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Women in the AIDS Epidemic: A Portrait of Unmet Needs

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INTRODUCTION

While rarely a month goes by that the topic of AIDS escapes discussion in the legal literature, a survey of legal publications reveals that the implications of AIDS for women has received scant treatment by legal commentators.[1] Unfortunately, this neglect is not unique to the legal community, but reflects a larger societal disinterest in women with AIDS.

In fact, this epidemic looks quite different from the perspective of women. The medical, social, and legal needs of women affected by AIDS are in many ways needs that preexisted AIDS, but which have been magnified by the threat and implications of HIV infection. Rather than creating new problems, AIDS and attendant governmental indifference have cruelly widened the cracks in a system that has never met the needs of persons who have been historically disenfranchised because of gender, race, and class.

In fashioning a legal, medical, and social response to the needs of women affected by HIV, one must be sensitive to the significant problems that poor women and women of color experienced prior to HIV infection gaining a foothold in various communities, as well as to the myriad social systems that traditionaly let them down. Too often,

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1. The Association of the Bar of the City of New York, *AIDS Bibliography*, 42 THE RECORD 260 (1987), 43 THE RECORD 94 (1988), 43 THE RECORD 760 (1988), 44 THE RECORD 559 (1989). For an excellent introduction to the problems facing women in the AIDS crisis, see AIDS: THE WOMEN (I. Rieder & P. Ruppelt ed. 1988).

those developing AIDS policy frame the problem in terms that ineluctably miss the needs of large numbers of persons whose lives are threatened by HIV. Unlike many middle class gay men, women do not come into the system by knocking on an "AIDS door." The way to reach women at risk is, for example, through pre-natal care, drug treatment, or Aid for Dependent Children (AFDC). For this reason, AIDS issues must be incorporated into systemic solutions to the needs of poor women in this country. For AIDS advocates to truly represent all persons affected by AIDS, they must recognize that many of the needs of women with AIDS are far more complex than those currently addressed by many AIDS organizations.[2]

For example, development of experimental drug therapies is vitally important, but is irrelevant for people whose lives never intersect with primary health care. Dissemination of safer sex information is key to preventing the spread of HIV, but AIDS hotlines have reported an alarming increase in calls from women who picked up safer sex literature and were met with a physically violent response from their male sex partners when they suggested condom use.

Similarly, all agree that drug abuse is a significant contributor to the spread of HIV, but by focusing HIV prevention resources on intravenous or injection drug use, a significant drug-related HIV risk for women remains unaddressed.[3] On the street, sex is the currency often used by women to subsidize a drug habit. In this context, multiple partners are the norm and barrier protection the exception.[4] Health educators in New York frequently report that some of their female clients have more than forty sex partners a week to support a drug habit. Accordingly, to exclude outreach to and treatment for drug addicts as part of an HIV prevention campaign is to ignore the needs of many women.

Too often, AIDS is discussed in a social, economic, and cultural vacuum. HIV infection in women has arisen in communities where women have little or no primary health care, rely on emergency room maternity care, have few reproductive options, experience dwindling power in sexual relationships,[5] and have always found that their needs

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2. Address by J. Hor, *A Descriptive Analysis of Patients Attending the Women's HIV Clinic at the Johns Hopkins Hospital*, V International AIDS Conference, Montreal, Canada (June 8, 1989).

3. Address by M. Chaisson, *Risk Factors for HIV-1 Infection in STD Clinic Patients: Evidence for Crack-Related Heterosexual Transmission*, V International Conference on AIDS, Montreal, Canada (June 6, 1989).

4. Brown, Mitchell, DeVore & Primm, *Female Intravenous Drug Users and Perinatal HIV Transmission* 320 NEW ENG. J. MED. 1493, 1494 (1989); address by A. Abramovitz, *Increased Crack Use Among Drug Users In an AIDS Epicenter: San Francisco*, V International AIDS Conference, Montreal, Canada (June 8, 1989).

5. Address by M. Fullilove, *Gender Roles As Barriers to Risk Reduction of Black Women*, V International AIDS Conference Montreal, Canada (June 7, 1989).

are regarded as dispensable by those charged with appropriating resources.

The feminization of poverty,[6] as well as governmental neglect of the longstanding needs of poor women, particularly women of color, have significantly contributed to the fact that between 1970 and 1986, the number of African American households headed by women increased from 28.2% to 41.8%.[7] By 1986, 52.9% of African-American female headed households and 51.3% of Hispanic/Latino-American female headed households fell below the poverty line.[8]

For women of color, the risk and implications of HIV infection have made escape from the grip of poverty all the more inconceivable. On a fundamental level, a community's willingness and ability to take the risks necessary to advance its social and economic standing depend on its confidence in the present and future health of its members. Ethicist Larry R. Churchill made a similar observation in *Rationing Health Care in America* when he wrote:

> [L]iberty (in any meaningful sense) is dependent upon a range of action and reflection only possible for the healthy, or those who are reasonably confident that their ill health, present or anticipated, will not become a barrier to their life-plans. For many people in this country the choice to seek medical attention is bought at the price of sacrifice of another of life's necessities.[9]

Poor women and women of color have always stood in a particularly powerless position to bargain for health care, personal autonomy, and economic rights. AIDS has merely raised the already high stakes for women on the economic margins. As will be more fully discussed below, the AIDS epidemic has increased those cultural and legal pressures that make women most vulnerable in this society.

I. DEMOGRAPHICS OF HIV DISEASE IN WOMEN

HIV is increasingly an epidemic of poor people and people of color. Twenty-seven percent of all persons with AIDS in the U.S. are African-American and 15% are Hispanic/Latino-Americans,[10] al-

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Dr. Fullilove has documented prevalent gender role beliefs among black women in which women are subservient to men and powerless to initiate and maintain pregnancy or HIV prevention behaviors.

6. *See generally* H. SCOTT, WORKING YOUR WAY TO THE BOTTOM: THE FEMINIZATION OF POVERTY (1984).

7. This compares with an increase from 9.1% to 13% in white female headed households during the same period. THE AMERICAN WOMAN 1988-1989: A STATUS REPORT 353 (S. Rix ed. 1988).

8. *Id.* at 395, Table 29.

9. L. CHURCHILL, RATIONING HEALTH CARE IN AMERICA: PERCEPTIONS AND PRINCIPLES OF JUSTICE 83 (1987).

10. Centers for Disease Control, HIV/AIDS SURVEILLANCE REPORT, Sept.,

though African-Americans make up only 12% and Hispanic/Latino-Americans make up only 6.4% of the national population. Of women with AIDS, 52% are African-American, and 19% are Hispanic/Latino-American.[11] In New York City, African-American and Hispanic/Latino-American women account for 84% of the adult female AIDS cases.[12]

As of August 1989 there were 9,346 cumulative cases of AIDS diagnosed in adult women in the U.S.[13] This figure roughly represents 10% of cumulative AIDS cases in the U.S.; however, this overall figure is deceiving in assessing the magnitude of the threat presented by HIV to women. In New York City, women represented 16% of the newly diagnosed cases of AIDS between Feb. 3, 1990, and Mar. 2, 1990.[14]

It is highly likely that there exists vast underreporting of HIV in women. This can be explained in essentially two ways. First, women fall through the epidemiological cracks because an AIDS diagnosis assumes a level of contact with health care professionals (HCP) that would make relevant diagnostic testing and immunological monitoring possible. Primary health care is not available, however, for many women at greatest risk for HIV infection. As a result, there are undoubtedly numerous women who die of HIV-related illnesses but who never receive a formal AIDS diagnosis.

