk.

18 percent of AIDS cases in the United States occurred among women whose only risk was heterosexual exposure. (CDC 1990a) (Kurth 1993)

1989 Awareness of heterosexual women and AIDS increases noticeably as evident in an increased number of publications. Activism becomes more specific in its

demands. A new focus of protest is women's exclusion from research and drug trials. (Corea 1992, 172) Lesbian vulnerability is still either obscured or denied outright:

> "...according to the CDC, at least 164 women, self-identified as having had sex with women, had been diagnosed with AIDS nationwide Of these 164, half of them had had sex only with other women since 1977. This statistic could not represent the total number of lesbians with AIDS because the CDC does not ask women for sexual identification or about cunnilingus as a sexual practice." (Corea, 195)

Increasingly, the information politics surrounding the AIDS crisis are confronted. The ACT UP Outreach Committee creates a crack and peel sticker featuring the front page of the New York Times and reading: "AIDS reporting is OUT OF ORDER" (AIDSDEMOGRAPHICS, 112/113).

Research on condom use catches up with first person accounts:

> "..the majority of women reported that their partners never used condoms. These behaviors not only increase risk of infection *but may facilitate transmission of the virus to non-drug using males and to future children.* One similarity between *women and black respondents* in this survey was that both groups lack a supportive network which is present in many gay communities. Lacking a network for disseminating information about the disease suggests that other means for providing information about the crucial role of behavior in AIDS to these groups must be explored." (E.J. Rickert, Differing Sexual Practices of Men and Women Screened for HIV (AIDS) Antibody, Psychological Reports, 1989, 64, 323-326).

Beginning official reflections on risk that is not voluntarily incurred:

> "The risk of acquiring HIV during rape is unknown, and to date, there is no effective prophylaxis against HIV." (JAMA, October 20, 1989-Vol 262, No.15).

Part of the reason information on rape is not available is because information on heterosexual transmission is incomplete.

1990 Awareness grows as women become the third wave of the epidemic:

> "Women constituted *the fastest growing group of persons with AIDS.* As of September 30, 1990 there were 14,452 reported cases of adolescent and adult women with AIDS, representing a 49 percent increase from the previous year. There are currently 140 reported AIDS cases among adolescent females ages 13-19 in the United States. This relatively low prevalence rate undoubtedly underestimates the true HIV infection rate in adolescents who, because of the long latency period of HIV, do not show symptoms of AIDS until they are in their 20s. The number of reported AIDS cases in adolescent women ages 13-19 increased a startling 71 percent between September 1989 and September 1990 in the U.S.- more than twice the increase among adolescent males of the same age for the same time period .. Although men greatly outnumber women in the total number of adult/adolescent AIDS cases, women outnumber men in the heterosexual exposure category." (CDC, HIV/AIDS Surveillance Report, October 1990.)

Social Security is still only available to those people who fit within the definition of AIDS based on the symptoms most commonly witnessed in gay men. HIV-positive women often failed to qualify. The CDC turns down the suggestion that HIV-positive women should have pap smears more frequently than once a year in order to detect cervical dysplasia. Clinicians had been observing that HIV-infected women had a high rate of abnormal pap smears.

In December, the first national conference on "Women and HIV Infection" was sponsored by the U.S. Public Health Service and coordinated by the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health. The three fold purpose of the conference held in Washington, DC was 1) to heighten awareness of the growing problem of HIV infection in women, 2) to facilitate information sharing about special medical, psychosocial, and prevention issues involved in caring for women with HIV/AIDS, and 3) to formulate recommendations for research on women and HIV. (NIAID and CDC, Clinical Courier, Vol.9, No. 6 August 1991)

As information about AIDS worldwide becomes known, the image of AIDS as an epidemic of homosexuals becomes untenable:

> "As of 1990, 60 percent of HIV infections worldwide have resulted from heterosexual intercourse. In developing countries, heterosexual sex is the predominant means of HIV transmission. In industrialized countries, the heterosexual spread of HIV is increasing slowly but steadily, especially in groups with high rates of sexually transmitted diseases and drug injecting" (Public Health Reports, vol. 106, no. 2, March-April 1991).

The number of pediatric AIDS cases increases and women are put under pressure to abort or to avoid pregnancy if they are HIV-positive. Reports from HIV-positive women of coercion pile up and activists politicize the patient-doctor power relationship.

> "The U.S. Public Health Service has projected that there will be approximately 3,000 cases of pediatric AIDS by the end of 1991, and most of these infants will have acquired the infection by transmission through their mothers." (Center for Population Options, 1990).
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> "Me First? This is a time for women to think about themselves. In New Jersey, over 20% of the people with AIDS are women." (Source unknown, 1990).

Lesbian safer sex information is created and distributed. Sapphex LEARN (Lesbians Educational AIDS Resource Network) creates Sappho's Cafe, Lesbian Safer Sex Menu. The menu features a range of non-risk or low risk sexual practices. (flyer)

"World AIDS Day, initiated by the world Summit of Ministers of Health on Programs for AIDS Prevention in 1988, continues to be the only international day of coordinated action against AIDS. The first World AIDS Day emphasized global mobilization against AIDS, and in 1989 it focused on the importance of youth in the AIDS epidemic. For 1990 the focus will be upon the issue of women and AIDS" (The Australian Nurses Journal, Vol. 20, No.3, October, 1990).

33 percent of AIDS cases in the United States occurred among women whose only risk was heterosexual exposure. (CDC 1990a)

1991 In FY 1991, Congress earmarked $7.8 million for basic research on pediatric HIV disease. These funds were used to augment ongoing activities in basic research relevant to maternal-fetal transmission and pediatric HIV infection. The NIH AIDS Budget related to women for FY 1991 is estimated at $74,903,000 and $80,100,000 for FY 1992. Statistical data released by the Centers for Disease Control (CDC) in October 1991 indicate that there have been 21,230 reported AIDS cases in women to date in the United States, representing 10.9 percent of all reported cases, and this does not reflect the thousands of women infected with HIV but not yet demonstrating symptoms of the disease. Researchers at the CDC estimate that there are over 416,000 women currently infected with HIV in the United States. (Status report on Women and AIDS Activities-The National Institutes of Health. January 10, 1992).

More than 18,000 women have been reported with AIDS in the United States. The majority of these women are women of color, live in large urban areas on the East Coast, and their acquisition of the virus is linked directly or indirectly with injection drug use. Fifty-one percent of women with AIDS have a history of injection drug use. Of all AIDS patients who have injection drug use in their background, approximately 28% are women. (NIAID and CDC, Clinical Courier, Vol.9, No. 6 August 1991)

Fragmentation of the system and agencies responsible for working on AIDS proves problematic, the challenges of the AIDS crisis reveal problems of disorder and uncertainty in responsible agencies:

> "Much is uncertain about the law as it pertains to HIV infection and AIDS. First, there are at least 156 sets of institutions making up the rules. With most legal issues, sooner or later all institutions begin to take a common approach. This hasn't happened yet with AIDS. Second, law on AIDS is being made quickly. Any answer that seems certain today could be wrong tomorrow." (Matt Coles, JD, "AIDS and the Law: Confidentiality and Disclosure," AIDS Clinical Care, January 1991, Vol.3 No.1).

1992 AIDS was recognized as one of the five leading causes of death among women 25-44 years of age in the United States based on the latest statistics from the CDC HIV-infection rates in these populations are expected to increase Many of these women are from impoverished, minority communities where intravenous drug use is prevalent. It was estimated that 50 percent of HIV-infected women were intravenous drug users. Evidence further suggested that an increasing number of women are acquiring HIV infection through heterosexual contact with HIV-infected men Worldwide, the World Health Organization (WHO) estimated the total number of women with HIV infection to be over three million. (Status Report on Women and AIDS Activities-The National Institutes of Health. January 10, 1992).

Women constituted approximately 13.5 percent of reported AIDS cases among adults and adolescents in the United States. (CDC 1993)

1993 Following much discussion, a new case definition was enacted in January 1993. Under the new definition, individuals with HIV and a CD4+ T-lymphocyte count of 200 cells/cubic mm or fewer (severe immunosuppression) automatically qualify as having AIDS, regardless of other symptoms. The new definition also included pulmonary tuberculosis, invasive cervical cancer, and recurrent pneumonia (occurring within the previous twelve months). These are conditions that tend to affect or are particular to women. It is thought that the definition change may increase 1993 cases by 75 percent (CDC 1993). Authors in New York state (exclusive of New York City) found that it might increase the reported number of AIDS cases in women by as much as 83 percent, nearly twice the expected increase in men (Smith et al. 1992). (Kurth 1993)

2

Problems of Definition

> The sad fact is that I should have been tested seven years ago for HIV. And the infection that I had been complaining about for almost two years prior to the hysterectomy should have been addressed. Doctors should really examine the reasons why they entered the "healing art" of medicine and maybe read the Hippocratic Oath once in a while And women shouldn't be getting sick and left to die because there is no research on women and HIV. Our women are dying untreated and without benefits because, although sero-positive, PID *(Pelvic Inflammatory Disease)* is not considered an opportunistic infection by the Center for Disease Control. Women are going untreated because they can't afford what little treatment there is. As women are the caregivers, if we allow our women to die, we are also condemning society to the same fate. (Positive Women 1992, 155/116)

What are the implications of the definition of AIDS?
How is the AIDS crisis defined?

While the year-by-year account of the crisis based on events and developments (or lack thereof) of particular relevance to women provides an overview to trace the unfolding of the crisis, the description of the following problems surrounding issues of definition is intended to prepare the ground for a more theoretical approach. The purpose of this chapter is twofold. to understand the AIDS crisis as a problem of systems and thus to suggest certain paths of action based on an awareness of dynamics not necessarily evident from the 'facts'; and to understand the AIDS crisis as a problem that is more than the medical phenomenon called AIDS. From this long-term perspective, the AIDS crisis functions as a lens for questions of social and institutional change.

Defining AIDS as a Disease, Defining AIDS as an Epidemic

> From a sociopolitical viewpoint, AIDS was recognized by epidemiologists because gay men, by the late 1970s, were a visible community. In order to perceive a possible epidemic in the apparently unrelated deaths from *Pneumocystis carinii* pneumonia (PCP) in 1980-81, doctors had first to recognize that the men shared a demographic trait in common. (Patton 1990,27)

AIDS, as a disease, traces its roots conceptually to the awareness of certain social groups as distinct from others. The phenomenon now called AIDS and ascribed a certain unity in itself was 'recognized' on the basis of its occurrence within a group of people that could be clearly differentiated, or excluded, from "the general population." In this sense the visibility of the gay population is pivotal to understanding that AIDS in its initial definition took shape based on the reality of the social exclusion experienced by homosexual men as a group in the United States. It was only the unity of this group identity that gave the future AIDS its boundaries and thus its unity as an immune disorder, rather than just a number of disconnected and untreatable illnesses.

In early histories of the epidemic, statements (arguing against the possibility of a viral transmission) such as the following are representative of a mainstream attitude: "The best evidence against contagion is that no cases have been reported to date outside the homosexual community or in women. That seemed most reassuring, if there was a danger, it seemed confined to a marginal group." (Grmek 1990, 9) Two of the key aspects of this definition by exclusion are gender and sexual orientation. Although science and society eventually have come around to realizing the inclusiveness of this disease, these two characteristics have set the scene for the developments surrounding and creating the AIDS crisis for over a decade in the United States. Gay visibility, combined with a degree of social acceptance of homosexuals within the communities within which AIDS was first recognized, have been the prerequisites for the epidemiological definition.

> It's almost, she said, like an invented game board has been placed on this epidemic: If you are in the box, you have AIDS. If you are outside the box, you don't. When you are in the box, you get benefits and are able to care for yourself and live longer. If you are outside the box, you have to spend the last few years of your life trekking around to hearings and fighting to convince government workers that you are actually dying.
>
> It is always women who are outside of the box.
>
> (Terry McGovern, Corea 1992, 269)

It has become evident that this definition of AIDS around one, and later many risk groups (the 'h's: homosexuals, heroin addicts, Haitians, hemophiliacs, and interestingly, hookers), has been the starting point of domino effect with far-reaching consequences for the unfolding of the AIDS epidemic in the United States. Even the discovery of a virus (HIV) by Western science has not been able to undo the erroneous understanding of the syndrome in terms of risk groups. This demonstrates to what degree the understanding of this epidemic is a product of social construction in which even the most factual argument will not necessarily succeed. The failed logic of initial thought and action regarding AIDS in the United States must be questioned. AIDS cannot be understood as solely a medical crisis defined by a socially contextless institution of science. AIDS needs to be explored in terms of the dynamics and realities of our society that it reveals by bringing them into open contradiction.

