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WOMEN AND HIV: THE BARRIERS TO PROTECTION

By J. P. Howlett[1]

Acquired Immunodeficiency Syndrome (AIDS),[2] known in the early years of the epidemic as "Gay Related Immune Disorder" (GRID), has evolved from a disease almost exclusively associated with gay men to one affecting an increasing number of women. The incidence of AIDS is escalating fifty percent more rapidly among women than among men.[3] AIDS is the leading cause of death for women aged 25-44 in nine major American cities.[4] In 1994, women represented over eighteen percent of the new reported AIDS cases,[5] compared with thirteen percent of new cases in 1992, ten percent in 1990, six percent in 1982,[6] and three percent in 1981.[7] Significantly, heterosexual contact has officially overtaken intravenous drug use as the mode of transmission of HIV among women, and there are reasons to believe that the danger of transmission through heterosexual contact is underrated.[8] This means that the primary mode of transmission for women is no longer a behavior that can be relegated to undesirable subsets of the general population of women.

Furthermore, heterosexual transmission of the virus is as many as eighteen times more likely to occur from man to woman than from woman to man.[9] Compounding this is the fact that the pool of infected

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1 Ms. Howlett is a 1996 graduate of the University at Buffalo School of Law.

2 AIDS actually refers to the latter stages of infection with the Human Immonodeficiency Virus and is often characterized by the emergence of opportunistic infections.

3 *See Beyond Pregnancy: The Care and Treatment of HIV(+) Women,* AIDS WEEKLY, Aug. 7, 1995, at 60.

4 *See* Rebecca Clark et al., *HIV: What's Different For Women?,* PATIENT CARE, Sept. 15, 1993, at 119.

5 *See Update: Acquired Immunodeficiency Syndrome -United States, 1994,* MORBIDITY AND MORTALITY WEEKLY REPORT, Feb. 3, 1995, at 64, 64-65.

6 *See* Symposium Commentary, *Women and HIV: Breaking the Silence,* 9 BERKELEY WOMEN'S L.J. 144, 145 [hereinafter *Breaking the Silence*].

7 *See* Charlotte Anastasio et al., *Self-Care Burden In Women With Human Immunodeficiency Virus,* J. OF THE ASSOC. OF NURSES IN AIDS CARE, May-June 1995, at 31, 32.

8 *See id.* at 33. *See also* Laurie Jones, *AIDS Focus Slowly Turning Toward Women,* AMERICAN MEDICAL NEWS, March 21, 1994, at 3.

9 *See* Jennifer Burroughs, *The Politics of Statistics,* BERKELEY WOMEN'S L.J.

men who could give HIV to women is much larger than that of women who could infect men, particularly among African Americans.[10] Adolescent females are at even greater risk of infection due to the immaturity of their bodies.[11] Among African Americans, the incidence of infection among teenage girls exceeds that of boys; among Hispanics, 47% of teens infected with HIV are female.[12]

The population of women who are increasingly infected, or at risk of infection, with HIV differs markedly from the community of gay men who, early on, were considered to be at risk of infection. Theoretically, the at risk population of women is huge, because in addition to women who have been exposed to contaminated blood or blood products, it includes any woman who has engaged in unprotected sex with a person of unconfirmed negative status in the past two decades. The women at risk of infection, or already infected, tend to be poor and disenfranchised and lack a cohesive community to which they can turn for support and advocacy.

Factors such as income level, cultural beliefs, education and drug use lead to the disproportionate impact of HIV/AIDS among women of color.[13] In 1994, fifty-three percent of the women who were reported as having AIDS were African American, and twenty-one percent were Latina.[14] Often, these same factors that put women at risk of HIV infection, including race, poverty, and drug use, also cause women to end up in prison.[15] Thus, unlike infection rates in the general population, the percent of women in prison who are HIV positive exceeds that of men.[16] Estimates are that one in four women in New York State's prisons and jails are HIV positive.[17]

152, 154 (1994).

[10] *See* Clark et al., *supra* note 4.

[11] *See* Jon Cohen, *Women: Absent Term in the AIDS Research Equation,* SCIENCE, August 11, 1995, at 777.

[12] *See* Center for Disease Control and Prevention, *Facts about HIV/AIDS and Race/Ethnicitiy,* December 1995. *See also* Suzanne C. Smeltzer, *Women and AIDS: Sociopolitical Issues,* NURSING OUTLOOK, July/August 1992, at 152.

[13] *See* CHARLES PERROW & MAURO F. GUILLEN, THE AIDS DISASTER: THE FAILURE OF ORGANIZATIONS IN NEW YORK AND THE NATION 8 (1990) (noting that concern with the general health or well-being of minority groups has never been high in America).

[14] *See* Symposium Commentary, *supra* note 6.

[15] *See id.*

[16] *See* Brenda V. Smith and Cynthia Dailard, *Female Prisoner and AIDS: On the Margins of Public Health and Social Justice,* AIDS & PUB. POLICY J., Summer, 1994, at 78 (noting that in 1988, researchers found that HIV infection rate for women in ten prisons and jail systems ranged from 2.5 to 14.7 percent for women,

This article will analyze the barriers that women face in protecting themselves from HIV infection and in obtaining proper treatment once infected. The first part of this article examines the legislative response to stopping the spread of HIV. It points out that the legislative response to HIV reflects and promotes a public policy that views women with mistrust; it is a policy that treats women as vectors for HIV disease who threaten men and children, and ignores the danger that HIV poses to the women themselves. Part two of this article examines the implications of viewing the HIV disease using a model which sees gay men as its primary victims. It argues that this model yields both discriminatory research, and ineffective patient care for women who are either at risk for HIV or already HIV positive. Such a model ignores the need to include women in clinical tests in order to understand the progression of the disease in women, and also fails to view women as "at risk" in patient care. Part three of this article examines the barriers to women's protection and care that are presented through social mores and gender roles. It argues that these social conditions have a negative impact on a woman's ability to negotiate safe sex for herself, and interfere with her ability to receive proper care. Part four argues that women face additional barriers because they lack a cohesive community to support and protect those at risk for HIV infection. The social stigma attached to the disease; the division of women by issues of race and class; and the criminal disenfranchisement associated with women in prison, intravenous drug use, and prostitution impede the formation of a politically empowered community to assume an advocacy role in relation to women and HIV.

This article concludes that in order to effectively prevent and treat HIV infection in women in this country, policy makers and service providers must be aware of all of the barriers to protecting women that exist today. Additionally, public policy which continues to insist on viewing AIDS as a disease which threatens only "high risk" groups, rather than as primarily a sexually transmitted disease, undermines efforts to effectively prevent further infection, and efforts to compassionately care for those already infected. It further argues that white women's groups must address their own racism and classism in order to effectively support efforts to prevent further infection among low income women, women of color, and women in prisons.

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and from 2.1 to 7.6 percent for men).

[17] *See* E. Rosenthal, *Doctors Behind Bars Balance Safety and Care*, NEW YORK TIMES, Jan. 1, 1994, at A1.

PART I - A DISCRIMINATORY LEGISLATIVE RESPONSE

This section examines three issues involving women and HIV which are, or could be, appropriately addressed through legislation. In each issue the goal of legislation is protecting persons from the transmission of HIV.[18] The first issue concerns decreasing or treating cases in which HIV passes prenatally from an infected mother to a fetus, and involves the testing of pregnant women or their newborn babies. The second issue deals with preventing the spread of HIV through commercial sex, and involves legislation providing for mandatory testing of persons arrested or convicted of prostitution.[19] The third issue is protecting women who undergo artificial insemination from contracting HIV through donor semen, and involves the federal regulation of sperm banks. The first of these two issues, dealing with pediatric HIV and commercial sex, has been addressed by legislatures in laws passed in a number of states. These pieces of legislation result in the infringement of women's privacy rights.[20] Legislatures have yet to address the third issue, infected donor semen, although women's advocates are urging them to do so.

A. Protecting Children

Two forms of proposed legislation address the issue of pediatric AIDS. The first is the routine screening of pregnant women for HIV.[21] The second is mandatory HIV testing of the newborn babies of all women who refuse voluntary prenatal screening.[22] The supposed aim

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[18] *See* 42 U.S.C.A. § 300ff-47. This federal statute conditions the disbursement of federal money to fund AIDS services to states who have enacted statutes criminalizing the transmission of HIV.