In addition, the presumptive case definitions of AIDS used by the Centers for Disease Control (CDC) have been based upon a male model of illness. This is not surprising, since most of the first cases of HIV disease were reported in gay men. Unfortunately, the CDC has been somewhat slow to adjust the presumptive definition of the disease to reflect the actual conditions acquired by the spectrum of persons affected by HIV. In September 1987 the CDC broadened the definition of AIDS in such a way that resulted in slightly more accurate reporting of women with HIV disease. However, clinicians continue to report that women present different manifestations of underlying HIV infection than do men.[15] For example, the current CDC case definition fails to include pelvic inflammatory disease and various other gynecological manifestations of HIV disease that are clinically observed in women as

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1989, at 11.

11. *Id.*

12. New York City Department of Health, AIDS Surveillance Unit, AIDS SURVEILLANCE UPDATE, Mar. 28, 1990, at 6 [hereinafter SURVEILLANCE UPDATE].

13. Centers For Disease Control, HIV/AIDS SURVEILLANCE REPORT, Sept., 1989, at 10.

14. New York Dept. of Health, AIDS Surveillance Unit, AIDS SURVEILLANCE UPDATE, Aug. 30, 1989; Joseph, *New York City AIDS Case Projections 1989-1993,* New York City Department of Health, March 1989.

15. Address by P. Kelly, *Difference Between Symptomatic HIV Positive Female and Male Patients,* V International AIDS Conference, Montreal, Canada (June 8, 1989).

a result of HIV-related immune suppression.[16]

Underreporting of HIV disease in women has very real consequences for the health care needs of women, since the appropriation of both federal and state health care dollars is intimately tied to an epidemiological showing that particular groups or communities have experienced AIDS-related mortality.

II. HIV ANTIBODY TESTING AS A MEANS OF IDENTIFYING "BAD" WOMEN

With the development of medical interventions that have been shown to delay the onset of HIV-related symptoms, we have witnessed a call for all persons who engage or have engaged in behavior that put them at risk of HIV infection to be tested for HIV antibodies.[17] It is hard to argue that voluntary testing is inappropriate for persons who have the ability to obtain prophylactic medical interventions and who have the support systems necessary to deal with the often devastating emotional impact of a positive HIV antibody test. However, those women who are most likely to test HIV antibody positive are the ones least likely to gain access to the potential benefits of widespread testing.

Federally run clinical trials of promising new AIDS drugs serve as a stark example of the inherent gender and race bias of the AIDS health care matrix. Until recently, the only manner in which persons with HIV disease have been able to obtain any treatment has been through participation in clinical drug trials, most of which are sponsored by the federal government. However, as of July 1989 only 6.5% of the slots in drug trials sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) have been filled by women. Similarly, African-Americans have been allowed only 8.4% participation and Hispanic/Latino-Americans only 11.1%.[18]

Public health policy has failed to emphasize the health care needs of women with AIDS. This derives, in significant part, from the far too popular view that health care dollars must be devoted to preventing HIV positive women from infecting other people in their lives. It is this elevation of the interests of all others over that of the HIV positive woman that results in unbalanced attention to babies and prostitutes. In other words, what lies at the heart of the medical neglect of HIV

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16. Address by H. Amaro, *Women's Reproductive Rights In the Age of AIDS, New Threats to Informed Choice*, 97th Annual Convention of the American Psychiatric Association, New Orleans, La. 1989 [hereinafter *A.P.A. Conference*].

17. *See* Hilts, *Major Changes for Health System Seen After Reports on AIDS Drug*, N.Y. Times, Aug. 19, 1989, at A1, col. 1.

18. Clinical trial demographic statistics maintained by National Institute of Allergy and Infectious Disease, Division of AIDS, Treatment Research Program, July 17, 1989.

positive women is the view that they are vectors of disease to so-called "innocent" others. When infants born with HIV antibodies are called "the innocent victims," the clear implication is that their mothers are in some way guilty or deserving of their infection. Rather than gaining access to positive medical interventions, it is safe to predict that women will experience overwhelmingly punitive consequences of a positive test, such as coerced abortions and sterilization, loss of custodial rights, and functional quarantine.

III. THE "PUBLICIZATION" OF PREGNANCY

In the AIDS context, the bulk of medical attention paid to women has come in the context of their role as child bearers. Public health officials in New York are anonymously testing all newborns for HIV antibodies.[19] The articulated justification for these seroprevalence studies has been to prevent future cases of AIDS in children. This is an important goal, but often lost in the testing schemes is the fact that testing newborns tells us far more about the HIV status of the mothers than it does about the present health status of the children. Only one third of the babies born to HIV positive women will be infected with the virus, although all of them will be born with HIV antibodies. This is because all babies are born with their mother's antibodies, and do not develop their own immune responses until six months to one year of age. Accordingly, antibody testing of newborns detects the *mother's* HIV antibody status, not the infant's.[20] Rarely is neo-natal HIV testing used as a means of identifying which women are in need of HIV-related health care.

Not only has neo-natal HIV antibody testing failed to result in affirmative medical care for mothers with HIV infection, but HIV antibody testing in this circumstance has had significant negative consequences for women. Many women who test positive during the first trimester of their pregnancies are met with coercive counseling to abort. Indeed, it appears this is the official policy of the two health care facilities in Rhode Island that will treat HIV positive women.[21] Yet, in the absence of coercive abortion counseling, knowledge of HIV infection has not been found to alter most women's decisions about whether or not to abort.[22] For many women, the personal and social importance of

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19. Novick, Berns, Stricof, Stevens, Pass & Wethers, *HIV Seroprevalence in Newborns in New York State*, 261 J.A.M.A. 1745 (1989).

20. *See* Blanche, Rouzioux, Moscato, Veber, Mayaux, Jacomet, Tricoire, Deville, Vial, Firtion, Crepy, Doward, Robin, Courpotin, Cirau-Vigneron, Deist & Griscelli, *A Prospective Study Of Infants Born To Women Seropositive For Human Immunodeficiency Virus Type I*, 320 NEW ENG. J. MED. 1643 (1989).

21. *See* Maynard & Indacochea, *HIV Infection in Pregnant Women in Rhode Island, 1985-1988*, 320 NEW ENG. J. MED. 1626 (1989).

22. *See* address by A. Sunderland, *Influence of HIV Infection on Pregnancy De-*

bearing a child outweighs a one-third chance a child would become infected with HIV. Those who feel inclined to substitute their judgment disfavoring childbearing by HIV positive women must bear in mind that in many poor communities in this country the infant mortality rate from non-AIDS causes exceeds that in most third world countries. As such, concerns about potential infection of a child with HIV, while important, cannot be isolated from the numerous pre-existing threats to maternal and child health imposed by the absence of health care through decades of poverty.[23] The fact that many women choose to bear children notwithstanding HIV infection reflects a much more complicated balancing of considerations than that applied by so-called experts who consider the issue as if HIV infection were the only factor in the equation.[24]

Even when HIV positive women voluntarily elect to terminate a pregnancy, they are met with hostility from many HCPs who perform abortions. A recent study in New York City found that, of HCPs advertising in the Yellow Pages that they performed abortions, two-thirds refused to treat HIV antibody positive women.[25] Indicative of a similar sentiment toward HIV positive women is the recommendation of a prominent physician in Puerto Rico that HIV positive women be sterilized so as to reduce the numbers of children with AIDS.[26]

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cisions, V International AIDS Conference, Montreal, Canada (June, 7, 1989); Selwin, Carter, Schornbaum, Robertson, Klein & Rogers, *Knowledge of HIV Antibody Status and Decisions to Continue or Terminate Pregnancy Among Intravenous Drug Users*, 261 J.A.M.A. 3567 (1989); address by M. Barbacci, *Knowledge of HIV Serostatus and Pregnancy Decisions*, V International AIDS Conference, Montreal, Canada (June 5, 1989).

23. *See, e.g.*, Braveman, Oliva, Miller, Reiter & Egerter, *Adverse Outcomes and Lack of Health Insurance Among Newborns in an Eight-County Area of California, 1982 to 1986*, 321 NEW ENG. J. MED. 508 (1989). The authors conclude that the lack of pre-natal health care with the absence of private health insurance has resulted in an increase of adverse outcomes in newborns, particularly for African-American and Hispanic/Latino-American women.

