

Journal of Law and Policy

Volume 6

Issue 1

INAUGURAL DAVID G. TRAGER PUBLIC

POLICY SYMPOSIUM:

Campaign Finance Reform: Will Anything Work?

Article 12

1997

Rights Discourse and Mandatory HIV Testing of Pregnant Women and Newborns

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Recommended Citation

Jennifer Sinton, *Rights Discourse and Mandatory HIV Testing of Pregnant Women and Newborns*, 6 J. L. & Pol'y (1997).

Available at: <https://brooklynworks.brooklaw.edu/jlp/vol6/iss1/12>

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RIGHTS DISCOURSE AND MANDATORY HIV TESTING OF PREGNANT WOMEN AND NEWBORNS

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INTRODUCTION

The question of whether pregnant women or their newborn infants should be mandatorily tested for the human immunodeficiency virus ("HIV")¹ has been publicly debated in state and federal legislatures, public health communities and the media the

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¹ This Note assumes the following definitions for HIV testing schemes. *Mandatory testing* is compulsory and cannot be refused by the subject. See Linda Farber Post, Note, *Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?*, 16 CARDOZO L. REV. 169, 170 n.4 (1994). In the mandatory testing schemes referred to, the subject is informed of the test result. If a newborn tests positive for HIV, it is automatically known that the mother is HIV-positive and the parents or guardians are informed of the result. See *id.* at 173. Therefore, when a newborn is tested for HIV without the mother's consent and the mother is subsequently informed of the result, the mother has effectively been subjected to mandatory testing because her HIV status has been identified. See *id.*

Mandatory testing differs from *blinded testing* or *screening*. See *id.* at 171-72 n.12. Routine HIV testing of newborns has been performed by most states for many years under blinded testing and blinded screening laws. See *id.* at 171. Under these state programs, which are supported by the Centers for Disease Control ("CDC") and the National Institute of Child Health and Human Development, newborns are tested without the consent or knowledge of their mothers, and the mothers are not informed of the result. See *id.* at 171-72 n.11. Test results remain completely anonymous and the tests are only conducted for epidemiological, i.e., statistical, purposes. See *id.* at 171-72.

last few years.² The public debate is characterized by proponents of mandatory testing as a fight between fetal rights and women's rights.³ The debate has also been viewed as a conflict between what is best for the public health, namely, preventing HIV transmission, and preserving the civil liberties and privacy rights of women.⁴ While opponents of mandatory testing have argued that mandatory testing is bad public health policy that harms women and children, proponents have ignored these assertions and drawn attention to opponents' legal arguments, that mandatory testing violates women's privacy rights, autonomy and freedom of choice.⁵ Proponents of mandatory testing argue that civil libertarians and feminists who seek to preserve women's rights have failed to consider the public health consequences of allowing women to seek testing voluntarily.⁶ For proponents, the health of an infant and the general public is paramount⁷ and infants, as "innocents," have rights that are more important than the privacy rights of women.⁸ Proponents argue that a woman has a "right to know" that she is infected with HIV,⁹ as opposed to the idea that a

² See *infra* Section I (providing background on the mandatory testing debate).

³ See Post, *supra* note 1, at 170-71 ("[T]his issue predictably has come to be framed in terms of maternal-child rights.").

⁴ See Martha A. Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402, 422-23 (1993) (stating that the mandatory HIV testing issue is often framed as one in which society must choose between public health and civil liberties).

⁵ See *infra* note 99 and accompanying text (referring to claims that women's rights are violated by mandatory testing).

⁶ See Nat Hentoff, *The New Tuskegee Experiment: Infected Has a Right to Be Told—No Matter What the ACLU Says*, VILLAGE VOICE, Oct. 1, 1996, at 8 (arguing that the American Civil Liberties Union ("ACLU") and other opponents of mandatory testing have attempted to mislead the public).

⁷ See Gretchen Buchenholz, *HIV Babies Have Rights, Too*, N.Y. DAILY NEWS, Jan. 18, 1994, at 15C.