[19] *See* IDAHO CODE § 39-604, OKLA. STAT. tit. 63, § 1-524 (1994) (mandating HIV tests for persons merely arrested for prostitution). Over 12 States mandate testing only after a conviction of prostitution.

[20] *See also* Michael L. Closen & Scott H. Isaacman, *Criminally Pregnant,* 76-DEC A.B.A.J. 76, 76-77 (1990) noting that statutes are aimed at criminalizing conduct which could result in transmission of the virus, might also be used to prosecute a mother who passes the virus to a fetus in utero. Such action does not seem farfetched given recent cases in which statutes aimed at criminalizing drug delivery to minors have been used to prosecute women who use drugs during pregnancy. *See, e.g.,* Johnson v. Florida, 578 So.2d 419 (holding that cocaine passing through umbilical cord after birth, but before cutting of cord, violated statutory prohibition against adult delivery of controlled substance to minor).

[21] *See* Taunya Lovell Banks, *Women and AIDS -- Racism, Sexism, and Classism,* 17 N.Y.U. REV. L. & SOC. CHANGE 351, 354 (1990) (noting that routine screening is conducted under conditions of consent or where consent is presumed).

[22] Members of both houses of Congress have agreed to draft legislation

of this legislation is to facilitate early identification and treatment of pediatric AIDS. A closer look reveals that each approach is problematic. Neither routine screening nor mandatory testing guarantees either the identification or treatment of infants with HIV. Additionally, mandatory testing represents a severe infringement on the privacy interests of the mother without addressing the treatment needs raised for the mother or her child The debates surrounding routine screening and mandatory testing are also significant. They reveal a public policy of mistrust toward women in general, and especially toward the women who are at greatest risk of HIV infection: low income women and/or women of color.

Under routine screening procedures a pregnant woman is tested for HIV along with a number of other possible ailments.[23] In order to avoid this prenatal HIV testing a women must sign a form indicating that she refuses to have the test, a practice that many find coercive.[24] Currently, the states of Florida and Michigan require routine HIV screening for pregnant women.[25]

Opponents of routine screening argue that widespread education and voluntary screening programs are a better approach. They point out that, unlike other diseases for which routine maternal screening has been deemed appropriate, there are currently no treatments for AIDS that do more than slow the progression of the disease. Mandatory testing programs for diseases lacking cures or vaccines are less effective in attaining public health goals.[26] This contention has been challenged by a recent study which indicates that

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calling for mandatory testing of newborns. This legislation would condition federal AIDS funding to states on mandatory newborn testing requirements for those infants whose mothers refused prenatal HIV testing. *See* Kevin Sack, *House Panel to Draft Bill Requiring AIDS Tests of Newborns,* THE NEW YORK TIMES, July 14, 1995, at A15.

[23] *See id.*

[24] *See* Carol Stevens, *Will HIV Test Follow Pregnancy?,* DETROIT NEWS, June 18, 1995, at A1. *See also* Rebecca Blumenstein, *State Bill Seeks Testing For AIDS While Pregnant,* NEWSDAY, March 29, 1995, at A48.

[25] *See* Risa Denenberg, *Pregnant Women and HIV,* WOMEN, AIDS AND ACTIVISM, 159 (Cynthia Chris & Monica Pearl eds., 1990). The CDC currently encourages medical professionals to offer HIV counseling to pregnant women as a matter of course and also to make voluntary testing available. *See* Frank Reeves, *State Will Urge Voluntary HIV Tests for Pregnant Women,* PITTSBURGH POST-GAZETTE, August 7, 1995, at B1.

[26] *See* Kathryn Boockvar, *Beyond Survival: The Procreative Rights of Women With HIV,* 14 B.C. THIRD WORLD L. J. 1, 28 (1994).

pregnant women who take AZT can reduce the risk of infection for their infant from approximately twenty-five percent to eight percent.[27] However, much is still unknown about the long-term affects of chemotherapy (AZT) on babies. Women's AIDS advocates express concern over the universal administration of AZT, in light of the fact that 75 percent of infants born to HIV positive mothers are likely to be free of HIV infection without such measures.[28]

Critics of routine screening further point out the dangers of "directive counseling" which often accompanies routine screening. Directive counseling advises an HIV positive pregnant women to abort, and an HIV positive nonpregnant woman not to become pregnant.[29] Considering the number of low income women of color who have contracted the virus, this message has serious racial overtones. Additionally, there is concern that poor women who have limited access to health care may consent to terminate their pregnancy, fearing the loss of medical treatment if they do not comply.[30] There are also concerns that women may delay prenatal care to avoid detection of their HIV status in order to avoid pressure to terminate their pregnancy.[31] That detection could result in significant social stigma, and the loss of medical insurance, employment, or even access to further medical care are also concerns.[32]

A realistic view of routine screening admits that it may raise as many concerns as it is supposed to address. Unless it is linked to appropriate care following the disclosure, routine screening of pregnant women is of questionable value.[33] Proper care will often only be available to a woman with private health insurance, and in many cases, the stigma that accompanies a woman's HIV positive status may cause

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27 *See AZT & Pregnancy,* Women Organized to Respond to Life-threatening Diseases, Oakland, CA, November 1995, at 3.

28 *See id.* (noting that the side effects of pregnant women taking DES didn't show up until the babies were grown).

29 *See* Smeltzer, *supra* note 12, at 155.

30 *See* Banks, *supra* note 21, at 354.

31 *See* Smeltzer, *supra* note 12 (noting reports of HIV positive pregnant women who delay prenatal care until the 24th week to avoid unwanted pressure to terminate their pregnancies).

32 *See* Diana K. Sugg, *AIDS, HIV Patients Hurt by Medical Bias,* THE BALTIMORE SUN, Sept. 21, 1995, at A1 (noting that at some clinics patients are told to go elsewhere because the doctors don't know how to deal with AIDS).

33 *See* Kevin J. Curnin, *Newborn HIV Screening and New York Assembly Bill No. 6747-B: Privacy and Equal Protection of Pregnant Women,* 21 FORDHAM URB. L. J. 857, 859-60 (1994).

her to lose her job, her home, and any chance of ever purchasing such insurance.[34]

The second type of proposed legislation calls for mandatory testing of newborns and is intended to prevent and treat pediatric AIDS. A recent bipartisan agreement in Congress to draft legislation conditioning federal funding for AIDS on mandatory testing of newborns suggests that legislation requiring mandatory testing of newborns will soon be enacted.[35] Virtually all children born to HIV positive mothers test positive for the virus as a result of receiving their mother's antibodies. However, approximately seventy-five percent of the newborns born of HIV infected mothers shed the antibodies within fifteen to eighteen months, indicating that they are free of the virus and were never actually infected.[36] As a result, the testing of newborn babies is an accurate indicator only of the HIV status of the mother, and not the infant. Therefore, testing of newborns results in the disclosure of mother's HIV positive status without her consent.[37]

The prevention and treatment of pediatric HIV is especially compelling because infants are portrayed and perceived as "innocent" victims. The subtext of this characterization is that the mother is somehow "guilty," either of infecting the infant, or of some other "bad" behavior which makes her deserve to be infected.[38] By casting the mother as a guilty player, it is easier to tolerate the invasion of her privacy that mandatory testing represents. Like routine screening,

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[34] *See* Stevens, *supra* note 24.

[35] *See* Curnin, *supra* note 33, at 867 (noting that blind testing circumvents the need for consent or counseling, because infants are tested immediately after birth anonymously, with no disclosure to the mother). From 1987 until May of 1995, the CDC sponsored "blind testing" of every newborn baby in 45 states to determine trends in the disease and to identify high risk populations. As the number of infants born to HIV infected mothers increased to approximately seven thousand a year, this testing became controversial. Some politicians viewed the blind testing as immoral because, unbeknownst to parents, infants who had tested HIV-positive were being sent home with their HIV-positive mothers without the benefit of medical advice or treatment for either. In May of 1995 the CDC suspended the program of anonymous screening of newborn infants, in response to political uproar. *See* Mike McKee, *Testing HIV Policy;* THE RECORDER, May 17, 1995, at 1. The controversy increased in light of the recent studies suggesting that transmission rates can be lowered with prenatal AZT. *See AZT & Pregnancy, supra* note 27.

