

# WOMEN AND AIDS — RACISM, SEXISM, AND CLASSISM

TAUNYA LOVELL BANKS\*

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## INTRODUCTION

As the number of babies with Acquired Immunodeficiency Syndrome [hereinafter AIDS] or Human Immunodeficiency Virus [hereinafter HIV] infection rises, people question the right of HIV-infected women to bear children. This Article focuses on the reproductive freedom issues that arise in the context of AIDS and HIV infection in pregnant women and women of childbearing age. Policies to screen for and counsel pregnant women and women of childbearing age about HIV infection present enormous possibilities for abuse through involuntary testing and directive counseling to abort or to be sterilized. The issue of health policies for fertile women with AIDS or HIV infection is complicated by the fact that most women currently identified as at risk in the United States are poor and/or women of color.

It is estimated that nationwide, more than seventy percent of women with AIDS are African-American or Latina.<sup>1</sup> Public health policies directed to-

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\* Professor of Law, The University of Maryland School of Law. The author wishes to thank Paulette Caldwell and Judy Scales-Trent for their comments on an earlier draft. An early version of this paper was presented at the Second Annual Conference of Women of Color sponsored by the N.Y.U. REVIEW OF LAW & SOCIAL CHANGE in October 1988.

1. Bakerman, McCray, Lamb, Jackson & Whitley, *The Incidence of AIDS Among Blacks*

ward fertile women with AIDS/HIV are and will be influenced by the fact that most HIV-infected women are poor women of color. Poor women of color most often receive their health care through government provided or funded facilities. Because these facilities are most likely to deal repeatedly with HIV-infected pregnant women, women of childbearing age, and babies, they will be the institutions developing and implementing HIV screening and counseling programs for women. This Article examines potential testing and counseling methodologies to be used in public institutions, and tests them for conformance with current equal protection and privacy constitutional standards.

## I.

### MEDICAL BACKGROUND AND PUBLIC HEALTH ISSUES

Women usually transmit or become infected with HIV in one of two ways: heterosexual contact<sup>2</sup> or intravenous drug use (by sharing dirty need-

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and Hispanics, 79 J. NAT'L MED. ASS'N 921, 922 (1988) (black women account for 49% of adult female cases, white women account for 30%, and Hispanic women 21%); Curran, Jaffe, Hardy, Morgan, Selik & Dondero, *Epidemiology of HIV Infection and AIDS in the United States*, 239 SCIENCE 610, 611 (1988) [hereinafter *Epidemiology of HIV*].

In 1988, African-American women between the ages of 15 and 44 were approximately nine times more likely to die from HIV/AIDS than white women of the same age. Chu, Buchler & Berkelman, *Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States*, 264 J. A.M.A. 225, 226 (1990) [hereinafter *Impact of HIV on Women*]. In 1987, AIDS was the eighth leading cause of death among women of reproductive age in the United States. The number of cases among women is increasing. If this trend continues, HIV/AIDS will be one of the five leading causes of death for women between 15 and 44 years of age by 1991. *Id.* at 229.

Initially, it was the policy of the Centers for Disease Control [hereinafter CDC] to report incidence of AIDS in the Asian, native American, and Pacific Islander communities collectively as "Other". This practice, which masked the impact of AIDS upon these communities, has been criticized by minority researchers and by the Final Report of the Secretary's Task Force on Black and Minority Health. UNITED STATES DEP'T OF HEALTH & HUMAN SERVICES, REPORT OF THE SECRETARY'S TASK FORCE ON BLACK AND MINORITY HEALTH, VOL. I: EXECUTIVE SUMMARY (1985) [hereinafter REPORT ON MINORITY HEALTH]. It also served to slow the development of AIDS education and prevention programs in these communities. Nickens, *AIDS, Race and the Law: The Social Construction of the Disease*, 12 NOVA L.J. 1179, 1183 (1988). Although the CDC use the designation "Hispanic", see, e.g., CDC, *Acquired Immunodeficiency Syndrome (AIDS) Among Blacks and Hispanics — United States*, 35 MORBIDITY & MORTALITY WEEKLY REP. 655 (1986), I choose to use the term Latina to emphasize that most of the Hispanic women with AIDS are Puerto Rican, Mexican-American, or from other parts of the Americas. See also Selik, Castro & Pappaioanou, *Racial/Ethnic Differences in the Risk of AIDS in the United States*, 78 AM. J. PUB. HEALTH 1539 (1988).

2. In 1982, only 1.1% of all reported AIDS cases were attributed to heterosexual transmission. *Epidemiology of HIV*, *supra* note 1, at 610. By 1985, that number increased slightly to 1.7%. Friedland & Klein, *Transmission of the Human Immunodeficiency Virus*, 317 NEW ENG. J. MED. 1125, 1128 (1987). However, by March 1985, approximately 4% of all reported cases in the United States were attributed to heterosexual transmissions. CDC, *Quarterly Report to the Domestic Policy Council on the Prevalence & Rate of Spread of HIV & AIDS in the United States*, 259 J. A.M.A. 2657, 2657 (1988) [hereinafter *Quarterly Report*]. In 1989, the total number of reported cases increased 9%. The largest proportional increases among HIV exposure groups occurred for persons exposed to HIV through heterosexual contact or perinatal transmission. CDC, *Update: Acquired Immunodeficiency Syndrome — United States, 1989*,

les).<sup>3</sup> Unlike men, women also can transmit HIV perinatally (from mother to child).<sup>4</sup> The epidemiologic data indicates that eighty percent of women with AIDS are of childbearing age.<sup>5</sup> Further, three-fourths of the pediatric AIDS cases involve perinatal transmission of the virus during the mother's pregnancy or during the immediate postpartum period.<sup>6</sup> It is estimated that thirty to fifty percent of infants born to HIV-infected mothers will become infected transplacentally.<sup>7</sup>

Women emerge as a target group primarily because of their ability to transmit HIV perinatally, *i.e.*, to fetuses in utero. Public health officials estimate that more than 200,000 AIDS cases will be reported in the United States by 1992.<sup>8</sup> According to some projections, women will account for twelve per-

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263 J. A.M.A. 1191, 1191 (1990). While the number of cases among adult transfusion recipients and hemophiliacs declined, and cases among gay or bisexual men increased more slowly, more dramatic increases are expected in the number of cases associated with heterosexual intravenous drug use, heterosexual contact, and perinatal transmission. *Id.* at 1192.

The number of deaths attributed to HIV/AIDS in women between the ages of 15 and 44 years of age in the United States increased from 18 in 1980 to 1430 in 1988. *Impact of HIV on Women*, *supra* note 1, at 226. In 1989, 2825 new cases in women were reported. *Id.* at 229. More specifically, the percentage of women who reported contracting HIV/AIDS through heterosexual conduct increased from 14% in 1982 to 28% in 1986 while the increase for heterosexual men over the same period was only 1% (increasing from 1 to 2%). Guinan & Hardy, *Women and AIDS: The Future Is Grim*, 42 J. AM. MED. WOMEN'S ASS'N 157, 157 (1987) [hereinafter *Women and AIDS*].

There is one reported case of female to female sexual transmission and another where this mode is suggested, but transmission of HIV in this manner is exceedingly rare. *Epidemiology of HIV*, *supra* note 1, at 614. Although lesbians are not currently considered at great risk of HIV infection unless they are also intravenous drug users, they may risk infection if they decide to become pregnant through artificial insemination, especially if the sperm is not tested or the donor is infected but does not test positive. *Cf.* 44% of Doctors Report Tests for AIDS on Donated Semen, N.Y. Times, Aug. 11, 1988, at A23, col. 1 (late ed.) (majority of physicians who perform artificial insemination do not test donated semen for HIV).

3. *Quarterly Report*, *supra* note 2, at 2657.

4. "Over 70% of the perinatally acquired AIDS cases were related to IV drug abuse in the child's mother or her sexual partner." *Epidemiology of HIV*, *supra* note 1, at 610-11.

5. *Women and AIDS*, *supra* note 2, at 157. Thirty-two percent of these women are between 20 and 29 years old. *Id.*

6. *Quarterly Report*, *supra* note 2, at 2657.

7. Hoff, Berardi, Weiblen, Mahaney-Trout, Mitchell & Grady, *Seroprevalence of Human Immunodeficiency Virus Among Childbearing Women*, 318 NEW ENG. J. MED. 525, 528 (1988) (20 to 60%); Selwyn, Schoenbaum, Davenny, Robertson, Feingold, Shulman, Mayers, Klein, Friedland & Rogers, *Prospective Study of Human Immunodeficiency Virus Infection and Pregnancy Outcomes in Intravenous Drug Users*, 261 J. A.M.A. 1289, 1290 (1989).

8. There is controversy within the health care community over AIDS case projections for the 1990s. Early predictions estimated that approximately 365,000 to 380,000 AIDS cases would be reported in the United States by 1992. Staver, *Knowledge About HIV Increasing, But AIDS Cure Remains Elusive*, Am. Med. News, July 1, 1988, at 2, 7. Recently a controversy over the projections surfaced in The Journal of the American Medical Association [hereinafter J.A.M.A.] when an article by Dennis Bregman and Alexander Langmuir claimed that the number of reported AIDS cases by the mid-1990s would be in the range of 200,000. Bregman & Langmuir, *Farr's Law Applied to AIDS Projections*, 263 J. A.M.A. 1522, 1522 (1990). Their methodology and figures were criticized. See Morgan, Curran & Berkelman, *The Future Course of AIDS in the United States*, 263 J. A.M.A. 1539 (1990); Gail & Brookmeyer, *Projecting the Incidence of AIDS*, 263 J. A.M.A. 1538 (1990). Gail and Brookmeyer note that in 1986, when

cent of these cases.<sup>9</sup> In addition, many more people, male and female, who do not have AIDS, are infected with HIV and capable of transmitting the virus to others.

The government, through the exercise of its health and safety power, has an interest in stopping the spread of AIDS and HIV infection without regard to the mode of transmission. However, since HIV can be transmitted by women *in utero*, special policies and guidelines are being developed to reduce this mode of transmission.<sup>10</sup> These policies advocate routine HIV screening to identify and counsel HIV-infected pregnant women and women of childbearing age.<sup>11</sup> Given the current state of obstetric technology, there are only two possible outcomes of this counseling which would prevent perinatal transmission: abortion for pregnant women and sterilization for all infected fertile women. Given the racial composition of the women currently thought to be at risk, HIV screening and counseling proposals designed to somehow prevent perinatal transmission have genocidal overtones.<sup>12</sup>

Although women of color currently have emerged as a target group and are most likely to be affected by policies developed to stem the transmission of HIV by women, a word of caution is warranted. The statistics may unfairly stigmatize African-American and Latina women because they may not reflect the true extent of HIV infection among all women. The primary sources of these statistics are state departments of public health which get information from hospitals, public health clinics, and private health care providers. The extent of underreporting among white women is unknown.<sup>13</sup> Historically, pri-

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there were fewer than 30,000 reported cases, the projection for 1991 was 270,000. They go on to assert that since one million people in the United States are currently estimated to be infected with HIV, and if a large number go on to develop AIDS, the number of reported cases by the mid-1990s will far exceed 200,000. *Id.* at 1538. In that same issue of the J.A.M.A., the CDC published an update indicating that only 10% of the one million people thought infected with HIV have been diagnosed with AIDS. Even though early treatment with Zidovudine (formerly called AZT) may slow the progression of the disease in asymptomatic individuals, the number of reported AIDS cases would continue to grow over the next seven years. CDC, *HIV Prevalence, Projected AIDS Case Estimates: Workshop, October 31-November 1, 1989*, 263 J. A.M.A. 1477, 1480 (1990).

9. Raymond, *Pilot Project: Preventing Further AIDS Spread Among Women, General Heterosexual Population*, 259 J. A.M.A. 3224, 3224 (1988).

10. See *infra* notes 26, 28, 32-33 and accompanying text.

11. CDC, *Public Health Service Guidelines for Counseling and Antibody Testing to Prevent HIV Infection and AIDS*, 36 MORBIDITY & MORTALITY WEEKLY REP. 509, 512 (1987) [hereinafter *Guidelines for Counseling*].

12. Genocide is a strong term, but it has been defined as including acts such as "imposing measures intended to prevent births within the group." Convention on the Prevention and Punishment of the Crime of Genocide, Dec. 9, 1948, art. II(d), 78 U.N.T.S. 277, 280. "Group," according to the United Nations Genocide Convention, means a national, ethnic, racial, or religious group. *Id.* In 1986, the United States ratified The Genocide Convention. 132 Cong. Rec. S1355-78 (daily ed. Feb. 19, 1986).

13. See Laumann, Gagnon, Michaels, Michael & Coleman, *Monitoring the AIDS Epidemic in the United States: A Network Approach*, 244 SCIENCE 1186, 1188 (1989) (suggesting that CDC undercounted the prevalence of AIDS among whites in higher socioeconomic classes and overestimated the prevalence in minority populations). *But cf.* Berkelman, Curran, Darrow, Dondero & Morgan, *Monitoring the U.S. AIDS Epidemic*, 245 SCIENCE 908 (1989) (a letter

vate health care providers have been notoriously bad about reporting stigmatizing medical conditions of patients, especially those conditions involving sexually transmitted diseases.<sup>14</sup> Arguably, the statistics may simply reflect the more limited access to health care available to women of color.<sup>15</sup> Thus, policies developed to stem the spread of HIV by women will not be effective unless all women who may be at risk are identified.

## II.

### HIV TESTING AND SCREENING METHODOLOGIES

Women of childbearing age who suspect that they may be infected are urged to be tested for the HIV antibody.<sup>16</sup> However, one potential threat to the reproductive rights of women of color comes from proposals to "screen"

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from the AIDS program at the CDC refuting the claims by Laumann, *et al.*); Conway, Colley-Niemeyer, Pursley, Cruz, Burt, Rion & Heath, *Underreporting of AIDS Cases in South Carolina, 1986 and 1987*, 262 J. A.M.A. 2859 (1989) (finding significantly poorer reporting among blacks than whites and among women).

14. A. BRANDT, NO MAGIC BULLET 42-43 (1985); *see also* Selik, Castro & Pappaioanou, *supra* note 1, at 1543 ("The possibility that the observed higher risk in Blacks and Hispanics may be due to biased data needs to be considered . . . . If private physicians were more concerned than other physicians about guarding the confidentiality of their patients, reporting of AIDS cases might be more complete in indigent (disproportionately Black and Hispanic) patients of public hospitals than in patients who can afford private medical care."). The authors go on to point out that it is unlikely that the figures would change significantly even if reporting bias exists. *Id.*

15. Many of the women currently identified as infected with HIV are unemployed or marginally employed with no access to private health care insurance. Staver, *Minority Women Grappling With Growing AIDS Problem*, Am. Med. News, Nov. 6, 1987, at 41. In 1985, a federal task force on black and minority health found that more African-Americans and Hispanics than whites have no usual source of medical care, and twice as many African-Americans and three times as many Hispanics as whites have no medical insurance. REPORT ON MINORITY HEALTH, *supra* note 1, at 17-18.