⁸ Gretchen Buchenholz, Director of the Association to Benefit Children, states that the "sacrifice of defenseless children on the altar of political expediency and special interests can no longer be tolerated." Gretchen Buchenholz, N.Y. DAILY NEWS, Mar. 17, 1995, at 37. Buchenholz identifies these "special interest" groups as "women's, minority and gay groups." *Id.*

⁹ See Letta Tayler, *New Rights for Moms in HIV Tests: Critics Fear Its Use, Abuse*, N.Y. NEWSDAY, Oct. 11, 1995, at A4.

woman has the right to decide for herself. Further, proponents believe that protecting a woman's "right not to know" her HIV status is a "perversion of human rights" that injures both women and the general public health.¹⁰ In this debate, the public emphasis on the relative rights of women, fetuses and infants¹¹ has resulted

¹⁰ See Robert T. Jensen, *HIV Testing of Pregnant Women and Newborns*, 265 JAMA 1525 (1991) (letter to the editor) ("[T]o have a national or international policy that enables people at risk of being infected with HIV voluntarily to choose not to know whether they carry HIV, a fatal, sexually transmitted disease, is a perversion of human rights and a formula for HIV disaster.").

¹¹ The mandatory HIV testing debate is only one of several public debates about the relative rights of women and their children. For example, the abortion debate exemplifies how fetal rights are used to temper the rights of women. Recently, the prosecution of women for fetal endangerment has also been hotly debated. See, e.g., Stephen Buttry, *Fetal Endangerment Issue Heats Up: Mother Cleared; New Law Urged*, OMAHA WORLD-HERALD, June 18, 1993, at 13SF (quoting a judge who said that "[s]ociety's interest in healthy children, preservation of life, and the potentiality of the young should clearly override the concern of treatment of the alcoholic mother"); *Help, Not Hostility, Is Needed*, CHRISTIAN SCI. MONITOR, Oct. 23, 1990, at 20 (arguing that pregnant and childbearing addicts need help rather than punishment and that fetal endangerment prosecutions weaken families). Our culture also seems to have a new fascination for stories of young mothers who give birth and harm or kill their infants. See, e.g., Marie McCullough, *Why Would Anyone Throw Away a Newborn Baby?*, BUFFALO NEWS, June 15, 1997, at H5 (noting that one law professor has found a "historical connection between infant murders and crackdowns on abortion, birth control and out-of-wedlock pregnancy"); Katharine Q. Seelye, *What Leads Young Women to Kill Their Newborns?*, FORT WORTH STAR-TELEGRAM, June 18, 1997, at 1 (exploring the psychological reasons that might motivate a woman to kill her newborn); Paul Wilborn, *Profiling Mothers Who Abandon or Kill Babies*, ST. PETERSBURG TIMES, July 4, 1997, at 1A (noting several recent cases of women who harmed their newborns); George Will, *Wicked Act of Tossing Baby in Trash Bin*, DES MOINES REG., June 18, 1997, at 9 (blaming women, school condom dispensers, television, popular music, the pro-choice movement and "today's abortion culture, with its casual creation and destruction of life," for the recent flurry of infant deaths). The proliferation of such popular narratives and the intense scrutiny under which we place these mothers reflect a cultural preoccupation with the stereotype of the indifferent and selfish mother. This bad mother is perceived to be the root of at least two of contemporary society's greatest ills, drug addiction and the disintegration of the nuclear family.

in a circular discourse which precludes consideration of the harmful effects of mandatory testing on Black and Hispanic and low-income women and children, who are disproportionately affected by HIV infection.¹²

¹² The AIDS epidemic has a disproportionate effect on the Black and Hispanic communities. See Centers for Disease Control and Prevention, *U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women*, MORBIDITY AND MORTALITY WKLY. REP., July 7, 1995, at 2 [hereinafter CDC Guidelines]. While AIDS was the fourth leading cause of death among all women between ages 25 and 44 in 1993, AIDS was the leading cause of death for Black women and the third leading cause of death for Hispanic women in this age group. See *id.* In 1991, AIDS was the seventh leading cause of death for children between ages one and four, but AIDS was the second leading cause of death for Black children in New Jersey, Massachusetts, New York and Florida, and the second leading cause of death for Hispanic children in New York. See *id.* In 1994, 77% of AIDS cases among women occurred in Black and Hispanic women. See Centers for Disease Control and Prevention, *Update: AIDS Among Women—United States, 1994*, MORBIDITY AND MORTALITY WKLY. REP., Feb. 10, 1995, at 1. The rate of AIDS cases for Black women was 16 times higher than that for White women; the rate for Hispanic women was seven times higher than that for White women. See *id.*