Knowledge about Women and AIDS

Information about AIDS has been controversial because it is scientifically (or more precisely epidemiologically) uncertain and socially distorted due to the stigma and prejudice which are attached to AIDS. Even more controversial and rare was awareness about women and AIDS. Since 1989, awareness and information have increased. Women were long thought to be unaffected by AIDS, but women have also been long known to be affected by AIDS. Since the first year of the identification of the immune disorder, women have suffered and have been known to suffer the effects of AIDS as a disease. The CDC reported its first female case in 1981 Even in the face of the established transmission of HIV to women in the eighties, some persisted in arguing that women do not get AIDS, that women and AIDS is not a subject of inquiry but a myth:

> "...there is almost no danger of contracting AIDS through *ordinary sexual intercourse*...Let me be very specific about what I mean by ordinary sexual intercourse. As I define it, it is penile penetration of a well-lubricated vagina...Nor do I believe that there is a danger of AIDS transmission by oral sex or deep kissing or the exchange of body fluids...a woman is quite safe from contracting AIDS."[4]

[4] Robert Gould, "Reassuring News About AIDS: A Doctor Tells Why You May Not Be At Risk", Cosmopolitan Magazine, January 1988

Others writing in the same time period (1987/1988) considered it not only to be an issue in its own right, but a very serious one :

> "In the United States over 6,000 women have so far been reported to have the disease. Some doctors think the real figure may be higher. One reason for possible under-reporting is that many doctors don't expect women to develop AIDS. There is also the possibility that because AIDS was defined in terms of symptoms first seen in gay men, the opportunistic infections that may be part of the spectrum of AIDS-related diseases in women go unrecognized."[5]

Or, more explicitly:

> "WHY IS THE CDC EXCLUDING WOMEN'S SYMPTOMS? The CDC claims many of them aren't life-threatening. Yet pelvic inflammatory disease is killing women with HIV."[6]

In these three examples, the controversial nature of the subject of women and AIDS is well recognizable. By juxtaposing various discussions of the same subject from the same time period, we learn here that the controversy is on many levels. First, whether women are indeed at risk for contracting HIV is questioned. Secondly, the definition of AIDS itself is presented as problematic. Thirdly, we learn that under-reporting and lack of acknowledgment of women's vulnerability are problems. Comparing these three quotes raises a number of problems of definitions: What is healthy sexuality, what is normal sexuality? What defines AIDS as a disease? What is the extent of the AIDS crisis as a social crisis? The following two sections of this chapter address the latter two questions. Answering the first question is outside the purpose of this chapter.

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[5] Diane Richardson, Women and the AIDS Crisis (London. Pandora Press, 1989), p 28.

[6] from an ACT UP poster with the title "Women Don't Get AIDS. They Just Die From It."

Who defines AIDS as a Disease?

In one of the first namings of the syndrome, GRID (Gay Related Immunodeficiency) the exclusion of women was most obvious. In subsequent namings it became less so, but the list of opportunistic infections (that had been observed in homosexual men) recreated this exclusion because it became the decisive definition of AIDS. It was not necessary to exclude women in an explicit sense; women's symptoms of HIV infection and AIDS did not appear in the definition. Women by definition did not get AIDS. Activists noted: "Women don't get AIDS. They just die from it." (ACT UP poster) As a result, women affected by the disease were unable to benefit from the few resources available to PWAs (Person With AIDS). Access to social security benefit was restricted to those who could demonstrate the symptoms on the list, who could fit the definition. Not only did women often fail to have the requisite infection, they also had infections unaccounted for by the official definition.

The available epidemiological statistics do not account for all cases of AIDS, they account only for cases that already fit the definition. The definition of AIDS generated by the Centers for Disease Control in Atlanta determines the creation of statistics on AIDS in the United States. An AIDS diagnosis is made when the definition of AIDS provided by this agency is met. The first definition in 1981 was based on the symptoms observed in gay men. The definition listed a set of opportunistic infections specific to this population. In the course of the eighties and the early nineties, the definition has repeatedly been changed to reflect a broader range of symptoms In January 1993, a new definition was accepted. Under the new definition, individuals suffering from severe immune depression (as defined by a CD4+ T-lymphocyte count of 200 cells/ cubic mm or less) meet the AIDS definition regardless of the symptoms they manifest. In addition, symptoms experienced predominantly or exclusively by women have been added to the previous list.

Although the developments of the past year are positive and will contribute to a more realistic picture of the extent of the epidemic in the United States and its impact on women, it is a very recent change that occurs after a twelve year history of women's exclusion from the definition. It is important to understand that this definition is long overdue. Throughout the eighties and into the early nineties, the CDC definition has not been successful in accounting for AIDS in women. AIDS was diagnosed in an HIV-positive individual when certain opportunistic infections or cancers were present or when HIV-related dementia or wasting syndrome was diagnosed. The CDC's definition was developed on the basis of the initial experiences with gay men. While it was changed during the eighties (1985 and 1987), it continued to be based on the opportunistic infections experienced by gay men. Many of the problems frequently encountered in HIV-infected women were not classified as AIDS-related, among them abnormal pap smears, syphilis infections, pelvic inflammatory disease and persistent vaginal candidiasis. In 1993, twelve years into the epidemic in the United States, conditions such as pulmonary tuberculosis, invasive cervical cancer and recurrent pneumonia were added to the definition. The CDC estimates that the change in definition may increase 1993 cases by 75 percent. (CDC 1993)

Women's exclusion from the statistical picture on the basis of the CDC's definition had a number of consequences: Women *were not counted.* They died *without diagnosis*, again they *were not counted.* Women *did not qualify* for health benefits or for social assistance benefits, such as child care, rent subsidies or other support services. *Underreporting* resulted in *lack of awareness* among institutions and health care professionals as to the extent of the epidemic among women. As a result, important services for and data about women who are HIV-positive or suffering from AIDS is *missing or has been delayed* with serious consequences. Finally, women who were concerned about or affected by HIV or AIDS *were not believed.* As a result of this history that many political activists and authors have referred to women with AIDS as the *invisible* epidemic within the AIDS epidemic. Women are spoken of as in *having been made invisible* by the definition of AIDS and its politics.

What is the extent of the AIDS crisis as a social crisis?

> In one sense, AIDS constitutes a revolution in concepts of diagnosis and disease, since the symptoms of AIDS are in fact other diseases. AIDS is *historically specific*, arising presumably at the moment when advanced technology could relate a primary causative agent to a set of extremely diverse symptoms. (Patton 1990) *(Italics mine)*

Because understandings of AIDS, from an epidemiological and medical point of view, have been contested, controversial and incomplete, it has been productive to examine the contexts and processes that create knowledge about AIDS. As a syndrome, AIDS does not offer a unified picture with definite boundaries. Because our knowledge of AIDS is in part grounded in social construction, we must invest special effort to understand *the reality of the context* in which the experience of AIDS by an individual occurs. In the absence of a magic bullet cure to the syndrome AIDS, efforts for care and prevention have been reliant on available information about the circumstances of physical bodies and lives in society.

Over the past decade, those involved in health care have come to the understanding that any long-term potential for public health necessitates a certain quality of social conditions within a country. In other words, the arrival of a magic bullet can no longer be seen as an end to the AIDS crisis because AIDS as an epidemic has brought into sharper focus systemic aspects of a crisis of social justice in the United States. Social justice as a precondition of public health informs a vision of social change that extends beyond AIDS; in realizing what is necessary to care for bodies it is inevitable that one must care for people. "For it is now clear that individual, community, and national vulnerability to HIV is directly connected with societal discrimination." (Kurth 1993, xii) To the extent that societies manage to fulfill this most basic task, they prevent the spread of HIV and are set up in such a way as to care for those in need of help.

The following section of this chapter will illustrate the connection between the promotion of human rights and the promotion of public health. Two examples of social injustice and their implications for the epidemic will be explored; the first is sexism (and heterosexism), the second is poverty/racism.

1) Sexism:

In an article titled "Voices," the women of ACE (AIDS Counseling and Education) from the Bedford Hills Correctional Facility created a list of and commentary on why AIDS was a particular problem for women. (Women, AIDS and Activism 1990, 151f) The following list was created in response to the question "Why are we making a workshop just on how AIDS affects women?":

> -It's a man's world, so AIDS stigmatizes women, such as prostitutes.
> -Our dependency on men makes us more vulnerable.
> -We have to deal with male cheating and double standards.
> -Women are caregivers: responsible for education and health of ourselves, our children, our spouses, and the people we work for.
> -Women are isolated and have to deal with all this individually and alone. We need to see it as a social problem so we can act together.
> -It's one more strike against Black and Latin women, already suffering from discrimination and racism. (151)

In first person accounts, political activist literature, and interdisciplinary approaches to AIDS there is a shared sentiment that AIDS cannot be isolated from other problems a woman experiences in her life. The basis of many women's vulnerability to infection (and inability to receive care) is often inseparable from the conditions of their lives. Their lives are defined by vulnerability. Some examples:

Drug use:

> Women who smoke crack cocaine may be at increased risk for HIV infection as a result such behaviors as exchanging sex for drugs or money with multiple anonymous partners who are themselves at risk for HIV through injection-drug use. Crack is of particular concern because its use is growing rapidly among younger inner city women. (Kurth 1993, 203)

Other people are the priority:

> Most women with HIV are caregivers first and patients second. (Kurth 1993, 202)...women will go to great lengths to obtain care for their children but fail to do so for themselves. (Kurth 1993, 204)

Poverty:

> Traditionally, socially disenfranchised minority women and children in the United States have been disproportionately affected by poverty (Simon 1989). (Kurth 1993, 202)

Multiple and Conflicting demands:

> For HIV-positive women, serostatus has been documented as only one of many factors that influence reproductive decision making. Other factors are individual, community-based, or religion-based morality or ethics regarding abortion; a desire to parent; the influence of partner, family, and friends; religious faith/optimism; risk evaluation (acceptable versus unacceptable odds); access to care; prior experience with HIV; maternal health concerns; cultural norms; parenting concerns; psychological adaptation to HIV; and non-HIV related psychological issues. (Kurth 1993, 60)

Enforced Power Differentials:

> There is a thriving tradition of violence and discrimination against prostitutes. This violence can manifest itself on the street in beatings, rapes, and vigilante attacks on working women. Because prostitution is defined as a crime, sex workers are extended minimal protection under the law. Prostitutes are subject to arrest, quarantine, and mandatory testing for sexually transmitted diseases. Because prostitution is illegal, employers are not responsible to sex workers in any way. Sex workers have no job-related health or disability benefits, making health care difficult to obtain. Economic conditions dictate that seropositive women sometimes have to continue to work during illness. (Women, AIDS and Activism 1990, 181)

2) Poverty/racism:

Helen Gasch and Mindy Fullilove, "Working with Communities of Women at Risk—A Chronicle," emphasize the need to understand the process of social change and its impact on culture when trying to understand women's lives. Their emphasis is on the need to not only understand the lives of women with AIDS but to understand them by considering women's lives in communities that are affected by AIDS. This approach reflects sensitivity to the currently documented distribution of AIDS cases (not necessarily representative of current HIV-infection patterns) in the United States. In response to the question "why is there excess risk for AIDS in the minority community?," Gasch and Fullilove researched aspects and consequences of community disintegration in urban minority communities.

In one example, Gasch and Fullilove examine the South Bronx. Between 1970 and 1980, the South Bronx, a part of New York City, suffered great destruction by fire. The vulnerability of houses to fire destruction was increased due to the density of the neighborhood. The more overcrowded a neighborhood the greater the likelihood of fire destruction. In addition to the factor of density, vulnerability to fire was related to lack of adequate fire services. Fires that might have been contained destroyed whole buildings instead of individual apartments or rooms. Uncontained fires with houses also contributed to "contagious housing destruction." "People who are burned out of their homes are forced to move to adjacent neighborhoods, disrupting their social ties and networks." Increased morbidity and decreased levels of health resulted from "contagious housing destruction." (Kurth 1993, 190)

Referring to a studies by Wallace and Wallace (1988, 1990), Gasch and Fullilove conclude that:

> The link between fire services and contagious housing destruction is probably Wallace's most important finding, as it allows us to observe *the role of the body politic in the maintenance of the integrity of the urban environment.* Maintaining populations at relatively high density requires adequate supplies of pure water, removal of waste, and maintenance of housing, among other services. Without these essential services, city residents will suffer from many kinds of discomfort, including rampant spread of such infectious diseases as AIDS. Yet the control of urban service delivery usually lies outside the minority neighborhoods, and often outside the city itself. (Kurth 1993, 191) (Italics mine)

The physical condition of neighborhoods is an element of the AIDS crisis. Poor neighborhoods of great density and with inadequate services present risks to health and safety directly, by fire, and indirectly, by undermining the continuity and organization of people's lives and social networks. AIDS vulnerability increases where security and power over one's life is undermined. AIDS vulnerability is higher in impoverished communities. Large scale solutions to the AIDS crisis need to address poverty as a form of social injustice that predisposes portions of the population to ill health and death.