If insured at all, most of the women currently infected with HIV are covered only by Medicaid. *See* Blendon, Aiken, Freeman & Corey, *Access to Medical Care for Black and White Americans: A Matter of Continuing Concern*, 261 J. A.M.A. 278 (1989) [hereinafter *Access to Medical Care*]; Munoz, *Care for the Hispanic Poor: A Growing Segment of American Society*, 260 J. A.M.A. 2711 (1988).

"[N]ot only are blacks less likely to have any insurance coverage, but they are considerably less likely to be covered by a private insurance carrier . . . . Moreover, on a recently developed measure of the breadth and generosity of states' Medicaid programs, blacks are significantly more likely to reside in states with the least generous programs . . . ." *Access to Medical Care*, *supra*, at 280.

"Hispanics, many times, cannot afford adequate health insurance and, if not covered by publicly financed health programs, often are not able to pay for care . . . . One third of Hispanics have neither private health insurance nor coverage through a governmental program such as Medicare or Medicaid, compared with 11% of the general U.S. population." Munoz, *supra*, at 2711.

As a result, African-American and Latina women are forced to rely on public hospitals and clinics for health care. They are therefore more likely to be identified and reported as being infected with HIV than women using private health care providers.

16. *Guidelines for Counseling*, *supra* note 11, at 512. For a comprehensive discussion of HIV testing issues, see Field, *Testing for AIDS: Uses and Abuses*, 16 AM. J.L. & MED. 34 (1990).

targeted groups of pregnant women and nonpregnant fertile women for HIV. The term "screening" is to be distinguished from the term "testing". Screening usually refers to mass testing of targeted populations to determine if they have a disease.<sup>17</sup> Screening measures for infectious diseases are usually designed to identify those persons who are likely to infect many others if their own infection is not discovered.<sup>18</sup> Testing, on the other hand, usually refers to testing of an individual.<sup>19</sup>

There are two types of medical screening: one to assess current health status, and the second to assess future health status known as predictive screening.<sup>20</sup> It is often difficult to distinguish between these two, but the distinction is important because predictive screening is more likely to raise legal problems. Specifically, predictive screening can be used as a basis for discriminatory treatment. For example, many African-Americans experienced discriminatory treatment in the 1970s when some states imposed mandatory screening for sickle cell disease. Misunderstanding about the medical significance of the sickle cell trait as opposed to sickle cell disease resulted in employment discrimination by the United States Army, several major airlines, New York Telephone Company, and the fire and transit departments in New York City.<sup>21</sup> Some life insurance companies even raised rates or dropped coverage of sickle cell carriers, without actuarial support.<sup>22</sup>

There are three levels of HIV testing used by public health officials: mandatory screening, routine screening, and voluntary testing. Mandatory or involuntary screening is required by law or public health regulation. Routine screening is recommended by health care providers<sup>23</sup> and often takes place

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17. Gostin, Curran & Clark, *The Case Against Compulsory Casefinding in Controlling AIDS — Testing, Screening and Reporting*, 12 AM. J.L. & MED. 7, 11 (1987) [hereinafter *Controlling AIDS*]. The authors use this definition only in the context of that article. However, Gostin has also defined screening as "the systematic use of a medical test on population groups (as distinguished from case-by-case testing of individuals)." Gostin, *Traditional Public Health Strategies*, in AIDS AND THE LAW 54 (H. Dalton & S. Burris eds. 1987) (citing Bayer, Levine & Wolf, *HIV Antibody Screening: An Ethical Framework for Evaluating Proposed Programs*, 256 J. A.M.A. 1768 (1986)). Further, both genetic and non-genetic screening is used to determine whether remedial or preventive health care is needed. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS: A REPORT ON THE ETHICAL, SOCIAL & LEGAL IMPLICATIONS OF GENETIC SCREENING, COUNSELING & EDUCATION PROGRAMS 2 (1983) [hereinafter SCREENING AND COUNSELING FOR GENETIC CONDITIONS].

18. *Controlling AIDS*, *supra* note 17, at 11.

19. *Id.* at 10.

20. SCREENING AND COUNSELING FOR GENETIC CONDITIONS, *supra* note 17, at 3.

21. Riskin & Reilly, *Remedies For Improper Disclosure of Genetic Data*, 8 RUT.-CAM. L.J. 480, 488-89 (1977).

22. *Id.* at 489.

23. Recently two physicians from Minnesota and the Infectious Disease section of Wisconsin Medical School recommended routine HIV screening of all persons under sixty. Rhame & Maki, *The Case for Wider Use of Testing for HIV Infection*, 320 NEW ENG. J. MED. 1248, 1253 (1989).

without the informed consent of the patient.<sup>24</sup> Voluntary testing occurs where the individual affirmatively asks to be tested and is provided with counseling.<sup>25</sup> Mandatory HIV screening is not yet recommended for any group of women. The Centers for Disease Control currently recommend routine HIV screening of pregnant women in certain high risk groups.<sup>26</sup>

The focus of this Article is on routine screening proposals. Routine HIV screening as used in this Article refers to screening individuals for HIV using an HIV antibody test. Screening is not compulsory (compelled by law) nor is

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24. Theoretically, routine screening should be done with the consent of the person to be tested after counseling. See Eickhoff, *The Acquired Immunodeficiency Syndrome (AIDS) and Infection with the Human Immunodeficiency Virus (HIV)*, 108 ANNALS INTERNAL MED. 460, 464 (1988) (position paper adopted by the Health and Public Policy Committee of the American College of Physicians and the Infectious Diseases Society of America). However, in a report sponsored by the Robert Wood Johnson Foundation, a national survey of 560 randomly selected non-government hospitals showed that many hospitals violate CDC guidelines by not obtaining patient consent to HIV antibody tests. Further, 3 to 4% of the hospitals never or only sometimes inform patients who test positive. Hilts, *Many Hospitals Found to Ignore Rights of Patients in AIDS Testing*, N.Y. Times, Feb. 17, 1990, at A1, col. 1. The Robert Wood Johnson Foundation report only confirms an earlier study of 183 United States hospitals that conduct infectious disease training and 103 Minnesota hospitals which found that 34% and 57% of the hospitals, respectively, rarely obtained patient consent to HIV antibody tests. Henry, Wilenbring & Crossley, *Human Immunodeficiency Virus: Analysis of the Use of HIV Antibody Testing*, 259 J. A.M.A. 1819, 1820 (1988). The earlier study did not distinguish between public and private hospitals, but the survey response rate for both groups of hospitals exceeded 90% and, consequently, some large urban public hospitals must have been included in the sample.

While a few states have laws requiring informed consent to HIV screening and pre- and post-testing counseling, many states do not, and the federal government does not enforce CDC guidelines. Hilts, *supra*, at A1, col. 1. The head of the AIDS program at the New England Deaconess Hospital in Boston, the largest AIDS center in New England, is quoted as saying, "There is a fundamental lack of leadership from the Federal level, particularly from the executive branch." *Id.* at A12, col. 5.

At least one court has refused to recognize that health care providers have a duty to obtain consent to HIV antibody tests conducted on blood drawn for other purposes. *Doe v. Dyer-Goode*, 389 Pa. Super. 151, 566 A.2d 889 (1989).

Finally, it is important to note that 38% of the sickle cell anemia programs during the 1970s screened without obtaining informed consent. Further, many facilities provided inadequate education and post-screening counseling. Farfel & Holtzman, *Education, Consent, and Counseling in Sickle Cell Screening Programs: Report of a Study*, 74 AM. J. PUB. HEALTH 373, 375 (1984).

25. Eickhoff, *supra* note 24, at 465.

26. Minkoff, *Care of Pregnant Women Infected with Human Immunodeficiency Virus*, 258 J. A.M.A. 2714, 2714 (1987). The CDC made the recommendation in 1985 and it was subsequently endorsed in 1987 by the American College of Obstetricians and Gynecologists. *Id.*

The Public Health Service [hereinafter PHS] recommends routine HIV screening for persons seeking treatment for sexually transmitted diseases, IV-drug users, persons who consider themselves at risk, and women of childbearing age with identified risks. But as to the latter, PHS recommends that decisions about screening in the community should be based on current estimates of the prevalence of HIV infection and demographic variables in infection. *Guidelines for Counseling*, *supra* note 11, at 512. The CDC also recommend routine screening of all persons with syphilis and active tuberculosis. CDC, *Recommendations for Diagnosing and Treating Syphilis in HIV-Infected Patients*, 37 MORBIDITY & MORTALITY WEEKLY REP. 600, 600-02, 607-08 (1988); CDC, *Diagnosis and Management of Mycobacterial Infection and Disease in Persons with Human T-lymphotropic Virus Type III/Lymphadenopathy-Associated Virus Infection*, 35 MORBIDITY & MORTALITY WEEKLY REP. 448, 448-52 (1986).

it truly voluntary in the sense that the individual tested has affirmatively requested testing. Rather, routine HIV screening is conducted under conditions of consent or where consent is presumed, like many other medical tests. The individual allows blood to be drawn, but may not have actual knowledge that she is being tested for HIV or, if she has knowledge, may not fully understand the possible ramifications of a positive test result.<sup>27</sup> For example, a pregnant woman usually has blood drawn during her prenatal treatment. That blood is tested for a variety of things. The woman consents to have blood tests done, but generally does not know what specific tests are being ordered by the physician.<sup>28</sup>

Routine prenatal HIV screening measures have been enacted by a few states<sup>29</sup> and proposed by many federal officials.<sup>30</sup> Routine prenatal HIV antibody screening<sup>31</sup> of pregnant women raises several questions. The first is whether HIV prenatal screening should be routinely administered without informed consent or any pre-test counseling. Some hospitals, especially those serving poor women of color, are routinely screening all pregnant women, with or without their written informed consent and without pre-test counseling.<sup>32</sup> The second question is whether infected pregnant women should be counseled to abort. To date no formal policies or guidelines prescribe direc-

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27. Medical ethicists Carol Levine and Ronald Bayer acknowledge that some physicians interpret routine to mean "testing first and talking about it later." They reject this definition of "routine". Levine & Bayer, *The Ethics of Screening for Early Intervention in HIV Disease*, 79 AM. J. PUB. HEALTH 1661, 1664 (1989) (citing Sherer, *Physician Use of the HIV Antibody Test: The Need for Consent, Counseling, Confidentiality, and Caution*, 259 J. A.M.A. 264 (1988)).

28. It should be noted that PHS guidelines define routine counseling and testing, in the context of HIV, as "a policy to provide these services to all clients after informing them that testing will be done." This means the clients are free to decline testing without loss of health care, except where testing is mandated by law. *Guidelines for Counseling*, *supra* note 11, at 511. However, clients may have to *affirmatively* decline to be tested. Specifically, some forms may indicate that clients will be tested for HIV unless they decline. This type of "consent" form places the burden on the client to decline testing rather than more properly placing the burden on the health care provider to explain why consent to test should be given.

29. Two states appear to require prenatal HIV tests: DEL. CODE ANN. tit. 16, § 708 (1988); TENN. CODE ANN. §§ 68-5-102, 68-5-602 (1987). Florida law requires prenatal screening for all sexually transmitted diseases including HIV. 14A FLA. STAT. § 384.31 (1989); *see* 14A FLA. STAT. § 384.23(3) (1989) (defining sexually transmissible disease). But it is reported that the state is clarifying its prenatal screening requirement so that only "high-risk" women will be tested for HIV. I AIDS: A PUBLIC HEALTH CHALLENGE 2-28 (M. Rowe & C. Ryan eds. 1987). Several states require HIV testings of patients when health care workers are exposed to blood. *See, e.g.*, S.C. CODE ANN. § 44-29-230 (Law. Co-op. Supp. 1987); VA. CODE ANN. § 32.1-45.1 (Supp. 1989). Others require testing of prisoners and/or persons convicted of sex offenses. *See, e.g.*, COLO. REV. STAT. § 18-3-415 (Supp. 1989) (all convicted sex offenders); GA. CODE ANN. §§ 42-5-52.1, 15-11-35.1 (1985) (prisoners and juveniles convicted of transmitting acts); OHIO REV. CODE ANN. § 2907.27 (Anderson 1988) (arrested sex offenders); R.I. GEN. LAWS §§ 42-56-37, 11-34-10, 21-28-4.20 (Supp. 1988) (prisoners, prostitutes, and IV-drug users); S.C. CODE ANN. § 16-3-740 (Law. Co-op. Supp. 1987).

30. Gostin, *Public Health Strategies for Confronting AIDS*, 261 J. A.M.A. 1621, 1625 (1989); Boodman, *More AIDS Testing Considered*, Wash. Post, Feb. 4, 1987, at A1, col. 1.

31. As used in this Article, HIV antibody screening means use of the ELISA and confirming tests, like the Western Blot, in order to test specific targeted populations.

32. *See supra* note 24. It is difficult to document unconsented HIV testing except through



tive counseling,<sup>33</sup> but no laws prohibit it. Given the racial composition and economic background of the women currently identified as at risk, it is not unreasonable to assume that some infected pregnant women are being urged to abort and that some "voluntary" decisions to terminate the pregnancy take place in a coerced atmosphere. Poor women and/or women of color have limited access to health care, and may consent to terminate their pregnancy fearing loss of medical treatment if they do not comply.<sup>34</sup> They are also least likely to seek legal redress because they lack direct access to competent legal assistance and may die before their cases are heard. In addition, we cannot assume that all health care providers in public facilities are sympathetic and nonjudgmental toward poor people of color, especially pregnant women infected with HIV.<sup>35</sup>

It is important that we examine the expected outcomes of such screening.

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anecdotal evidence since health care providers may be subject to legal action in many states for testing without obtaining the informed consent of the patient.

In 1987, the AIDS Discrimination Unit of the New York City Commission on Human Rights noted: "[i]t has been alleged that in certain parts of the country women are routinely screened for HIV antibodies with neither their knowledge nor their consent. Talk of the mandatory sterilization of, or abortion for, the seropositive women thus identified has made the rounds of 'health committees' nationwide." THE AIDS DISCRIMINATION UNIT OF THE NEW YORK CITY COMMISSION ON HUMAN RIGHTS, AIDS AND PEOPLE OF COLOR: THE DISCRIMINATORY IMPACT 16 (Updated Report, Aug. 1987).