[36] *See* Denenberg, *supra* note 25, at 159.

[37] *See* Kevin J. Curnin, *supra* note 33.

[38] *See* Carol Beth Barnett, *The Forgotten and Neglected: Pregnant Women and Women of Childbearing Age in the Context of the AIDS Epidemic,* 23 GOLDEN GATE U. L. REV. 863, 865 (1993).

mandatory testing of newborn children strips a women of her right to choose whether or not she wants to know her HIV status without guaranteeing her protection from discrimination, or treatment for her condition. The mandatory nature casts the debate in absolute terms. The issues are framed as competing interests: the mother's privacy interests versus the health interests of her child.[39] Such a perspective exposes the attitude of mistrust which is a recurring theme in HIV legislation that affects women. It reflects and promotes the false perception that a mother's privacy, along with her associated interests in employment, insurance, and freedom from discrimination, do not correspond to the interests of the child.[40]

B. Protecting Men

The second issue which has been the subject of legislation is controlling the spread of HIV through commercial sex. These laws mandate HIV testing in connection with charges of prostitution.[41] Like mandatory testing of newborns, they result in infringement of women's right to privacy. A number of states provide for mandatory testing only after a conviction for prostitution,[42] but some have gone as far as to mandate testing for persons who are merely arrested on such charges.[43] Additionally, where the person tests HIV positive, numerous

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[39] *See* Stevens, *supra* note 24 (noting that the resulting stigma and discrimination associated with being HIV positive are likely to lead to loss of employment and the inability to acquire health insurance).

[40] *See id.*

[41] Remarkably, a number of states that call for mandatory testing of HIV for persons convicted of prostitution require testing only of the prostitute, and not the client. Thus, in these states, it is clear that the legislation is concerned with protecting the client, not the woman, from the spread of HIV. *See* TENN. CODE ANN. §39-13-513; W.VA. CODE §16-3c-2(5)(1995); GA. CODE ANN.§16-5-60 (1995). *But see* GA. CODE ANN. §17-10-15 (mandating HIV testing of those who are convicted of solicitation of sodomy).

[42] *See* Cal. Penal Code §1202.6 (Deering 1995); Colo. Rev. Stat. Ann. §§ 18-7-201.5 (West 1995); Fla. Stat. Ann. § 796.08 (West 1995); Ga. Code Ann. §31-17-1 (1995); Ill. Ann. Stat. ch. 730, para 5/5-5-3(g) (Smith-Hurd 1995); Ky. Rev. Stat. Ann. §529.090 (Baldwin 1995); Mich. Comp. Laws Ann. §333.5129 (West 1992); Nev. Rev. Stat. Ann. §201.356 (Michie 1995); N.D. Cent. Code §23-07.7-.01 (1995); S.C. Code Ann. §16-15-255 (Law Co-op. 1995); Utah Code Ann. §76-10-1311 (1995); Va. Code Ann. §18.2-346.1 (1995); Wash. Rev. Code Ann. §70.24.340 (West 1992); W. Va. Code §16-3c-2(5) (1995); TENN. CODE ANN § 39-13-521 (1995).

[43] *See* IDAHO CODE § 39-604, OKLA. STAT. tit. 63, § 1-524 (1994) (mandating HIV tests for persons merely arrested for prostitution).

jurisdictions call for prosecution under felony prostitution provisions which incur more severe punishments.[44]

While it is true that both men and women can be charged with such a crime, the overwhelming majority of persons arrested for prostitution are women. The motivation for such legislation is the concern that prostitutes will act as a "bridge" for the transfer of HIV into the heterosexual community.[45] There is no evidence that widespread transmission of the virus is occurring through infected prostitutes.[46] Sex workers are more likely to receive infection through shared needles or from infected sex partners, than they are to infect their clients.[47] Indeed, the evidence shows that female prostitutes are at

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[44] *See* COLO. REV. STAT. ANN §18-7-201.7 (West 1995); OKLA. STAT. tit. 21 §1031 (1995); TENN CODE ANN § 39-13-516 (1995) (Aggravated Prostitution).; FLA. STAT. ANN. §775-0877 (West 1995); UTAH CODE ANN. §76-10-1302; NEV. REV. STAT. ANN §201.358 (1995); 18 PA.CONS.STAT. ANN. § 5902 (1995) which provide for felony prostitution charges regardless of whether the prostitute uses condoms or engages in acts of safe sex. *Compare* Ky. Rev. Stat. Ann § 529.090 (Baldwin 1995) which limits enhanced charges to HIV+ persons who commit, offer, or agree to commit prostitution by engaging in sexual activity in a manner likely to transmit HIV.

[45] *See* James Grant Snell, *Mandatory HIV Testing and Prostitution: The World's Oldest Profession and the World's Newest Deadly Disease,* 45 HASTINGS L.J. 1565, 1568 (1994).

[46] *See* Bruce Lambert, *AIDS Among Prostitutes Not as Prevalent as Believed, Studies Show,* THE NEW YORK TIMES, September 20, 1988, at B1 (noting that of 360 men interviewed who regularly frequented prostitutes only 8 tested HIV positive. Of those, only three did not have other high risk behaviors, and those three had had over 300 visits with prostitutes, and did not use condoms. *See also* Donna King, *Prostitutes as Pariah in the Age of AIDS: A Content Analysis of Coverage of Women Prostitutes in the New York Times and the Washington Post September 1985-April 1988,* 16 WOMEN & HEALTH 155, 157 (1990) (noting that cumulative figures from 1979 to 1989 from the New York City Department of Health showed that only seven out of nearly 17,000 men with AIDS whose risk factor was listed as "sex with women at risk."). Ms. King also describes an October 18, 1985 report in *The Journal of the American Medical Association* that published findings from a study at the Walter Reed Army Medical Center. According to the study, 15 of 41 military persons diagnosed with AIDS claimed to have contracted the virus from a partner of the opposite sex, including prostitutes. On the same day *The New York Times* reported on the army study, emphasizing prostitution as the "heterosexual link in AIDS cases." In neither of these two articles was the high motivation of such men to conceal homosexual activity acknowledged, considering that such activity was grounds for termination from the military. *See also,* RANDY SCHILTZ, AND THE BAND PLAYED ON, POLITICS, PEOPLE AND THE AIDS EPIDEMIC, 511 (1987).

[47] *See* Diana Hartel, *Gender Bias in AIDS Research,* NEW POLITICAL SCI., Summer 1994, at 33, 38.

risk of being infected by their clients, but not the reverse.[48] Male-to-female transmission is as many as eighteen times more likely than female-to-male putting female sex workers who engage in unprotected sexual activity at a much greater risk than their clients.[49]

A more likely "bridge" to the heterosexual community are bisexual men who unknowingly pass the virus to their female sexual partners. Bisexuality is more widespread than is commonly believed.[50] Another "bridge" may be found in the large numbers of intravenous drug users (IVDU's) who are middle and upper class.[51] Like the emphasis in the media and the scientific community on infected prostitutes being the bridge between intravenous drug users and the "general public," legislation aimed at prostitutes is also largely baseless.[52]

This focus on female prostitutes as potential carriers of HIV is revealing. Long a social pariah, prostitutes are an easy target for fears of contamination and transmission of disease.[53] By focusing attention on prostitutes, policymakers adhere to a view that AIDS is contained within certain "undesirable" populations; attention shifts from uncomfortable possibilities to an old and easy scapegoat.[54] Given the lack of evidence to support this concern, such legislation reflects the heterosexual male bias of the public and policymakers.[55] It distorts the importance of viewing women as susceptible to HIV infection in their own right, whether or not involved in prostitution.

C. Protecting Women?

A third issue which should be addressed by the legislature to prevent the spread of HIV is federal regulation of donor sperm. Seventy-five thousand women a year are artificially inseminated.[56]

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48 *See* Lambert, *supra* note 46 (noting that CDC officials did not know of a single confirmed case in which a prostitute had infected a client).

49 *See* Burroughs, *supra* note 9.

50 *See* Obie Leyva, *Que es un Bisexual?, in* BI ANY OTHER NAME: BISEXUAL PEOPLE SPEAK OUT, 201, 202 (Loraine Hutchins & Lani Kaahumanu eds.1991).

51 *See* PERROW ET AL, *supra* note 13, at 13.