24. The analysis of John Arras, a medical ethicist and Director of the Department of Social Medicine at Montefiore Hospital in Bronx, New York, particularly suffers from a failure to acknowledge the complexity of historic poverty, sexism, and racism, as well as cultural norms different from his own, in ethical decision-making by women affected by HIV. At a workshop on HIV positive women and reproductive choices at the V International Conference on AIDS in Montreal, Canada in June, 1989, Arras was charged with answering the question "Should HIV positive women have children?" and concluded that society's interest in avoiding the costs of babies with AIDS outweighs the judgment of many African-American and Hispanic/Latino-American women that a one third chance of bearing a child with HIV infection was a risk worth taking in light of the significant cultural premium placed on child bearing.

25. Address by K. Franke, *HIV-Related Discrimination in Abortion Clinics in New York City*, A Report by The New York City Commission on Human Rights, V International AIDS Conference, Montreal, Canada (June 6, 1989).

26. Address by C. Zorrilla, Associate Professor, School of Medicine, University of Puerto Rico, *AIDS in Puerto Rico and Among the Puerto Rican Population on the*

Societal contempt for HIV positive women who chose to bear children despite their serostatus derives, in part, from an increasingly popular view of women as reproductive vessels. According to this view, once a woman becomes pregnant, her life, lifestyle, and medical options become subject to public scrutiny and control. From this perspective, the womb is a quasi-public territory where a woman's right to bodily integrity and autonomy receives minimal respect. The "publicization" of pregnancy was endorsed by the U.S. Supreme Court in *Webster v. Reproductive Health Services*,[27] wherein the Supreme Court plurality found that a state can lawfully proclaim that life begins at conception, and then legislate in such a way that elevates the state's interest in "potential human life" over the pregnant woman's interest in bodily integrity, privacy, and reproductive decision making.

This publicization of pregnancy has also resulted in a growing body of "fetal rights" jurisprudence in which pregnant women have been compelled to undergo particular therapies or medical procedures for the benefit of the fetus,[28] but to the detriment of the mother. In some circumstances, women have been jailed or placed under house arrest during the duration of their pregnancy; in other cases, they have been charged with criminal abuse of their fetuses when they engaged in any activity that departed from their physicians' or the local district attorney's view of appropriate maternal conduct.[29] The growing jurisprudence of "fetal rights" and the push to compel HIV positive women to abort are really two sides of the same issue, for they both derive from an increasingly popular desire to substitute the reproductive judg-

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Mainland, Conference, Washington, D.C. (Aug. 28, 1989).

27. 109 S. Ct. 3040 (1989).

28. *See* Gallagher, *Prenatal Invasions and Interventions: What's Wrong with Fetal Rights*, 10 HARV. WOMEN'S L. J. 9 (1987); Terry, *The Body Invaded: Medical Surveillance of Women as Reproducers*, 3 SOCIALIST REV. 13 (1989); *In re* A.C., 533 A.2d 611 (D.C. 1987), *reh'g en banc granted*, 539 A.2d 203 (D.C. 1988) (terminally ill pregnant woman ordered to undergo cesarean section contrary to her wishes and that of her physician and family. Neither the mother nor the baby survived the operation); Kolder, Gallagher & Parsons, *Court-Ordered Obstetrical Interventions*, 316 NEW ENG. J. MED. 1192 (1987); Nelson & Milliken, *Compelled Medical Treatment of Pregnant Women; Life, Liberty, and Law in Conflict*, 259 J.A.M.A. 1060 (1988).

29. In August 1989 a Florida woman was convicted of prenatally delivering drugs to her two children after she was found to have used drugs during her pregnancy. State v. Johnson, No. 89-890 (18th Cir., Seminole County, Fla. filed July 13, 1989), *appeal pending*, No. 89-1765 (5th Dist. Ct. App., filed Sept. 5, 1989). In another case, a judge in the District of Columbia sentenced a first time offender, convicted of forging checks, to serve out the term of her pregnancy in jail so as to protect the fetus from the mother's alleged drug use. *Pregnant Woman Jailed Until Birth*, San Francisco Chron., July 25, 1988, at A8, col. 2. Pamela Rae Stewart was charged with contributing to her infant's death because she used drugs and had sex during her pregnancy against the advice of her doctor. *Woman Accused of Contributing to Baby's Demise During Pregnancy*, L.A. Times, Oct. 1, 1986, at 1 (Metro Section), col. 4.

ment of others for that of pregnant poor women.[30]

Most recently we have witnessed a growing public outrage directed at women who use illicit drugs during their pregnancies. Again, women are viewed as victimizing their children without any sensitivity to the complex reasons why increasing numbers of young women have been driven to crack and other drugs by hopelessness and an institutionalized absence of educational and employment opportunities. Given the fact that federal and state governments are unwilling to appropriate drug prevention resources commensurate with the enormity of the epidemic of drug addiction in poor communities and communities of color, it is grossly illogical for the government to commit these scarce resources to criminalizing women *after* they have delivered a child affected by pre-natal drug use, rather than developing strategies for assisting women to stay off drugs *before* they conceive.

Most notably absent from the discussion of drug use by pregnant women is the fact that it is virtually impossible for pregnant women to obtain drug treatment. In New York City, where drug use reached epidemic proportions years ago, almost all residential drug treatment programs will not accept a pregnant woman and will expel any woman who gets pregnant during the course of her treatment.[31] Just as with HIV antibody testing of newborns, routine toxicology testing of infants for the presence of illicit drugs is used to identify "bad" mothers and "victimized" babies. This has resulted in a presumptive determination of unfitness to parent rather than in identification of women who are in need of drug treatment.[32]

IV. SCAPEGOATING PROSTITUTES FOR THE AIDS EPIDEMIC

Just as pregnant HIV positive women are primarily viewed as victimizers of future children, considerable public opprobrium has been

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30. For a wonderful discussion of the connections between HIV and reproductive rights, see H. Amaro, *A.P.A. Conference, supra* note 16.

31. *See* McNulty, *Combatting Pregnancy Discrimination in Access to Substance Abuse Treatment for Low Income Women*, 23 NAT'L CLEARINGHOUSE FOR LEGAL SERVICES 21 (1989). Recent legislative efforts in Washington to address this problem perpetuate the misallocation of resources and the scapegoating of drug addicted mothers. The pending Drug Abuse During Pregnancy Prevention Act of 1989 (S. 1444, 101st Cong., 1st Sess. § 6 (1989)) introduced by Senator Pete Wilson, proposes to require states to make it a crime to give birth to an infant injured or impaired by substance abuse by the mother during pregnancy, and to require HCPs to report such infants to authorities, as a precondition for the receipt of federal grants for drug treatment programs for pregnant women, mothers, and infants.

32. Contrast *In re* Sharon Fletcher and Lisa Flynn, N.Y.L.J., October 25, 1988, at 25, col. 2 (Fam. Ct. N.Y. City) (pre-natal drug use by mother found not to constitute child abuse under N.Y. Family Court Act) and *In re* Mark A., Naguann W., and Shamegua B. v. Felicia B., N.Y.L.J., June 30, 1989, at 27, col. 3 (Fam. Ct. Nassau County) (drug use during pregnancy found basis for neglect).

directed at female sex workers[33] as a result of the myth that they are responsible for the spread of HIV infection.[34]

In fact, the most common modes of HIV transmission are male to male or male to female unprotected anal or genital sexual intercourse, particularly receptive anal intercourse, and use of unclean injection drug equipment. Female to male sexual transmission of the virus in the U.S. is infrequent compared to male to female or male to male transmission. Indeed, if prostitutes were a primary cause of transmission of the virus, we would expect a much larger percentage of heterosexual men to be infected with the virus.[35] As of July 1989, 30% of female cases of AIDS were due to infection from heterosexual contact, while only 2% of males who acquired AIDS identified heterosexual sex as the cause.[36]

Not only are women in general less likely to transmit the virus to men than men are to transmit the virus to women in sexual intercourse, but female sex workers have been found to have no greater incidence of HIV infection than other women.[37] Indeed, female sex workers may well be at *lower* risk for either receiving or transmitting the virus while engaging in sexual relations with male customers than women who engage in non-commercialized unprotected sex. This can be explained in two ways. First, most female sex workers require their customers to use condoms, and are more likely to require condom use than women who are not getting paid for sex.[38] Second, the most common type of sex requested of female sex workers by male customers is oral sex, rather

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33. Many women who exchange sex for money prefer this term to "prostitute."