33. PHS recommends counseling before and after testing, but where pre-test counseling is impractical, PHS recommends that individuals be informed that they are being tested for HIV antibody, that the results are confidential to the extent permitted by law, and that counseling is available. *Guidelines for Counseling*, *supra* note 11, at 511. Dr. Howard L. Minkoff from the State University of New York Health Science Center at Brooklyn recommends counseling infected pregnant women about: (1) the impact of HIV on pregnancy and the effect of pregnancy on progression of the disease; (2) the risk of transmission of HIV to the child; and (3) the risk of transmission to sexual partners and possible infection in older children. Minkoff, *supra* note 26, at 2714-15.

Another article on this issue discussed the problems inherent in establishing a prenatal program to screen and counsel for HIV. Sachs, Tuomala & Frigoletto, *Acquired Immuno-deficiency Syndrome: Suggested Protocol for Counseling and Screening in Pregnancy*, 70 OB. & GYN. 408 (1987) [hereinafter *Protocol for Pregnancy*]. These authors set up a voluntary program and positive patients were "provided counseling, which includes the option of an induced abortion." The test is repeated during the third trimester and "[i]f the patient has seroconverted or initially decided against the option of an induced abortion (where recommended), counseling is provided and the pediatric service notified." *Id.* at 409. In this program the counseling is uniform and performed by specially trained social workers and nurses. This counseling includes the following information: "[t]he exact risk of an infant's developing AIDS-related illness is unknown, but may be as high as 65%. The patient is offered the option to terminate the pregnancy; if this is unacceptable, pediatric follow-up . . . is arranged. . . . Counseling services are made available to discuss the issues of future childbearing." *Id.* at 410. Counseling is done prior to testing and includes a discussion of the disadvantages of being tested. In addition, a written consent form must be signed. *Id.*

34. One commentator notes that women, regardless of color or education level, are less likely than men to question doctor's orders. Nsiah-Jefferson, *Reproductive Laws, Women of Color, and Low-Income Women*, 11 WOMEN'S RTS. L. REP. 15, 26 (1989).

35. In fact, there is evidence to the contrary. There is evidence that among medical residents the AIDS epidemic has created a high perception of risk and a dislike for HIV patients. Cooke & Sande, *Sounding Board: The HIV Epidemic and Training in Internal Medicine*, 321 NEW ENG. J. MED. 1334, 1334-35 (1989). The medical literature indicates that practitioners

Some individuals argue that HIV-infected pregnant women should be counseled to abort rather than give birth to babies who may be infected and die, or who may shortly become orphans when their infected mothers (and fathers) die of AIDS.<sup>36</sup> This practice constitutes directive counseling. There are two basic forms of medical counseling, directive and nondirective. Directive counseling occurs where the counselor has a duty not only to inform the woman or couple about possible genetic or other outcomes of pregnancy, but also must instruct the woman or couple on whether or not to bear children.<sup>37</sup> Nondirective counseling can take several forms, but tries in varying degrees to preserve the client/patient's autonomy in decision making.<sup>38</sup>

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still are fearful of persons with AIDS. See, e.g., Gerbert, Maguire, Badner, Altman & Stone, *Why Fear Persists: Health Care Professionals and AIDS*, 260 J. A.M.A. 3481 (1988).

In addition, there is evidence of continuing racial bias in medicine. See, e.g., CDC, *Black-White Differences in Cervical Cancer Mortality — United States, 1980-1987*, 263 J. A.M.A. 3001, 3002 (1990) (higher mortality rate for black women from cervical cancer only partly explained by socioeconomic status); Council on Ethical & Judicial Affairs, Am. Medical Ass'n, *Black-White Disparities in Health Care*, 263 J. A.M.A. 2344, 2344 (1990) (noting persistent and often substantial differences in health between blacks and whites, even when blacks have access to the health care system, and citing obstetrics as one of the areas studied); Egbert & Rothman, *Relation Between the Race and Economic Status of Patients and Who Performs Their Surgery*, 297 NEW ENG. J. MED. 90, 90 (1977) (noting that blacks were more likely to be under the care of resident surgeons even when they could afford to pay for medical services); Eisenberg, *Sociologic Influences on Decision-Making by Clinicians*, 90 ANNALS INTERNAL MED. 957, 958 (1979) (noting that the race of the patient can influence clinical decisions); Wenneker & Epstein, *Racial Inequalities in the Use of Procedures for Patients with Ischemic Heart Disease in Massachusetts*, 261 J. A.M.A. 253 (1989) (even taking into account socioeconomic status, patient preference, and severity of disease, study results suggest racial inequality in the use of procedures for patients hospitalized with coronary heart disease).

36. Finck, *Speakers Note AIDS Threat to Black Community*, Am. Med. News, Dec. 11, 1987, at 17 (quoting Dr. Beny J. Primm, President of the Addiction Research & Treatment Corporation in Brooklyn). Ronald Bayer, an associate at the Hastings Center, a medical ethics think tank, and someone who favors nondirective counseling of HIV-infected women, said, "I think it would not be a mistake to say abortion is a good idea." Gross, *Added AIDS Services Are Set for Poor Women*, N.Y. Times, Mar. 7, 1988, at Y17, col. 5 (nat'l ed.).

37. A. ELIAS & G. ANNAS, *REPRODUCTIVE GENETICS AND THE LAW* 42-44 (1987); D. KEVLES, *IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY* 257-58 (1985) ("In the early years of genetic counseling, some geneticists had sought to turn the practice to eugenic advantage — to reduce the incidence of genetic disease in the population, and by extension to reduce the frequency of deleterious genes in what population geneticists were coming to call the human gene pool. To that end, some claimed that it was the counselor's duty not simply to inform couples about the possible genetic outcome of their union but also to instruct them whether or not to bear children at all. Through the fifties, however, the standards of genetic counseling had turned strongly against eugenically oriented advice — that is, advice aimed at the welfare of the gene pool rather than that of the family. The standards also had it that no counselor had the right to tell a couple not to have a child, even for the sake of the couple's own welfare.") (footnote omitted).

38. Dr. John Arras cites three examples of nondirective counseling: (1) nondirective supportive counseling where the counselor simply provides factual information and supports the client/patient in her decision, whatever it is; (2) nondirective probing counseling where the counselor confronts the client/patient with any contradictions between the client/patient's value system and stated wishes; and (3) nondirective educational counseling which he claims respects the decision-making autonomy of the client/patient, but rejects the notion that this autonomy is unfettered. Instead the counselor not only informs, but raises moral issues posed by the client's choices. Arras, *HIV Infection and Reproductive Decisions: An Ethical Analysis* 7-

HIV screening of nonpregnant fertile women raises an additional question, namely whether infected women should be counseled to be sterilized. Many medical personnel believe that infected fertile women, especially poor women who are unmarried intravenous drug users or are the sexual partners of intravenous drug users, have no right to bear children.<sup>39</sup> As one New York physician noted: "There are people out there who would find it suitable if these women [African-American and Latina] stopped having babies altogether. It is too easy to feed into those racist agendas."<sup>40</sup>

### III.

#### A HISTORY OF RACIST MEDICINE

While reproductive freedom issues affect all women, HIV screening and counseling policies directed at women will have a disproportionate impact on women of color, especially African-American and Latina women. Given the history of racist medicine sanctioned by the United States government,<sup>41</sup> there is ample reason to be suspicious of policies developed by federal and state governmental entities that disproportionately impact on women of color. Specifically, there is a history of sterilization abuse by government employees against women of color. For example, medical residents in many public teaching hospitals have forced women of color to be sterilized so that they could get more practice at performing tubal ligations and hysterectomies.<sup>42</sup> More than

9, Presentation at The Fifth International Conference on AIDS, Montreal, Canada (June 4-9, 1989) (on file with author). Dr. John Arras is philosopher in residence and Associate Professor in the Department of Epidemiology and Social Medicine at Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, New York.

39. Donovan, *AIDS and Family Planning Clinics: Confronting the Crises*, 19 FAM. PLAN. PERSP. 111 (1987).

40. Gross, *Bleak Lives: Women Carrying AIDS*, N.Y. Times, Aug. 27, 1987, at A1, col. 1, B5, col. 3 (quoting Dr. Peter A. Selwyn of the Montefior Medical Center in Boston).

41. See, e.g., A. CHASE, *THE LEGACY OF MALTHUS: THE SOCIAL COST OF NEW SCIENTIFIC RACISM* (1980); J. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1981); J. HALLER, *OUTCASTS FROM EVOLUTION: SCIENTIFIC ATTITUDES OF RACIAL INFERIORITY 1859-1900* (1971); T. SAVITT, *MEDICINE AND SLAVERY: THE HEALTH CARE AND DISEASES OF BLACKS IN ANTEBELLUM VIRGINIA* (1978); W. STANTON, *THE LEOPARD'S SPOTS: SCIENTIFIC ATTITUDES TOWARD RACE IN AMERICA 1815-1859* (1968). The most recent highly publicized example of race medicine involves the Tuskegee Syphilis Experiment conducted by the Public Health Service from 1932 to 1972 on more than 400 African-American sharecroppers and day laborers in Alabama. This government study was designed to determine the effects of untreated syphilis in African-American males, and medical treatment was intentionally withheld from the study subjects who thought they were being treated for all medical conditions. The study was conducted despite the fact that it violated state law. J. JONES, *supra*. For a discussion of racist medical and social assumptions underlying the initiation of the Tuskegee Study, see Brandt, *Racism and Research: The Case of the Tuskegee Syphilis Study*, HASTINGS CENTER REP., Dec. 1978, at 21. For another example of racist medicine, see Axelsen, *Women Victims of Medical Experimentation: J. Marion Sims' Surgery on Slave Women, 1845-1850*, 2 SAGE 10 (1985).

42. Larned, *The Epidemic in Unnecessary Hysterectomy*, in SEIZING OUR BODIES 202 (C. Driefus ed. 1977). See generally Asaro, *The Judicial Portrayal of the Physician in Abortion and Sterilization Decisions: The Use and Abuse of Medical Discretion*, 6 HARV. WOMEN'S L.J. 51, 93-101 (1983); Grosboll, *Sterilization Abuse: Current State of the Law and Remedies for Abuse*,

twenty-five percent of native American women are sterilized; in one year alone, 132 women were sterilized at the federally operated Claremore, Oklahoma Indian Hospital.<sup>43</sup> Forty-three percent of the women sterilized in federally funded population programs are African-American.<sup>44</sup> Latina women fare no better. As recently as 1981, a psychologist found that sixty-five percent of Puerto Rican women in Hartford, Connecticut and fifty-five percent of all Latina women in Springfield, Massachusetts had been sterilized.<sup>45</sup> Some of these women undoubtedly wanted to be sterilized, but paternalistic attitudes about poor women and women of color often cause physicians to believe that sterilization is the only method of birth control poor women of color are capable of handling.<sup>46</sup>

In the 1970s, disclosure that an illiterate African-American mother was tricked under the auspices of an Office of Economic Opportunity program into consenting to the sterilization of her two daughters, ages 12 and 14, helped lead to the requirement of written informed consent and waiting periods where federal funds are used for sterilization.<sup>47</sup> Even with this requirement, thousands of poor women, usually women of color, continue to be sterilized without their informed consent.<sup>48</sup>

Another chilling example is the sterilization between 1971 and 1974 of ten nonconsenting Mexican-American women by a public hospital in Los Angeles. The women sued and presented evidence that the hospital staff pressured the women to consent during intensive labor by: (1) withholding

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10 GOLDEN GATE L. REV. 1147, 1153-56 (1980); Nsiah-Jefferson, *supra* note 34, at 20-23, 30-32.

43. G. GREER, *SEX AND DESTINY: THE POLITICS OF HUMAN FERTILITY* 133 (1984).

44. *Id.* at 331.

45. Nsiah-Jefferson, *supra* note 34, at 31 n.120 (citing personal communication from Dr. Vickie Barnes, Brookside Family Health Center, Jamaica Plain, Boston, Apr. 1985). The author discusses several other forms of sterilization abuse like the removal of female reproductive organs from women with fibroid tumors. *Id.* at 31.

46. *Id.* (citing MARTHA ELIOT HEALTH CENTER, *REPRODUCTIVE HEALTH REPORT* 1-2 (1985)) ("Classism and racism lead physicians and other health care providers to urge sterilization on patients they believe incapable of using other methods effectively. For example, a Boston clinic serving primarily black clients reported that 45 percent of its black clients 'chose' tubal ligation as a method of birth control after their first child was born."). For a more detailed discussion of subtle forms of sterilization abuse, see Clarke, *Subtle Forms of Sterilization Abuse: A Reproductive Rights Analysis*, in *TEST TUBE WOMEN* 188, 199 (R. Ardititi, R. Klein & S. Minden eds. 1989).

47. D. KEVLES, *supra* note 37, at 275-76 (1985). Their mother thought that her 'X' on the paper authorized her daughters to receive "shots." *Id.* at 276; see also *Relf v. Weinberger*, 372 F. Supp. 1196 (D.D.C. 1974), *vacated*, 565 F.2d 722 (D.C. Cir. 1977); 42 C.F.R. §§ 441.250-.259 (1988); 42 C.F.R. §§ 50.201-.210 (1989) (regulations requiring written informed consent and waiting periods).

48. Magar, *Medicaid Sterilization Rules Violated: Group*, 67 A.B.A. J. 1249 (1981) (reporting alleged violations of the age and waiting period requirement and noting that it is impossible to document continuing abuses without information supplied by health care workers). Another reason the federal regulations are often ignored is there are no civil or criminal sanctions imposed for violations. The only sanction is loss of reimbursement for the sterilization. *Id.*; 42 U.S.C. § 1397(a)(1) (1982). This is not a very effective sanction for a doctor in a public hospital who is on salary. Magar, *supra*.

medication, (2) not informing women that the procedure was permanent, or (3) pressuring some husbands to sign consent forms after their wives refused.<sup>49</sup> In some cases no attempt was made to obtain consent.<sup>50</sup> The women's lawyers presented testimony for two and a half weeks to support their claim that the plaintiffs had not given informed consent.

The defendants presented no opposing expert witnesses or rebuttal of plaintiffs' witnesses, nor did they cross-examine the plaintiffs. Instead, they called each of the physicians in question to comment on the medical procedures used. Each physician asserted that the women consented despite the language barrier.<sup>51</sup> The federal trial judge entered judgment for the defendants, finding that there was a breakdown in communication between the women and the physicians, and that the physicians could not be blamed for misinterpreting the women's actions.<sup>52</sup>

Given the racial composition of women currently identified as infected with HIV, and in light of the recent history of abuse, there is reason to believe that the abuse of reproductive rights will continue with HIV-infected women. Recently in New Mexico a Latina with AIDS who lacked money for an abortion was offered a free abortion only if she submitted to a tubal ligation.<sup>53</sup> In addition, some people alarmed at the increased number of pregnant drug addicts, many of whom are poor women of color, are calling for sterilization of all drug addicted women of childbearing age.<sup>54</sup> Since a large number of HIV-infected women are also drug users, there is reason to believe fertile HIV-infected women will be viewed similarly.<sup>55</sup>

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49. Velez-I., *The Nonconsenting Sterilization of Mexican Women in Los Angeles*, in *TWICE A MINORITY: MEXICAN-AMERICAN WOMEN* 235, 240, 242 (M. Melville ed. 1980).