52 *See* Hartel, *supra* note 47,at 37. *See also* Lambert, *supra* note 46.

53 *See* SCHILTZ, *supra* note 46 at 158.

54 *See* PERROW ET AL, *supra* note 13, at 13.

55 *See* SCHILTZ, *supra* note 46, at 510 (noting huge press coverage surrounding two San Francisco police officers arresting a female prostitute who expressed concern that she might have AIDS. The next morning she was a front page news story; the next evening she led the local television news, where newscasters described her as "a human time bomb").

There is no question that HIV can be transmitted through semen, yet there is no federal regulation to ensure that artificially inseminated women are not unknowingly exposed.[57] While the Center for Disease Control and Prevention, the American Medical Association, and the Food and Drug Administration have all published guidelines to ensure the safety of sperm specimens, there is evidence that these guidelines are not being followed by some practitioners and facilities.[58] As a result, inseminated women have been infected with HIV as well as other sexually transmitted diseases.[59] While some states have enacted legislation requiring sperm banks to register and semen donors be tested for HIV antibodies, private physicians can bypass these regulations by obtaining semen from out of state sperm banks.[60] Without a federal system to regulate this $164 million-a-year industry, women are not being effectively protected from potential infection.[61]

These legislative decisions reflect a public perspective which is mistrustful of women, viewing them as vectors of the disease, rather than as individuals who are at risk of infection and worthy of attention and prevention efforts. Women's value as mothers, caretakers, and sexual partners has likely contributed to the view that AIDS in women is important only because of their role as potential vectors, transmitters, or infectors to their children and partners.[62] States' willingness to test women for HIV amounts to a legislative check on women's capacity in these roles. Women, as mothers, are regulated through the routine screening of pregnant women, and mandatory testing of newborns. Yet, fathers, through their sperm, are not. Women, as sexual partners, are regulated through mandatory testing of prostitutes, yet men, as clients, are not. In the policymaking arena, it is likely that deeply held beliefs about appropriate sex roles have encouraged legislation in reference to

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[56] *See Study Documents HIV Risk Via Artificial Insemination: Loopholes*, AIDS ALERT, May, 1995, at 71. *See also* Andrew McCullough, M.D., *Preventing Aids Transmission In Artificial Insemination,* THE DES MOINES REGISTER, February 3,1996, at T2 (noting the dramatic increase in the demand for donor semen resulting from the general increase in the age of pregnancy, a rate of male infertility that is approaching 40 percent, and a growing number of single women and lesbian couples seeking pregnancy).

[57] *See* Cheryl L. Meyer, *Transmission of HIV Through Donor Semen,* WOMEN'S RIGHTS L. REPORTER, 115, 122 (1994).

[58] *See id.* at 118.

[59] *See id.*

[60] *See id.* at 121.

[61] *See id.* at 122.

[62] *See* Smeltzer, *supra* note 12, at 155.

certain behaviors, while overlooking others.[63] By reinforcing discriminatory valuations of women, such a legislative scheme promotes a discriminatory perspective of women with HIV. It is a scheme which offsets women's deservedness for care and support by the extent that they have betrayed the obligations of these valued roles.

A discriminatory legislative scheme and public policy is only one of the barriers that women face as victims in the AIDs epidemic. The discussion now turns to the barriers that women face as a result of their absence from the early statistical picture of AIDS.

PART II: DISCRIMINATORY RESEARCH/MEDICAL PRACTICES

A. Epidemiological Invisibility

The initial identification of HIV/AIDS as a gay disease[64] led to a model of HIV which is based on observations of opportunistic infections[65] that appeared in gay men.[66] This model of HIV has become entrenched in the official method of tracking the epidemic and investigating its causes. As a result of early resistance to a broad definition, the CDC surveillance case definition of AIDS,[67] and the

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[63] *See* Jean Reith Schroedel and Paul Peretz, *A Gender Analysis of Policy Formation: The Case of Fetal Abuse,* 19 J. HEALTH POL. POL'Y & L. 335, 336 (1994).

[64] *See 1,112 and Counting in* LARRY KRAMER, REPORTS FROM THE HOLOCAUST, 37 (1994) (noting that in 1983, 72.4 percent of all serious AIDS cases were in gay and bisexual men). *See also* Center for Disease Control and Prevention, *AIDS Cases By Age Group, Exposure Category, And Sex,* December, 1995 (table indicating that men who have sex with men account for 275,259 of the total of 470,288 cases of AIDS in the U.S. to June of 1995).

[65] *See* Alexandra Levine, *Acquired Immunodeficiency Syndrome: The Facts,* 65 S. Cal. L. Rev. 423, 424 (1991). "An opportunistic infection is a severe or life-threatening infection caused by an organism that normally lives with humans, to the advantage of both, and does not cause disease due to the presence of an intact immune, or defense, system in normal individuals. When that immune system is disrupted by the presence of underlying malignancy these germs take the opportunity of the host's weakened resistance and may cause serious infection."

[66] *See* Risa Denenberg, *What the Numbers Mean, in* WOMEN, AIDS & ACTIVISM 3, 3 (Cynthia Chris & Monica Pearl eds., 1990).

[67] Until 1993, AIDS was diagnosed when an individual was found to have one or more of the following illnesses: (1) opportunistic infection (2) Kaposi's sarcoma (3) high-grade, B-cell lymphoma (4) AIDS- dementia/encephalopathy syndrome (5) wasting syndrome (slim disease). *See* Levine, *supra* note 65, at 424. In 1993, this definition was expanded to include invasive cervical cancer, pulmonary turbuculosis, and recurrent bacterial pneumonia, symptoms more likely to occur in women. Burroughs, *supra* note 9, at 153.

method of assigning transmission of the virus women have, until recently, remained invisible victims in this epidemic. Women have been undercounted, underreported, unexamined and unexplained. Women's absence from the statistical and research pictures has led to the failure of many physicians to consider women to be at risk for HIV, and to counsel and treat women accordingly.[68]

From early on, American researchers resisted a broad-based definition of AIDS that would allow for women's visibility in the epidemic. Several commentators note that by the early 1980s, American researchers knew but suppressed information that the disease was being transmitted by heterosexual contact, perinatal transmission, and intravenous drug use.[69] The name "Gay Related Immune Deficiency" (GRID), assigned in 1982, exclusively associates gay men with the syndrome. As early as 1981, six months before the name was proposed, the American Academy of Pediatrics rejected a paper documenting the incidence of HIV infected infants, born to the sexual partners of intravenous drug users.[70] In so doing, they contributed to women's invisibility from the medical, social, and political picture of AIDS.

The CDC surveillance case definition of AIDS is used to track the spread of the epidemic. It was established based on the observation of opportunistic infections which appeared in the gay men who were suffering from "GRID."[71] The CDC definition is used by others, including federal and state agencies, to determine eligibility for services or participation in clinical trials.[72] It is also used by the American medical establishment, and has had devastating implications for female sufferers of HIV. Before 1993, the definition did not include any of the opportunistic infections that were likely to develop in women, but not in men.[73] As a result, many women died without ever having been recognized as having AIDS.[74] In addition to not being included in the statistical picture, they also died without obtaining any of the services that are tied to an AIDS diagnosis, including health benefits, child care, rent subsidies and other support services.[75]

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68 *See* Burroughs, *supra* note 8.

69 *See* PERROW ET AL, *supra* note 13, at 15. *See also* SCHILTZ, *supra* note 46, at 147.

70 *See* SCHILTZ, *supra* note 46, at 104.

71 PERROW, *supra* note 12, at 15.

72 Smeltzer, *supra* note 11, at 153.

73 *Id.*

74 Denenberg, *supra* note 24, at 3.

In 1993, the CDC expanded the definition of AIDS to include conditions that were common to women sufferers, including recurrent bacterial pneumonia and pulmonary tuberculosis, as well as invasive cervical cancer.[76] The expansion of the CDC definition in 1993 led to an increase by 151 percent of the number of reported AIDS cases among women over a twelve month period.[77] While the CDC's past suggestion that changing the case definition of AIDS would make no difference, the facts proved otherwise.