34. One Study concluded that a prostitute in a five-year period would be responsible for the spread of HIV infection to 20 people and one fetus. The author makes prostitutes responsible not only for the spread of HIV to their own customers, but also for the subsequent transmission of HIV from the male customers to their female sexual partners and then to the unborn children of those female sex partners. In deriving these conclusions, the author falsely assumes all sexual practices of prostitutes are high risk practices and large numbers of prostitutes are infected with HIV. Nahmias, *A Model of HIV Diffusion from a Single Source*, 26 J. SEX RES. 15 (1989).

35. Friedland & Klein, *Transmission of the Human Immunodeficiency Virus*, 317 NEW ENG. J. MED. 1125, 1129 (1987); Decker, *Prostitution as a Public Health Issue*, in AIDS AND THE LAW 81 (Dalton ed. 1987); Rosenberg & Weiner, *Prostitutes and AIDS: A Health Department Priority?*, 78 AM. J. PUB. HEALTH 418, 421 (1988).

36. Centers for Disease Control, *HIV/AIDS Surveillance Report*, July 1989, at 8.

37. Centers for Disease Control, *Antibody to Human Immunodeficiency Virus in Female Prostitutes*, 36 MORBIDITY & MORTALITY WEEKLY REP. 157, 158 (1987) [hereinafter *Antibody*].

38. Except in cases where the male customer refuses to use condoms, and even then, sometimes female sex workers are able to slip a condom on the customer without the customer's knowledge. Alexander, *Prostitutes are Being Scapegoated for Heterosexual AIDS*, in SEX WORK: WRITING BY WOMEN IN THE SEX INDUSTRY 248, 253-55 (F. Delacoste & P. Alexander eds. 1987) [hereinafter *Prostitutes*]; Alexander, *A Chronology, of Sorts*, in AIDS: THE WOMEN 169, 171 (I. Rieder & P. Ruppelt eds. 1988).

than anal sex or vaginal intercourse.[39]

Among those female sex workers who are HIV positive, then, the most common risk factor is not their exchange of sex for money, but either their use of injection drugs or unprotected sex with steady boyfriends who are at risk of infection. Many female sex workers have stated that condom use with boyfriends and husbands is less common than condom use with customers.[40] A study of HIV-antibody prevalence and risk factors in U.S. female sex workers found that only 16% of boyfriends or husbands of prostitutes used condoms during vaginal intercourse, compared to 78% of customers.[41]

This culture's discomfort with women getting paid for sex causes people to blame female sex workers for the spread of sexually transmitted diseases, whether warranted by the facts or not. Historically, when public concern about such diseases has reached a fever pitch, the first group to be targeted for punitive measures has been female sex workers. Never have male customers been similarly targeted.[42] For example, during the World War I, when the military found that 13% of its recruits had syphilis or gonorrhea, it began a comprehensive campaign to close down red-light districts, and to quarantine over 20,000 female sex workers. Not only did the military not quarantine the men who were infected, but it refused to issue condoms to its troops, even though it was already well-known that condoms provided the best method of preventing the transmission of syphilis. The quarantine of female sex workers had no appreciable effect on the rate of venereal disease but provided a politically expedient, quick response to the problem at the expense of a marginalized community. Instead, it merely changed the place where commercial sex took place, making streetwalkers and call girls the predominant type of female sex workers.[43]

The judicial system routinely upheld laws authorizing the detention and testing of female sex workers—followed by quarantine of those found to have venereal disease—on public health grounds, the rationale being that prostitution in and of itself furnished sufficient basis to infer that woman had venereal disease, without further evidence of actual infection and high risk behavior.[44] The judiciary continued to

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39. *Prostitutes*, *supra* note 38, at 255; Decker, *supra* note 35, at 85.

40. Rosenberg & Weiner, *supra* note 35, at 421.

41. *Antibody*, *supra* note 37, at 158.

42. Bergman, *AIDS and Prostitution*, 21 J. MARSHALL L. REV. 777, 791 (1988); J. D'EMILIO & E. FREEDMAN, INTIMATE MATTERS: A HISTORY OF SEXUALITY IN AMERICA 202-15 (1988).

43. Brandt, *The Syphilis Epidemic and Its Relation to AIDS*, 329 SCIENCE 375, 377 (1988), J. D'EMILIO & E. FREEDMAN, *supra* note 42, at 211-13.

44. Bergman, *supra* note 42, at 797. *See, e.g.*, *Ex parte* Dayton, 199 P. 548 (Cal. Ct. App. 1921); *Ex parte* Company, 139 N.E. 204, 205 (Ohio 1922); *Ex parte* Brown, 172 N.W. 522 (Neb. 1919). However, judges sometimes released particular women from custody because there was insufficient evidence to reasonably believe the woman

uphold laws blatantly violating due process and equal protection guarantees of the Constitution into the 1970s.[45] In 1973 the Tenth Circuit upheld repeated two-day detention of female sex workers for venereal disease examinations, on the assumption that they were the prime source of venereal disease and could be reasonably suspected of having venereal disease. The court held that female sex workers, rather than their customers, were the source of venereal disease.[46]

Having learned nothing from previous bad public health policy, in the current AIDS epidemic the U.S. military once again has blamed female sex workers for the infection of those of its "innocent" recruits that have HIV. It will not acknowledge the fact that recruits become infected with HIV as a result of high-risk unprotected sex or needle-sharing activities.[47]

The attention given to prostitution in the AIDS crisis is reflected in two types of state laws that have been passed relating to AIDS: those criminalizing the practice of various forms of prostitution when the person has HIV infection, and those requiring testing for HIV infection of persons arrested for or convicted of a variety of sexual offenses, including prostitution. While the latter types of laws are not directed solely at prostitution, the former ones are.

Nevada and Florida have passed laws providing for criminal penalties when female sex workers with HIV continue to sell sex. Nevada's law makes all types of prostitution and soliciting for prostitution felonies after a female sex worker has been told that she has tested positive for HIV.[48] Thus, even activities that could not possibly transmit the virus (*e.g.*, soliciting) or that have extremely low to non-existent possibility of transmission (*e.g.*, manual manipulation) are made felonies, if done by a sex worker who knows she has the virus. Florida's law is an enhancement law. It provides that anyone who commits or procures another to engage in prostitution with himself or herself by sexual activity likely to transmit HIV and who knows (s)he has tested positive for HIV and has been told (s)he could possibly transmit the virus through sexual activity is guilty of a misdemeanor.[49]

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had venereal disease. *See, e.g.*, *Ex parte* Shepard, 195 P. 1077 (Ca. App. 1921); *Ex parte* Arata, 198 P. 814 (Cal. App. 1921); Rock v Carney, 185 N.W. 798 (Mich. 1921).

45. Brandt, *supra* note 43, at 377-78; Bergman, *supra* note 42, at 796-97.

46. Reynolds v McNichols, 488 F.2d 1378 (10th Cir. 1973). The Tenth Circuit reaffirmed the reasoning of this decision in 1989 in Dunn v White, 880 F.2d 1188 (10th Cir. 1989) in which the court upheld non-consensual HIV testing of prisoners.