50. *Id.* at 240.

51. *See id.* at 244-45 (physicians testified that they spoke "obstetrics spanish" and all the women were Spanish-speaking and spoke limited English.).

52. *Madrigal v. Quilligan*, No. CV 75-2057 JWC, slip op. at 6 (C.D. Cal. June 30, 1978).

53. Abraham, *Pregnant Women Face AIDS Dilemma*, *Am. Med. News*, July 22, 1988, at 35 (citing Jane Aiken, a law professor at Arizona State University and an attorney for Mobilization Against AIDS in Phoenix).

54. *Ideas & Trends: Punishing Pregnant Addicts: Debate, Dismay, No Solution*, *N.Y. Times*, Sept. 10, 1989, at E5, col. 1 (late ed.) (citing Dr. Jan Bays, Director of Child Abuse Programs at Emanuel Hospital in Portland, Oregon who said: "I consider myself quite liberal and never would have thought this a few years ago. But now I'm fed up with seeing damaged babies born who lost the right to make what they can out of life. . . . But we can't force people into treatment [for drug addiction], even if they're in jail. She can go out and have more children. So, people are talking about sterilization and that gets into reproductive rights. . . . We can't say forever that people have unlimited rights to have a child"); *see also* Boyer, *Time To Sterilize Addicted Mothers*, *Blue Bell, Pa., Observer*, Sept. 6, 1989, at 32 (wherein a columnist in a Philadelphia area newspaper wrote that "[w]omen who are irresponsible enough to become pregnant over and over while addicted to harmful drugs do not deserve to crow about their civil rights." The writer advocates the "temporary" sterilization of women of childbearing age who are addicts suggesting that a contraceptive implant, Norplant, be used).

55. In fact, at the Fifth International Conference on AIDS held in Montreal, Canada, June 4-9, 1989, at least one panelist discussing HIV infection and reproductive decision making argued that it might be ethical to counsel women infected with HIV not to have children; it might even be ethical, he implied, to counsel pregnant women infected with HIV to abort. He did, however, stop short of calling for sterilization of infected women. Arras, *supra* note 38.

Despite the history of racist public medicine in this country, and the current disproportionate impact of HIV screening policies on women of color, the equal protection clause is unlikely to afford any relief. While proof that a facially neutral government policy has a disparate impact on women of color may be evidence of a racially discriminatory intent, the existence of a disparate impact alone is not enough to trigger strict scrutiny of the policy by the courts.<sup>56</sup> The courts look for additional factors to satisfy the racial animus requirement.<sup>57</sup> The existence of blatant racist medical practices by the Public Health Service into the 1970s,<sup>58</sup> and the more limited access to medical care which African-Americans from all income levels receive due to lingering racial discrimination,<sup>59</sup> would not be enough for courts to find an intent to discriminate in the initiation of routine prenatal HIV screening programs.<sup>60</sup>

The difficulty of demonstrating racial animus (intent to discriminate) in

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56. *Village of Arlington Heights v. Metropolitan Hous. Dev. Corp.*, 429 U.S. 252, 266 (1977); *Washington v. Davis*, 426 U.S. 229, 241 (1976).

Even though screening programs would be directed only at infected women of childbearing age, it would be difficult to challenge routine HIV prenatal screening on pure sex discrimination grounds in light of *Geduldig v. Aiello*, 417 U.S. 484 (1974). In *Geduldig*, the Court upheld California's disability insurance program which exempted from coverage work loss due to pregnancy. Justice Stewart, writing for the majority, wrote: "[I]t does not follow that every legislative classification concerning pregnancy is a sex based classification." The Court noted that it is necessary to show that pregnancy is merely a pretext for some intentional gender-based discrimination. *Id.* at 496 n.20. Since *Geduldig*, the courts consistently have refused to recognize sex equality claims based on reproductive differences. One recent example of the courts' hostile attitude toward pregnancy is *International Union v. Johnson Controls, Inc.*, 886 F.2d 871 (7th Cir. 1989) (en banc) (upholding trial court decision that an employer's "fetal protection" policy precluding fertile women, but not men, from working in high lead exposure position was a bona fide occupational qualification under Title VII), *cert. granted*, 110 S. Ct. 1522 (1990). For early discussions of the failure of formal equality doctrines to provide real equality for women engaged in childbearing, see Freedman, *Sex Equality, Sex Differences, and the Supreme Court*, 92 YALE L.J. 913, 931-37 (1983); Law, *Rethinking Sex and the Constitution*, 132 U. PA. L. REV. 955, 982-1002 (1984); Scales, *Towards a Feminist Jurisprudence*, 56 IND. L.J. 375, 398 (1981). The dialogue between feminist scholars on this issue continues and has developed various alternative dialogues. For a discussion of the differences among feminist legal scholars on this issue, see Williams, *Deconstructing Gender*, 87 MICH. L. REV. 797 (1989).

57. *Arlington Heights*, 429 U.S. at 267-68 (factors examined include history of the problem sought to be remedied and legislative or administrative history).

58. See *supra* notes 41-52 and accompanying text (discussions of the Tuskegee experiment and sterilization abuse).

59. See generally REPORT ON MINORITY HEALTH, *supra* note 1. Former Surgeon General C. Everett Koop said that improved access to health care for blacks and Hispanics is essential to the fight against AIDS. He also said that discrimination in access to health care, language problems, and poverty are as much at the heart of the epidemic as drug use and promiscuity. *Koop Cites Poverty and Bias as Factors in AIDS Spread*, N.Y. Times, Nov. 15, 1988, at C9, col. 3; see also *supra* note 35.

60. Even if racial animus were a factor, but not the primary motivating factor, in the implementation of the policy, it would be difficult to strike down under current equal protection doctrines. See *Hunter v. Underwood*, 471 U.S. 222, 232 (1985); *Arlington Heights*, 429 U.S. at 270-71 n.21. But even if an intent to discriminate could be shown, because the discrimination is directed only at African-American and Latina women, courts would likely try to characterize the action as a sex-based rather than a race-based claim. For a discussion of the failure of claims by African-American women, see Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and An-*

order to trigger strict scrutiny of government-conceived screening measures, coupled with the courts' traditional deference to health care policies,<sup>61</sup> makes an equal protection argument difficult in this case. The unavailability of a strong equal protection argument in the face of past and lingering racial bias in medicine and medical policies illustrates the failure of formal equality doctrines to provide women and men of color protection from real and harmful discriminatory actions by government. The requirement of proof of intent before racial discrimination is considered unlawful under the equal protection clause legitimizes discriminatory policies that result from "unconscious" or structural racial bias.<sup>62</sup>

#### IV.

### A CRITIQUE OF POLICIES FOR STEMMING PERINATAL TRANSMISSION OF HIV

#### A. Prenatal Screening

##### 1. In General

Public health regulations in some states mandate prenatal screening of pregnant women for certain medical conditions like syphilis,<sup>63</sup> maternal rubella, blood group, and RH status.<sup>64</sup> All of these conditions, if detected prior to the end of pregnancy, can be treated and the fetus protected.

There is a second category of health-threatening, but detectable, conditions that usually is not subject to mandatory or routine screening. Tests for sickle cell disease, Tay-Sachs, and other diseases of genetic origin generally are

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*tiracist Policies*, 1989 U. CHI. L.F. 139; Scales-Trent, *Black Women and the Constitution: Finding Our Place, Asserting Our Rights*, 24 HARV. C.R.-C.L. L. REV. 9 (1989).

61. See, e.g., *Jacobson v. Massachusetts*, 197 U.S. 11 (1905) (upholding compulsory smallpox vaccination law). But cf. *New York Ass'n for Retarded Children v. Carey*, 612 F.2d 644, 648 (2d Cir. 1979) (holding that public health agencies must adhere to constitutional and statutory standards). *Carey* indicates that current courts may not be as deferential to public health regulations that disproportionately impact people against whom such regulations have been applied discriminatorily in the past.

62. For a discussion of anti-discrimination law's failure to address adequately actual racial discrimination, see Crenshaw, *Race, Reform and Retrenchment: Transformation and Legitimation in Antidiscrimination Law*, 101 HARV. L. REV. 1331 (1988) (discussing the impact of liberal and radical scholarship on legal thinking about anti-discrimination law); Lawrence, *The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism*, 39 STAN. L. REV. 317 (1987) (critiquing the theories to determine suspect classification).

63. ARIZ. REV. STAT. ANN. § 36-694(B) (1986). See also CAL. HEALTH & SAFETY CODE § 3222-23 (West 1979); COLO. REV. STAT. § 25-4-201 (1989); CONN. GEN. STAT. ANN. § 19a-90 (West 1986); ILL. ANN. STAT. ch. 111 1/2, para. 4801 (Smith-Hurd 1988); N.J. STAT. ANN. § 26:4-49.1 (West 1987); N.M. STAT. ANN. § 24-1-10 (1978); N.Y. PUB. HEALTH LAW § 2308 (McKinney 1985); OHIO REV. CODE ANN. § 3701.50 (Anderson 1988); OKLA. STAT. ANN. tit. 63, § 1-515 (West 1984); TENN. CODE ANN. § 68-5-602 (1987); TEX. REV. CIV. STAT. ANN. art. 4419b-1 (Vernon 1976); WYO. STAT. § 35-4-502 (1977) (all specifying mandatory prenatal testing for syphilis).

64. Smith, *Genetics, Eugenics, and Public Policy*, 1985 S. ILL. L. REV. 435, 442 (citing Frankel, *The Specter of Eugenics*, 57 COMMENTARY 25, 29 (1974)).

not required or performed routinely.<sup>65</sup> In 1970 when an inexpensive and reliable test for sickle cell hemoglobin was developed, several states enacted mandatory screening programs which resulted in unjustifiable discrimination against African-Americans.<sup>66</sup> Subsequently, six states (Georgia, Illinois, Maryland, Massachusetts, New York, and Virginia) and the District of Columbia repealed their mandatory screening laws.<sup>67</sup> Currently, the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act authorizes federal grants for voluntary genetic testing and counseling programs.<sup>68</sup>

Amniocentesis, which tests for chromosomal abnormalities and hereditary diseases and is recommended for pregnant women over thirty-five years of age, is also not required.<sup>69</sup> It is performed only with the informed consent of the woman. In fact, amniocentesis is not recommended for all pregnant women because of the fear that the test might lead to unnecessary abortions.<sup>70</sup> What distinguishes the first from this second category of medical conditions is that the latter cannot be treated prior to delivery and can only be avoided by not becoming pregnant or by abortion.

Since few genetic diseases respond to medical treatment, the primary purpose of genetic testing is to detect carriers and counsel fertile women about the genetic risks of childbearing.<sup>71</sup> Therefore, voluntary testing, as opposed to routine screening, for genetic conditions is encouraged.

There are three types of genetic testing: (1) screening of newborns, (2) carrier screening, and (3) prenatal screening.<sup>72</sup> Carrier testing is offered to persons of reproductive age to detect recessive disorders before conception.<sup>73</sup> Prenatal screening is used to determine whether the fetus has genetic disorders or congenital defects.<sup>74</sup>

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65. P. REILLY, *GENETICS, LAW AND SOCIAL POLICY* 102-06 (1977).

66. *Id.* at 72-74.

67. Comment, *Sickle Cell Legislation: Beneficence or "The New Ghetto Hustle"?*, 13 J. FAM. L. 278, 278 n.6 (1973-1974).

68. 42 U.S.C. §§ 300b-1 to 300b-6 (1988).

69. UNITED STATES DEP'T OF HEALTH, EDUC. & WELFARE, TASK FORCE REPORT: PREDICTIONS OF HEREDITARY DISEASE OR CONGENITAL DEFECTS, CONSENSUS DEVELOPMENT CONFERENCE ON ANTENATAL DIAGNOSIS 35-47 (1979).

Amniocentesis, developed during the late 1960s and 1970s, is a reliable and safe prenatal screening test. It is usually performed during the 14th or 16th week of pregnancy. A needle attached to a syringe is inserted into the uterus and a sample of the fluid surrounding the fetus is removed. This sample, which contains fetal cells, is cultured for two to four weeks. The cultured cells are then examined for any of approximately one hundred genetic conditions. Warren, *The Law of Human Reproduction: An Overview*, 3 J. LEGAL MED. 1, 49-50 (1982).

70. Annas, *Is a Genetic Screening Test Ready When the Lawyers Say It Is?*, HASTINGS CENTER REP., Dec. 1985, at 16.

71. Note, *The Constitutionality of Mandatory Genetic Screening Statutes*, 31 CASE W. RES. L. REV. 897, 905 (1981).

72. SCREENING AND COUNSELING FOR GENETIC CONDITIONS, *supra* note 17, at 11-12. Genetic screening as used in this Article refers primarily to prenatal or carrier screening.

73. *Id.* at 17-18.

74. *Id.* at 23.



There are four reasons given to justify mandatory or routine genetic screening: (1) to save society money by controlling health costs; (2) to allocate resources fairly; (3) to improve society's "genetic health"; and (4) to protect the helpless from harm.<sup>75</sup> Ethicists believe that only the last argument is sufficiently plausible to justify compulsory genetic screening.<sup>76</sup> Even when compulsory genetic screening is appropriate, it should be implemented only after voluntary measures have failed.<sup>77</sup> Further, compulsory genetic screening measures when initiated must not only reach the targeted population, but also must provide for needed follow-up services, something that rarely occurs in practice.<sup>78</sup>

Screening pregnant women for HIV is much like genetic screening in that currently there is no medical cure for the infection and the virus can be transmitted to another.<sup>79</sup> HIV infection, like several genetic conditions, may result in death or serious medical complications. Like genetic conditions, voluntary testing as opposed to routine HIV screening should be the standard practice.

## 2. HIV Prenatal Screening

Screening for reproductive reasons is inherently genetic.<sup>80</sup> Proponents of

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75. *Id.* at 47-52.

76. *Id.* at 50-51.