Another aspect of the CDC's epidemiology which disserves the understanding of women's susceptibility to HIV is the method of designating the probable mode of exposure. Under this system, all female AIDS cases are classified using hierarchical exposure categories. If a woman falls into more than one category she is deemed to have contracted the virus based on the first category.[78] Women's exposure categories, in hierarchical order, are as follows:

1) Injection Drug Use;
2) Hemophilia/Coagulation Disorder;
3) Heterosexual Contact, which is further broken down by:
    a) sex with an injection drug user
    b) sex with a bisexual male
    c) sex with a person with hemophilia
    d) sex with a transfusion recipient with HIV infection or
    e) sex with an HIV infected person of unspecified risk;
4) Receipt of a Blood Transfusion, Blood Components, or Tissue, or
5) Unidentified/Unreported Risk.

For instance, if an infected woman who used intravenous drugs one time in her life but has frequently engaged in unprotected sex with high risk men, her exposure to HIV will be attributed to the intravenous

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[75] *See id.*(noting that the government provides services or funding for services to people with AIDS, which are available in varying degrees in different parts of the country, but that the government conditions the receipt of such services on an official AIDS diagnosis).

[76] *See supra* text accompanying note 66.

[77] *See Update: Impact of the expanded AIDS surveillance case definition for adolescents and adults on Case Reporting, MORBIDITY AND MORTALITY WEEKLY REPORT, Mar. 11, 1994 at 160. See also*, Clark, *supra* note 4, at 120.

[78] *See* Denenberg, *supra* note 25, at 2.

drug use rather than heterosexual contact, because drug use is listed before heterosexual contact in the hierarchy.[79] This system of hierarchical exposure ranking does not take into account individualized differences, including those associated with gender, which would logically reduce the weight of particular factors for an individual.

The hierarchical ranking procedure does not take into account the greater likelihood that an HIV positive man will transmit the virus to a woman during heterosexual contact. As noted earlier, women are as many as eighteen times more likely to be infected with HIV through sexual contact with a man than the reverse.[80] The significance of this "efficiency" is highlighted when male AIDS cases attributed to sexual contact between men are removed from the statistical picture.[81] Of the remaining male AIDS cases, 7.4 percent can be attributed to heterosexual contact. Among women, heterosexual contact accounts for 36.4 percent.[82] Not to account for the greater likelihood of male-to-female transmission in the exposure rankings distorts the data related to heterosexually acquired female AIDS cases.

By weighting the risk factor based on the observation of HIV progression in gay males, the CDC categories reify the gay male standard of HIV. The statistics gathered using this methodology have led to the underestimation of the extent of heterosexually transmitted HIV to women, overestimated the percent of women who acquire HIV through contaminated needles, and minimized women's risks of being infected. Statistics gathered through this classification system are used to track the spread of the disease, to prioritize funding for education and outreach, and to suggest further research. Given these uses, such misinformation has negative implications for women's research, educational funding and outreach.

Other failings of the CDC hierarchical transmission categories are the exclusion of categories of multiple risk for women, as well as woman to woman contact.[83] Whereas the third category in the

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79 *See* Burroughs, *supra* note 9, at 154.

80 *See id.*

81 *See* King, *supra* note 46, at 157 (commenting that the use of scientific jargon describing female-to-male transmission as "less efficient" obscures the importance of gender in considering heterosexual transmission risk).

82 *See* Center for Disease Control and Prevention National AIDS Clearinghouse, *HIV/AIDS Surveillance Report 6/95*, at 9-10 (comparison of tables for male and female adult/adolescent AIDS cases by exposure category through June 1995).

83 *See* Denenberg, *supra* note 25, at 3.

transmission hierarchy for men lists "Men Who Have Sex with Men and Inject Drugs," a category acknowledging multiple exposure, no multiple exposure category exists for women.[84] Additionally, several documented cases of women with HIV infection have shown that the only possible route of transmission was sex with an HIV positive woman.[85] However, woman to woman contact is excluded from the transmission hierarchy.[86] As a result, this creates the perception that lesbians are not at risk of infection.

The failure to consider lesbians at risk of infection is partially a result of the CDC definition of lesbian, which is limited to women who have had sexual contact exclusively with women for the previous ten years.[87] A recent survey among San Francisco Bay Area women who self-identify as lesbian or bisexual revealed a rate of HIV infection three times higher than the general population of women in this area.[88] The results of this study highlight the disparity between projections based on the CDC definition and the realities of a self-defined lesbian community. Such misinformation perpetuates the belief among women who have sex with women that they are not at risk of infection, and therefore do not need to protect themselves when engaging in sexual activity.[89]

The result of these failings in the tracking of the spread of HIV/AIDS among women is to overrepresent injection drug use as a mode of HIV transmission and, once again, to underrepresent heterosexual activity as a mode of transmission. The moral stigma attached to transmission through intravenous drug use hinders the development of a compassionate public response and has grave psychological impact on sufferers.[90] This moral stigma can influence

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[84] *See* Center for Disease Control and Prevention National AIDS Clearinghouse, *supra* note 81.

[85] *See* Zoe Leonard, *Lesbians in the AIDS Crisis, in* WOMEN, AIDS & ACTIVISM 113, 114-115 (Cynthia Chris & Monica Pearl eds., 1990).

[86] *See* Denenberg, *supra* note 25, at 3.

[87] *See* Susan B. Foster et al., *Offering Support Group Services for Lesbians Living with HIV,* WOMEN & THERAPY, 1994 at 69, 71.

[88] *See* Burroughs, *supra* note 9, at 155.

[89] Also significant is the fact that lesbian women, cloaked in a false sense of safety, may be unaware of the danger posed through artificial insemination.

[90] *See* Sugg, *supra* note 32, (describing a woman who lied, saying she had contracted the virus through a blood transfusion rather than admitting to having contracted HIV through unprotected sex because she couldn't face another harsh reaction from nurses). *See also* Melinda Singleton, *Fighting For My Life, in* WOMEN, AIDS & ACTIVISM 45, 51 (a patient with AIDS describing nurses who

the type of care that is offered and can cause sufferers to deny the actual mode of transmission. In addition to these failings of hierarchical transmission categorization, the current procedure also fails to account for other possible modes of transmission, such as women to women contact.[91]

B. A Lack Of Research: The Implications For Treatment And Care Of Women

With the revision of the CDC definition of AIDS in 1993 to include several conditions more common to women,[92] women now represent eighteen percent of all persons with AIDS in this country.[93] However, women still remain invisible from much of the medical research.[94] This is, in part, due to the fact that women's health problems have historically been overlooked by the medical community as the subject of research.[95] It is not surprising that women have been overlooked as the focus of AIDS research since the beginning of the epidemic. When women were included in early studies, the focus was on prevention of perinatal transmission from an infected mother to her child, or transmission to a woman's sexual partners.[96] Such studies reflect the public policy, as discussed above, which views women as vectors of transmission rather than victims in their own right. For years the Department of Health and Human Services and the Food and Drug Administration excluded women of childbearing potential from trials of promising AIDS drugs unless they could prove that they would not become pregnant, proven by measures such as surgical sterilization.[97] The FDA changed these guidelines in 1993. The new guidelines probably will not change women's access to clinical drug trials because they do not require that women be included, they simply do not exclude

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refused to clean her room for or wash her for days when she asked.).

91 *See Breaking The Silence, supra* note 6.

92 *See supra* note 67.

93 *See HIV Infection in Women: An Escalating Health Concern,* 54 AMERICAN FAMILY PHYSICIAN 1541 (October 1996) (noting that the percentage of women infected with AIDS in the U.S. has increased from seven percent in 1985 to eighteen percent by 1994).

94 *See* Cohen, *supra* note 11.

95 *See* Terri D. Keville, *The Invisible Woman: Gender Bias in Medical Research,* 15 WOMEN'S RIGHTS L. REPORTER 123 (1994). *See also* Smeltzer, *supra* note 12, at 152.

96 *See* Patricia J. Kelly & Susan Holman, *The New Face of AIDS,* AM. J. OF NURSING, March 1993 at 26, 29.