47. Bergman, *supra* note 42, at 819-20.

48. NEV. REV. STAT. § 201.358 (1987).

49. FLA. STAT. §§ 796.08(5)-(6) (1986). A number of states have passed laws criminalizing transmission of the virus, though such laws are not limited to prostitutes. Missouri law, for example, makes it a felony for a person to "deliberately create a grave and unjustifiable risk of infecting another with HIV through sexual or other contact when an individual knows that he is creating that risk." MO. REV. STAT. §

As for the other type of law pertaining to the criminal system—mandatory testing—at least three states have passed statutes requiring HIV antibody testing of persons accused or found guilty of certain sexual offenses. Georgia allows a court to order anyone who has been found guilty of or pled guilty or *nolo contendere* to an "AIDS-transmissing crime"—which is defined to include prostitution—to undergo an HIV test.[50] Colorado requires any person who is bound over for trial after a preliminary hearing on charges pertaining to any sexual offense involving sexual intercourse, cunnilingus, fellatio, anilingus, or anal intercourse to undergo the HIV test.[51] Illinois requires any person convicted of certain sexual offenses, including prostitution—defined as performing, or offering or agreeing to perform certain sexual acts in return for money—pandering, patronizing prostitution, keeping a house of prostitution, and pimping, to be tested for sexually transmitted diseases, including HIV. The judge can decide to whom the test results should be released.[52]

In August 1989 a state trial court judge in Illinois struck down this last law as unconstitutional as it pertained to female sex workers.[53] The judge held the testing to be an infringement on the constitutional rights to privacy, freedom from unreasonable searches, and equal protection. The court found the following factors—inaccuracy in test results,[54] the lack of connection between testing and conduct likely to cause transmission of the virus—because even those who do not engage in any high-risk sexual activities as part of their sex work are subject to

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191.677.1(2) (1988).

50. GA. CODE ANN. §§ 17-10-15(b); 31-22-9.1(a)(3) (Supp.1989).

51. COLO. REV. STAT. §§ 13-3-401(6)—18-3-415 (Supp. 1989).

52. ILL. ANN. STAT. ch. 38, para. 1005-5-3(g) (Smith-Hurd Supp. 1989).

53. People v. Madison, No. 88-123613 (Cook County Cir. Ct., Ill. filed Mar. 3, 1988 (appeal pending); People v. Adams, No. 87-281577 County Cir. Ct., Ill. filed Dec. 3, 1987 (appeal pending).

54. The tests used to determine if a person has been exposed to the virus do not always accurately determine if a person is infected with the human immunodeficiency virus. The standard HIV tests (ELISA and Western Blot) test for the presence of *antibodies* to the virus, not for the presence of the virus itself. These antibodies do not appear for a period of time after the person has acquired the virus, and, in some people, never appear. Moreover, there is no definitive agreement as to when a test should be considered positive for antibodies, and different labs use different criteria. The decision as to whether or not to label a test positive or negative depends in part on the darkness of the colors or bands that show up on the test strip, and thus the decision is partly a subjective one by the lab technician. *See* statement of L. Miike, Analyst of Office of Technology Assessment. *Quality AIDS Testing: Hearing Before the Subcommittee on Regulation and Business Opportunities of the House Committee on Small Business*, 100th Cong., 1st Sess., Oct. 18, 1987, at 11. People v Madison, *supra* note 53, at 8-9; People v Adams, *supra* note 53, at 10-11; Imagawa, Lee, Wolinsky, Sano, Morales, Kwok, Sninsky, Nishanian, Giorgi, Fahey, Dudley, Visscher & Detels, *Human Immunodeficiency Virus Type 1 Infection In Homosexual Men Who Remain Seronegative For Prolonged Periods*, 320 NEW ENG. J. MED. 1458 (1989).

the law—the lack of victims of sexual contact—as there would be in rape, for example—and the lack of any compelling government interest in the testing requirement—all necessitated striking down the statute.

The mandatory testing programs seem to have no purpose other than testing for the sake of testing. Such testing merely stigmatizes those who are labeled as positive, resulting in harassment, discrimination, and social isolation. Moreover, testing is counter-productive as a public health matter, as it gives a false sense of security to those who have been labeled as negative.[55] By focusing public attention on a formulation of risk defined as membership in so-called "risk groups," *i.e.*, female sex workers, these laws implicitly give people permission to act irresponsibly if they do not belong to a "risk group."

A criminalization approach to the AIDS epidemic is most likely to have a disproportionate impact on women. Using the criminal law against female sex workers to attempt to control the spread of HIV infection allows prosecutors, judges, and members of the public to vent their disdain for commercialized sex, but, as in past campaigns against venereal disease, the target will be misplaced. Instead, such laws will merely result in widespread police intrusion into the most intimate affairs of members of the society, and will encourage police misconduct through operations designed to entrap those women targeted for prosecution.[56]

V. QUARANTINING THE "BAD" WOMEN

With the rise of the AIDS epidemic have come calls for quarantine as a solution. Female sex workers have been the most common target of these calls for quarantine, but the present use of *de facto* quarantine against pregnant women is a fearful harbinger of the future

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55. A person who does not presently have the virus should nonetheless avoid high-risk activities. Public education programs should emphasize the importance of *all* persons avoiding conduct that might result in transmission or acquisition of the virus. Moreover, such testing programs are expensive, and a waste of precious economic resources that could be better spent on drug treatment programs, neo-natal care, and public education programs regarding AIDS and transmission of the virus. Testing costs an average of $62 for each *confirmed* case of HIV infection—$6 for each ELISA test (which must be repeated at least once) and $50 for each Western Blot test (which must be given in addition to the ELISA tests before a blood sample is considered positive for HIV). Miike, *supra* note 54. Both former Surgeon General Everett Koop and the Institute of Medicine of the National Academy of Science oppose mandatory testing, with the Institute of Medicine specifically opposing the compulsory testing of prostitutes. U.S. DEPT. OF HEALTH AND HUMAN SERVICES, SURGEON GENERAL'S REPORT ON ACQUIRED IMMUNE DEFICIENCY SYNDROME 33 (Oct. 1986); INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, CONFRONTING AIDS: UPDATE 1988, at 10 (1988) [hereinafter INSTITUTE OF MEDICINE] (WASHINGTON, D.C.: NATIONAL ACADEMY PRESS).

56. *See* Gostin, *The Politics of AIDS: Compulsory State Powers, Public Health, and Civil Liberties*, 49 OHIO ST. L.J. 1017, 1044 (1989).

treatment HIV positive women will receive.

Quarantine is a radical public health measure implemented when casually-transmittable, highly contagious diseases sweep a community. As such, quarantine is a short-lived remedy designed to serve the important community goal of preventing or slowing further rapid spread of disease and has been upheld by the courts as within the police power of the state.[57] Quarantine thus makes sense when used to slow or stop the spread of air-or water-borne diseases such as smallpox or cholera.

The use of quarantine has not, however, always been fair. It has been used to discriminate against racial minorities and prostitutes. For example, at the turn of the century, health officials quarantined a predominantly Chinese area of San Francisco, in response to nine deaths from bubonic plague, but exempted non-Chinese families from the quarantine.[58] During World War II, Japanese-Americans were sent to internment camps, an action upheld by the United States Supreme Court.[59] The pretext for discrimination in that case was not contagious disease, but wartime safety. Quarantine was also used during World War II against female sex workers, as it had been during the World War I.[60] With the onset of the AIDS epidemic, calls for quarantine again have been made, and at least one court has confined a female sex worker with AIDS to her home and ordered her to wear an electronic monitor to signal police if she went more than 200 feet from her telephone.[61]

Similarly, many pregnant women currently have experienced *de facto* quarantine when a judge desires to protect the fetus from "infection" with drugs or other substances ingested by the mother. It requires little foresight to predict that these same economically disadvantaged women, mostly African-American and Hispanic/Latino-American, will be vulnerable to functional quarantine as a measure to reduce the risk of pre-natal exposure to HIV.