77. *Id.*

78. *Id.* at 52. Lawrence Gostin and two other public health specialists assert that HIV screening of selected populations is unlikely to result in any real benefit to the public health service since currently there is no effective treatment or cure for an HIV infection. *Controlling AIDS*, *supra* note 17, at 19. They argue that the personal and economic costs of compulsory screening programs far outweigh any benefit to public health. *Id.* at 20. Gostin sets forth five criteria to apply when evaluating compulsory screening proposals. First, any screening should be directed toward a narrowly targeted population with a potentially high rate of infection. Second, the population targeted for screening must also pose a high risk of transmitting the infection to others. Third, if all persons within the targeted population are to be screened, then the information obtained must be used to effectively minimize the risk of transmission. Fourth, the consequences to the individual of screening should not outweigh the benefits to public health. Fifth, there must be no less restrictive or intrusive means to accomplish the public health objective. *Id.* at 21-24. Applying these criteria to routine HIV prenatal screening, the first two are met, but there are questions about the remaining three.

There is much controversy over recent assertions that early treatment intervention with zidovudine (also known as AZT) slows the progression of the virus in asymptomatic infected individuals. Compare NISID, *Recommendations for Zidovudine: Early Infection*, 263 J. A.M.A. 1606 (1990) (National Institutes of Health recommendation for early intervention with AZT) and Volberding, Lagakos, Koch, Pettinelli, Myers, Booth, Balfour, Reichman, J.A. Bartlett, Hirsch, Murphy, Hardy, Soeiro, Fischl, J.G. Bartlett, Merigan, Hyslop, Richman, Valentine, Corey & AIDS Clinical Trial Group of NIAID, *Zidovudine in Asymptomatic Human Immunodeficiency Virus Infection*, 322 NEW ENG. J. MED. 941 (1990) (favors early intervention) with Cotton, *Controversy Continues as Experts Ponder Zidovudine's Role in Early HIV Infection*, 263 J. A.M.A. 1605 (1990) (reporting that investigators at the Veteran's Administration and in Europe are skeptical about the early use of AZT, especially in light of the short clinical study — less than one year) and Friedland, *Early Treatment for HIV: The Time Has Come*, 322 NEW ENG. J. MED. 1000 (1990) (worries that early intervention may cause patients to become resistant to AZT).

79. *Controlling AIDS*, *supra* note 17, at 19.

80. SCREENING AND COUNSELING FOR GENETIC CONDITIONS, *supra* note 17, at 3.

routine HIV prenatal screening raise the same arguments as proponents of compulsory or routine genetic screening. Assuming that the first three arguments for mandatory or routine genetic screening are not valid bases for imposing mandatory or routine HIV prenatal screening, I turn to the fourth argument that preventing a medical condition which threatens the health of a woman or fetus and which can be detected before or during pregnancy is clearly an important state goal.

First, there has been no showing that voluntary HIV testing has been ineffective.<sup>81</sup> In fact, until very recently there were no voluntary HIV testing programs directed toward women who might be at risk.<sup>82</sup> Second, routine HIV screening proposals tend to ignore follow-up services. These services can be costly, and they rarely are provided unless private insurance pays for them.<sup>83</sup> If needed follow-up services are not available to fertile HIV-infected women, little is gained by screening.

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81. See Walters, *Ethical Issues in the Prevention and Treatment of HIV Infection and AIDS*, 239 SCIENCE 597, 599 (1988) ("To date, most commentators on the ethics of HIV antibody screening have argued that only carefully targeted, voluntary screening programs are morally justifiable and that such programs are morally justified only if they fulfill three conditions: (i) the programs include adequate counseling of screenees; (ii) they protect the confidentiality of information about individuals, except in carefully specified exceptional circumstances; and (iii) they are conducted in a context that provides guarantees of nondiscrimination to seropositive individuals.").

To date, publicly funded voluntary HIV testing programs have been directed toward the gay and bisexual community. Only 12.6% of the programs have been available at family planning centers; 10.1% at prenatal/obstetrics clinics; and 3.5% at drug-treatment centers. CDC, *Publicly Funded HIV Counseling and Testing — United States, 1985-1989*, 39 MORBIDITY & MORTALITY WEEKLY REP. 137 (1990).

82. Two authors writing in a medical journal allege that women at risk for exposure to HIV are often discouraged from having the test. *Women and AIDS*, *supra* note 2, at 158.

"With little exception, HIV research and programs have focused exclusively on homosexual men and intravenous drug users. As a result, there is limited information about the course of HIV infection in women." REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC 13 (1988) [hereinafter PRESIDENTIAL AIDS COMMISSION].

A letter in a prominent medical journal alleges that although the first reported diagnosis of a woman with AIDS occurred in 1981 in New York City, the earliest reported birth in New York City of a baby with AIDS, where maternal transmission was presumed, was in 1977. Thomas, O'Donnell, Williams & Chiasson, *HIV Infection in Heterosexual Female Intravenous Drug Users in New York City*, 319 NEW ENG. J. MED. 374, 374 (1988) (letter from New York City Dep't of Health); see also Lambert, *Unlikely AIDS Sufferer's Message: Don't Think It Can't Happen To You*, N.Y. Times, Mar. 12, 1989, at 29, col. 1 (upper class white woman with AIDS who was not tested earlier because of her background).

83. Several health care providers warn that sound screening programs for pregnant women are costly. See, e.g., *Protocol for Pregnancy*, *supra* note 33, at 411 ("At this time, with only a few pregnant patients who are human immunodeficiency virus-positive, it is possible to provide such a service. But we are concerned that if the incidence increases, we will be forced to cut corners."); Selwyn, Carter, Schoenbaum, 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, 3568 (1989) [hereinafter *Knowledge of HIV Antibody Status*] ("Given the likelihood of more widespread HIV antibody testing during pregnancy, and the consequent identification of infected women, it is critical that sufficient resources to provide such support and follow-up be made available in all areas where testing is undertaken.").

On the other hand, the HIV antibody test is a simple blood test which poses no significant medical risk to women. Many women, upon learning of their antibody status, voluntarily choose to either terminate or forego pregnancy.<sup>84</sup> HIV prenatal screening can also provide an indirect benefit to the fetus since physicians might be able to detect an HIV-infected fetus earlier and perhaps prolong its life after it is born.<sup>85</sup> In addition, public health officials have a long history of mandatory and routine screening for sexually transmitted diseases,<sup>86</sup> and HIV can be transmitted sexually.

Opponents of genetic screening argue that because few genetic diseases respond to medical treatment, the real function of screening is detection of carriers to discourage them from having children.<sup>87</sup> They contend that this purpose threatens women's reproductive freedom, and, when done by the state or federal government, raises serious right to privacy issues.<sup>88</sup>

The practical value of routine HIV prenatal screening is also questionable. Screening may mean fewer health benefits to women since the medical community remains uncertain about the effects of pregnancy on HIV-infected women.<sup>89</sup> Moreover, most information gained through prenatal screening can be discovered through newborn screening.<sup>90</sup> Thus, although the stated health interest — protection of the health of the mother and the fetus — could be

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84. See *supra* notes 122-28 and accompanying text.

85. A wrongful birth or wrongful life action might lie against a physician who failed to determine that the HIV-infected infant's mother was infected and capable of transmitting the virus perinatally. See Note, *Genetic Screening, Eugenic Abortion, and Roe v. Wade: How Viable Is Roe's Viability Standard?*, 50 BROOKLYN L. REV. 113, 137-41 (1983). Theoretically the fetus may benefit by not being born if there is a substantial risk that it will be infected with the virus.

86. A. BRANDT, *supra* note 14, at 85. By 1918 thirty-two states had laws requiring compulsory examination of prostitutes for venereal disease. *Id.*; see, e.g., *Reynolds v. McNichols*, 488 F.2d 1378 (10th Cir. 1973) (upholding regulation allowing detention of one suspected of having a venereal disease); *People ex rel. Baker v. Strautz*, 386 Ill. 360, 54 N.E.2d 441 (1944) (upholding detention of prostitutes without bond for examination of venereal disease); *Ex parte Company*, 106 Ohio 50, 139 N.E. 204 (1922) (regulation authorizing quarantine of persons suspected of having venereal disease). But cf. *Wragg v. Griffin*, 185 Iowa 243, 252-53, 170 N.W. 400, 402-03 (1919) (Iowa Supreme Court held that one cannot be compelled to give blood on a mere suspicion that she has a venereal disease).

87. Note, *supra* note 71, at 905.

88. Waltz & Thigpen, *Genetic Screening and Counseling: The Legal and Ethical Issues*, 68 Nw. U.L. REV. 696, 711-12 (1973). See generally Note, *supra* note 71.

89. Early reports expressed concern that pregnancy accelerated the progression of the disease. Today, however, there is little evidence that pregnancy will enhance the disease's progression. No information is available on the impact of abortion during the first or second trimester on the disease's progression. Minkoff, *supra* note 26. "Although uncontrolled observations from two studies suggest a high frequency of AIDS and associated conditions in women during the months after delivery, the identification or selection of cases to follow could be biased and the variable that is probably the most important in determining clinical HIV infection — duration of infection — is unknown in almost all cases." Allen & Curran, *Prevention of AIDS and HIV Infections: Needs and Priorities for Epidemiologic Research*, 78 AM. J. PUB. HEALTH 381, 383 (1988).

90. Levine & Bayer, *supra* note 27, at 1662 (the level of test accuracy for infants varies quite a bit since infants born to infected mothers may test positive for up to 15 or 16 months following birth, but not be infected). There is no proven treatment for asymptomatic infected

sufficient to permit routine screening, the actual screening procedure does not usually accomplish this purpose. Intensive educational programs directed at women of childbearing age, accompanied by access to free or low cost voluntary testing, might be as effective.

Additionally, routine HIV prenatal screening may prompt many HIV-infected women to forego needed prenatal care to avoid detection of their antibody status. These women have good cause to be afraid that HIV prenatal screening will affect their access to further health care. There are anecdotes of obstetricians refusing to care for pregnant women unless they are screened for HIV.<sup>91</sup> In such cases consent to screen, if requested, is obtained by coercion.<sup>92</sup> Further, because of the lack of opportunity to consider specific adverse consequences, routine HIV prenatal screening which relies on a general consent form may not constitute informed consent, especially when there is no pre-test counseling.<sup>93</sup>

The stigma of a positive HIV antibody test — loss of employment, insurance, housing, and other economic or social harm — provides another reason for women who suspect they are infected with HIV to avoid routine prenatal screening.<sup>94</sup> Even though persons infected with HIV or AIDS have some pro-

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infants. *Id.* There is also controversy over using experimental treatments on infants. *Id.* at 1663.

91. There are reports that, at an Atlanta hospital that does routine HIV prenatal screening, women sign a general consent form and there is no pre-test counseling. Abraham, *Pregnant Women Face AIDS Dilemma*, Am. Med. News, July 22, 1988, at 35. The testing functions primarily to protect the hospital staff because "universal precautions are still not widely used." *Id.*

92. See, e.g., Sullivan, *Unconstitutional Conditions*, 102 HARV. L. REV. 1415 (1989) (government may not grant a benefit conditioned on the surrender of a constitutional right.).

93. There are two different standards for informed consent. The older, traditional standard holds that informed consent is only required where the medical practice or procedure deviates from the accepted medical practice of a reasonable physician in similar circumstances. The more modern view, called the prudent patient standard, requires the physician to provide all the information a reasonable patient would need to make an informed decision. See generally Comment, *Informed Consent: From Disclosure to Patient Participation in Medical Decision-making*, 76 NW. U.L. REV. 172 (1981); Kabnick & Meisel, *Informed Consent to Medical Treatment: An Analysis of Recent Legislation*, 41 U. PITT. L. REV. 407 (1980); Comment, *New Trends in Informed Consent*, 54 NEB. L. REV. 66 (1975).

Most commentators do not consider HIV antibody testing a usual procedure. Eickhoff, *Hospital Policies on HIV Antibody Testing*, 259 J. A.M.A. 1861 (1988) (editorial). "[U]ntil the civil rights issues, which are tragically real, are adequately addressed by society, they will remain of major concern and essentially mandate individual informed consent by the patient to be tested. Ultimately, one hopes that an HIV antibody test may be ordered, on appropriate indication, by physicians in the same way that any other medical diagnostic test may be ordered, but that is unlikely to be the case for years yet to come." *Id.*

Donald Francis, AIDS advisor to the CDC said that the HIV antibody test "is not like any other test. . . . Can you think of any other test in which children's houses are burned down because they have a positive test?" Staver, *CMA Vetoes Restrictive AIDS Related Proposals*, Am. Med. News, Mar. 5, 1988, at 1, 30.

94. The Presidential Commission on the HIV epidemic noted that discrimination against persons with HIV "is impairing this nation's ability to limit the spread of the epidemic." Unless the discrimination is limited, it will be difficult to collect epidemiological data and implement various health strategies. PRESIDENTIAL AIDS COMMISSION, *supra* note 82, at 119; see also

tection from discrimination under federal and some state laws, this protection is not adequate.<sup>95</sup> Many such laws do not apply to housing, health insurance, access to nonemergency health care, or employers with small workforces.<sup>96</sup> Further, the social stigma and economic harm often result from willful or negligent disclosure of a person's HIV antibody status. Currently, no federal law, and few state laws, provide adequate confidentiality guarantees for HIV test results.<sup>97</sup> Finally, as mentioned previously, HIV-infected women may be

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Chalk v. United States Dist. Ct., 840 F.2d 701, *modifying* 832 F.2d 1158 (9th Cir. 1988) (unanimous court ordered injunctive relief for a high school special education teacher with AIDS who was denied a classroom teaching assignment); Schatz, *The AIDS Insurance Crisis: Underwriting or Overreaching?*, 100 HARV. L. REV. 1782 (1987). A positive test result may have another severe, even fatal, consequence because of the intensity of emotional responses upon learning of a positive test result. About half of the AIDS-related suicides occurred in black or Latino patients. Thus the importance of informed consent and counseling in conjunction with HIV screening programs cannot be over-emphasized. Glass, *AIDS and Suicide*, 259 J. A.M.A. 1369 (1988) (editorial). However, women with AIDS seem less likely than men to commit suicide. Marzuk, Tierney, Tardiff, Gross, Morgan, Hsu & Mann, *Increased Risk of Suicide in Persons with AIDS*, 259 J. A.M.A. 1333, 1336 (1988).

95. PRESIDENTIAL AIDS COMMISSION, *supra* note 82, at 119. Several federal laws prohibit discrimination against the disabled, and HIV is considered a handicapping condition. The Americans with Disabilities Act [hereinafter ADA] will greatly increase protection against discrimination because it is not limited to recipients of federal monies. Pub. L. No. 101-336, §§ 101(5), 301(7), 401(a), 104 Stat. 327, 330, 354, 359, 366 (1990). Nevertheless, the ADA cannot be used against employers until July 1992. Pub. L. No. 101-336, § 108, 104 Stat. 337. The ADA does not apply to any public accommodation until January 1992 and will not apply to the smallest public accommodations until July 1994. Pub. L. No. 101-336, § 310, 104 Stat. 365. In the meantime, existing federal law only applies to recipients of federal monies. The private sector is free to discriminate unless prohibited by state law from doing so. More than half of the states prohibit discrimination against the disabled; many of these states' laws cover HIV-infected individuals. *Science Panel, D.C. Group Oppose AIDS Discrimination*, REP. ON DISABILITY PROGRAMS, Jan. 26, 1989, at 13. The major weakness of federal disability and antidiscrimination law is that it only applies to programs receiving federal financial assistance and "does not significantly extend into the private sector." Gostin, *supra* note 30, at 1628. The Fair Housing Amendments Act of 1988 extends protection to the disabled, "so that private landlords and owners may no longer discriminate against people infected with HIV." *Id.* All the states and the District of Columbia provide some protection for the disabled, and 34 states formally or informally recognize HIV infection as a disability. *Id.* Nevertheless the scope of the protection is uneven.