3

Translating Invisibility into Work for the Social Sciences

Gena Corea: "Women in this male-dominated society sometimes have the sensation they are **invisible**...During crucial years of the epidemic, it appeared that women didn't get AIDS because for many medical professionals women are dark shapes in dark shadows who don't come into focus unless they are seen as endangering either men or fetuses." (Corea, 131)

Mirko D. Grmek: "Neither sort of definition characterized AIDS: a disorder without its own specific symptoms marked only by **invisible**, subcellular lesions, and induced by an agent undetectable before the most recent analytical methods."(Grmek, x)

Marcia Millman and Rosabeth Moss Kanter: "Indeed, today it is impossible to escape noticing features of social life that were **invisible** only ten years ago." (quoted by Harding in Feminism/Postmodernism, 91)

Dorothy Smith: "Bifurcation of consciousness is experienced as women move between these two modes with a working consciousness active in both. We are situated as sociologists across a contradiction in our discipline's relationship to our experience of the world. Traditional gender roles deny the existence of the contradiction; suppression makes it **invisible**, as it has made other contradictions between men and women **invisible**." (Smith, 19)

Sandra Harding: "...masculine bias in social inquiry has consistently made women's lives **invisible**, that it has distorted our understanding of women's and men's interactions and beliefs and the social structures within which such behaviors and beliefs occur." (Harding 1986, 85)

Gisela Bock: "Yet the view that women's history is irrelevant to the history of racism is merely the obverse of the opinion already mentioned, which imply that the history of racism is irrelevant to history of women. It condemns half the victims of racism to historical **invisibility**." (Beyond Equality and Difference, 92)

Patton: "The world of AIDS knowledge mobilizes a dispersed panopticism which directs everyone's eyes to the sex lives of gay men." (Inventing AIDS, 55)

In Chapters One and Two, the history and analysis of events of importance to women reveal invisibilities as problems. But what is the subtext of these invisibilities, what are the qualities that underlie and connect different instances of invisibility? What can we learn about invisibility analytically? In this chapter, invisibility is considered in two primary categories: epistemology and social justice.

The term 'invisibility' is a vague substitute for a specific explanation, a marker of the unexplored. Speaking of the invisible means speaking of something that resists

definition; speaking about being invisible means speaking of a perceived absence of agency and entitlement. Whatever is invisible demands a response but cannot be seen. When we encounter the invisible (or the suspicion thereof), translation, new definition and the adjustment of perspective is necessary. Invisibility challenges our vantage point in such a way that we must not only question our perspective *but also the quality of our sight*. Because the invisible exists next to us, it is not really invisible—it would be just as well said that we fail to see and fail to understand what it is that we see. This chapter explores the potential for visibility based on an analytical understanding of invisibility.

The use of the term 'invisibility' is therefore a beginning point in research because it indicates a problem without providing an explanation thereof. In the case of AIDS, invisibility can be a question of definition. In Chapter Two, I have described some of the problems and consequences attached to definitions of AIDS as a disease and of AIDS as a crisis. Definitions have resulted in invisibilities. These invisibilities have had negative consequences for women. Invisibility can stand for such things as the lack of priority, fragmentation of organization, lack of definition, fragmentation of the body, denial of diversity, absence of representation, and marginality. It is necessary to examine instances of invisibility, to outline the nature of different kinds of invisibilities as well as their nature. Invisibility is a point of departure for trying to understand, for trying to see, and for this reason it is necessary to differentiate the sources and qualities of different kinds of invisibilities as well as the ways in which they can be undone.

Because invisibility implies something that resists definition, it cannot be said that the term implies a specific pro em, or type of problem, or that it implies one source and one solution. Because invisibility means that we fail to see, we must hold a light up to each usage in order to determine what it conceals. In this chapter, I will present two types of invisibility, epistemological invisibility and invisibility that makes it difficult to recognize problems of social justice.

Many feminist theorists and authors writing about women in the AIDS crisis use the term '**invisibility**' to denote a circumstance or an experience that has gone unattended to with the implication that the invisibility whatever it may is be problematic. Gena Corea entitled her book "The **Invisible** Epidemic," Dorothy Smith, in The Conceptual Practices of Power, writes that "traditional gender roles deny the existence of contradiction; suppression makes it **invisible**, as it has made other contradictions between women and men **invisible**" (19) and Sandra Harding uses the term when she explains the feminist charge that "masculine bias in social inquiry has consistently made women's lives **invisible**, that it has distorted our understanding of women's and men's interactions and beliefs and the social structures within such behaviors and beliefs occur." (Harding 1986, 85) Gisela Bock comments on how the taboo of analyzing the holocaust in terms of anything else than race "condemns half of the victims of racism to historical **invisibility**."[7]

My interest in the AIDS crisis' impact on women began in a bookstore. There were tons of books on AIDS that had virtually nothing to say about women. Women were invisible in the very basic sense that one could not easily learn about them. There was a dearth of information about women and AIDS in the eighties even though women were from the beginning affected by AIDS, as "persons living with AIDS" themselves, as caretakers of others, as health care providers and as activists.

The theoretical work on this topic is necessary because some invisibilities that disadvantage women originated in the conceptualization of the nature of the crisis. In this chapter I will apply the work of two feminist theorists on the AIDS crisis. My project is to articulate concepts of invisibility by determining their relationship to understandings of society described by feminist theory. I do not deny that invisibility could be critically

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[7] Gisela Bock, "Equality and Difference in National Socialism" in Beyond Equality and Difference edited by Susan James and Gisela Bock (Routledge London and New York, 1992)

understood in a variety of other ways. I am interested in discovering what tools the theoretical texts offer: What kinds of 'invisibility detectors' can be constructed?

This chapter is organized around three sections: first, I present the work of Iris Marion Young in her book Justice and the Politics of Difference. I have chosen three chapters that I find relevant to understanding the situations of women in the AIDS crisis. Second, I lay out two feminist epistemologies and the perspective that results from the intersection between feminist thought and postmodernist thought. Sandra Harding's work constitutes the basis of this section. In particular, I will draw on Whose Science? Whose Knowledge? and The Science Question in Feminism. Having presented my *tools*, I will apply them to the invisibilities of women's experience in the AIDS crisis. Third, I will explain the potential of my theoretical tools to create visibility.

Iris Young: Distribution, Oppression and Impartiality

The central project of Justice and the Politics of Difference is to draw a picture of the problems we neglect and the type of injustice we further when we subscribe to political theory's reduction of social reality to a unified subject or homogeneous public. This theory lends itself to a project about invisibility because of this problematization of what is visible to us through familiar perspectives. Also important are the implications for our politics. These are indicated by Young in the problematization of the preference of commonness and sameness over difference and particularity. I will examine each of the three selected chapters in turn and lay out the analytical perspective. This analytical perspective will be used in the final section where the story of women and AIDS is retold in such a way that it emphasizes visibilities which can be created through an application of Young's theory.[8]

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[8]Carol Smart, in Feminism and the Power of Law, has chosen a more specific focus for her problematization of the relationship of liberation movements to law. In her problematization of feminism's interaction with law, she articulates the advantages but also the risks and limitations that may result from the invocation of law on the part of feminists. Smart uses women's history to demonstrate how rights and the appeal to rights oversimplify complex power relations and create the often misleading notion that power differences can and will be resolved by the acquisition of rights. Although her work appears at first sight more radical than that of Young, Feminism and the Power of Law and Justice and The Politics of Difference share important insights on the obstacles projects of social justice face. Both authors are creating a greater space for accounts other than those provided by legal institutions.

A: Understanding Invisibility/Visibility through Distributive Justice

Chapter One, "Displacing the Distributive Paradigm," explains how the prevailing 'distributive paradigm' of justice "ensnares" reflections on justice in such a way that we are more likely to consider questions involving material goods that can be thought of easily in terms of distribution. Young speaks of the distributive paradigm as a limitation on the scope of social justice to "the morally proper distribution of benefits and burdens among society's members." (Young 1990, 15) The distributive paradigm brings into sharp focus the allocation of material benefits and goods but leaves obscure the social structures and the institutional contexts that underlie question of distribution. Without context, individuals appear as atoms. The distributive paradigm defines persons in terms of possessions, and ignores the relations between persons in society as relevant context to questions of social justice. Social justice in accordance with the distributive paradigm requires that questions of injustice be reconceptualized as violations of things or their distribution.

Two main criticisms of the paradigm are presented by Young. First, there is the concern that distribution as a focus detracts from questioning how distributive patterns come about. When we look at distribution as the sole locus of justice or injustice, we lose sight of the context. Young wants to bring this context into focus and this means taking a look at "issues of decision making power and procedures, division of labor, and culture." (Young 1990, 15) Secondly, the distributive paradigm is not applied to some areas where it would help the project of social justice. We could examine the distribution of power, opportunity or self-respect, but, as Young rightly points out, distribution is unable to extend beyond the material dimension. "When metaphorically extended to non material social goods, the concept of distribution represents them as though they were static things, instead of a function of social relations and processes." (Young 1990, 16)

Young's project is not to abandon distributive justice. On the contrary, she explains that basic human survival which necessitates the provision of basic material goods entails distributive considerations. She proposes an expansion of the paradigm along with an analysis of its shortcomings as necessary prerequisites for the potential of 'social justice.' Under consideration as issues of 'social justice' are "all aspects of institutional rules and relations insofar as they are subject to potential collective decision." Thus, in her criticism of the paradigm, she wants to bring under examination "metaphysical presuppositions, unquestioned terminology, characteristic questions, lines of reasoning, specific theories and their typical scope and mode of application " (Young 1990, 16) Also, Young spells out the ontological assumptions the paradigm rests on and points out the ways in which they are influential in understanding what constitutes justice. Her acknowledgment of the distributive paradigm as key to our conceiving of justice as *central* thus raises questions about what becomes *peripheral or even invisible* through the distributive paradigm. For justice as a concrete project, Young's analysis of the paradigm indicates that issues or aspects of issues that should have come under *the eye* of justice have not because they lacked essential qualities that would have made them *visible as injustice*. By 'justice' Young means social justice which she defines as "the elimination of institutionalized domination and oppression." Social justice requires that "any aspect of social organization and practice relevant to domination and oppression is in principle subject to evaluation by ideals of justice." (Young 1990, 15)

Young argues that the acceptance accross ideological bounds of the distributive paradigm indicates how basic assumptions about justice are. One of the assumptions Young identifies is the social atomism of the distributive paradigm that fails to conceive of the relevance of relations between individuals and groups. The individual as constituted by the social atomist view becomes a threshold, what falls beneath this threshold becomes *invisible* to our traditional considerations of justice. On the same note, Susan Okin, in Justice, Gender and the Family, points out out a *blind spot* in our

treatment of justice, namely that the family has more often than not been ignored as a site of justice. Marxists point out a similar dynamic when defining features of systems are taken as given and relations of production fail to constitute an issue in their own right for the inquiry of justice. Thus, Young addresses the ontological and structural assumptions that frame *the field of visibility* traditionally considered to be relevant to justice.

It becomes *clear* that the paradigm is critical to forming our sense of (collective) responsibility. What does not fit the paradigm, or fits only with difficulty, is less likely to be conceived of as an issue that demands justice. In this sense, the paradigm shapes what we collectively feel responsible for—we can *see* something as injustice. Invisibility often originates where responsibility cannot be easily assigned. This reiterates Young's first criticism of the distributive paradigm; we are directed towards some issues and distracted from others that are difficult to quantify or form part of the stage on which justice is played out.

By implication, this view also contains another criticism—the paradigm may misconstrue other issues if it does consider them. "Applying a logic of distribution to such [social] goods produces a misleading conception of the issues of justice involved. It reifies aspects of social life that are better understood as functions of rules and relation than as things." (Young 1990, 25) For example, opportunity is not a thing. Opportunity expresses enabling conditions and a 'right' is not a thing but a relationship. Distribution fails to grasp the dependence that defines an "entity", such as opportunity or rights. On the contrary, the distributive paradigm posits an independence. As a result, the distributive paradigm restricts the scope of justice. It therefor cannot span the whole of political relations.

'Intent' is a crucial limitation that follows from the paradigm. Power and its effects are only considered where intent is recognizable. The consequences of such an individualist ontology are that structural injustice, not readily identified with a well defined agent, remains *invisible* to justice. Important forms of domination and oppression

resist conceptualization under this model. Domination and oppression can be structural and institutional in a way that will tend to fall beneath the threshold of distributive justice. I will address oppression more thoroughly in the following examination of "Five Faces of Oppression," Chapter Two of Justice and the Politics of Difference.