Given the modes of transmission of HIV infection, quarantine is a totally inappropriate response to the AIDS epidemic. Few people —except, in very rare circumstances, those receiving blood and blood products in medical situations—are in danger of getting the virus today if they use proper precautions. Since the virus is not casually transmitted, those with the virus can eat, work, and live with persons who do not have the virus without danger of transmitting the virus to such persons.

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57. Ford & Quam, *AIDS Quarantine: The Legal and Practical Implications*, 8 J. LEGAL MED. 353, 366 (1987); BERGMAN, *supra* note 42, at 787-89.

58. *See* Jew Ho v Williamson, 103 F. 10 (N.D. Cal. 1900), where the court struck down this quarantine on the grounds that it was an unreasonable regulation and discriminatory.

59. Korematsu v Texas, 323 U.S. 214 (1944).

60. Ford & Quam, *supra* note 57, at 366; Bergman, *supra* note 42, at 787-89.

61. Mills, Wofsy & Mills, *The Acquired Immunodeficiency Syndrome: Infection Control and Public Health Law*, 314 NEW ENG. J. MED. 931, 934 (1986).

Persons engaging in sex can protect themselves from transmission of the virus by avoiding the types of sexual practices that transmit the virus and can substantially reduce the likelihood of transmission even in sexual practices that can transmit the virus by using barriers such as condoms. Those using intravenous drugs can use clean works and avoid sharing works. Even HCPs can avoid infection in almost all situations by using precautions recommended by the CDC.[62]

Not only is quarantine non-sensical as a response to the AIDS crisis, but a quarantine is unworkable and counter-productive. Calls for quarantine only drive people away from voluntary testing and medical care—if the result of being identified as HIV positive is to risk being incarcerated for life,[63] who would voluntarily allow herself to be tested, particularly when there is no cure for AIDS at the present time? Given the impossibility of mass quarantine,[64] the more likely result of the use of quarantine in the AIDS crisis, particularly given the past use of quarantine against politically less powerful grounds, is selective quarantining of those who are most vulnerable—prostitutes, gay men, poor pregnant women, and illegal drug users. A reliance on quarantine as the answer to the AIDS epidemic diverts attention from the necessity of massive public education, so *all* persons can learn how to avoid being exposed to the virus.

VI. CHILD CUSTODY RIGHTS OF WOMEN WITH HIV INFECTION

Women with HIV infection face the loss of their own health, loss of control over their right to make non-coerced decisions regarding pregnancy, and loss of their very freedom when the state seeks to quarantine them. They also face the danger of the courts taking their children away from them precisely because of their HIV infection, or because of the stigma accompanying HIV infection, due to a court's

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62. Friedland & Klein, *supra* note 35. In New York State Society of Surgeons v Axelrod, N.Y.L.J., Nov. 17, 1988, at 29, col. 5 (Super. Ct. Albany County, New York verified June 13, 1988) (upheld the state health commissioner's determination that AIDS is not a contagious disease).

63. Since there presently is no cure for HIV, those quarantined due to their positive HIV serostatus would face lifelong incarceration. This is the approach used by Cuba for those who have tested positive for HIV infection. Such persons are sent to a sanitorium outside Havana. Only limited contact with family and friends is permitted. Bayer & Healton, *Controlling AIDS in Cuba: The Logic of Quarantine*, 320 NEW ENG. J. MED. 1022, 1023 (1989). *But see* Gordon & Paya, *Controlling AIDS in Cuba*, 321 NEW ENG. J. MED. 829 (1989).

64. As many as 1.4 million persons are carriers of the HIV, so a quarantine designed to include everyone who has the virus if all such persons could be identified would result in the incarceration, for life, of at least 1.4 million people. INSTITUTE OF MEDICINE, *supra* note 55, at 4. Also, as previously discussed *supra* note 54, the tests for HIV infection are not 100 percent accurate, so that some people would be quarantined even though they do not have the virus, and others who have the virus would not be quarantined.

assumption that a woman with HIV is either a female sex worker or drug addict. In either case, in the eyes of many courts, HIV infection is likely to be the marker of a "bad mother."[65]

In a number of cases, trial courts have severely restricted, or even terminated, the custody and visitation rights of a parent with HIV infection. While these cases have involved restrictions on fathers that had HIV infection, the same ignorance exemplified in those decisions can be expected to be used against mothers with HIV infection. In the extreme case of, *Stewart v. Stewart*,[66] an Indiana court terminated the visitation rights of a father infected with HIV. This decision was overturned on appeal. However, a dissenting opinion claimed it was theoretically possible for a parent to infect his child, by cutting his finger while extracting the child's tooth, and therefore the termination of custody should be upheld.[67] In other cases, the visitation rights of an HIV-infected father have been limited to supervised visitation,[68] and in one case a court conditioned the temporary custody rights of a mother who worked as a nurse treating AIDS patients on the mother taking the test for HIV infection.[69]

As more judges have become aware of the fact that HIV is not transmitted through casual contact,[70] courts have begun to rule against

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65. A harbinger of this type of misuse of HIV testing is a recent law journal article that suggests the use of HIV testing during divorce proceedings as an evidentiary means of identifying "morally culpable" spouses who have engaged in high-risk behavior. While the author purports to oppose compulsory HIV testing in a divorce proceeding where there is no evidence of misconduct, he believes a spouse's refusal to voluntarily undergo an HIV test could legitimately be used by a court as evidence that the spouse is a less fit custodian. Schepard, *AIDS and Divorce*, 23 FAM. L. Q. 1, 5-6, 12-28 (Spring 1989). An excellent analysis of the misuse of HIV infection by courts in child custody determinations was made in Note, *Public Hysteria, Private Conflict: Child Custody and Visitation Disputes Involving an HIV Infected Parent*, 63 N.Y. U. L. REV. 1092 (1988).

66. Stewart v. Stewart, 521 N.E. 2d 956 (Ind. Ct. App. 1988).

67. *Id.* at 967 (Conover, J., dissenting).

68. G.R.M. v J.R.A., #RF-84-0000 (Sup. Ct. of P.R. May 5, 1986) (father with AIDS limited to visitation under supervision of sister-in-law, and father's physical contact with children restricted); Jordan v Jordan, #FV 12-1357-84 (Sup. Ct. of N.J., Ch. Div., Middlesex County May 6, 1986) (father with AIDS limited to supervised visitation).

69. *See* Buck v Grein (Champaign County, Il., 1985) Sept. 1986 LESBIAN/GAY LAW NOTES OF BAR ASSOCIATION FOR HUMAN RIGHTS OF GREATER NEW YORK 54-55.

70. As to lack of casual transmission of HIV, see M. CAMPBELL, MEDICAL ASPECTS OF AIDS-RELATED LITIGATION, in AIDS PRACTICE MANUAL: A LEGAL AND EDUCATIONAL GUIDE, (Albert, Graff & Schatz 2d. ed. 1988); Center for Disease Control, *Summary: Recommendations for Preventing Transmission of Infection with Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus in the Workplace*, 34 MORBIDITY & MORTALITY WEEKLY REP. 712-15 (1985); Friedland, Saltzman, Rogers, Kahl, Lesser, Mayers & Klein, *Lack of Transmission of HTLV-III/LAV Infection to Household Contacts of Patients with AIDS or AIDS-Related Com-*

those seeking to limit the custody rights of HIV-infected parents.[71] A detailed trial court decision in New York refused to order HIV testing of the parent, on the grounds that HIV infection, if any, would not warrant restrictions on the custody rights of the father.[72] The first appeals court decision on the issue came in 1988 in the *Stewart* case, where the court reversed the trial court's termination of the custody rights of a man with HIV infection.