96. PRESIDENTIAL AIDS COMMISSION, *supra* note 82, at 119. Until the ADA becomes effective, existing federal law covers recipients of federal funds who have at least 15 employees. The extent to which antidiscrimination law protects HIV-infected individuals seeking public or private housing is unclear. No federal law and few state laws require health care facilities to treat HIV-infected individuals in nonemergency situations. Under the ADA, health care providers and hospitals are considered places of public accommodation and they will not be able to discriminate in providing services to persons infected with HIV. However, private remedies under the ADA are limited to injunctive relief. Americans With Disabilities Act, Pub. L. No. 101-336, § 301(7)(F), 104 Stat. 327, 354 (1990). Insurance companies are free to deny health care coverage. See generally Dickens, *Legal Rights and Duties in the AIDS Epidemic*, 239 SCIENCE 580 (1988).

97. PRESIDENTIAL AIDS COMMISSION, *supra* note 82, at 119-20. Although most state public health laws have confidentiality provisions, these provisions usually apply only to sexually transmitted diseases. A small number of states have enacted HIV or AIDS specific confidentiality provisions but the degree of protection varies greatly. There is no federal regulation that specifically insures confidentiality of HIV antibody test results. *Controlling AIDS*, *supra* note 17, at 46-47.

coerced or directed to abort if pregnant or to be sterilized if of childbearing age.

Routine HIV prenatal screening is apt to occur in a public setting because the public facilities are more likely to have large numbers of patients at risk. Poor women of color, because of their limited access to adequate health care, are more likely to use these facilities than to seek private health care, and thus a policy of routine HIV screening is more likely to disproportionately affect poor women of color. If routine HIV prenatal screening causes many poor women of color to avoid prenatal medical care, health risks to both mother and fetus will increase,<sup>98</sup> aggravating the high infant mortality rates in urban communities of color.<sup>99</sup> Therefore, the benefits of routine HIV prenatal screening (i.e., knowledge that one is infected) are outweighed by the negative consequences (avoidance of prenatal care, forced or coerced sterilization or abortion, economic harm, and social stigma).

### B. Directive Counseling

#### 1. In General

There is some division over the role of counseling in genetic screening.<sup>100</sup> Some genetic counselors argue that the only valid purpose for counseling is to benefit society by reducing the "genetic load." Under this view, counseling the family is secondary to the goals of directive counseling.<sup>101</sup>

A few of these geneticists contend that persons with genetic trait abnormalities should have no right to bear children.<sup>102</sup> They argue that society has

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98. Former Surgeon General C. Everett Koop opposes mandatory prenatal screening because he fears it would cut down on access to prenatal care for women. Patton, *Resistance and the Erotic: Reclaiming History, Setting Strategy as We Face AIDS*, RADICAL AM., Nov.-Dec. 1986, at 68, 78.

99. For example, less than 50% of Puerto Rican mothers in the United States received prenatal care in their first trimester and 10% received no prenatal care prior to delivery. Worth & Rodriguez, *Latina Women and AIDS*, RADICAL AM., Nov.-Dec. 1986, at 63, 65. The 14th annual report of the nation's health status, *Health United States 1989*, reported that while infant mortality rates improved slightly in 1988, the rate for African-American infants was more than twice that for white infants. Further, only 61% of African-American mothers compared to 79% of white mothers received prenatal care during the first three months of pregnancy. *Health Data Show Wide Gap Between Whites and Blacks*, N.Y. Times, Mar. 23, 1990, at A17, col. 1. In addition, during the past decade the number of pregnant women who received either no prenatal care or care late in their pregnancy increased dramatically. *Infant Deaths*, Wash. Post, Mar. 13, 1990, at A24, col. 1 (editorial).

100. Note, *supra* note 71, at 908 (citing Lappe, *The Genetic Counselor: Responsible to Whom?*, HASTINGS CENTER REP., Sept. 1971, at 6).

101. *Id.*

102. Responding to the remarks of noted geneticist Professor Hermann Mueller, Francis Clark, co-discoverer of the structure of DNA, said in 1962 that there should be no right to have children, especially for persons with genetic problems. G. GREER, *supra* note 43, at 342 (citing G. WOLSTENHOLME, *MAN AND HIS FUTURE* 259 (1963)). More recently another commentator remarked: "Perhaps world conditions have become so complex and resources so valuable that society now has a compelling interest in restricting reproduction by those who, although not (manifestly unfit) themselves, perpetuate human suffering by giving birth to genetically defective offspring." Smith, *supra* note 64, at 446-47.

an interest in prohibiting people with genetic disorders or conditions from perpetuating human suffering by giving birth to children who are genetically "defective."<sup>103</sup> In fact, directive genetic counseling was used by some geneticists in the early part of this century to eugenic advantage.<sup>104</sup> Specifically, these geneticists used directive counseling to reduce the incidence of genetic disease in the general population. They actively advocated the sterilization of those deemed "genetically unfit"; women of color were included in this category.<sup>105</sup>

The advice offered by a counselor doing directive genetic counseling depends on the extent of the risk. There are three categories of genetic risks: (1) random risk where the chance of transmission of the genetic condition is no greater than the risk for any population, (2) high risk where the chance of transmission is at least one in ten and more often one in four, and (3) moderate risk where the chance of transmission is less than one in ten, but greater than one in thirty.<sup>106</sup> Most couples involved in genetic counseling accept moderate risks and avoid high ones.<sup>107</sup> Some prospective parents choose to abort the fetus when provided negative information while others will not.<sup>103</sup>

Other genetic counselors argue that personal counseling of the family about the genetic risks of childbearing is the only valid purpose of screening.<sup>109</sup> These individuals favor nondirective counseling. They argue that a genetic counselor has no right to tell a woman or couple not to have a child, even where the risk of transmitting a serious genetic disorder or congenital defect is great.<sup>110</sup> This approach is currently favored by most genetic counselors.<sup>111</sup>

Nondirective counseling has been challenged as inconsistent with traditional medical practice where physicians are more likely to suggest the preferable course of action.<sup>112</sup> Further, some geneticists argue that directive counseling against childbearing is sometimes appropriate, for example, where one or more potential parent carries the Huntington's gene (a progressive, fatal neurological deterioration).<sup>113</sup>

The real problem with genetic counseling is that the counselor has divided loyalties. It may be difficult for the counselor to decide whether the primary duty is owed to the prospective parents, the fetus, or society.<sup>114</sup> This

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103. Smith, *supra* note 64, at 446-47.

104. D. KEVLES, *supra* note 37, at 257-58.

105. Smith, *supra* note 64, at 446-47.

106. Peters & Fineberg, *Genetic Counseling and Screening*, TRIAL, Jan. 1984, at 82, 83.

107. Friedman, *Legal Implications of Amniocentesis*, 123 U. PA. L. REV. 92, 121 n.162 (1974).

108. D. KEVLES, *supra* note 37, at 257. However, "[w]hen couples abort a fetus after discovering that it has a birth defect, they have often suffered severe guilt reactions, termination of sexual relations, and even divorce." *Id.* at 298.

109. Note, *supra* note 71, at 908.

110. D. KEVLES, *supra* note 37, at 257-58.

111. *Id.*

112. SCREENING AND COUNSELING FOR GENETIC CONDITIONS, *supra* note 17, at 37-38.

113. *Id.* at 38-39.

114. Capron, *Tort Liability in Genetic Counseling*, 79 COLUM. L. REV. 618, 645 (1979);

argument has relevance today since it is possible that babies born with genetic defects might have a cause of action against a genetic counselor (wrongful life/birth) for not being more directive.<sup>115</sup> A similar action might lie against a woman who either refused genetic counseling when she had reason to suspect a genetic condition or who refused to follow the directions of the genetic counselor after screening.<sup>116</sup>

## 2. HIV Directive Counseling

Some health care officials say that HIV-infected women should be strongly encouraged not to become pregnant, or, if pregnant, to consider abortion.<sup>117</sup> Concern for the health of the woman was one reason initially given for this approach. Early reports expressed concern that pregnancy accelerated the progression of the disease, but today there is little evidence that pregnancy will enhance the progression of the disease.<sup>118</sup> In addition, no information is available on the impact of abortion during the first or second trimester on progression of HIV or AIDS.<sup>119</sup>

HIV infection is presumed to be fatal, but there are several genetic conditions that may result in serious medical problems and even death.<sup>120</sup> No mandates are present for abortion for these genetic conditions. The only major difference between HIV infection and a serious genetic condition is that HIV may also be transmitted sexually.<sup>121</sup> Since HIV is a mildly communicable disease whose perinatal transmission impinges on reproductive freedom, the cau-

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Comment, *Confidentiality of Genetic Information*, 30 UCLA L. REV. 1283, 1291 n.51 (1983) (citing P. REILLY, *GENETICS, LAW AND SOCIAL POLICY* 156 (1977)).

115. The argument would be that the counselor breached a medical duty of care owed the fetus for not acting reasonably and leaving it up to the child's stupid or irrational parents who predictably brought the child into the world.

116. See, e.g., Robertson, *Procreative Liberty and the Control of Conception, Pregnancy, and Childbirth*, 69 VA. L. REV. 405, 448-49 (1983). Dialogue among scholars over fetal rights has increased the significance of the right of pregnant women to refuse treatment designed to benefit the fetus or to engage in conduct which may be harmful to the fetus. See, e.g., Goldberg, *Medical Choices During Pregnancy: Whose Decision Is It Anyway*, 41 RUTGERS L. REV. 591 (1989); Johnsen, *From Driving to Drugs: Governmental Regulation of Pregnant Women's Lives After Webster*, 138 U. PA. L. REV. 179 (1989) [hereinafter *From Driving to Drugs*]; Johnsen, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy, and Equal Protection*, 95 YALE L.J. 599 (1986); Lichtenberg, *Gestational Substance Abuse: A Call for a Thoughtful Legislative Response*, 65 WASH. L. REV. 377 (1990).

117. Donovan, *AIDS and Family Planning Clinics: Confronting the Crisis*, 19 FAM. PLAN. PERSP. 111, 113 (1987).

118. See *supra* note 89.

119. Minkoff, *supra* note 26, at 2714.

120. Polycystic Kidney Disease, a fatal hereditary disease, is an example. Peters & Fineberg, *supra* note 106, at 84.

121. "Society has been much more willing to limit individual freedom in the service of protecting people from certain communicable diseases . . . than from equally serious genetic diseases. This difference occurs in part because the likelihood of transmission is often less certain in the case of genetic disease and because genetic transmission occurs within the family, rather than the public at large. But more fundamentally, it reflects the facts that the prevention of genetic disease can impinge on reproductive freedom . . ." SCREENING AND COUNSELING FOR GENETIC CONDITIONS, *supra* note 17, at 47-53.



tion exercised for regulation of genetic diseases should also apply for efforts to stem the perinatal transmission of HIV. Assuming the concern here is providing the woman with the information needed to make an informed decision about bearing a child, there is no reason to treat HIV-infected women of childbearing age differently from women with serious genetic conditions.

Directive counseling of HIV-infected women may be coercive to some women and ineffective for others. Various studies indicate that some HIV-infected pregnant women are choosing to continue their pregnancies. One study at the State University of New York Health Center in Brooklyn found that eighteen out of sixty HIV-infected women received their test results in time to abort, yet only three chose abortion.<sup>122</sup> In addition, ten of the sixty women became pregnant a second time.<sup>123</sup> The same pattern was found in Miami, the Bronx, and Harlem.<sup>124</sup>

A more recent longitudinal study of women intravenous drug users in New York City found that 50% of HIV-infected women compared to 44% of uninfected women chose to terminate their pregnancies before twenty-four weeks' gestation.<sup>125</sup> The researchers characterized their counseling as "supportive and nondirective."<sup>126</sup> Forty-three percent of the HIV-infected women knew of their status prior to becoming pregnant, and 67% of those women terminated their pregnancy.<sup>127</sup> By comparison, 58% of the women who knew they were seronegative subsequently became pregnant, and 57% of these pregnant women terminated their pregnancies.<sup>128</sup>

The reasons why some HIV-infected women become pregnant and choose to continue their pregnancy are complicated. In the same longitudinal study researchers found that women who had a prior history of abortion were more likely to terminate their pregnancy.<sup>129</sup> Significantly, neither the threat of perinatal transmission of HIV nor concern about developing AIDS during the pregnancy was a determining factor in the decision to terminate pregnancy.<sup>130</sup> "Seropositives who chose to continue their pregnancies cited the desire for a child and religious beliefs as the most important reasons for their choices."<sup>131</sup> Even though the research findings are limited to intravenous drug users, the researchers conclude that sensitive and supportive counseling is of critical importance for HIV-infected women, for whom the element of HIV infection might be seen as only one aspect of a complex pattern of values, culture, and behavior.<sup>132</sup> Knowledge that one is infected with HIV alone is not sufficient to

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122. Abraham, *supra* note 53, at 3.

123. *Id.*

124. *Id.*

125. *Knowledge of HIV Antibody Status*, *supra* note 83, at 3568.

126. *Id.*

127. *Id.*

128. *Id.*

129. *Id.* (77% compared to 38% of women not reporting prior elective abortion).

130. *Id.* at 3569.

131. *Id.* at 3570.

132. *Id.* Psychologists Vickie Mays and Susan Cochran note the critical need for public

reduce the transmission of the virus perinatally.

While the government's interest in stopping the spread of AIDS and HIV infection is significant, that interest does not warrant routine HIV prenatal screening of "high risk" women or directed counseling of infected women. Further, routine screening and counseling should not be implemented without stringent procedural safeguards. In addition to equal protection concerns, a woman's right to privacy is violated by routine HIV screening without written informed consent or pre-test counseling, and by directive counseling. The choice whether or not to bear a child should be made by each woman, not by the government. Less intrusive means for satisfying the government's interest are available.