The latest statistics show that these racial disparities continue. In 1996, AIDS cases among Whites dropped by 13%, but only dropped by 5% among Hispanics and did not decrease at all among Black populations. See Sheryl Gay Stolberg, *U.S. Says AIDS Cases Fell in '96, Ending 16-Year Rise*, N.Y. TIMES, Sept. 19, 1997, at A26 (reporting CDC findings). Disparities in the demographics also encompass class, as most HIV-infected women are poor and have limited access to health care. See *id.* In addition, the number of new AIDS cases in women rose 2% between 1995 and 1996, but the number of new cases in men declined by 8%. See *id.*

Because of the disproportionate impact that AIDS has on low-income, Black and Hispanic women, the mandatory testing issue has race and class implications, as well as gender implications. This Note analyzes mandatory testing with the perspective that most women who are identified as HIV-positive through mandatory testing programs will probably be poor, Black and Hispanic. Although the term "women of color" is broader than the Black and Hispanic women who are disproportionately impacted by HIV, I frequently use this term because it acknowledges that the categories "Black" and "Hispanic" women are not necessarily mutually exclusive or easily determined. I use the terms "low-income women" and "women of color" in conjunction to emphasize the different axes of race and class. However, these categories are also not mutually exclusive.

This Note argues that mandatory testing harms both women and children, principally because coercive medical policies drive women from health care, and that mandatory testing is not clearly justified by recent medical advances in AIDS treatments.¹³ This Note shows how rights discourses have enabled the justification of the mandatory testing policy and made criticism of this policy difficult. Part I of this Note provides background on the issue of mandatory HIV testing for infants and pregnant women and reviews recent federal legislation which may result in nationwide mandatory testing. Part II outlines the major problems with mandatory testing and shows why mandatory testing constitutes bad public health policy. Part III surveys the rhetoric of mandatory testing and shows that the public debate has been limited to a struggle between fetal rights, or saving babies, and women's rights of autonomy and privacy. Part IV examines how rights discourse constructs opposition between women and children, results in the blaming of women for larger societal problems and veils the racist impetus behind mandatory testing. Part V discusses the problems of arguing for the abandonment of rights discourse, but contends that opponents should continue their efforts to re-frame the public debate by exposing mandatory testing as a flawed public health policy and a hasty, ill-advised attempt to make up for previous failures of government and community to address the needs of affected women and children. This Note concludes that if opponents of mandatory testing can move the focus away from the relative rights of women, fetuses and newborns, mandatory testing will be exposed as a seriously flawed policy behind which lie only the workings of power, coercion and racism.

I. BACKGROUND

During most of the first decade of the AIDS epidemic, AIDS activists were largely successful in thwarting proposals to mandate

Most of the women affected by HIV are both poor and women of color.

¹³ See *infra* Section II (explaining the negative effects of mandatory testing on women and children and questioning the assumption that infants will benefit from new AIDS treatments).

HIV testing and to initiate other coercive measures such as quarantines.¹⁴ They argued that discrimination against infected individuals was so widespread that it would be unjust to forcibly compel testing.¹⁵ In addition, public health officials and health care workers generally agreed that people at risk for infection are more likely to seek health care when HIV testing is consensual and anonymity or confidentiality is assured.¹⁶ As a result, many states