97 *See AIDS Study Prejudice Charged,* AIDS WEEKLY, Aug. 8, 1994.

them.[98] In order to ensure that promising clinical trials include women other barriers must also be addressed, such barriers include women's child care and transportation needs.[99]

In the past, representatives of the CDC have defended the lack of medical research directed at women by implying that information from studies based on men is applicable to women.[100] Gender-specific conditions, such as cervical abnormalities and the enhanced HIV transmission rates among women who have sexually transmitted diseases, suggests that this implication is dubious at best. It also suggests a need for gender specific research on the transmission and progression of HIV.[101]

The failure to recognize both the risk and the symptoms of HIV infection among women has implications for prevention, diagnosis and treatment. Physicians and specialists remain unaware of the risk of AIDS, of the factors that might increase the risk, and of the symptoms that are likely to appear in infected women. Many HIV infected women fall through the cracks, and receive no treatment for their infection.[102] As a result, women with HIV develop AIDS faster and die sooner.[103]

Consider the implications of the underestimation of the risks of heterosexual contact for physician's care and treatment of women. As a result of this underestimation, physicians are reluctant to assess risky sexual practices or suggest HIV testing for patients who are not homosexual men or intravenous drug users, often for fear of offending them.[104] A substantial number of primary care physicians fail to regularly counsel their patients regarding the prevention of heterosexually transmitted HIV.[105] The counsel of such doctors and other health care professional can be a powerful tool in overcoming resistance to behavioral changes, including the use of condoms.

Common abnormalities often requires different treatment in an HIV infected woman. In failing to view non-injection drug using

98 *See* Newsletter, *Women Organized To Respond To Life Threatening Diseases*, Oakland, Ca, Novermber 1995, at 4.

99 *See* Kelly et al, *supra* note 96. (The author goes on to note that "[t]he Community Based Programs for Clinical Research in AIDS are sensitive to these barriers and are now making drug-treatment trials accessible to more women").

100 *See* Smeltzer, *supra* note 12, at 153.

101 *See id.* at 154.

102 *See id.* at 152.

103 *See* Sugg, *supra* note 32.

104 *See id. See also* Kelly et al, *supra* note 96, at 26.

105 *See* J. Loft et al., *HIV Prevention Practices in Primary Care Physicians - U.S., 1992,* MORBIDITY AND MORTALITY WEEKLY REPORT, Jan. 7, 1994, at 988, 989.

women as at risk, physicians may fail to recognize that common symptoms, such as yeast infections, abnormal pap smears, genital warts or pelvic inflammatory disease, may be early signs of HIV infection.[106] Since sexually transmitted diseases (STDs) are thought to enhance the likelihood of transmission, STDs should signal the appropriate advice from a physician.[107] When a women with these symptoms is HIV positive, a different course of treatment is required.[108] Assigning treatment for ailments in an HIV positive woman as though she were not infected, may be, at least, ineffective or, at worse, harmful.

To reiterate, the model of HIV that has been used thus far, which sees gay men and intravenous drug users as the primary people at risk, is not effective for tracking the spread of HIV in women, or for guiding the care and treatment of HIV infected women by their physicians.

PART III - SOCIAL MORES AND GENDER ROLES

A third barrier to a women's ability to effectively protect herself from infection with HIV, or to being properly cared for upon infection, are those inherent in her role as a woman in this society. This section will consider the profound effect that socially constructed gender roles have on a woman's ability to protect herself from the virus. It also considers how, once infected, her role as caregiver often conflicts with her ability to care for herself.[109] A woman's socialization will also affect her access to health care services. Often a woman's cultural background will interrelate with all of the above considerations, and 75 percent of all reported AIDS cases are among women of color.[110]

Among heterosexual women, the problem of protection from HIV is intertwined with deeply held ideas about the power and sexuality of men and women. For women having sex with men how to negotiate safe sex can be a severe and subtle dilemma.[111] Many straight men find the use of condoms distasteful, or feel it interferes with their sexual pleasure. If a woman insists on the use of a condom, her male partner may interpret it as evidence of her infidelity, or as an insinuation

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106 *See id.* at 28.

107 *See id.*

108 *See id.*

109 *See* Clark et al., *supra* note 4, at 142.

110 *See* Center for Disease Control and Prevention, *Facts about HIV/AIDS and Race/Ethnicitiy,* December 1995.

111 *See* Monica Pearl, *Heterosexual Women and AIDS, in* WOMEN, AIDS & ACTIVISM 187, 188 (1990).

that the man has AIDS.[112] The fact that women are often dependent on men economically, psychologically and socially, and thus fear the reprisals which may result from suggesting that their partner use a condom, compounds the problem of the male partner's resistance to condom use.[113] Within abusive relationships, the ability to demand protection from sexually transmitted diseases may not be within the woman's domain.[114] In these situations, the transmission of HIV to women through heterosexual sex is another form of violence.[115]

Women's vulnerability within relationships is compounded by the sexist bias of the media in describing the risk of heterosexual transmission. Often a woman will engage in unsafe sex with a long-term partner based on a belief that person is not at risk of infection with HIV. To a large extent this belief is supported by the media and the scientific community through perpetuation of the myth that the risk of AIDS occurs only within "high risk groups," a term which excludes heterosexuals. This myth ignores the reality of heterosexual risk of transmission for women.[116]

It is often impossible for a woman to know whether her sexual partner has engaged in high risk behavior at any time in his life.[117] The expectation that she should know this hints at the tendency of viewing AIDS sufferers as caste-like members of assigned groups. Public opinion that lacks sympathy for intravenous drug users, *and their spouses,* is telling on this point.[118] What it reveals is the extent to which

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112 *See id.* at 189.

113 *See id.*

114 *See Women and AIDS Project Links HIV Risk to Violence Against Women,* AIDS WEEKLY, April 4, 1994.

115 *See id.*

116 *See* Philip J. Hilts, *Spread of AIDS by Heterosexuals Remains Slow,* THE NEW YORK TIMES, May 1, 1990, at C1 (noting that "only about 5 percent of full fledge AIDS cases in this country have been officially attributed to heterosexual transmission," yet when the statistics are broken down by gender, it reveals that heterosexual transmission rate accounts for 31 percent of all female cases, and 2 percent of male). *See also* MICHAEL FUMENTO, THE MYTH OF HETEROSEXUAL AIDS, (1990) (pointing out that HIV is not very contagious, especially through ordinary sex, and especially from men to women).

117 *See* Letter to Editor, *If I could Be HIV Positive, Any Woman Can,* THE NEW YORK TIMES , June 16, 1990, at 20 (noting "Clearly, I contracted the acquired immune deficiency syndrome virus through Heterosexual contact. Whoever he is (or was)he was either a recipient of a tainted blood transfusion or bisexual or an intravenous drug user. Equally clearly, that man would today be classified as a risky sexual partner, but it was not apparent to me at the time.").

118 *See* Sugg, *supra* note 32, at 9.

the public clings to the perception that the people who get AIDS, or who form relationships with people who get AIDS, are distinct from the rest of the population. It also reveals the extent to which the public considers women responsible for their male partner's behavior, even when they are powerless to control it.

Gender roles, particularly within certain cultural groups, may encourage or sanction "high risk" behavior among men, including multiple sexual partners or man to man sexual contact. At the same time, these roles promote an attitude among the female partners of general passivity in sexual matters and ignorance and denial of their partners' activities.[119] Cultural gender roles for women combined with high risk behaviors in men create a spiraling infection rate among Hispanic women, most of whom are monogamous.[120] Hispanic women with AIDS have the highest rates of heterosexually transmitted HIV infection of all racial/ethnic groups.[121] Like most men of color, Hispanic men do not identify as gay or bisexual even though they may engage in sexual activity with other men.[122] As a result, the message of HIV risk which is aimed at "gay" behavior does not resonate with many gay or bisexual Hispanic men, who go on to unknowingly infect their female partners. Even if an Hispanic woman is aware that her husband may be infected, or engages in high risk behavior, cultural values of "machismo," economic dependence, and concern over the well-being of her children may interfere with her ability to ask him to use a condom.[123]

Another example of how cultural and gender roles interact can be found in the Haitian community. As among Latinas, heterosexual sex is a primary route of transmission of AIDS to Haitian women, and

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119 *See Economic Vulnerability of Women Adds to AIDS Risk,* AIDS WEEKLY, Sept. 5, 1994.

120 *See* Sunny Rumsey, *AIDS Issues for African-American and African-Caribbean Women, in,* WOMEN, AIDS & ACTIVISM, 103 (1990).

121 *See* CDC National AIDS Clearinghouse, *supra* note 83, at 10.