## V.

### PRIVACY PROTECTION

In *Skinner v. Oklahoma* the Supreme Court recognized that the right to procreate is fundamental and that efforts by the government to sterilize individuals will be strictly scrutinized.<sup>133</sup> Two later decisions, *Griswold v. Connecticut*<sup>134</sup> and *Eisenstadt v. Baird*,<sup>135</sup> recognized the right of the individual to decide whether to bear a child. Subsequently, in *Roe v. Wade*, the Court extended this fundamental right to include the right of a woman to choose an abortion.<sup>136</sup> Any government action that literally proscribes either choice — sterilization versus pregnancy or pregnancy versus abortion — is constitutionally suspect.

The Court in *Roe* recognized that the fundamental right to an abortion is not absolute.<sup>137</sup> Similarly, the Court in *Skinner* recognized that the right to procreate is not absolute.<sup>138</sup> However, in general, the Court has recognized

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health officials to understand the importance of race and culture in fighting HIV within all segments of the African-American community. Mays & Cochran, *Acquired Immunodeficiency Syndrome and Black Americans: Special Psychosocial Issues*, 102 PUB. HEALTH REP. 224 (1987); accord Dalton, *AIDS in Blackface*, 1989 DAEDALUS 205. More recently, Mays and Cochran suggest that HIV prenatal screening and counseling programs often fail "to be sensitive to the special value of children for Black and Latina women. Much psychological research has centered on parents' socioemotional and individualistic reasons for bearing and nurturing children. . . . [Planners must realize that culturally] [t]he ability to reproduce was seen as a powerful tool in the fight for liberation." Mays & Cochran, *Issues in the Perception of AIDS Risk and Risk Reduction Activities by Black and Hispanic/Latina Women*, 43 AM. PSYCHOLOGIST 949, 953 (1988). Researchers at the Multicultural Inquiry and Research on AIDS Project connected with the University of California at San Francisco's Center for AIDS Prevention Studies also note that, in order for HIV prevention programs to work in the African-American community, we need to recognize the existing cultural values which impact on male-female sexual relationships. M. Fullilove, R. Fullilove, Haynes & Gross, *Black Women and AIDS Prevention: A View Towards Understanding the Gender Rules*, 27 J. SEX RES. 47, 48 (1990).

133. 316 U.S. 535, 541 (1942).

134. 381 U.S. 479 (1965) (married couples).

135. 405 U.S. 438 (1972) (unmarried persons).

136. 410 U.S. 113 (1973).

137. *Id.* at 154.

138. *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

that the state may not unduly burden either right unless it can demonstrate some compelling interest.<sup>139</sup> As this Article has discussed, the state arguably has a compelling interest in preventing the spread of a mildly contagious, but often fatal, disease, HIV, especially when the possible target of infection is a newborn child. Thus, at issue is whether a program of routine HIV prenatal screening is the appropriate means to accomplish this compelling state interest.

Routine HIV prenatal screening, when conducted by the government, constitutes an undue burden on an infected woman's procreational choices.<sup>140</sup> In essence, the only reason for the HIV prenatal screening is to identify pregnant women infected with HIV and to counsel them to abort or submit to medical treatment. This policy effectively denies HIV-infected pregnant women bodily autonomy over the choice of continuing their pregnancy or aborting the fetus.

The state may argue that absent termination of pregnancy or compelled medical treatment, the government will not be able to protect the health of potential life, an objective that at least three members on the current Supreme Court have recognized as a "permissible" governmental interest.<sup>141</sup> Additionally, the government may raise the financial argument that absent these measures it will be forced to provide costly care for seriously ill newborns and

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139. The exact standard to be applied in these cases is unclear in light of the Court's recent decisions in *Webster v. Reproductive Health Services, Inc.*, 109 S. Ct. 3040 (1989), and *Hodgson v. Minnesota*, 110 S. Ct. 2926 (1990). In prior cases, the Court regularly applied a standard first set out in *Maher v. Roe*, 432 U.S. 464 (1977), which interpreted the constitutional right protected in *Roe* as a woman's fundamental right to be free only "from unduly burdensome interference with her freedom to decide whether to terminate her pregnancy." *Maher v. Roe*, 432 U.S. at 474. However, the Court has applied this standard inconsistently. *See, e.g., Thornburgh v. American College of Obstetricians & Gynecologists*, 476 U.S. 747 (1986) (striking down a statute requiring the presence of a second physician because it lacked an emergency clause); *Planned Parenthood Ass'n of Kansas City, Mo. v. Ashcroft*, 462 U.S. 476 (1983) (upholding a state law requiring the presence of a second physician at an abortion); *City of Akron v. Akron Center for Reproductive Health, Inc.*, 462 U.S. 416 (1983) (striking down a statute requiring hospitalization for second trimester abortions).

In *Webster*, a majority appeared to apply the *Maher* standard, holding that restrictions on the use of public employees and facilities for nontherapeutic abortions place "no governmental obstacle in the path of a woman who chooses to terminate her pregnancy." 109 S. Ct. at 3042 (quoting *Harris v. McRae*, 448 U.S. 297, 315 (1980)). However, a plurality of the Court then expressly rejected the *Roe* trimester framework in order to rule that a state statute requiring certain "necessary" viability tests need only be reasonably designed to further legitimate state interests. *Id.* at 3058. The dissent appropriately termed this a "dressed up rational basis standard." *Id.* at 3076 (Blackmun, J., dissenting). Justice O'Connor argued that the statute could have been upheld under the *Maher* standard and that, therefore, the plurality should not have reconsidered *Roe*. *Id.* at 3060 (O'Connor, J., concurring).

140. There is a raging debate at the CDC about the content of the guidelines to prevent perinatal transmission of HIV. A key concern is whether elective abortion should be mentioned as an option when counseling HIV-positive women. *See, e.g., Grimes, The CDC and Abortion in HIV-Positive Women*, 259 J. A.M.A. 1176 (1987); *Gunn, The CDC and Abortion in HIV-Positive Women*, 259 J. A.M.A. 217 (1988) (reply to Grimes).

141. *See Webster*, 109 S. Ct. at 3057. For a general discussion of the implications of *Webster*, see Olsen, *Unraveling Compromise*, 103 HARV. L. REV. 105 (1989).

orphan children. However, financial arguments alone cannot be allowed to override a fundamental right, and, even when coupled with some interest in protecting potential life, there is little evidence that routine HIV prenatal screening of pregnant women is sufficiently narrowly tailored to achieve these purposes.

Even voluntary HIV prenatal testing, when coupled with directive counseling by the government, raises serious privacy concerns. Directive counseling may be coercive if abortion or sterilization is perceived by poor women as a condition for receiving medical care.<sup>142</sup> Further, the threat of compelled medical treatment should she continue her pregnancy may leave an infected woman feeling she has no control over her body or her reproductive choices, so that any decision is not truly voluntary.

Prior to *Webster*, the Supreme Court invalidated state laws that substantially discouraged or dissuaded women from exercising their right to choose between terminating or continuing pregnancy.<sup>143</sup> Following *Roe v. Wade*, some states tried to interfere with this choice by enacting so-called informed consent laws.<sup>144</sup> Other states tried to impose waiting periods before a woman could voluntarily terminate her pregnancy.<sup>145</sup> A majority of the Court viewed these state laws as impermissible interferences with the right of a woman to control the reproductive aspects of her body.

For pregnant women infected with HIV, directive counseling to abort is analogous to those state laws. Even in light of *Webster*, the government cannot claim that directive counseling furthers the government's interest in protecting potential life, because the objective of the counseling, in the case of an already pregnant woman, is the destruction of the fetus.

The privacy cases dealing with reproductive rights can be bifurcated. In one set of cases, the Court protects the right of individual choice prior to conception (*Skinner*, *Griswold*, and *Eisenstadt*). In the second set of cases the Court is protecting that right after conception (*Roe*, *Akron*, *Thornburgh*, and *Webster*). Once a woman has affirmatively exercised the right to procreate,

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142. See Sullivan, *supra* note 92.

143. The Court in *Roe* did not prevent states from regulating abortions. See *supra* note 139. However when these regulations apply to pre-viability abortions, the state must demonstrate some compelling interest in protecting maternal health and the regulation must be narrowly tailored. *City of Akron v. Akron Center for Reproductive Health, Inc.*, 462 U.S. 416, 427 (1983). For example, the Court has struck down laws that require all pre-viability abortions be performed in licensed hospitals. *Doe v. Bolton*, 410 U.S. 179 (1973). The Court has upheld certain minor regulations, including laws requiring that the abortionist be a licensed physician, *Connecticut v. Menillo*, 423 U.S. 9 (1975) (*per curiam*), or that hospitals keep accurate records of abortions performed, *Planned Parenthood of Central Mo. v. Danforth*, 428 U.S. 52 (1976).

144. See, e.g., *Akron*, 462 U.S. 416, where the attending physician was required to explain in graphic detail the development of the fetus, various abortion techniques, and potential emotional complications. But cf. *Planned Parenthood of Central Mo. v. Danforth*, 428 U.S. 52, in which the Court upheld the requirement that a standard medical consent form be executed by the woman seeking an abortion.

145. See, e.g., *Akron*, 462 U.S. 416.

governmental interference becomes more personal and invasive. Thus, as previously stated, it should be more difficult for the government to establish a sufficiently compelling interest in directive counseling to abort or to claim that the counseling process is sufficiently narrowly tailored to justify interfering with a woman's procreational choices. Since the risk that a mother will transmit HIV is estimated to be between thirty and fifty percent and since the women most often counseled are women of color, a court should find directive counseling not sufficiently narrowly tailored to achieve the stated goal of preventing perinatal transmission of HIV. Unlike the regulations challenged unsuccessfully in *Webster v. Reproductive Health Services, Inc.*,<sup>146</sup> the state is *not* encouraging potential life, but is trying to prevent it through forced abortion or sterilization. Following this line of reasoning, directive counseling of HIV-infected women of childbearing age impermissibly interferes with procreational choices. Thus, counseling should be closely regulated to ensure protection of women's procreational rights.

Both the abortion and sterilization issues involve the right of a woman to control the reproductive aspects of her body. While the government has an interest in protecting the woman's health in each instance, the government conceivably has no compelling interest in sterilizing a woman against her will or in forcing her to abort.<sup>147</sup> A government policy which advocates sterilization through directive counseling of fertile HIV-infected women or abortion for pregnant women infected with HIV is precisely the kind of interference with private decision making that *Skinner* and *Roe* attempt to prevent. Directive counseling raises the specter of an Orwellian nightmare, prohibited not only by the substantive due process right to privacy found in the fifth and fourteenth amendments, but also by the "liberty of conscience" concept that underlies the first amendment.<sup>148</sup> Thus, government instituted or sanctioned routine HIV screening and directive counseling programs would conflict with the spatial and decision making spheres of privacy that the federal Constitution guarantees.

If directive counseling is permitted for pregnant women with HIV, then the door is open for other governmental restrictions on women's reproductive rights, arguably in the name of maternal or fetal health. There are already a few cases of court-ordered, forced prenatal invasions.<sup>149</sup> Therefore, HIV

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146. 109 S. Ct. 3040 (1989).

147. At least one commentator disagrees and suggests that "the state's interest in improving the quality of a population's gene pool in order to minimize suffering, to reduce the number of economically dependent persons, and possibly, to save mankind from extinction arguably justifies the infringement of individuals' civil liberties." Smith, *supra* note 64, at 443 (citing Vickowich, *The Dawning of the Brave New World — Legal, Ethical and Social Issues of Eugenics*, 1971 U. ILL. L.F. 189, 208). As long as any people advocate eugenics, the courts must closely monitor government policies with eugenic overtones.

148. See generally M. ATWOOD, *THE HANDMAID'S TALE* (1985); D. RICHARDS, *TOLERATION AND THE CONSTITUTION* (1986).

149. Gallagher, *Prenatal Invasions & Interventions: What's Wrong with Fetal Rights*, 10 HARV. WOMEN'S L.J. 9, 48 n.203 (1987) [hereinafter *Prenatal Invasions*]. A recent study of

counseling of pregnant women and women of childbearing age done with federal or state funds must be conditioned on a guarantee to do nondirective counseling and be accompanied by stringent reporting requirements and monitoring.<sup>150</sup>

HIV-infected women who exercise their right to conceive and bear children must be supported. Many HIV-infected women may have no health care insurance because they are unemployed or marginally employed.<sup>151</sup> HIV-infected women often have a long history of poor health prior to diagnosis.<sup>152</sup> For the right to choose to have any meaning, HIV-infected pregnant women must have access to appropriate health care. To do otherwise not only makes the principles of *Skinner* and *Roe v. Wade* meaningless for infected women, but calls into question the rationale for HIV prenatal screening and counseling.

Women who choose not to continue their pregnancies also must be supported. However, according to the Supreme Court, a woman's constitutional right to control the reproductive aspects of her body does not include an abortion paid for by government.<sup>153</sup> This is true even if the policy effectively operates to deny poor women access to abortion, be it therapeutic or non-therapeutic.<sup>154</sup> Thus, abortion may not be a financial option for poor women of color. Since *Webster*, a dwindling number of states provide funds for abor-

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physician and hospital court-ordered obstetrical intervention found that 81% of the women involved were black, Asian, or Hispanic. All the women were treated in teaching-hospital clinics or were receiving public assistance. Court-ordered intervention occurred in 86% of the cases. Kolder, Gallagher & Parsons, *Court-Ordered Obstetrical Interventions*, 316 NEW ENG. J. MED. 1192, 1192 (1987).

These forced invasions fall into two general categories, forced cesareans and forced treatment. Unfortunately, most of the forced cesarean cases are unreported. *Prenatal Invasions*, *supra*, at 11-12 & n.16. Some of the reported cases include: *In re A.C.*, 533 A.2d 611 (D.C. 1987), *vacated and remanded for reh'g en banc*, 539 A.2d 203 (D.C. 1988); *Jefferson v. Griffin Spalding City Hosp.*, 247 Ga. 86, 274 S.E.2d 457 (1981). Examples of forced treatment include: *Bouvia v. Superior Ct.*, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (1986); *Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 42 N.J. 421, 201 A.2d 537, *cert. denied*, 377 U.S. 985 (1964); *In re Jamaica Hosp.*, 128 Misc. 2d 1006, 491 N.Y.S.2d 898 (Sup. Ct. 1985) (forced blood transfusion). *But cf.* *Taft v. Taft*, 388 Mass. 331, 446 N.E.2d 395 (1983) (refusing to order surgery on pregnant woman to prevent probable miscarriage). For an excellent argument against compelled treatment of pregnant women, see Annas, *Protecting the Liberty of Pregnant Patients*, 316 NEW ENG. J. MED. 1213 (1987).

150. Any public health program which undertakes directive counseling in the reproductive arena, absent specific legislative authorization, would undoubtedly be an arbitrary and capricious use of administrative authority in violation of the Administrative Procedure Act, 5 U.S.C. § 551 (1988). Unfortunately, such an argument is beyond the scope of this Article.