¹⁴ See Field, *supra* note 4, at 405 n.8 (discussing involuntary testing and quarantine proposals). The fact that in 1993 only federal prisoners were forcibly administered HIV tests evidences that mandatory testing proposals were, until recently, unsuccessful. See Mireya Navarro, *Testing Newborns for AIDS Virus Raises Issue of Mothers' Privacy*, N.Y. TIMES, Aug. 8, 1993, at A1 (discussing the conflict between mandatory testing proposals and informed consent laws). Proposals to quarantine people with AIDS early in the epidemic were denounced by the scientific community as unnecessary and absurd. See Bernadette P. Sadler, Comment, *When Rape Victims' Rights Meet Privacy Rights: Mandatory HIV Testing, Striking the Fourth Amendment Balance*, 67 WASH. L. REV. 195 (1992). It has been suggested that the "panic response" to AIDS is "due to the fear underlying societal taboos related to human sexuality, social stigma, helplessness, mental illness, and death." Field, *supra* note 4, at 405 n.8; David I. Schulman, *AIDS Discrimination: Its Nature, Meaning and Function*, 12 NOVA. L. REV. 1113, 1115-17 (1988).

¹⁵ When the AIDS epidemic first hit the gay male community in the 1980s, the first policy initiatives were aimed at protecting HIV-positive gay men from homophobia and discrimination. See Juliet J. McKenna, *Where Ignorance Is Not Bliss: A Proposal for Mandatory HIV Testing of Pregnant Women*, 7 STAN. L. & POL'Y REV. 133, 147 n.56 (1996). One has to wonder if the general success that the gay male community had in protecting themselves from coercive, discriminatory measures is due in part to the relative political currency and economic power of that community. Because poor women and women of color suffer greater political and economic disadvantages, it is more difficult for them to affect legislative policy and combat coercive measures. See Lynda Richardson, *Progress on AIDS Brings Movement for Less Secrecy*, N.Y. TIMES, Aug. 21, 1997, at A1, B4 (quoting Ronald Bayer, Professor, Columbia University School of Public Health: "There is no question in my mind, had it been an epidemic of poor black and Hispanic drug users early on, that the contours of public health policy would have looked very different, much more authoritarian to begin with, less commitment and respect for notions of informed consent and privacy.").

¹⁶ See Larry Gostin, *Screening for AIDS: Efficacy, Cost, and Consequences*, 2 AIDS & PUB. POL'Y J. 14, 14-15 (1987) (stating that "[s]pecific consent based on information about HIV infection has been considered a requisite part of HIV antibody testing since the earliest public recommendations of the Public Health

enacted statutes and promulgated regulations which ensure confidentiality for those tested for HIV¹⁷ and allow testing only with the subject's consent.¹⁸

Service," and outlining a similar position adopted by the World Health Organization); Navarro, *supra* note 14, at A1 (stating that AIDS experts believe that "the epidemic can be slowed only through changes in behavior that require the cooperation of those infected").

¹⁷ See Lawrence O. Gostin et al., *The Case Against Compulsory Casefinding in Controlling AIDS — Testing, Screening and Reporting*, 12 AM. J.L. & MED. 7, 47 n.201 (1986) [hereinafter Gostin, *Compulsory Casefinding*]. By 1989, almost half the states had statutes ensuring confidentiality for AIDS-related information. See Larry Gostin, *Hospitals, Health Care Professional, and AIDS: The 'Right to Know' the Health Status of Professionals and Patients*, 48 MD. L. REV. 12, 47 (1989) [hereinafter Gostin, *Hospitals*].

¹⁸ See Suzanne Sangree, *Control of Childbearing by HIV-Positive Women: Some Responses to Emerging Legal Policies*, 41 BUFF. L. REV. 309, 367 (1993). By 1993, thirty states required that a patient specifically consent to an HIV test because of the "potentially grave psychological and social significance" of an HIV test. See *id.* The legislative intent of the New York confidentiality and consent law expresses the rationale behind confidentiality and consent requirements as follows:

The legislature recognizes that maximum confidentiality protection for information related to [HIV and AIDS] is an essential public health measure. In order to retain the full trust and confidence of persons at risk, the state has an interest both in assuring that HIV related information is not improperly disclosed and in having clear and certain rules for the disclosure of such information. By providing additional protection of the confidentiality of HIV related information, the legislature intends to encourage the expansion of voluntary confidential testing for [HIV] so that individuals may come forward, learn of their health status, make decisions regarding the appropriate treatment, and change the behavior that puts them and others at risk of infection.