B: Seeing and Recognizing Oppression

For Young, 'oppression' signifies the failure of what she argues justice should entail – "the institutional conditions necessary for the development and exercise of individual capacities and collective communication and cooperation."(39) Injustice as 'oppression' makes sense from the point of view of contemporary movements of emancipation. 'Oppression' also serves for Young the purpose of distancing a discussion of justice from liberal individualism and its corresponding political discourse that, in Young's opinion, cannot undertake the project of social justice she *envisions*. Speaking of oppression, rather than injustice, makes it clear that the social experience will be privileged in contrast to the format and processes of law and its institutions. Also, Young uses the term "oppression" to refer to a condition of groups. Because the source of oppression is located in institutionalization of unjust social dynamics and in the larger organization of society, making injustice visible will mean recognizing patterns and identifying positions vis à vis justice by observing the workings of the system. Looking at groups has as a consequence that the context of distribution must be considered. People belong to a group when they share a social experience that cannot be reduced to a coincidence of similarity but rather indicates a mechanism that operates regardless of individual experience.[9]

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[9] Women who are HIV-positive or are suffering from AIDS are a group if we are looking at the medical systems scientific relationship to sex, but it is not a group if we are looking at the conditions of women's lives or the specific quality of actual medical care different women receive. Groups (and boundaries of groups) must be determined by the size of the pattern that is being considered.

Young starts out with an understanding of groups that is based on the claim of being oppressed made by diverse political movement and proceeds from there to systematize what she means by groups and oppression:

> A social group is a collective of persons differentiated from at least one other group by cultural forms, practices, or way of life. Members of a group have a specific affinity with one another because of their similar experience or way of life, which prompts them to associate with one another more than with those not identified with the group, or in a different way. Groups are an expression of social relations; a group exists only in relation to at least one other group. Group identification arises, that is, in the encounter and interaction between social collectivities that experience some differences in their way of life and forms of association, even if they also regard themselves as belonging to the same society. (Young 1990, 43)

A group is the result of the functioning of societies that are not homogenous; it is a product of social processes that differentiate some people from others. Young uses the example of the sexual division of labor in almost every society to illustrate this notion of a group. For Young, groups are neither aggregates nor associations. Instead, her concept of a group is informed by her concern for the systemic nature of oppression-groups experience disadvantage or discrimination relative to other groups but the more privileged group is not necessarily an oppressor.

Having introduced 'groups' and 'oppression,' I would like to return to the question of intent. Young suggests that there has been a shift in the meaning of 'oppression' and this shift is related to the question of intent in an important way. Whereas 'oppression' was previously associated with the tyranny by a ruling group, Young explains that new social movements have appropriated the term to describe "the everyday practices of a well-intentioned liberal society."

Young acknowledges the oppression of tyranny, but explains:

> ...oppression also refers to systemic constraints on groups that are not necessarily the result of the intentions of a tyrant. Oppression in this sense is structural, rather than the result of a few people's choices or policies. Its causes are embedded in unquestioned norms, habits, and symbols, in the assumptions underlying institutional rules and the collective consequences of following these rules.. We cannot eliminate this structural oppression by getting rid of rulers or making some new laws, because oppressions are systematically reproduced in major economic, political, and cultural institutions. (Young 1990, 41)

The systemic and structural quality of oppression makes it invisible from the point of view of intent. If intent is central to a concept of justice oppression will not be visible as an injustice.

Thus, there need not be an agent of oppression that consciously carries that self-understanding. Even where intentional harm is not present, oppression, and therefore injustice if we accept social justice as Young defines it, exists. What is more easily recognizable is that some groups are privileged in relation to others, yet this, under the distributive paradigm, is insufficient as an indication of the existence of an 'oppressor.' Young's understanding of social justice disposes of the necessity of an individual oppressor or oppressor groups as identified by intent: "The systemic character of oppression implies that an oppressed group need not have a correlate oppressor group." (Young 1990, 41)

Once we overcome the *silence* imposed by the intent-driven model of justice, social reality itself, in its everyday qualities, is opened up as the site of injustice/justice and people can speak of their social experience as political and as an issue of justice. Individuals communicating about their day-to-day lives discover commonalties, they discover that important aspects of their lives are not based on individual differences but rather that there exist recognizable patterns. In the section subtitled "The Faces of Oppression," Young discusses exploitation, marginalization, cultural imperialism and violence as examples of oppression, and we will see that these examples are important for understanding the AIDS crisis. In the discussion of these examples, Young takes on the

work of making oppression visible as injustice and politicizing the "normal processes of everyday life."

C: Impartiality as an 'Invisibilizer'

The notion of impartiality holds a central place in Justice and the Politics of Difference because of its close and difficult relationship to difference. Young recognizes in the search for impartiality among those that exalt is that plurality is inevitably sacrificed to unity. The goal of impartiality entails the sorting out of particularities, impartiality produces invisibilities by sweeping particularities out of sight. "Reducing differences to unity means bringing them under a universal category, which requires expelling those aspects of the different things that do not fit into the category. Difference thus becomes a hierarchical opposition between what lies inside and what lies outside the category, valuing more what lies inside the category than what lies outside." (102)

The ideal of impartiality is also what Young sees as a source of dichotomies, ranging from the public/private over justice/care to liberal/communitarian and subject/object, that create fields of vision unproductive for the project of social justice and misleading in the project of traditional justice. Her conclusion about the possibility of achieving the ideal of impartiality and the desirability thereof is clear: "Not only is impartiality impossible, however, but commitment to the ideal has adverse ideological consequences." (Young 1990, 112) More specifically, she problematizes the insistence on the ideal of impartiality, on the basis of a critique of identity that is postmodernist in its awareness of the pitfalls of a reductionist attempt at establishing a first principle.

Young's critique of the ideal of impartiality is useful for my project in the sense that she is concerned with *exclusion and expulsion.* Rather than enter into a discussion about impartiality or identity per se, I would like to point out the mechanisms of the ideal of impartiality that exclude and expel. Exclusion and expulsion support my own project of invisibility/visibility where they suggest or explain ways of understanding how aspects of social reality are *hidden from sight.*

What Young regards as problematic in the ideal of impartiality is the project of "reducing the plurality of subjects to one universal point of view." (103) The danger of this reduction is twofold; the illusion of the possibility of impartiality, and the semblance of a general will that stands in contrast to particular interests perceived as selfish. Young has already touched on this question of situatedness in the introduction of Justice and the Politics of Difference:

> Because I understand critical theory as starting from a specific location in a specific society, I can claim to speak neither for everyone, to everyone, nor about everything...As a white, heterosexual, middle-class, able-bodied, not old woman, I cannot claim to speak for radical movements of Blacks, Latinos, American Indians, poor people, lesbians, old people, or the disabled But the political commitment that motivates my philosophical reflection tells me that I also cannot speak without them. (Young 1990, 13/14)

The message is that impartiality categorizes and silences people and social reality. Where impartiality is appealed to, special *watchfulness* is required in order to understand the dynamics of reduction that occur when "reason abstracts from *the particular experiences and histories that constitute a situation.*" (100) The unity of impartiality must expel elements of heterogeneity. This means that what makes a person is expelled and determined to be irrelevant to the project of moral reasoning in which impartiality engages. This echoes some of the concerns about the distributive paradigm's social atomistic ontology that shuts off possibly relevant parts of social reality from consideration.

Summary Section One

From Iris Young's work I take three *tools*.

The first tool is knowledge of the dominant paradigm and its implications. From it follows the necessity of questioning the distributive paradigm. By using the awareness of the paradigm's underlying assumptions about what constitutes social justice, the scope of justice can be expanded. We must ask: What does such a paradigm render *invisible* to justice?

Contextual treatment of questions of social justice is the second tool that provides increased invisibility. A contextual approach makes *visible* structural oppression and an awareness of potential *blind spots* that might be undone if we can escape the confines of the intent-driven model.

The third tool is to look for what is defined as marginal or excluded; it is necessary to problematize knowledge or judgement where it presents itself to us as the product of impartial reasoning. What are the categories that were appealed to in the process of paring down the various dimensions and particularities of social reality? What is the logic for appealing to these categories? What is the effect?

Sandra Harding: problematizing the production of knowledge

> ...masculine bias in social inquiry has consistently made women's lives invisible, that it has distorted our understanding of women's and men's interactions and beliefs and social structures within such behaviors and beliefs occur (Harding 1986, 85)

Sandra Harding dedicates a full chapter of her book, The Science Question In Feminism, to the questions shared by the natural and the social sciences. She addresses issues of women's invisibility, or distorted visibility. The approach in this chapter is especially helpful because the notion of crisis is limited neither to the scientific nor the social. Chapter Four, "Androcentrism in Biology and Social Science," fundamentally asks one question: Is the problem "bad science" or "science as usual"? At the extreme of a possible spectrum of answers to this question, Harding locates Donna Haraway's suggestion that "if sexist science is science as usual, then the best methodology in the world will not prevent us from attaining those conclusions unless we change paradigms." (Harding 1986,103)

Harding explains the relevance of social science to natural scientific inquiry and argues that the subject matter of the social sciences is not distinct from that of the natural sciences. From the perspective of gender, the distinction between the social scientific and the natural scientific likewise appears artificial. A feminist analysis of the AIDS crisis makes visible both the bias of science and its institutions and of society and its institutions because feminist theory chooses for its standpoint the lives of women who are inevitably affected by both. By addressing the unity of experience of bias in its cumulative effects on a woman's life, the distinction between social science and natural sciences is blurred because what is substantively at stake are the effects of gender bias on women, not the clarification of constructed academic categories or disciplines. By shifting the focus to *the effects of bias*, continuities between disciplines may be discovered.

Breaking down inquiry into levels illustrates the possible entry points for bias that the social sciences share with the natural sciences. From the definition of what counts as a scientific problem, the formation of concepts and theories, the choice of method to the interpretation of research, *uncovering bias that can result in invisibility is a task that must span the whole of the process by which knowledge is created.* It is for this reason that Harding takes on the task of outlining epistemologies which different schools of feminists have employed in their empirical work as well as in their analyses of science and philosophy. I will outline two different epistemological criticisms of science as well as the feminist postmodernist perspective that Harding works through. I will argue later that each of the differently grounded perspectives lends itself to grasping different aspects of the AIDS crisis; the epistemologies are not competing with each other here. In my application, I will concentrate on showing how the different epistemologies *together* reveal the complexity of the crisis.

> sexism and androcentrism are social biases correctable by stricter adherence to the existing methodological norms of scientific inquiry. (Harding 1992, 24)

Feminist empiricism can help an analysis of the AIDS crisis by pointing out inconsistencies in the practice of science that depart from the principles of method. The points of departure can be understood as entry points for androcentric bias (or any other kind of bias). Thus, feminist discontent with the projects and interpretation of science can be argued on the ground of science itself. *The burden falls on science rather than, as is often the case, on feminists who must justify the validity of their claims.* Feminist empiricism and Young's work—on taking democracy seriously—share a simple but effective beauty; they place the burden of a problem back onto the system that produced it by appealing to its most fundamental and cherished values.[10] Many questions of knowledge are not so complex that they necessitate the rigor and commitment of a feminist approach. In some cases common sense itself suffices. The utility of this approach is a realistic one and it acknowledges that women's well-being is not prioritized in our society. Still, its effects can be very important, especially where information creates a domino effect of practical consequences.

Because feminist empiricism makes a persuasive and non-confrontational argument, its chances of being heard are increased. Feminist work enters the mainstream body of science through such a strategy. The fact that feminist empiricism is at heart a conservative justificatory strategy should not deter feminists of all kinds to take seriously its virtues. In the final analysis Harding asks: "Why should we limit our strategies to only

[10]Feminist empiricism is a label that perhaps misrepresents those whose hold this view. Harding correctly explains that "practitioners do not label it at all, they see themselves as primarily following more rigorously the existing rules and principles of the sciences " (Harding 2,111)

one when plausibility, not mystically transhistorical epistemology, is the goal?" (Harding 1992, 114)

> men's dominating position in social life results in partial and perverse understandings whereas women's subjugated position provides the possibility of more complete and less perverse understandings. (Harding 1992, 25)

Feminist standpoint epistemologies are the mainstream of academic feminism today. The straightforward argument being made here is that where relations are defined by hierarchy, the subjugated perspective is less distorted than the dominant one. Harding explains the basis for the claim that the subjugated perspective is preferable: "Knowledge of the empirical world is supposed to be grounded in that world (in complex ways)." (Harding 1992, 121) To the extent that women's lives have been *neglected as starting points for research* and supposedly gender-neutral knowledge has been produced, the knowledge resulting from such research has failed to account for the gender-stratification in our societies and the different lives that men and women lead. Thus the grounded experience of women's lives can be used to challenge and criticize dominant knowledge claims, "which have primarily been based in the lives of men in the dominant races, classes and cultures" and thus "can decrease the partialities and distortions in the picture of natural and social life provided by the natural and social sciences." (Harding 1992, 121) [11]

Women's perspectives are valuable in the sense that the perspective of the outsider tells us things that that of the insider cannot. "Feminism teaches women (and men) to see male supremacy and the dominant forms of gender expectations and social relations as the bizarre beliefs of a social order that is "other" to us. *It* is "crazy", we are not." (Harding 1992, 125) Whereas the social order may appear functional to those

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[11] Harding is careful to underline that it is not women's experience or speech per se that should be considered the grounds for feminist claims, rather the theory and observations that *become possible* from the perspective of women's lives

around whose lives it was constructed, *the seams and the cracks become visible from the perspective of those people for whom the social order is dysfunctional.* "Women's oppression gives them fewer interests in ignorance." (Young 1992, 125) Since women have less to lose by social change than men, feminist research is more likely to challenge the status quo and produce original appraisals of reality. This parallels Young's comment that one must have a stake in what one is researching. Young writes:

> It is impossible to reason about substantive moral issues without understanding their substance, which always presupposes some particular social and historical context; and one has no motive for making moral judgments and resolving moral dilemmas unless the outcome matters, unless one has a particular and passionate interest in the outcome. (Young 1990, 104)

Feminist standpoint epistemology's claim for validity or at least for *preferability* is based on the understanding that resistance to oppression creates less partial and less distorted accounts.