122 *See* Obie Leyva, *supra* note 50. In the Chicano and Latino community, only the man who plays the role of "the bottom" during sexual activity is considered gay, or "joto." In contrast, the partner who plays the role of "the top" retains his "machismo," and his status as a heterosexual man is not threatened. In other words, he is still considered to be heterosexual.

123 *See* Ruth Rodriguez, *We Have the Expertise, We Need Resources, in* WOMEN, AIDS & ACTIVISM 99,100 (1990) (describing AIDS prevention and education of Latina women, urging them to protect themselves by using condoms, in which the women ask "Will you speak to my husband?"). *See also Economic Vulnerability of Women Adds to AIDs Risk,* AIDS WEEKLY, Sept. 15, 1984.

Haitian men are likely to have multiple sexual partners.[124] Haitian women tend to be very uncomfortable talking about sex.[125] Additionally, a Haitian woman's sense of self-preservation may not be effective to promote condom use because most Haitians are more community minded than they are concerned with themselves as individuals.[126] In the Haitian community, educators have found that promoting condom use for the sake of one's children or one's extended family can be much more effective as a motivating force than promoting condom use for one's own self-preservation.[127]

Women's traditional role as caretaker of their children, spouses, and extended families, also effects women's ability to properly care for themselves if they become infected with the AIDS virus.[128] A woman is often too busy caring for others to give her own health needs the priority they deserve when she is suffering from HIV infection or AIDS.[129] The demands of preparing special meals, acquiring equipment and drugs, and taking medications are particularly burdensome on top of caretaker duties.[130]

The HIV infected woman may also be uncomfortable focusing on herself rather than the needs of others. She may lack the support of family, who continue to view her primarily as a caregiver, even after her diagnosis. She may need childcare services or transportation to be able to make appointments, attend support groups, or receive legal or other services.[131]

HIV positive mothers have a host of other dilemmas associated with their role as mothers. These include the decision whether or not to disclose their status to their children, guilt or anxiety about transmitting the virus to their children, and concern over what will happen to their children if they become very sick or pass away. An HIV-positive mother may also be reluctant to seek care or make her infection known in an effort to protect her children from the harassment they may face.[132] If the virus has been transmitted to her child she will

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124 *See* Yannick Durand, *Cultural Sensitivity in Practice, in* WOMEN, AIDS & ACTIVISM, 85, 86 (1990).

125 *See id.*

126 *See id.*

127 *See id.* at 88.

128 *See* Smeltzer, *supra* note 12, at 154.

129 *See id.*

130 *See id.*

131 *See* Charlotte Anastasio et al., *supra* note 7, at 38-9. *See also* Clark et al., *supra* note 4, at 147.

likely make sure the child's appointments are kept and prescriptions filled before her own.[133]

In addition to the actual demands of fulfilling their role as mothers and caretakers, women pay enormous psychological burdens in failing to maintain these roles, or in having to be cared for by one's sisters, children, or parents. This is especially so given that the woman would normally have been caring for the people who are now being called on to care for her. Yet another set of dilemmas is faced by HIV positive women who wish to become mothers, but fear society's reprisals if they choose to do so.[134] Thus, caring for an HIV positive woman who has children, or wants to have them, must include attention to how HIV infection disrupts a mothers relationship with, and responsibilities to, her children.[135]

In summary, preventing HIV infection among women, and allowing women living with the virus to achieve the proper level of care must include attention to the social mores and gender roles that define women's lives. As has historically been the case, the disadvantages associated with a woman's gender roles and roles in society jeopardizes her health. The severity of these disadvantages are magnified with regard to women and HIV.

PART IV - THE COMMUNITY OF HIV POSITIVE WOMEN

In examining the barriers to women's protection and care in the face of the rate of HIV infection among women, it is useful to consider whether or not a "community" exists which HIV positive women can turn to for support and advocacy. Such a network is crucial to assist women in their struggle to cope with infection. To understand the importance of community in coping with HIV, the success of the gay community in responding to an epidemic which has devastated its ranks is telling. This is especially true in light of what many consider the

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132 *See* Clark et al., *supra* note 4, at 147.

133 *See* Kelly et al, *supra* note 96, at 32.

134 *See* Clark et al., *supra* note 4, at 142 (noting that one study of women with HIV found that knowledge of one's status or the risk of infecting their babies did not motivate most women to terminate pregnancies or prevent them in the future). *See also* Rebecca Denison, *The Hardest Decision I Ever Made,* WOMEN ORGANIZED TO RESPOND TO LIFE THREATENING DISEASES, November, 1995, at 1 (describing her decision to become pregnant and forego prenatal treatment of AZT, which reduces the likelihood of transmissison to the fetus, 12 years after learning of her HIV positive status).

135 *See* Clark et al., *supra* note 4, at 142.

government's failure to provide leadership in response to the AIDS crisis.[136]

Upon recognition of the government's lack of effective response to the "Gay Cancer," gay leaders emerged and gay community members came together to form organizations, coalesce protest groups, write editorials, and provide services. The activism of the gay community and gay men's organizations played an important role in forcing the government to act and in framing the medical, political, and social response to AIDS. Remarkable political and social systems were formed by gay men in the early 1980s. These include *Gay Men's Health Crisis (GMHC),* which, by 1988 had become the largest nongovernmental AIDS organization in the country and the world; *AIDS Coalition To Unleash Power (ACT-UP),* an ad-hoc community protest group to fight for the release of new drugs and call attention to pharmaceutical companies prices and profits; and the Shanti Project, which enrolls thousands of volunteer counselors to assist those affected by the illness by providing a range of services to patients, their lovers and their families.[137]

Two important factors undoubtedly figure in the ability of gay men to mobilize in the face of government homophobia and inactivity. The first is the political, social, and economic resources of their leaders, many of whom are white, male, educated, wealthy, politically empowered and media savvy.[138] The second is the central aspect of gayness in association with the danger that the disease posed, and the fact of an existing community based on that aspect of identity. In short, gay men were dying, and the gay community understood that they would have to take care of their own. AIDS threatened the physical, social, and political well-being of members of the gay community.

In contrast, women infected with HIV do not have a cohesive community in place to mobilize in response to this threat posed to its members. Thus, the two factors which infused the community of gay

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136 *See* Simon Watney, *Forward to* LARRY KRAMER, REPORTS FROM THE HOLOCAUST 33, 37 (1994). *See also, 1,112 and Counting in* LARRY KRAMER, REPORTS FROM THE HOLOCAUST, xv, xxvii (1994).

137 *See* PERROW ET AL., *supra* note 13, at 112-115 (noting that both GMHC and Shanti Project were initially funded largely by money from the gay community and that both organizations have been accused of neglecting minorities, drug users, and women).

138 *See* LARRY KRAMER, REPORTS FROM THE HOLOCAUST (1994); RANDY SCHILTZ, *supra* note 46, at 253-254 (1987); Mike Mc Kee, *A Bar Under Siege,* THE RECORDER, Jan. 20, 1990, at 1; DENNIS ALTMAN, AIDS IN THE MINDS OF AMERICA 83 (1986).

men with organizational strength are absent from the community of HIV infected women. First, women at risk of infection with HIV are overwhelmingly poor and many are socially, educationally, and economically disempowered.[139] Second, women are not organized. They are diverse in their ethnic and socioeconomic backgrounds and do not have a unifying aspect of identity which forms the basis of community.[140] These factors, which have a devastating impact on women's ability to form powerful and effective organizations, have rendered women invisible as participants in the epidemic. This, in turn, has robbed women of a recognizable identity when seeking services, causing them to feel embarrassed and ashamed in asking for help.[141]

Because women with HIV infection are often poor, they do not have access to social, political and economic networks that facilitate the creation of influential organizations capable of supplementing huge gaps in services.[142] The association of HIV infected women with IV drug use, either as IVDUs themselves, or as the partners of IVDUs is very prejudicial, since drug addicts are even more devalued by society than gay men.[143] Drug use, like prostitution, and prison time, stigmatizes women at risk of HIV, an effect that may also interfere with women's sense of entitlement to services. The equation between AIDs and homosexuality is powerfully set in many people's minds. As a result, homophobia, and the desire to distance oneself from the AIDS/homosexuality equation, taints victims from every community, including heterosexual women. Interestingly, because so many women in prison are HIV positive, prisons may provide an ideal setting for community-based empowerment strategies. However, inhospitable prison environments are likely to thwart such efforts.[144]

Finally, given that seventy-five percent of the women who have AIDS in this country are women of color, groups will have to overcome the barriers posed by racism in seeking AIDS related

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139 *See* Smeltzer, *supra* note 12, at 154.