Due to the ignorance of many judges as to the modes of HIV transmission, their prejudice against women who are sexual outside of marriage—whether with males or females—and the hysteria over drug use, women with HIV face the punitive wrath and substituted judgment when it comes to custody just as they have with respect to pregnancy.

VII. PLANNING NEEDS OF WOMEN WITH HIV INFECTION

Women who have HIV infection, ARC, or AIDS face a pressing need to plan for their own future care, as well as for the care of their minor children when they become too ill to care for them or die. Such women, as well as other persons with life-threatening diseases, face numerous barriers to exercising such control over their lives. Most states lack laws that explicitly provide for the designation of health care surrogates to make medical care decisions, and few states have adequate provisions for the care and custody of children of ill or deceased parents. This need is particularly acute for women affected by AIDS since

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plex with Oral Candidiasis, 314 NEW ENG. J. MED. 344 (1986); Fischi, *Evaluation of Heterosexual Partners, Children, and Household Contacts of Adults with AIDS*, 257 J.A.M.A. 640 (1987); INSTITUTE OF MEDICINE, *supra* note 55, at 3-4; Friedland & Klein, *supra* note 35, at 1131-33; Peterman, Stonerburner, Allen, Jaffe & Curran, *Risk of Human Immunodeficiency Virus Transmission from Heterosexual Adults with Transfusion-Associated Infections*, 259 J.A.M.A. 55 (1988).

71. *In re* Smalley, No. 83-112, (Muskingum County Dom. Rel. Ct., Columbus, Ohio, Dec. 1986); Jane W. v John W., 519 N.Y.S. 2d 603 (N.Y. Sup. Ct. 1987) (father with AIDS not precluded from visitation with daughter, *pendente lite*); Doe v Roe, No. 20894, (Cir. Ct. Montgomery Co., Md., May 1988) (joint physical custody restored to gay father with AIDS). In W. v W., (under court seal), (Cir. Ct. of San Bernadino County, Calif. 1988), a 1988 settlement approved by the trial court in San Bernadino County, California, gave primary physical custody of the minor child to a father with AIDS. In J.R. v L.R., (under court seal), (Cir. Ct. of St. Louis County, Mo. 1986), and Conkel v Conkel, 509 N.E. 2d 983, 987 (Ohio Ct. App. 1987), the courts dealt with allegations that men alleged to be gay should have custody rights restricted because they might get HIV infection. In J.R. v L.R., the trial court refused to order periodic HIV testing of the father. In *Conkel*, the court refused to restrict visitation rights. In Anne D. v Raymond D., 528 N.Y.S. 2d 775 (N.Y. Sup.Ct. 1988), the court refused to order an HIV test of a spouse accused of adultery. The National Center for Lesbian Rights, 1370 Mission St., San Francisco, CA 94103 (415-621-0674) keeps abreast of this area of the law and has publications regarding AIDS and child custody.

72. Doe v Roe, 526 N.Y.S. 2d 718 (N.Y. Sup. Ct. 1988).

many of them have at least one child and no other custodial parent.

A. Health Care Surrogate Needs

Traditionally, when a person becomes too sick to make her own health care decisions, HCPs have looked to the patient's spouse or various blood relatives to make such decisions. Several states have enacted laws specifically authorizing HCPs to look to such persons to make health care decisions.[73] These laws are grounded in a white, middle class notion of family and fail to recognize different family structures common in other cultures. Very often, women with AIDS will not want their legal spouse or blood relatives to make health care decisions for them. Some women will wish a trusted non-blood-related family member, or a close friend, to make such decisions.[74] Many HCPs moreover, are increasingly becoming reluctant to talk with anyone else about a person's medical condition, without clear legal authority to do so. Thus, there is a critical need for health care surrogate laws to be adopted in order to provide a legal mechanism to recognize the diverse family structures that many women have constructed.

A few states have passed laws that specifically permit a person to designate another to make health care decisions for her when she becomes unable to make such decisions herself. Typically, such laws are called Durable Powers of Attorney for Health Care or, sometimes, Health Care Surrogate Laws.[75] Other states provide for appointment of health care agents only for making decisions as to whether or not to continue life-sustaining procedures when the person is dying.[76] Most states, however, still lack any such provisions. In those states that have

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73. Solnick, *Proxy Consent for Incompetent Non-Terminally Ill Adult Patients*, 6 J. LEGAL MED. 1, 19 (1985).

74. A study of gay men with AIDS in San Francisco found that 45% would designate their partners or friends as health care surrogates, 32% would choose blood relatives, and 14% their physician. Steinbrook, Lo, Moulton, Saika, Hollander & Volberding, *Preferences of Homosexual Men with AIDS for Life-Sustaining Treatment*, 314 NEW ENG. J. MED. 457 (1986). While the preferences of gay men with AIDS may not be the same as women with AIDS, the study demonstrates the inadequacy of merely looking to legally-recognized relatives to make health care decisions.

75. *See, e.g.*, California (CAL. CIV. CODE §§ 2430-44, 2500-08 (West Supp. 1989)); Colorado (COLO. REV. STAT. § 15-14-501 (Supp. 1986)); Illinois (ILL. REV. STAT., ch. 110½, para. 804-2 to 804-12 (1987)); Nevada (NEV. REV. STAT. §§ 449.800-449.860 (Supp. 1987)); North Carolina (N.C. GEN. STAT. §§ 32A-1 to 32A-2, 32A-8 (1986)); Pennsylvania (PA. STAT. ANN. tit. 20, §§ 5602(a)(8) & (a)(9) (Purdon Supp. 1986)); and Rhode Island (R.I. GEN. LAWS § 23-4.10, (Cumm. Supp. 1988)).

76. *See, e.g.*, ARK. STAT. ANN. §§ 20-17-201—20-17-217 (Supp. 1987); FLA. STAT. ANN. § 765.05(2) (West 1985); IOWA CODE ANN. § 144A.7.1(a) (West Supp. 1985); LA. REV. STAT. ANN. § 40:1299.58.3.c.(1) (West Supp. 1989); TEX. REV. CIV. STAT. ANN. art. 4590h-1 (Vernon Supp. 1990); UTAH CODE ANN. § 75-2-1106 (SUPP. 1989).

adopted the Uniform Probate Code,[77] or the Model Special Power of Attorney for Small Property Interests Act,[78] a person might be able to use those acts to designate someone to make health care decisions; however, the adoption of explicit legislation authorizing such designations will eliminate any ambiguity and will encourage HCPs to recognize such documents. Such laws should authorize a person to designate another person of her choosing to make health care decisions for her whenever she lacks capacity to make those decisions herself.[79]

Such legislation will also reduce the involvement of states' probate courts in guardianship proceedings. Probate judges are ill-equipped to decide who should be the guardian of a woman who lacks capacity to make health care decisions. A male judge will often substitute his own culturally biased judgment as to an appropriate custodian for the judgment of a poor, minority, or lesbian woman with a lifestyle different from that of the judge's. Thus, throwing the decision as to who should be custodian into the probate court takes the power to make this decision away from the mother. Moreover, guardianship proceedings entail substantial delays in providing needed medical care. Such delays may result in a significant worsening of the woman's condition, or even death, while the guardianship proceedings are pending. This is particularly likely to occur if there is a dispute as to whom should be appointed as guardian, and if the person seeking guardianship is not a spouse or blood relative. Finally, the attorney and expert witness fees

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77. *See, e.g.*, ALA. CODE §§ 13.06.005-13.36.100 (1972); ARIZ. REV. STAT. ANN. §§ 14-1101—14-7307 (1973); COLO. REV. STAT. §§ 15-10-101—15-17-101 (1973); FLA. STAT. ANN. §§ 731.005-735.302, §§ 737.101-737.512 (West 1974); HAW. REV. STAT. §§ 560:1-101—560:8-102 (1976); IDAHO CODE § 15-1-101—14-7-307 (1971); KY. REV. STAT. ANN. §§ 386.650—386.670 (Baldwin 1976); ME REV. STAT. ANN. tit. 18, §§ 1-101 -8-401 (1979); MICH. COMP. LAWS ANN. §§ 700.1-700.993 (West 1978); MINN. STAT. ANN. §§ 524.1-101—524.8-103 (West 1974); MONT. CODE ANN. §§ 72-1-101—72-5-502 (1974); NEB. REV. STAT. §§ 30-2201—30-2902 (1974); N.M. STAT. ANN. §§ 45-1-101—45-7-401 (1975); N.D. CENT. CODE §§ 30.1-01-01—30.1-35-01 (1973); S.C. CODE ANN. §§ 62-1-100—62-7-603 (Law. Co-op. 1986); UTAH CODE ANN. §§ 75-1-101—75-8-101 (1975).