By 'less partial' Harding means that feminist standpoint epistemology claims an interested standpoint that openly embraces its situatedness rather than concealing it and thereby gains an epistemological advantage: "A feminist epistemological standpoint is an interested social location ("interested" in the sense of "engaged," not biased), the conditions for which bestow upon its occupants scientific and epistemic advantage." (Harding 1986, 148) The advantage comes from having a larger view of social reality than is afforded by the typical or dominant social experiences of men. Harding argues that those who engage in activities that are subjugated have both the knowledge of their own, subjugated, experience and the dominating experience. An appreciation of reality is made possible by the subjugated experience that is denied the dominant one because from the perspective(s) available from the dominant experience, the subjugated experiences is defined as background conditions and not points of interests in themselves. So, 'less partial' means literally that the perspective is less limited in terms of what it provides a view of and that the claiming of social location itself has advantages over the denial of

situatedness. The denial of situatedness does not allow the same quality of engagement that gives feminist standpoint theory the width and depth of its perception of reality.

Harding's claim that feminist standpoint theory produces 'less partial' accounts at first glance seem to contradict Young's critique of impartiality. There are two important differences that prevent this contradiction. Firstly, the appeal to impartiality which Young critizes does not incorporate its social location or situatedness openly into its perspective, the experiences from which it starts must be guessed at or unearthed in order to determine their specificity. Where situatedness is not openly acknowledged and accounted for, claims of general validity or impartiality distort other social experiences. The appeal to impartiality is grounded in the priviledging of a single rule or principle, the requirement of dispassion and the mastery of heterogeneity. (Young 1990, 100) Engagement, as defined above, contrasts with dispassion and the acknowledgment of the importance of social location negates the goal of eliminating heterogeneity.

Secondly, 'less partial' indicates that impartiality is an impossibility. Young and Harding both call into doubt the possibility of an absolute and genuine impartiality. Instead, they argue that impartiality as a goal or a value hides important aspects of social reality. Both of them dismiss as inadequate and even dangerous the idea of the one subject who ,as an impartial reasoner, "can adopt the view of everyone." (Young 1990, 105) But to problematize impartiality is not the same as to promote epistemological chaos. When Harding expresses that feminist standpoint theory has the potential to create 'less partial' accounts, she is already starting from the basiss that the idea of impartiality is problematic. Impartiality is hidden partiality; 'less partial' does not refer so much to the the failure of achieving an ideal of impartiality as much as it addresses the impossibility of an absolute impartiality. The word 'less' is already an indication of Harding's position on impartiality; 'less,' a difference of degree, is a key to understanding that feminist standpoint theory does not operate on any notion of symmetry between truth and falsity. In defending feminist standpoint theory against postmodernist thinkers, Harding writes

that the notion of giving up the telling of stories because we can make no claim to tell the one ultimate story is absurd. The point is to tell a better story, a 'less partial,' or more complete one.

Harding takes special care to remind us that feminist standpoint theories are not essentialist in their claims of validity. The claim of feminist standpoint theory is not that all women share a quality that makes their appraisals of reality preferable to those of men. The message is rather that starting point for research matter in the sense that who we are as people and what our experiences are in society provides different perspectives and different experiences that will inevitably shape our research in fundamental ways. Power is central to this scenario; our perspectives and the range of issues that we will find relevant topics of research are the products of important power differentials in our society. Feminist standpoint theory, in contrast to feminist empiricism, explains the relationship between the lives that we live daily and dominant types of beliefs that we hold about our lives.

C: Feminist Postmodernism

> seeking a solidarity in our oppositions to the dangerous fiction of the naturalized, essentialized, uniquely "human" (read "manly") and to the distortion and exploitation on behalf of this fiction. (Harding 1992, 26)

Feminist Postmodernism and the intersections between feminist theory and postmodern thought challenge the notions of transsocially firm foundations for knowledge and thus problematize the project of epistemology itself. The foundationalism of feminist empiricism and the feminist standpoint epistemology theories is viewed from this perspective as excessive in the sense that those approaches may reify and essentialize 'woman' who is not be 'found' and therefore cannot be represented. The rejection of the Enlightenment project in feminist theory 'begins' in feminist standpoint epistemologies where knowledge and reason are understood as socially situated. (see my comments on social situatedness and its epistemological consequences in the previous section- "Feminist Standpoint Theory") Feminist postmodernism takes this critique a step further by taking as its starting point *the fractured identities* inevitably produced by modern life. The necessity of solidarity with all kinds of oppression grows out of this starting point. We can see commitment to this understanding reflected in Young when she speaks of a non-hierarchical conception of oppression and structural oppression that is pervasive even though the experience of structural oppression cannot be generalized.

Feminist postmodernism unites the more radical elements of other kinds of feminist theories. It does this with a background of skepticism about the possibility of justifying a preferable perspective. In the face of the role that women like men share in the perpetuation of oppression related to race, class and homophobia, how can a feminist standpoint proclaim any kind of intrinsic political innocence? Further, *if there is no reality out there to find the key to it becomes nonsensical to think that feminists will have a better chance at constructing that key.* The postmodernist critique of the feminist

standpoint reiterates mainstream discontents with modern theories in their relation to reason, rationality and reality.

Summary Section Two

Harding's analysis of these three feminist perspectives provides me with different starting points at which to address the production of knowledge in the AIDS crisis. Each one carries a different understanding of the extent to which knowledge or information can be problematic and each one respectively indicates what the possibilities are for rectifying the problem it addresses. Three places are suggested by the different perspectives where I can look for invisibilities. Three sources of distortion and misrepresentation are defined

Feminist empiricism: emphasizes the need to determine entry points of bias Are there inconsistencies in the way research was conducted or evidence was gathered? What is the distance between the evidence and the interpretation offered? *Feminist standpoint* epistemology underlines the importance of perspective What are the dysfunctionalities of the system that are invisible to a dominant or ruling perspective? What can we discover if we examine the social order as other to us? *Feminist postmodernism*: highlights the pitfalls of representation. Where has the assumption of a privileged perspective created or furthered forms of oppression? Where have fictions been created that distort and exploit?

Using the tools and the starting points to analyze the impact of the AIDS crisis in the United States on women

Six examples of disadvantage that women have suffered in the AIDS crisis will be related to the three tools from Young and the three starting points from Harding. The task at this point is to make specific different kinds of invisibilities, the mechanisms or acts that produce them and the ways of revealing them. The subtext is: Why has it been so difficult to conceive of women's needs in AIDS as a crisis?[12]

[12] This last question is misleading in the sense that it implies that recognition would automatically produce a reaction. This is simply not true in general of any problem and it has in particular not been true in the case of AIDS in the United States. Also, it has not been difficult to conceive of women's needs for the women in question.

*A: Examining the threshold of justice in the **Definition of the AIDS crisis***

***Tool:** An awareness of the functioning of the distributive paradigm and its implications for understanding justice. What does such a paradigm render invisible to justice?*

What makes AIDS a crisis? From the point of view of science, AIDS represents a crisis because the virus to this day remains an unsolved puzzle. "When AIDS first made its appearance in the early 1980s, it shattered the illusion that advanced industrial societies had placed behind them the threat of infectious disease."(Bayer and Kirp 1992, 8) AIDS as a scientific mystery does not necessarily imply a social crisis Young's argument that politics in its inclusive sense represents the sphere within which justice must be considered carefully permits a different possibility for defining the crisis. What becomes visible under such a definition of crisis are the instances and patterns of injustice. If we can look at the crisis from the perspective of social justice rather than from the secure position of separate disciplines and institutions with carefully defined spheres of action and responsibility, we can advance towards creating a more realistic picture of what AIDS has meant, a picture that would be recognizable to different kinds of people affected by HIV and AIDS in different ways.

An international comparison of personal accounts (Rudd and Taylor 1992) (Rieder and Ruppelt 1988 and 1991) reveals that "AIDS" is a product of the circumstances of a woman's life. The accounts of women from Western European countries and Canada differ significantly from those of their U.S. counterparts. In the United States many women are heavily burdened by poverty and the access problems this creates for them. Having enough money to pay for a bus fare, let alone a baby-sitter, to get to an offered service cannot be taken for granted. Accounts written by European women were reflective, contemplative and not seldom inspirational in their insights about life. Such contrasts in experience express very well that the nature of "AIDS" is highly contingent on circumstances one might consider to be independent of HIV infection. In

the absence of an available magic bullet cure to AIDS, the impact of the epidemic on women must be considered in the specific circumstances that define their lives. This is a hopeful conclusion because it implies that there is a lot which can be done in the absence of a medical magic bullet solution. How can one recognize and fulfill needs that are not perceived as such? This is the challenge that invisibility presents to those working for an improvement of the well-being of women in the crisis. It is important to identify invisibilities that impede remedying situations of social injustice in women's lives because AIDS, or HIV for that matter, does not constitute a useful basis for deriving knowledge or solutions.

The necessity of understanding problems as complex and interrelated, rather than limiting the scope of justice to the possibilities of the distributive paradigm, has proven a difficult challenge for people working to lessen the impact of the AIDS crisis. Consider the following case of the complexity of everyday life getting in the way:

> Helen Cover, on probation, was reunited with her boyfriend Tim and her two children. At first, Lesley Noble, a young woman from the National Center on Institutions and Alternatives who had helped her win probation, was happy for her. Maybe now her life would turn around.
> But Helen missed some of her drug counseling appointments. The program provided no child care and she had trouble finding baby-sitters. Without a car, she had to arrange rides to the clinic and then get herself from site to site when she was weak and in pain. (Corea, 158)

Helen Cover, whose story is told by Corea in order to show the multiple and unsuspected difficulties that AIDS brings to the surface in women's lives, is caught in a web of complications and competing demands. This is an appropriate example of how the reaction to AIDS even where it has sought to help women has been thoroughly lacking and therefore ineffective in the last instance. Helen Cover's example illustrates the extent to which circumstances outside of AIDS as an immune deficiency determine women's lives. Helen's interaction with the legal system makes the situation even more complicated because in the eyes of the law she is guilty for using drugs and again

becomes guilty for violating the conditions of her probation, which, seen in the context of her life, are impossible to fulfill. The invisibility of Helen's oppression arises from a neglect of related circumstances over which she has little or no control but which are interpreted through the legal system as products of her intent, action and therefore responsibility. Helen appears to the system simply as a delinquent who fails to make use of offered services. The decontextualization of her case makes Helen appear as a delinquent rather than as a victim of the systemic effects of oppression associated with poverty. Effectively, services and programs to help women with AIDS will fail if they do not start from the lives of women. Young's parallel statement is that there can be no project of social justice that does not start from the oppression of all kinds in people lives, since oppression in its substantive dimensions must remain invisible from a perspective trained to search for intent and agency.

The study of the AIDS crisis has demonstrated to what extent there exists a socioeconomic crisis which predisposes people to infection and makes the possibility of receiving adequate care unlikely. The distributive paradigm of justice cannot account for these underlying causes of the crisis. The oppression and deprivation, that constitute the socioeconomic crisis from which AIDS is inseparable, are not readily understandable through a 'social atomism' lens. Since the poor have not been deprived by anyone of a material good they could be said to be entitled to under the distributive model there is no case for the correction of distribution. Thus, the cause and the result of the crisis evade the distributive paradigm of justice and it is a challenge to formulate the crisis in such a way that it could be easily politicized as an instance of injustice Young' s critique of the paradigm signals how responsibility for resolutions of the crisis is obscured and scattered. As a consequence, the definition of the crisis itself shifts away from such socioeconomic problems that are at the base of vulnerability and inadequate care.