151. Staver, *Minority Women Grappling with Growing AIDS Problem*, Am. Med. News, Nov. 6, 1987, at 43. In 1985, a federal task force on black and minority health found that twice as many blacks and three times as many Hispanics as whites have no medical insurance. REPORT ON MINORITY HEALTH, *supra* note 1, at 17-18.

152. Staver, *supra* note 151, at 43.

153. *Williams v. Zbaraz*, 448 U.S. 358 (1980); *Harris v. McRae*, 448 U.S. 297 (1980); *Poelker v. Doe*, 432 U.S. 519 (1977); *Maher v. Roe*, 432 U.S. 464 (1977); *Beal v. Doe*, 432 U.S. 438 (1977).

154. *Harris v. McRae*, 448 U.S. at 315 (therapeutic); *Maher v. Roe*, 432 U.S. at 474 (non-therapeutic).

tion under Medicaid.<sup>155</sup> Ironically, federally funded sterilizations remain free on demand.<sup>156</sup> If abortion is not a viable option for poor women of color, there is little reason for routine prenatal HIV screening. Therefore, if routine HIV prenatal screening is implemented, both federal and state governments need to reexamine their stance on publicly funded abortion.<sup>157</sup>

## VI.

### ADDITIONAL LEGAL ISSUES

#### A. Screening and Counseling

Several legal issues need to be addressed which are beyond the scope of this Article. For example, while the right to privacy also applies to minors,<sup>158</sup> "states have a 'significant' interest in supporting certain abortion regulations aimed at protecting children that is not present when the state seeks to regulate adults."<sup>159</sup> Several states allow minors to consent to testing and treatment of sexually transmitted disease and to prenatal treatment.<sup>160</sup> One question is whether HIV screening of a minor female would be included within the statutory definition of sexually transmitted disease or prenatal care in the case of pregnant minors, and thus be exempt from parental notification requirements.<sup>161</sup> This is important since AIDS is usually not classified as a venereal

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155. Brotman, *Mixed Emotions, Jumbled Laws in Wake of Webster, States to Vary More on Abortion Statutes*, Chicago Tribune, Jan. 14, 1990, at 1 (noting that 37 states have passed laws forbidding the use of Medicaid funds for abortion in almost all circumstances since the passage of the Hyde Amendment, which took effect in 1977).

156. "By 1977 the passage of the Hyde Amendment in Congress had mandated the withdrawal of federal funding for abortions, causing many state legislatures to follow suit . . . Since surgical sterilizations, funded by the Department of Health, Education and Welfare, remained free on demand, more and more poor women have been forced to opt for permanent infertility." A. DAVIS, *WOMEN, RACE & CLASS* 206 (1981).

157. Even where public or private funding for abortion is available to HIV-infected pregnant women, there is still the issue of health care providers refusing to perform abortions on these women. Donovan, *supra* note 117. A recent study of abortion clinics in New York City found that two-thirds refuse to treat women infected with HIV. Zarembka & Franke, *Women in the AIDS Epidemic: A Portrait of Unmet Needs*, 9 ST. LOUIS U. PUB. L. REV. 519, 525 (1990).

158. *Carey v. Population Services, Int'l*, 431 U.S. 678, 693 (1977); *Planned Parenthood of Central Mo. v. Danforth*, 428 U.S. 52, 74 (1976).

159. *Hodgson v. Minnesota*, 853 F.2d 1452, 1466 (8th Cir. 1988), *aff'd*, 110 S. Ct. 2925 (1990) (citing *City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 427 n.10 (1983)). The Minnesota law upheld in *Hodgson* requires minors who want an abortion to notify both parents or obtain special permission from a judge. This provision applies even where the minor's parents are divorced or separated or have deserted the minor. It is the most restrictive notification law in the country. 110 S. Ct. at 2932.

160. Illinois, Minnesota, Nevada, and Utah all allow minors to consent to be tested and treated for sexually transmitted diseases, prenatal care, and medical care for the minor's child without parental consent or notice. ACLU REPRODUCTIVE FREEDOM PROJECT, *PARENTAL NOTICE LAWS* 31 nn.60-61, 32 n.63 (1986) [hereinafter *PARENTAL NOTICE LAWS*].

161. *Ohio v. Akron Center for Reproductive Health*, 110 S. Ct. 2972 (1990). Prior to the Supreme Court's decisions in the Ohio and Minnesota parental notice/consent cases decided last term, 21 states had parental notice or consent laws on the books but did not enforce them; 13 states had statutes in effect; and 16 states had no restrictions on minor women. Brotman,

or sexually transmitted disease.<sup>162</sup>

Even if parental consent is not required for HIV screening, some health care providers may feel obligated to inform the minor's parents if the test results are positive, especially if the minor is also pregnant. The legal rights of minor females and the legal and ethical obligations of health care providers in this area are unclear.

Another issue is whether the fourth amendment protection from unreasonable searches and seizures could be used to successfully challenge compulsory HIV prenatal screening proposals directed at women of color. Some commentators are doubtful that courts would strike down compulsory HIV screening proposals.<sup>163</sup> However, the focus of these discussions is on men rather than on pregnant women or fertile women who also are people of color. The issue may well be different when the focus is on women because procreational rights and race are also involved.

Another legal concern is the extent of legal protection afforded women's procreational rights under federal law. While the recently enacted Americans with Disabilities Act [hereinafter ADA] extends coverage to privately operated places of public accommodation,<sup>164</sup> the ADA denies monetary damages to private litigants.<sup>165</sup> On the other hand, some courts have granted compensatory damages under the Rehabilitation Act of 1973.<sup>166</sup> This law prohibits

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*supra* note 155. For further information on states, see PARENTAL NOTICE LAWS, *supra* note 160, at 29 n.1 (1986). Planned Parenthood Ass'n of Kansas City, Mo. v. Ashcroft, 462 U.S. 476 (1983); City of Akron v. Akron Center for Reproductive Health, Inc., 462 U.S. 416 (1983); H.L. v. Matheson, 450 U.S. 398 (1981); Bellotti v. Baird, 443 U.S. 622 (1979) (requirement that minors obtain either parental consent to abortion or judicial consultation following parental consultation invalid); Planned Parenthood of Central Mo. v. Danforth, 428 U.S. 52 (1976) (right of mature minor to abortion without parent's consent).

162. There are several reasons why some states are reluctant to classify AIDS or HIV infection as a sexually transmitted rather than a communicable disease. First, most sexually transmitted disease laws permit unconsented testing whenever there is reasonable cause to suspect an infection. Second, those laws also allow other restrictive or invasive measures such as quarantine, and mandatory reporting and contact tracing, all measures which public health officials fear might discourage people at high risk from seeking HIV testing. Lewin, *A State Judge in New York Refuses to Declare AIDS a Sexually Transmitted Disease*, N.Y. Times, Nov. 16, 1988, B1, col. 3, B6, col. 6 (late ed.).

163. See, e.g., Note, *Mandatory Testing of Public Employees for the Human Immunodeficiency Virus: The Fourth Amendment and Medical Reasonableness*, 90 COLUM. L. REV. 720 (1990); Richards, *Communicable Disease Control in Colorado: A Rational Approach to AIDS*, 65 DEN. U.L. REV. 127, 143 (1988); Note, *AIDS: Legal Issues in Search of a Cure*, 14 WM. MITCHELL L. REV. 575, 617 (1988) (providing government demonstrates the epidemic is endangering public health or draining financial resources); Note, *The Constitutional Rights of AIDS Carriers*, 99 HARV. L. REV. 1274, 1287 (1986) (if shown to be necessary to advance public health).

164. Pub. L. No. 101-336, § 301(7), 104 Stat. 327, 354 (1990).

165. Pub. L. No. 101-336, § 308(a), 104 Stat. 327, 363 (1990).

166. 29 U.S.C. § 794 (1982 & Supp. V 1987). Courts generally agree that damages are available under § 504 of the Rehabilitation Act. See *Smith v. Robinson*, 468 U.S. 992, 1020 n.24 (1984) (noting, but expressing no opinion on, the availability of damages under § 504); *Martin H. v. Austin Indep. School Dist.*, 714 F.2d 1348, 1356-57 (5th Cir. 1983); *Micner v. Missouri*, 673 F.2d 969, 979 (8th Cir.), *cert. denied*, 459 U.S. 909 (1982).



discrimination against the handicapped by recipients of federal funds. Most hospitals and many health care providers receive federal funds, including Medicaid payments. Persons infected with HIV are covered by the Rehabilitation Act.<sup>167</sup>

### B. Additional Legal Issues for Women

Unfortunately, routine HIV screening of women may result in loss of child custody for infected women. Many public hospitals in urban areas are routinely testing pregnant women for illicit drugs.<sup>168</sup> Women with positive drug tests are often reported to child protective services, forcing these women to prove to government that they are fit mothers.<sup>169</sup> Thus it is conceivable that similar policies may be imposed on women with HIV.

In addition, there is also the possibility that women who become pregnant after learning of their antibody status will be prosecuted criminally if their children are born infected with HIV.<sup>170</sup> Finally, the infected children might be able to bring civil suits against their mothers for the willful or negligent transmission of HIV.<sup>171</sup>

### CONCLUSION

There is a compelling need for federal legislation which recognizes the race, class, and privacy issues involved in routine HIV prenatal screening and

167. In the Civil Rights Restoration Act of 1987, Congress amended sections 503 and 504 of the Rehabilitation Act to include persons with contagious diseases and infections. Pub. L. No. 100-259, 102 Stat. 31 (current version at 29 U.S.C. § 706 (Supp. 1989)).

168. Franke, *Turning Issues Upside Down*, in AIDS: THE WOMEN 226, 228 (I. Rieder & P. Ruppelt eds. 1988). For a discussion of the issues involved, see Robin-Vergeer, *The Problem of the Drug-Exposed Newborn: A Return to Principled Intervention*, 42 STAN. L. REV. 745 (1980) (opposing maternal drug screening).

169. Franke, *supra* note 168, at 228. A Michigan state court allowed evidence of a mother's drug use during pregnancy to be used as proof of neglect or abuse in a state-initiated proceeding to deprive her of custody of her new born child. *In re Baby X*, 97 Mich. App. 111, 293 N.W.2d 736 (1980).

170. Franke, *supra* note 168, at 228. Lynn Paltrow, a lawyer with the American Civil Liberties Union's Reproductive Freedom Project, notes that there is a racial bias in the prosecution of pregnant drug addicts. Specifically, despite relatively equal number of white women and women of color who are drug users, poor women and/or women of color are more likely to be prosecuted because "public hospitals, where poor women go for care, are most vigilant in their drug testing and more likely than private hospitals to report women whose tests show drug use." Kolata, *Bias Seen Against Pregnant Addicts*, N.Y. Times, July 20, 1990, at A13, col. 1. Ms. Paltrow claims that 80% of all pregnant drug users prosecuted are women of color. There is a fear that this discriminatory prosecution will "drive poor women away from prenatal care out of fear that a trip to the doctor can end up as a term in jail." *Id.*

Recently a woman was criminally prosecuted for delivering drugs to her newborn via the umbilical cord moments after birth. *State v. Johnson*, No. 89-890-CFA (Fla. Cir. Ct. 1989), cited in Sherman, *Keeping Babies Free of Drugs*, Nat'l L.J., Oct. 16, 1989, at 1, col. 4 (discussing ten cases in five different states); *From Driving to Drugs*, *supra* note 116, at 208-11 (unsuccessful prosecution of Pamela Stewart for child abuse).

171. Franke, *supra* note 168, at 230-31. There is some precedent. See *Grodin v. Grodin*, 102 Mich. App. 396, 301 N.W.2d 869 (1980) (child sued mother for taking tetracycline during pregnancy resulting in discoloration of child's teeth).

directive counseling. This legislation would apply to all federal facilities and any other facility receiving federal funds and would require that all HIV testing of women of childbearing age be performed with written consent. Consent forms must be written in the woman's native language. In order to preserve privacy and autonomy, special assistance by a person of the woman's choice must be provided for women who are either actually or functionally illiterate. In addition, the proposed legislation would prohibit the use of directive counseling.

If mass HIV screening programs are going to be endorsed by the government, certain prerequisites must be met. First, there must be community participation in the planning and implementation of any HIV screening program involving poor women and women of color. Each of these communities has a different culture and history that must be taken into account when designing mass screening programs.

Second, pilot projects should precede any mass screening. Pilot programs test the feasibility of any mass screening proposal directed at a targeted group or area. Pilot projects allow program adjustments to be made quickly and minimize risk of harm to the targeted population.

Third, screening procedures must be adequate. This means that where screening is routine, the written informed consent of clients should be obtained and consent forms should be simply written. Furthermore, there should be short waiting periods for tests and test results, and adequate counseling both before testing and after the receipt of test results.

There is some question about what constitutes adequate counseling. Without question, adequate counseling includes counselors who are fluent in the women's native language and who, where needed, have had cross-cultural training. Adequate counseling may mean that fifteen to thirty minutes with a client may not be enough, especially where the client has a positive test result. The shock of learning that one has a positive test may negate any attempt to counsel on safe sex and other personal matters. Any woman may not fully understand the reproductive implications of a positive HIV antibody test after only one counseling session. Even where the counselor is nondirective, misinformation about the nature of the risk of transmission to sexual partner or fetus may have the same effect as directive counseling. Careful monitoring of counseling is essential.

Finally, mass HIV screening programs must adequately protect the targeted community.<sup>172</sup> This raises the issue of anonymous versus confidential HIV testing. Although several commentators claim that anonymous screening is more likely to create confidence in those who must be tested,<sup>173</sup> where

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172. Similar recommendations were made for mass genetic screening programs. SCREENING AND COUNSELING FOR GENETIC CONDITIONS, *supra* note 17, at 33.

173. See, e.g., *Confronting AIDS*, *supra* note 17, at 124 ("The committee believes that the largely undesirable social response to the identification of individuals as being antibody positive argues for voluntary, anonymous systems of testing, but this would entail potential loss of certain public health benefits.").

prolonged counseling is necessary, confidential testing may be more appropriate. Of course, in states which mandate reporting of all positive HIV antibody tests, anonymous testing may be more effective until adequate anti-discrimination and confidentiality provisions are enacted.

Because the potential for abuse of HIV-infected women's reproductive rights is great, the implications of HIV screening programs directed at fertile women cannot be ignored. Women currently identified as at greatest risk of HIV infection are poor women and/or women of color. Because these women are invisible or are considered by some to be less valued members of society, the threat to their rights is at risk of being ignored. There is too much at stake to allow that to happen. If fertile HIV-infected women lose their right to choose, then all women will lose. Our indifference to women infected with HIV will have dramatic consequences for future generations of women. At the very *least* some protective legislation must be enacted at the federal and state level.