140 *See id.*

141 *See* Foster et al., *supra* note 87, at 70. *See also* Iris Davis, *No Names and No Pictures, in* WOMEN, AIDS & ACTIVISM 95, 97 (1990) (describing a woman who sought services at an HIV family care center, who had told no one about her infection or her visits for services, and never thought about AIDS).

142 *But see* WOMEN ORGANIZED TO RESPOND TO LIFE THREATENING DISEASES (W.O.R.L.D.) a newsletter by, for, and about women facing HIV disease, P.O. Box 11535 Oakland, CA 94611.

143 *See* PERROW ET AL, *supra* note 13, at 76.

144 *See* Smith et al, *Justice, supra* note 16, at 78.

services, money, media and government attention on women's behalf. Historic divisions along lines of race and class within the white feminist community have interfered with effective advocacy as most women's groups have yet to direct significant attention to HIV among women.[145] If white women's groups are to participate in the campaign for support and advocacy, they will have to first face their own racism and classism.[146]

Conclusion

The HIV infected or at-risk woman is often poor. She is likely to be educationally disadvantaged and politically disempowered.[147] She may be a single parent struggling with child care responsibilities as well as with poverty. She may know or suspect that her husband is infected with HIV, but be unable to insist that he use a condom due to religious beliefs, cultural mores, or fear that such a request will endanger the well-being of her children. She may have to deal with problems associated with drug use, her own or her partners. She may be in prison. She may be an immigrant.

Service providers, policy makers, AIDS activists, and women's rights groups should be aware of the barriers that women face in gaining protection from, or treatment for, HIV infection. These barriers include public and legislative policy which replicates women's socially constructed roles, and promotes a view of women as vectors of HIV, guilty of transmitting the virus to their children and their partners. Such policy ignores the danger of HIV infection among women, and allows important facts about what puts women at risk of infection to be swept aside. Laws mandating prenatal testing of pregnant mothers, testing of newborns, or directive counseling infringe on women's right to privacy and reproductive freedom, without furthering the goal of preventing or treating pediatric AIDS. They also advance a view of women as untrustworthy and of women's rights as adverse to the needs of an unborn fetus. Furthermore, in light of the hugely disproportionate impact of HIV infection among women of color, they smack of racism and resonate with the history or racist practices related to the

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145 *See* Jones, *supra* note 8.

146 Additionally, the impact of AIDS among more economically privileged white women is underestimated. A number of commentators have noted that private practitioners are more likely to protect their patients from stigma and discrimination by opting not to report patient's HIV infection to the CDC.*See* Banks, *supra* note 21, at 352. *See also* Letter to the Editor, *supra* note 117, at A20.

147 *See* Banks, *supra* note 21.

reproductive freedom of women of color.[148] With such a legislative scheme the focus on what can be done to protect and treat women is eliminated from the picture. As the population of women who are infected with HIV continues to increase, the need for women focused leadership in public policy related to the AIDS crisis becomes increasingly crucial.

In every society, there is a predisposition to view the world through an analytical lens that replicates and reinforces existing gender and cultural biases.[149] To the extent that the subtext of the debate over testing pregnant women and newborn babies has an undercurrent of blame, men's responsibility for the child's welfare is removed. But should it be? The fact is that the same act which impregnated a woman may have infected her, yet there is no suggestion that fathers be routinely screened. Where the semen is donated, the same absence of legislative attention highlights how unconscious beliefs about appropriate gender roles may work themselves into public policy decisions. The view that mothers are primarily responsible for children is deeply embedded in our culture; by "infecting" an unborn child a woman is betraying this responsibility. It is likely that at some level, this betrayal has influenced the public's willingness to sacrifice a mother's privacy interests. Men's responsibility, on the other hand, is still largely seen as providing for a family's economic well-being. The fact that infected semen does not implicate that obligation may at least partly explain why there is no legislative attention to the issue of infected semen and unborn children. What remains unexamined and unattended to is the need to address the danger posed to the women themselves, as victims of transmission, either by men or other as yet unexplored factors, rather than simply as a source of infection.

As the number of cases of HIV infection among women increases, it becomes increasingly apparent that the current gay male model of HIV infection cannot account for the spread of the virus in women. Of the female AIDS cases reported in 1994 to 1995, the CDC did not know the transmission route in fully twenty-one percent.[150] That is almost double the rate for men.[151] Such wide statistical gaps indicate the broad lack of understanding and study related to the spread

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148 *See id.*

149 *See id.* at 356.

150 *See* Center for Disease Control and Prevention, *HIV/AIDS Surveillance Report, 1995; Table 3.*

151 *See id.*

of HIV in women. Since most of what is known about HIV transmission is based on studies of gay, white men, to apply that knowledge to the mostly African American or Latina HIV-positive women requires transcending boundaries of both race and gender.[152] As the standard for measuring the spread of the disease remains predominantly male, the lack of study focusing on the spread of HIV in women becomes more and more glaring, highlighting the need for such attention.

The CDC's epidemiological construction of AIDS perpetuates the stigma which encourages society to blame people with AIDS for their own condition.[153] The overemphasis on intravenous drug use reinforces a stigmatized view of HIV and its victims. Indeed, scientists outside the U.S. characterize the treatment of the AIDS epidemic in this country as "moralized" rather than "medicalized," and note that the American researchers define the disease largely by its social rather than its biological aspects.[154] In order to address women and HIV, we must question the policy behind describing and defining HIV in terms of high risk groups, rather than as a sexually transmitted disease. When we view HIV as primarily a sexually transmitted disease, it becomes clear how much one strains to preserve "high risk" categories. This is especially true in reference to heterosexually transmitted HIV. One commentator attempts to preserve these categories by making a distinction between heterosexually acquired AIDS involving people who "had sex with drug users, bisexuals, people infected with blood transfusions" and those who *"simply caught it themselves heterosexually."*[155] One has to ask--what is the difference, and why are people trying so hard to preserve it?

If women are to be taken seriously as victims and potential victims in the AIDS epidemic, education, outreach, and patient care must all be sensitive to the cultural and gender problems that women

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152 *See* Kelly et al, *supra* note 96, at 26.

153 *See* Hartel, *supra* note 47, at 35 (pointing out that "transmission studies often read like a veiled set of accusations... [T]he analyses are shallow; categories and labels are crude; images of contagion are added to preexisting social prejudices").

154 *See* PERROW ET AL, *supra* note 13, at 7.

155 *See* Hilts, *supra* note 116, at C1. (noting that "[a]bout 60 percent of the heterosexual transmission cases reported through March 1990 involved people who had sex with drug users, bisexuals, people infected by a blood transfusion or others at high risk of AIDS. About 10 percent got the disease from other heterosexuals who are believed to fit none of the risk groups, but simply caught it themselves heterosexually.").

face. As one commemtator articulates, "Until issues related to women and their place in society are considered within the sociopolitical context, women who are at risk for HIV infection, those infected with HIV, or those with AIDS will continue to receive inadequate attention."[156] Practically speaking, AIDS organizations must have multicultural staffs in order to reach a broader spectrum of the affected populations and to effectively educate these groups.[157]

Considering the hurdles that must be overcome in reaching the community of women who are HIV positive, and recognizing how broad the community of at risk women really is, the need for leadership in shifting the perception of who is at risk for HIV is clear. By the year 2000, over half the people in the world with AIDS will be women.[158] The disparity between the social, political and economic power of at risk/infected women and the organizing strength of the gay community points to the dramatic need for a governmental and epidemiological shift in reference to HIV. At-risk women cannot be expected to overcome these hurdles as well as gay men have. With fifteen years now invested in this epidemic, numerous commentators have exposed the governmental mistakes that were made which forced the gay community to take action. We cannot afford to make those mistakes again.

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156 *See* Smeltzer, *supra* note 12, at 156.

157 *See* Durand, *supra* note 124, at 89.

158 *See* Wendy Koch, *AIDS Among Women in Spotlight China Conference to Take Up Issue*, DAYTON DAILY NEWS, August 7, 1995, at A12.