B: Politicizing the AIDS crisis as an Intersection of Disadvantages

Tool: *A definition of injustice that makes visible structural oppression and an awareness of potential blind spots that might be undone if we can escape the confines of the intent-driven model.*

The complexity of "Women and AIDS" is not necessarily grasped as an issue that necessitates attention to the connections and reinforcement active within the intersection between medical/scientific, racist, sexist, heterosexist, classist and ableist disadvantages. After all, one might argue, racism, sexism, heterosexism, classism and ableism have existed before and outside of the AIDS crisis. If however, we ask what we can do for women in the AIDS crisis it is inevitable that we will have to deal with the issues, especially in regard to a long-term concern for women's well-being. *Invisibility can originate where no one feels addressed as responsible.* Where justice is driven by intent and measured by responsibility, issues that do not recognizably spring from the actions or fall with the realm of responsibility of relatively well defined agents fail to pass the threshold of visibility. In this sense, justice under the distributive paradigm needs explicit ownership to function. This is problematic where nobody 'owns' the structures or the system and therefore their effects remain unaccounted for. The social atomism of the distributive paradigm rules out the ascription of responsibility to collectivities.

The concern with structural oppression follows from Young's critique of the distributive paradigm. Essentially, we are alerted to the presence of problems that resist conceptualization. A good example of this is the intersection of various disadvantages that groups and individuals have suffered in the crisis. As a disease, AIDS has the potential for making visible the oppressions suffered as having concrete effects: some people have been refused care, some women have been refused abortions and others forced into them on account of their HIV status, families have rejected individuals whose illness was understood as indicative of a lifestyle they could not accept.

Under Young's concept of structural oppression it would be possible to seek solutions to such issues as racism, sexism, heterosexism, homophobia, classism and ableism. For the AIDS crisis this is important since all the condoms in the world cannot restructure the heterosexual power dynamics in such a way that would lead to the empowerment of women necessary to protect themselves and set the framework for a relationship that would be accommodating of their needs as well as their demands. In contrast to short term solutions, long term solutions and prevention strategies need to be formulated in terms of undoing structural oppression that predisposes women to infection. Whereas short term solutions raise very important questions of distribution-such as distribution of care, medication, hospital beds, social services, drugs and financial support-the long term project of improving the well-being of women and other disadvantaged groups in our society escapes the narrowness of distribution.

To the extent that an analysis of the AIDS crisis can produce a concrete correlation between the socioeconomic factors and their effect on something like the rate of infection, or the average period of survival after diagnosis (highest for homosexual men and lowest for minority women), the definition of the AIDS crisis must extend to cover the intersection of disadvantage that in effect forms the individual's place (and therefore their experience) in the crisis.

C: The Consequences of an 'Impartial'/Ungendered Concept of AIDS

***Tool:** The necessity of problematizing knowledge or judgment where it presents itself to us as the product of impartial reasoning. The questioning of the categories that are appealed to in paring down the various dimensions and particularities of social reality.*

An impartial account of AIDS pares down the "details" that result from the particular perspective and creates a uniform definition applicable to all instances of AIDS. However, the tendency of the medical establishment, under the guise of supposed impartiality, for privileging studies involving the male body has created distortions and invisibilities that are visible in the initial definition of AIDS that was so narrow that it practically excluded women.

Impartiality at times in the AIDS crisis has meant constructing programs of care that did not reflect the needs of a particular groups.[13] One problematic consequence of these projects has been the lack of access to shelter, support programs and hospices, as well as drug rehabilitation programs for women with children. (The example of Helen Cover's inability to have child care when she needed to take care of herself also falls into this category.) Impartiality can mean creating the illusion of doing something for everyone when in fact no single group may profit from the arrangements brought about under the attempt to achieve impartiality of treatment.

This treatment of difference has more often than not disadvantaged women in the crisis. The impartiality of calling on all those who are sexually active to negotiate safer sex with their partners has likewise been unproductive. Sometimes impartial sounding demands make no sense: everybody cannot wear a condom because not everybody has a

[13]The ideal of impartiality obscures the relationship that exists between groups and contributes to the experience of which an impartial account is to be given Group experience and relative group privilege contribute to the experience of the individual within the system in fundamental ways Where social atomism is applied the form of oppression and disadvantage that individuals experience as members of groups disappear from sight. What are the conditions of the individuals existence within a society? What is it that cannot be grasped by assuming the individual as a basic unit of analysis for considerations of justice?

penis. Lack of differentiation that aspires to impartiality neglects differences that are crucial and that persist despite the veil of impartiality. "Commitment to an ideal of impartiality thus makes it difficult to expose the partiality of the supposedly general standpoint, and to claim a voice for the oppressed." (Young 1990, 116) In regard to AIDS, outreach organizations have realized this and have designed different kinds of educational materials that are sensitive to difference and the power dynamics that establish and reproduce difference.

*D: Examining the **Research on AIDS***

***Starting point:** Feminist empiricism: entry points of bias. Are there inconsistencies in the way research was conducted or evidence was gathered? What is the distance between the evidence and the interpretation offered?*

Clinical drug testing has perhaps been the most crucial area that one could align with the kinds of criticisms feminist empiricism makes of scientific practice. "Mice have a better chance of getting experimental drugs than women—Open all AIDS drug trials to women," reads the text of an ACT UP demonstration poster. (Women, AIDS and Activism 1990, 68) The question of treatment and trials has been critical to the AIDS crisis and it has brought science and its practices into the spotlight.

The necessity for doing studies about women and AIDS or doing research on and for women that would create drugs appropriate for women's bodies has often been dismissed on account of the "rare occurrence" of HIV and AIDS in women. In the absence of studies, one wonders how it is possible to know at all that the occurrence is rare. One explanation that has been put forward is that women's symptoms, where known, have been admitted to the definition more reluctantly than symptoms commonly witnessed in men. This has been a recognizable inconsistency often noted by health-care professionals and scientists trying to help women. The Centers for Disease Control have been accused of discriminating against women by failing to include symptoms frequently witnessed in women in the official definition of AIDS. As a result, these symptoms fail to constitute the legitimate projects for AIDS research. Activists demand:

> WHY IS THE CDC EXCLUDING WOMEN'S SYMPTOMS? The CDC claims that many of them aren't life threatening. Yet pelvic inflammatory disease is killing women with HIV. The CDC claims these symptoms occur in people not infected with HIV. But so does common herpes, which *is* included in the current definition. Herpes is included because it can become severe and difficult to treat in the presence of HIV. But so can vaginal candidiasis. The same criterion must be applied to all symptoms of AIDS. (from an ACT UP flyer)

Feminist empiricism provides the grounds on which demands for consistency in scientific practices can be made without challenging science as such. In the quote about the CDC (above), activists are demanding consistency in the medical-scientific criterion. The symptoms of AIDS that are included in the official definition have concrete implications for access to treatment and Medicare and social security benefits. Women's invisibility in this case is produced by an inconsistency in the formulation of definitions. The non-inclusion of women's symptoms produces a domino effect: since doctors do not know about these symptoms they are more unlikely to associate them with a possible HIV infection; women are falsely diagnosed, diagnosed late or not diagnosed at all, underdiagnosis combined with underreporting results in the invisibility of women who are affected by HIV and AIDS and leads to the false perception that women do not need to be considered as a group affected by AIDS. The circle is complete when scientists conclude that AIDS does not appear to affect women to such an extent that more studies and research might be necessary. Lack of information on how AIDS affects women means that treatment is either unavailable or tailored to the needs of men. As a consequence, women's quality of life and length of survival is inferior to that of men.

It does not simply suffice to say that in the United States we will never know the number of women who have been infected with HIV. Rather, it is more useful to understand why this is so and to examine the process by which information, such as statistics about women's HIV infection, are generated. As I have argued in Chapter Two, the definition of AIDS has been problematic in that it has in its initial versions not contained symptoms frequently observed in women. As a result many women were never diagnosed as having AIDS, and this leads to under-reporting. The extent of AIDS' impact on women could only be underestimated using such a definition.

E: Starting from the Experience of Affected/Involved Women

***Starting point:** Feminist standpoint: importance of perspective. What are the dysfunctionalities of the system that are invisible to a dominant or ruling perspective? What can we discover if we examine the social order as other to us?*

Anthologies of first person accounts by women reveal patterns of difficulties in dealing with systems, institutions, authorities and health care professionals. Also, it becomes obvious that difficulties that seem relatively insignificant out of context cumulatively add up to serious impediments. These impediments are invisible from the point of view of the system, the institutions, authorities and, to some extent, the health care professionals. In the absence of inquiries into the experience of individuals and groups *from the perspective of their experience* these difficulties remain invisible. To use a simpler example, investigating wheelchair accessibility on college campuses is done by getting into a wheelchair and trying to get to where you want to go. The difficulties and impossibilities present themselves from the perspective of concrete experiences. If every building were individually responsible for assuring accessibility, buildings would be internally accessible but there would be spaces between and beyond buildings that no one would feel responsible for. Fragmented accessibility means no accessibility in most cases. One set of stairs and you are stuck or dependent on someone else who may or may not come along.

In the United States, the present organization of the health care system, where it exists and where people are involved in it at all, cannot meet the challenge of the AIDS crisis, especially because part of this crisis stems from the form of organization that is in place. Health care is an opaque, torn patchwork of services that is stratified by class, fragmented because no comprehensive health care plan is provided and specialized with the result that different doctors deal with different body parts. It is inevitable that the unity of the individual's experience in encountering the system is lost. Where the individual is not or cannot be treated as a whole individual, important invisibilities arise

that cannot be undone from the perspective of a fragmented system reuniting distinct services with carefully outlined responsibilities. The individual as a whole person disappears. Based on such an analysis, the AIDS crisis presents itself as an organizational and economical problem. Added to these problems, women have experienced the disadvantages of not fitting the misleading white gay male paradigm of AIDS. Where it has been impossible for white gay men to receive adequate care it is hardly surprising that women's chances, especially where another intersecting disadvantage is cumulatively present, are even worse.

Taking the perspective of the affected also reveals other groups of people affected by AIDS who have remained invisible. More invisible than straight women, lesbians have received a minute amount of attention in the institutional reaction to the crisis. In my own research evaluating the language and stated goals of clinical AIDS research programs, it is obvious that the focus is on "women of reproductive age" where it is implicit that women are heterosexual. The focus on women in their functions of mother and the sexual partners of men produces results that are to the benefit of children or embryos and men. Women are considered as vectors, as potentially dangerous to other people. Many studies that involve women produce very little that is directed towards women themselves. The vector view of women produces invisibilities: not all women are of reproductive age, or straight.

> ...they threw a spotlight on women who were more invisible than most: lesbians. If a lesbian were not bearing children or threatening to infect men with AIDS, there was apparently no reason to pay any attention to her at all. (Corea 1992, 195)

The invisibility of lesbians in the crisis has resulted in a lack of information about the risks of transmission in lesbian sex practices. Moreover, it has reified the identity definition of risk that has proven unproductive where practices and not identities need to be examined.

In other cases, often the choice of language is key. Especially when the message is this urgent, terms such as "exchange of bodily fluids" are ineffective and cause dangerous delays while wasting much needed funds on bad educational and social technologies. While institutions may have formal requirements for published materials, they often prove to be counterproductive. A quote from Corea illustrates the difficulty of this issue. Sandra Elkin, a former PBS producer, created an educational video on AIDS for the HIV Center in New York City. In the following quotation, a revealing video is being rejected by the very agency that funded it:

> The official objected to the language in the script, was displeased that the prostitute delivered the message, and thought that the soap opera character Tamara risked losing her man if she told him, before she had the test, that she had been exposed to HIV. Best to keep mum till after the result came in, the official thought. That wasn't all.
>
> "Do you know there are six 'fucks' in that script?" she asked Elkin, irate.
>
> Elkin had never actually counted them. After hanging up, she did. The official was wrong. There were seven.
>
> Elkin couldn't believe it. Dollars were being poured down the drain making AIDS education videos that didn't work, that gave people no help in protecting themselves from the virus, because some government officials were concerned about language and propriety. (Corea 1992, 155)

In addition to using excessively formal language, AIDS education messages have often targeted women as either primarily or at least equally responsible for safer sex, despite the fact that many women are not necessarily in the position to tell their partner what or what not to do. A big gap exists between the education strategies of formal institutions used to dealing with relatively circumscribed tasks and peer education groups that ask the hard questions like "What are the issues between a man and a woman, for example that make it hard for a woman to demand that her man use a condom?" (Women, AIDS, and Activism, 147) The severity of the impact of power differentials between men and women cannot become institutionally visible when social questions are only pursued halfheartedly. Social reality which is constituted by these power differentials becomes a given in terms of AIDS but at the same time it critically contributes to the spread of HIV.

Accounts of the AIDS crisis from an institutional perspective are likely to impede an acknowledgment of the seriousness of gender inequality in our society From the points of view of some women's experiences they are unavoidable and often central

F: Being careful about the solutions...

***Starting point:** Feminist postmodernism: Where has the assumption of a privileged perspective created or furthered forms of oppression? Where have fictions been created that distort and exploit?*

Doctors have been reluctant to test women. Arguments against the testing of women were often based on the risk group model of the epidemic, within which, with exception of the categories ascribed to IV drug users and Haitians, there was little space for female infection. The risk group model did not offer a profile many women at risk and their doctors could identify with. Before this background female HIV or AIDS cases were likely to seem implausible or marginal at most. There is an expression which sums up this situation: "Women don't get HIV, they die of AIDS."