78. Arkansas (1965), Delaware (1973), North Dakota (1971), Oklahoma (1971), Wyoming (1965). *See, e.g.*, HANDBOOK OF THE NATIONAL CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS AND PROCEEDINGS OF THE ANNUAL CONFERENCE MEETING (Aug. 2-19, 1985) (1989) [hereinafter HANDBOOK OF UNIFORM STATE LAWS].

79. *See* Peters, *Advance Medical Directives: The Case for the Durable Power of Attorney for Health Care*, 8 J. LEGAL MED. 37 (1987); Fowler, *Appointing an Agent to Make Medical Treatment Choices*, 84 COLUM. L. REV. 985 (1984); UNIFORM LAW COMMISSIONERS' MODEL HEALTH-CARE CONSENT ACT, HANDBOOK OF UNIFORM STATE LAWS, *supra* note 78, Comment to § 6-101, at 164. For proposed laws, see UNIFORM LAW COMMISSIONERS' MODEL HEALTH-CARE CONSENT ACT, *supra* at 161. The New York State Task Force on Life and the Law, *Life-Sustaining Treatment: Making and Appointing a Health Care Agent* (July, 1987), 149-59, available free by writing to the Task Force at 5 Penn Plaza, 3rd Floor, New York, NY 10001-1803.

involved in guardianship proceedings could better be used to provide needed medical care to ill women.[80]

B. Care and Custody of Children While Their Mother Is Ill

In addition to health care surrogate laws allowing adults to designate the person(s) to make health care decisions when they lack capacity to make decisions for themselves, laws must also deal with the care and custody of minor children of adults who are too ill to care for them.

While some state laws allow parents to grant another person the care and custody of their minor children through a power of attorney,[81] such laws may well be inadequate to deal with the issues of concern to mothers with HIV, ARC, or AIDS. First, such laws sometimes allow a designation only for a limited period of time. This requires the mother to periodically renew the power of attorney, adding an unnecessary and burdensome task to a mother who is having to manage many other matters. Not only that, but the mother may be mentally incapacitated by the time the power of attorney needs to be renewed. Second, many states do not allow a "springing" power of attorney, that is, a power of attorney that goes into effect only upon the happening of a future event (for example, the mental or physical incapacity of the mother). Thus, a woman who is presently able to take care of her children cannot, under such statutes, provide for the orderly transition of her children to the care of another at the point in the future when she becomes incapable of caring for them.

Third, currently drafted laws on powers of attorney do not adequately respond to the volatile nature of AIDS. What is needed are powers of attorney that provide for the power to "spring" into existence for a limited period of time, and permit the power to "lapse" when the mother regains her ability to care for the children and then "spring"

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80. An example of the problems of delay and expenses caused by disputes over appointment of guardian occurred in the case of Nancy Klein. Ms. Klein suffered serious brain damage in an automobile accident while she was pregnant. Her husband sought to be appointed as guardian, in order to terminate Ms. Klein's pregnancy, as the pregnancy was a danger to her life and health. He also sought the right to authorize other necessary medical procedures to save her life. Two anti-abortion activists who did not know either of the Kleins filed a petition to be appointed as guardians of Ms. Klein and the non-viable fetus, causing a contested probate hearing over the question who should be appointed as guardian of Ms. Klein. Not only did Mr. Klein have to bear the expense of his three medical experts and attorney's fees at the hearing, not to mention the trauma of the unwarranted interference by total strangers in the private affairs of the Kleins, but the proceedings delayed the appointment of Mr. Klein as guardian for at least 10 days. Had New York had a health care surrogate law and if Mr. and Ms. Klein had appointed each other as health care surrogates in the event of incapacity, the delays, expense, and trauma would have been avoided. *In re* Klein, 538 N.Y.S.2d 274 (N.Y. App. Div. 1989).

81. *See, e.g.*, MO. REV. STAT. § 475.024 (1986).

back into existence when the mother becomes incapacitated again. Powers of attorney under most current laws lack the necessary flexibility needed by a woman who has an illness that goes into active phases and then remissions on an unpredictable basis. Fourth, the custodial instruments described above will eliminate frequent problems experienced by women when children are left to the care of the probate and family courts. Often the person given custody of the children refuses to return the children to the mother when the mother is able again to take care of the children. Alternatively, the mother might find a long-absent father has reappeared to take custody of the children, or the state (if the mother is poor) has placed the children in foster care during her hospitalization. In these cases, the mother faces an expensive and emotionally exhausting court battle to regain custody of her children, often in front of a judge who does not share the woman's culture or her lifestyle.

Laws need to be adopted to provide for these situations. Such laws should allow a parent to designate another person of her choosing to have custody of the minor children only during the parent's incapacity. If the father has been absent from the home for a long period of time, without consistent involvement with the children, he should not have priority over the custodian designated by the mother to serve during the mother's incapacity. Once the woman's incapacity ends, she should have a legally enforceable, automatic right to regain custody, without having to go to court to prove her fitness to regain custody. Only if someone files suit in court challenging the woman's fitness to regain custody should the courts become involved.

C. Custody of Children Upon Death of the Mother

Women face not only concern about their own health care during their lifetime and the care of their children when they are incapacitated, but also concern regarding the care of their children upon their death. Many poor women will not make a will, as many lay people think of making a will only when they have assets. Even with a will stating the mother's desires with regard to custody, the preferences of the mother as to who should become guardian of the children is not binding on the courts. To reduce the likelihood that the custody of the children will become the subject of a lengthy court battle, laws should be adopted permitting a person to designate, in a document other than a will (as well as within a will), the person or persons to be guardians of the children upon the parent's death. Such a designation should be deemed sufficient to provide another with legal custody upon the parent's death, without the necessity of court action after the mother's death. Only if another person filed suit to challenge the designation should the court be authorized to intervene.

Thus, the following laws are needed to help women gain as much control as possible over their own future and that of their children:

- A Health Care Surrogate law, permitting a person to designate another (the "surrogate") to make health care decisions for her when she lacks the capacity to make such decisions herself.
- A Minor's Custodian Law, permitting a person to designate a temporary custodian for the minor children whenever the parent lacks the capacity to make such decisions.
- A Guardian Upon Death law, permitting a person to designate the person or persons to serve as guardians of the minor children upon the person's death, without the necessity for further legal proceedings.

CONCLUSION

The AIDS epidemic, just like people with HIV disease, is not a monolith. Unfortunately, public health, medical, legal, and social responses to AIDS have been modeled upon a middle class, white, and male experience of illness. To truly meet the needs of women affected by HIV, those developing AIDS policy must recognize the ways in which poor women and women of color lost control over parts of their lives long ago. AIDS has just made their lives that much more unmanageable.

The health care needs of women with HIV disease have gone unmet. Women with HIV infection have been subject to loss of choice over reproductive options, criminalization, quarantine, and loss of custodial rights. A meaningful response to the needs of women with HIV disease, as well as to society's need to slow the spread of this epidemic, will require a shift away from punitive measures toward policies that increase women's access to health care, increase their power to demand sexual encounters on their own terms, and provide them the tools to order their lives without the imposition of others' values and judgment.