The progressive and liberal response to the AIDS crisis has been education. The most prominent symbol of safer sex is the condom. It is for this reason that I have chosen to focus on the condom as expressive and therefore potentially critical representative of the liberal response to AIDS. *The purpose of this section is to explore the implications of the condom strategy in regard to the fictions that it upholds and those that it creates. How do they distort or exploit?*

The urgency of reacting to the immediacy of the crisis may often preclude more in depth analyses of the entire involved problematic. In light of the seriousness of the situation and in absence of medical 'solutions,' a long term approach would be of benefit. In this sense safer sex would represent only part of larger change. Indeed, 'sex as safe' is a controversial issue in itself. Many women writers underline that for women sex has never been safe. The danger of sex preexists AIDS and HIV. The concept of 'safer sex' thus merely marks the entry of men into the realm where sex and danger are inextricable. Cindy Patton explains that "[e]ven the notion of "safer sex" is new for many gay men, precisely because they are men raised in a culture that leaves responsibility for the

"safety" of sex up to women. Women are more accustomed to making the multi-layered choices about the psychological and physical safety of sex "(Patton 1985, 139)

By redefining sex as safe on the basis of non-infection, it becomes clear that the sex under consideration is male sex since HIV does not represent the advent or the disruption of danger for women in the same way. There are of course plausible and non-sexist reasons for the present or at least the original concept of 'safe sex' The concept was born out of the gay community's effort of self-help. In the context of male homosexuality the concept makes a lot more sense and has been quite effective at significantly reducing the rate of infection Its application to heterosexuality remains problematic because safety (along with choice and control) in general for women is a precondition to HIV safety. The necessity for a safer sexuality, rather than merely safe sex, for women surfaces through the discrepancies that become *visible* in the extension of safer sex to include women.

AIDS education and information about AIDS are thus critical in focusing attention and politicizing some problems while negating others. To date, the importance of social status and power have not been addressed in discourses about AIDS. A recent study has shown that the developmentally disabled are vulnerable to HIV infection because of their relative powerlessness. (Tynes LL, et al. 1993) This illustrates the need to rethink what is meant by risk or risk activity. Groups (such as the developmentally disabled) are vulnerable to all types of abuse. (Elvik SL, et al. 1990) Previously, risk has been treated as a conscious choice on the part of a person who might have just as well not taken the risk. A new and additional definition of risk would include those people who find themselves at a significant disadvantage in relationship to power, be it cultural, socioeconomic, physical or mental.

Defining sexuality by defining sexual transmission therefore entails the definition of people that engage in it, "[to] control the definition of desire is to obtain the power necessary to effect sexual liberation or maintain oppression." The concept of 'safer sex'

in a heterosexist society therefore comes to mean reinforcing the position of power and normalcy attributed to men and heterosexual men more specifically, "[in] the U S. men are socialized to feel sexual agency."(Patton 1985, 114) *Agency* emerges as a key factor and with it the condom. How does the condom relate to female agency? Because 'safe sex' originates as a self-help measure in the gay male community and advocates the usage of condoms against HIV it is what one might call phallocentric and *although it does not consciously negate female agency, it is by its nature not concerned with it either.* Programs designed for other groups have been modeled on the examples of such organizations as the Gay Men's Health Crisis in New York alongside of others who have been highly successful in reducing the rate of infection among male homosexuals. However, little effort has been invested in determining the difficulties in translating such approaches as the condom into the heterosexual context especially in consideration of women.

The German lesbian linguist Luise Pusch remarks that people who speak of the absolute necessity of the condom for sex really want to convince us that those people who wear them, namely men, are irreplaceable as well as absolutely necessary for sex. Further, the emphasis on condoms in her opinion supports a definition of sex as one involving sperm and penetration, in other words, men. In this sense, AIDS education is challenged to devise a message that does not implicitly or explicitly negate female agency and sexuality by overemphasizing that of men (Pusch 1990, 130). Lack of information for and research on lesbians is perhaps the most illustrative example of how the focus on the condom, meaning penis, creates *blind spots* in the crisis. Women, we find, can be '*absent*' in the discussion about AIDS even when heterosexuality is explicitly addressed.

Metaphors of the AIDS virus posit the human body as a fortress, impenetrable by the virus. Katherine Cummings, in "Of Purebreds and Hybrids: The Politics of Teaching AIDS in the United States," explains how the image of the body as fortress is gendered: "The enclosed body is a recognizable synedoche for male bodies in a society where

bodily impenetrability, integrity, has been systematically enlisted to signify 'male' and penetrability its opposite, 'non-male' " There exists a crisis which has merely become more aggravated and therefore visible, namely that there exists an urgent need for the creation of circumstances that would facilitate an active (female agency) and safe female sexuality, whether lesbian or heterosexual This crisis is not a new crisis in the way one might consider AIDS to be relatively new crisis In the past two decades it has been repeatedly remarked upon by the feminist health movement and other activists It has however attained a renewed visibility and importance because of AIDS The AIDS crisis presents an occasion for change, change that might work toward the establishment of woman-positive circumstances. This must inevitably involve "seeking a solidarity in our oppositions to the dangerous fiction of the naturalized, essentialized, uniquely "human" (read "manly") and to the distortion and exploitation on behalf of this fiction." (Harding 1986, 26) After all, a distortion that lacks a concept of female agency endangers women's real existence. Feminist postmodernism presents the challenge of understanding the AIDS crisis on the level of agency and reveals that female agency is a critical issue for long-term change.

If the condom is not to become the symbolic Band-Aid, it is necessary that underlying, non-AIDS specific social patterns and attitudes be brought under consideration. Women need methods of protection they can control as well as supportive relationships in which their health is prioritized. Approaches to the AIDS crisis that lack concepts of female agency are unlikely to nurture such developments as *problems remain invisible without the validity of agency.* The facilitation of female agency might be one possible long-term approach to the crisis.[14]

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[14] This section is not meant as a criticism of safer sex methods I have problematized *the focus* on the condom, not *the usage* of condoms

4

Conclusion

Summary

A: Problems resulting from definitions

Women's exclusion from the statistical picture on the basis of the CDC's definition had a number of consequences: Women *were not counted.* They died *without diagnosis*, again they *were not counted.* Women *did not qualify* for health benefits or for social assistance benefits, such as child care, rent subsidies or other support services. *Under-reporting* resulted in *lack of awareness* among institutions and health care professionals as to the extent of the epidemic among women. As a result, important services for and data about women who are HIV-positive or suffering from AIDS is *missing or has been delayed* with serious consequences. Finally, women who were concerned about or affected by HIV or AIDS *were not believed.*

The consequences of the definition of AIDS have been the delay and denial of women's vulnerability to HIV. As a result, women across the board are still (even though a more inclusive definition has been enacted recently) less likely than men to receive the best care that could have been available and the best care that was available. The quality and length of women's lives has been significantly affected by the vicious circle created by the initial definition's misrepresentation of both women's risk to HIV and their suffering from AIDS. The definition resulted in a lack of awareness among health care workers and women about women's vulnerability and this delayed the recognition of the extent to which women were affected by AIDS as well as the recognition of how women

were affected by AIDS. Under-reporting due to women's failure to meet the prescribed criteria for AIDS diagnosis perpetuated this cycle. Research funding was justified on the basis that women were only marginally affected by HIV and AIDS. As a result, important information is still missing or less useful for women because only men were enrolled in many drug trials for drugs that would also be prescribed for women. The ultimate results have been that women have been systematically disadvantaged.

B: AIDS reveals a social crisis and it reveals health as a substantive test of politics:

Vulnerability to HIV and the availability of care to women who are living with AIDS needs to be regarded in the context of everyday lives. Everyday life, with its risks and possibilities, is a crucial factor in understanding the impact of AIDS on women, especially in the absence of a magic bullet solution provided by science. Everyday life refers to the circumstances of women's lives that determine the quality of their life and are decisive in creating and securing the well-being of women in the broadest sense. Obstacles to the well being of women include sexism, racism, poverty and heterosexism. More specifically, women's quality of life suffers (making them more vulnerable to HIV infection and less likely to receive proper care if they have AIDS) because of some of the following realities of their lives:

Women and children are disproportionately present among the poor in the United States and for minority women and children this situation is even more pronounced. The poorer people are the less likely it is that their everyday lives will secure a situation of overall health and safety. Because women are disproportionately among the poorest in the United States, less women than men have health insurance. Poverty means that women have fewer choices and relatively less control over their lives. Poverty may be tied to lack of access to important information about health and creates problems of access for women that deny them the benefit of available services and care.

Women are care givers more frequently than men. For women who are socialized to caring for others, self-care may not be a priority Women caring for children are likely to subordinate their own needs to those of their children Where scarcity of resources determine women's lives, the fact that they are care givers may mean that they do not receive vital care and important services. Where women in families or communities are relied on as 'natural' care givers, the burdens of care giving are added to preexisting responsibilities

Women are frequently in situations of lesser power relative to men. Women are at risk for HIV infection where they cannot set the terms of their sexual relationships or their social life. The prevalence of violence and sexual violence against women in the United States means that women are vulnerable to HIV infection.

Women's ability to care for themselves or the likelihood that they will be cared for is affected by their social, economic, religious, cultural, ethnic and educational identity and status. Some of these effects are negative. Because we live in a sexist society, some of these affects that might also touch the lives of men are intensified in the lives of women. The impact of the AIDS crisis on women cannot be understood by positing women as a monolithic group: it is necessary to consider the situation of the lives of individual women as well as the situations of life for different groups of women. Demands, identities and memberships in a woman's life may overlap and create unique tensions that adversely affect the possibility for a woman to remain healthy or to avoid further degeneration of health. IV-drug use, racism and poverty are the most crucial factors that need to be considered at this point in the United States. Understanding women's lives within their communities must be central.

Although HIV vulnerability was largely seen as a matter of consciously incurred risk in the eighties, it became evident that this misrepresents the nature of risk and vulnerability, especially for women. I define risk as multiple disadvantages often resulting from societal discrimination, powerlessness or structural situations of social injustice that reduce the quality of women's lives and increase their risk for contracting HIV and for being insufficiently cared for when they have AIDS. The social and political dimensions of AIDS make women vulnerable and less likely to be properly cared for In short, everyday life puts women at risk It is necessary to realize the political, social and economic dimensions of this risk. Reducing risk means undertaking long term change of the larger situations that determine women's lives as well as addressing conditions created by social injustice.

C: Six definitions of Invisibility:

From Sandra Harding's work I take three starting points for looking for invisibility. The first starting point comes from the approach of *feminist empiricism.* We can start looking for possible invisibilities by examining the relative distance between evidence and interpretation. Inconsistency in procedure and application of criteria are entry points for bias. Bias creates invisibilities.

The second starting point, provided by *feminist standpoint theory,* entails questioning the perspective from which problems for research or conclusions are formulated. Whose social experience makes such projects and perspectives valid or meaningful? We start looking for the origin of invisibilities in the social experience that social science presupposes. Different people have different social experiences and therefore different perspectives on social reality. Since power enters into this scenario on all levels, we must ask what is the effect of the perspective of the socially powerful for whom the system is functional. What could have been learned if the researcher experienced the system as other? What can we learn about the system or social order if we experience it as dysfunctional? The discrepancy between the perspectives and experiences of the powerful and those of people for whom the system is dysfunctional is a space of potential invisibility.

Feminist postmodernism, the third starting point, attacks the assumption of the possibility of coherent representation is a source of invisibility. Privileged perspectives further forms of oppression even within emancipatory projects, and fictions are created that distort and exploit. What are the deepest assumptions of representation? Where representation is pursued despite fragmentation, invisibilities are created

From Iris Young's work I take three *tools.* The first tool is based on the awareness of the functioning and implications of the dominant paradigm, in this case the distributive

paradigm. Young's message is that it is necessary to recognize the dominant paradigm in order to understand how justice is understood and what is understood as justice. What does such a paradigm render *invisible* to justice? As a tool to detect invisibility, understanding the distributive paradigm means recognizing that injustice occurs even where there is no recognizable, intent-driven agent who is responsible for whatever action resulted in the injustice. Invisibilities are created and perpetuated by a model of justice that only recognizes injustice where intent to create injustice is identifiable.

The second tool is based on the requirement that justice be considered contextually. What is meant by context here is structure of societies, a definition of injustice that makes *visible* structural oppression and an awareness of potential *blind spots* that might be undone if we can escape the confines of the intent-driven model. Structural oppression is made visible by such a definition of justice.

Finally, what was defined as marginal or excluded? The demands of the third tool are the problematization of knowledge or judgment where it presents itself to us as the product of impartial reasoning. What is pared down in order to create supposedly impartial accounts or definitions? On what basis are characteristics of a person or experience regarded as particularities that are marginal? Which aspects of social reality are sacrificed to impartiality? What function does the appeal to impartiality fulfill in terms of legitimizing knowledge? Invisibilities are created where the specifics of experience and situation are subordinated or eliminated for the purpose of creating general accounts that claim to represent a broad range of experience and situations.

Self-Criticism: Virtues and Limitations

Power instead of Invisibility

The potential visibility implied by a concept of invisibility cannot be taken to mean a resolution of all problems. Although there may be conceptual realization and resolution, it is equally important to understand that increased visibility for the issues concerning different kinds of women in the AIDS crisis has not always been matched by the actual change on the part of institutions or relevant individuals. Situations where visibility has been achieved but not acted upon reveal circumstances of social injustice and power differentials that are resistant to providing better conditions for women's lives. The creation of visibility reveals relations of power by reducing or eliminating the reasons for non-action.

The resolution of a conceptual problem can create the preconditions for action and change but it cannot resolve the relations of power that keep necessary change from happening. This situation allows for a politicization of the events surrounding the conceptualization of AIDS as a social crisis in the sense that the priorities and imperatives of institutions, structures and systems become apparent and are subjected to political debate Examples of this occurring in the context of the AIDS crisis include: the CDC definition of AIDS (see Chapter Two), the action and inaction of the government, the actions of pharmaceutical companies, the actions of institutions of health.[15]

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[15] AIDS activism has been central to the creation of visibility for problems related to AIDS It has put important facts and revealing quotes from powerful public officials within reach of citizens By exposing neglect and the arguments against action employed by president Reagan, president Bush, Cardinal O'Connor, New York City health commissioner Stephen Joseph and others in position critical to securing public health, ACT UP put the visibility of the crisis into the context of power relations ACT UP's strategy was very straightforward contrast the horrific facts about people's suffering with the statements of neglect, profiteering, homophobia, racism and sexism One poster that provides such a contrast is trimmed with the text "We recognize that every AIDS death is an act of racist, sexist and homophobic violence"

Specific examples of this strategy include

1) AIDSGATE, a poster featuring a picture of Ronald Reagan with AIDSGATE stamped on the picture and the demand that "The political scandal must be investigated!" followed by facts about the AIDS crisis 54% of people with AIDS in NYC are Black or Hispanic, AIDS is the No.1 killer of women between the ages of 24 and 29 in NYC, by 1991, more people will have died of AIDS than in the entire

The direct limitation of the concept of invisibility as a problem is that its opposite, visibility, implies the resolution of that problem. It needs to be clarified that invisibility conceals or distorts problems from different levels of decision making. Although this concealment or distortion is a problem, it is not the problem that is concretely at issue initially. Rather, it is the problem that hinders action on a situation of social injustice AIDS activists have created visibility as a protest and as the basis for future action ACT UP has created visibility to enrage people into action. Eventually, invisibility itself comes to be realized as an instance of injustice, especially where patterns of invisibility become evident. The creation of visibility politicizes the situation of invisibility in such a way that the invisibility is understood as the perpetuation of a situation of social injustice From an activist perspective, the creation of visibility allows those who suffer from social injustice to define and create their own account of that injustice, and to make their own demands. In the context of politicized information this is a crucial skill and an important power: to define, rather than to be defined. So, although invisibility itself must not be confused with the initial problem, it can also not be separated from it.

This impossibility of separation renders invisibility a more complex concept than would be indicated by the six definitions of invisibility that I provide. The difference between this explanation of invisibility and the individual examples that I explore in

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Vietnam War "What is Reagan's *real* policy on AIDS? Genocide of all Non-whites, Non males, and Non-heterosexuals? SILENCE=DEATH" (AIDSDEMOGRAPHICS, 36)

2) A picture of George Bush stamped GUILTY accompanied by a quote from his first presidential campaign "Testing is more cost-effective than treatment." (AIDSDEMOGRAPHICS, 12)

3) AIDS 1 in 61 This poster puts the numbers into context and adds an hypothesis "One in every sixty-one babies in New York is born with AIDS or born HIV antibody positive So why isn't the media telling us that heterosexuals are at risk? Because these babies are black these babies are Hispanic" The conclusion in bold "Ignoring color ignores the facts of AIDS STOP RACISM FIGHT AIDS" (AIDSDEMOGRAPHICS, 42)

4) THE GOVERNMENT HAS BLOOD ON ITS HANDS ONE AIDS DEATH EVERY HALF HOUR (AIDSDEMOGRAPHICS, 80)

5) A quote from an official of the pharmaceutical company Hoffman La Roche, Inc "One million [People with AIDS] isn't a market that's exciting Sure it's growing, but it's not asthma" (AIDSDEMOGRAPHICS, 96)

Chapter Three is one of size and context. The six examples are meant as specific tools that can be employed towards specific ends whereas the larger problematization of invisibility, as in the example of AIDS activism, is a more general commentary on a political phenomenon; namely, that facts aren't always facts and that visibility has a lot to do with power, entitlement and agency. This insight forms the background to what my actual project has been in this thesis.

In the more direct sense, invisibility implies a problem of power that should be resolved. That is not to say that it would be advisable to pass over a consideration of invisibility directly to the question of power. The concept of invisibility itself implies that such a direct strategy is impossible or at least misleading. Because invisibility is a political phenomenon that determines our perceptions of political phenomena, it is necessary to consider the following questions: What shapes awareness of a particular problem? How are boundaries of a problem determined? Who or what defines problems? Who or what is excluded from the process of defining problems? Who or what does not appear in the definition of problems? Whose problems get dealt with, whose do not? Is the definition of a particular problem motivated by specific interests? What are these interests? Equally as important, are there patterns of problem definition specific to certain societies, systems or communities? What are these patterns? To whose benefit do they function systematically? These questions all relate to the problems of invisibility and would, if taken seriously, improve the identification of relations or circumstances of power that create specific problems such as the ones experienced by women in the AIDS crisis. Invisibility, as I have been approaching it, signifies the necessity of such considerations. Its virtue as a concept contrasts with the specific uses the definitions of invisibility explored in Chapter Three have as tools.

More serious limitations of the concept of invisibility include its basis in a vocabulary of perception. If social scientists seek to honor the importance of first-hand experience and the intrinsic value of the personal account, we cannot in any serious way

speak of invisibility as a problem, real problems afflict people and they are not only visible but painful. Invisibility denotes a failure to be seen on the part of those who are, in fact visible and real, only not perceived in society Invisibility, being unable to be seen, is the flip side of not being able to see When speaking of invisibility it is implied that there is a duty or a necessity that those who cannot see invest their energy to make visible that which is not seen. Otherwise, this concept is useless and misleading. The problem of perception should not be shifted to people who should be entitled to attention.

Despite this objection to a concept of invisibility, I argue that it is an important starting point for research As shown in this chapter, behind invisibility hide dynamics that resist definition. Invisibility implies that there are connections yet to be made about a social problem, it expresses the need for discovering causes and reasons for patterns of disadvantage. The project of this paper has been to attempt to provide theoretical possibilities for understanding aspects of the AIDS crisis. Using the term "invisibility" serves the following purposes. first, it picks up on a frequent usage of the term, secondly, it provides me with a vocabulary of perception with which I can point out a quality of similarity in different theoretical explanations of problems or circumstances, thirdly, because invisibility is part of the set visibility/invisibility, *invisibility implies the potential for visibility* -how will this visibility be achieved? what will be the consequences of visibility? - and therefore demands a consideration of actions and alternatives.

'Invisibility' as a concept is interesting for two reasons On the one hand, there is the manner in which feminist activists as well as feminists theorists use the term as an abbreviation or an indication of a problem that cannot be resolved because it is not *perceived* by non-feminists, or non-activist for that matter On the other hand, the problem of invisibility provokes the problematization and investigation of what *is* visible. Also, 'invisibility' demands that investigations extend beyond a task oriented perception of the crisis where familiar tasks and responsibilities are superimposed on the crisis such that invisibilities are created

The Future

A: Interdisciplinary work:

The AIDS crisis requires interaction and cooperation between different disciplines as well as between different services. The AIDS crisis is not a single issue crisis (and one suspects that few *crises* really are) and therefore strategies to confront the situation must acknowledge the connectedness of health with politics and science on the most general level, and the connectedness of the entire individual experience on the most immediate level. The AIDS crisis necessitates an approach in which what is being studied are real life situations and not some fragment thereof, determined by the specialty or focus of a specific institution or scholarly discipline. Invisibilities are created where the natural cohesion of experience fails to be addressed or is fragmented.

Women with AIDS have been frustrated by the intractability of the health system, especially where no one retains an overview of a patient's present situation and medical history and where there exists a lack of resources for women with multiple medical and social problems. Treatment of women has been fragmented into the work of specialists rather than the assessment of the whole ensemble of issues confronting them. The AIDS crisis demands an interdisciplinary approach in order to think about solutions to the hardships of women from the perspective of the person requiring help and services.

This is true for health services as well as for addressing the social realities of women. It makes little sense to think about helping women if there is no willingness to address the needs of a woman's family along with her own. Women's lives need to be understood in context; otherwise, many plans for help will be misconceived. Understanding women's lives in context presupposes the realization that women in the United States are not a preconceived group of monolithic character with the same conditions of life or with the same needs. The current distribution of AIDS cases shows that minority (Black and Hispanic) women are disproportionately affected.

Consequently, understanding their situations will mean addressing issues of racism and poverty within the communities in which they live Another challenge of the AIDS crisis is that different forms of societal discrimination are pitted against each other The struggle against one form ought not to be fought at the cost of another, "the struggle against racism ought not to be fought at the cost of sexism " (Kurth 1993, 195)

On the level of health services, interdisciplinary models have been elaborated and experimented with. The desired ideal would be an arrangement that provides full health care for a woman and all of those people who she provides care for This integrated facility would provide necessary specialists but would designate one person as a case manager. This person would be primarily responsible and would coordinate treatments and keep an overview of all information relevant to a client. Such an integrated system would imply that information be freely shared between the various providers. (Kurth 1993, 223)

On the level of prevention programs and educational messages, women's diversity needs to be considered. Programs that are most likely to succeed are those that take into account the variables of a woman's life that determine willingness and ability to change behaviors that put them at risk. These variables include economic, social, and physical needs, attitudes, beliefs, behaviors, skills, access to information and services, and social norms. Even when women are informed about AIDS, HIV and condom use, they will not necessarily be able or willing to practice or insist on safer sexual practices, they may fail to perceive a threat to their own personal well being, they may have negative associations with condom use, or be unable to negotiate their use They may not be able to afford condoms Both women and their partners need to know how to properly use condoms, and the partner's correct use of condoms is not directly controlled by women A partner's refusal to wear condoms is equally out of the control of women The complexity of these variables and their interaction is best evaluated in cooperation with the women or communities in question. Successful plans for reducing risk will be those that do not

isolate cultural, socioeconomic and biological factors that put women, who are generally less in a position of power to effect necessary changes, at increased risk.

B: Cooperation between Public Health and the Social Sciences:

An important area of cooperation for an interdisciplinary approach designed to conform the AIDS crisis lies between the social sciences and organizations of Public Health. AIDS challenges the distinctions between these areas of research in as much as the complexity of the AIDS crisis effectively combines questions of health with questions of life in communities, societies and systems It has thus become inconceivable to separate questions of health from the circumstances of women's lives or even from human rights.

Controversy has arisen where public health plans have threatened to impinge on the space of human rights with such strategies as mandatory testing, contact tracing, quarantine, and use of placebos in drug trials where the experimental drug may be a person's only hope for survival. The protection of human lives in the face of human rights violations has become highly politicized in the past decade. This double challenge confronting the United States demands long term strategy for successfully dealing with the circumstances that aggravate and fuel the epidemic in the United States Public Health experts increasingly agree that the promotion of human rights and the goals of public health are inseparable AIDS has brought the connections between individual, community, national health, and societal discrimination into clear focus. Concern for such issues as consent, confidentiality, and nondiscrimination regarding HIV-infected people and people with AIDS is important if traditional public health work is to be effective. (Kurth 1993, xii)

The AIDS crisis provides the social sciences with a special opportunity for understanding U S. society and, conversely, the social sciences have important contributions to make to strategies for long term change in response to the AIDS crisis AIDS as a lens opens up a view of many social and political issues not connected or brought into such sharp relief under other circumstances. Addressing AIDS in the social

sciences means addressing the circumstances of different lives as they are determined not only by infection but also by the social and political realities of the United States Seeking solutions to the AIDS crisis means contemplating and planning systemic change In the United States, the current administration is seeking to establish national health care on a previously inconceivable scale This represents a form of systemic change and many sensitive and sensible voices are needed to decide what form and content these change will have and to assure that this changes leads in a beneficial direction. Social scientists have important contributions to make in this process.

The AIDS crisis challenges the predisposition of objectivity and impartiality in the social sciences. I mean that the resolution of the AIDS crisis implies an understanding and resolution of multiple and overlapping instances of social injustice AIDS has the potential of sparking more applied projects in the social sciences, gradually breaking down the silence between scholars and activists.[16]

16

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