The legislature also recognizes that strong confidentiality protections can limit the risk of discrimination and the harm to an individual's interest in privacy that unauthorized disclosure of HIV related information can cause. It is the intent of the legislature that exceptions to the general rule of confidentiality of HIV related information be strictly construed.

N.Y. PUB. HEALTH LAW § 2780 (McKinney 1988). See § 2781 for the consent requirements and § 2782 for confidentiality provisions.

In recent years, proposals for the mandatory testing of specific groups of people, for example, those groups presumed more likely to transmit HIV, have gained support.¹⁹ Because women can transmit HIV to fetuses in utero and to infants during and after birth,²⁰ women and newborns have become highly-targeted groups for mandatory HIV testing.²¹ Proposals for the mandatory testing of pregnant women and newborns further intensified following a

¹⁹ Such groups include sex offenders, prisoners, sex workers, athletes and health care workers and patients. See generally Gostin, *Hospitals*, *supra* note 17, at 12 (discussing proposals to mandate testing for health workers and patients); Jennifer L. Johnston, *Is Mandatory HIV Testing of Professional Athletes Really the Solution?*, 4 HEALTH MATRIX 159 (1994) (athletes); Kathleen Knepper, *Responsibility of Correctional Officials in Responding to the Incidence of the HIV Virus in Jails and Prisons*, 21 NEW ENG. J. ON CRIM. & CIV. CONFINEMENT 45 (1995) (prisoners); David Kennon Moody, Note, *AIDS and Rape: The Constitutional Dimensions of Mandatory Testing of Sex Offenders*, 76 CORNELL L. REV. 238 (1990) (sex offenders); James Grant Snell, *Mandatory HIV Testing and Prostitution: The World's Oldest Profession and the World's Newest Deadly Disease*, 45 HASTINGS L.J. 1565 (1994) (sex workers).

²⁰ HIV can be transmitted by four bodily fluids: blood, semen, vaginal secretions and breast milk. See Michael A. Grizzi, *Recent Developments: Compelled Antiviral Treatment of HIV Positive Pregnant Women*, 5 UCLA WOMEN'S L.J. 473, 479 n.22 (1995) (discussing the mechanics of vertical transmission). Most commonly, HIV is transmitted by the intermingling of bodily fluids during sexual intercourse and when intravenous drug users share needles. *Id.* at 479. In what is termed "vertical transmission," women can transmit HIV to a fetus in the womb, during delivery or after birth, if an HIV-infected woman breast-feeds. *Id.* at 479-80.

²¹ Taunya Lovell Banks, *Women and AIDS — Racism, Sexism, and Classism*, 17 N.Y.U. REV. L. & SOC. CHANGE 351, 353 (1990) (exploring the discriminatory implications of mandatory testing). The focus on women has increased as the numbers of women and infants infected with HIV have surged, and at a time when AIDS cases are increasing at a greater rate among women than men. See Deborah L. Shelton, *Is It the Time . . .*, AM. MED. NEWS, Sept. 2, 1996, at 23. While women represented 7% of AIDS cases in 1985, they represented 19% in 1995. *Id.* Currently, almost all cases of HIV infection in infants are the result of vertical transmission. See Robin D. Gorsky et al., *Preventing Perinatal Transmission of HIV - Cost and Effectiveness of a Recommended Intervention*, PUB. HEALTH REP., July-Aug. 1996, at 335. Each year approximately 7,000 infants are born to HIV-infected women nationwide. See S.F. Davis et al., 274 JAMA 952-55 (1995). It is estimated that 15 to 30% of these infants will become infected in the absence of intervention. See Gorsky, *supra*, at 335.

1994 study, commonly referred to as Clinical Trial 076. This study found that administering zidovudine ("AZT")²² to HIV-positive pregnant women before and during childbirth and then administering AZT to newborns after birth decreased the newborns' chances of becoming HIV-infected by 67.5%, as compared to those infants born without the administration of AZT.²³ The ability of AZT therapy to reduce perinatal transmission²⁴ has increased support for mandatory testing.

In July 1995, the CDC published Public Health Service guidelines recommending that all health care providers counsel pregnant women to voluntarily test for HIV.²⁵ The CDC guide-

²² AZT is the most widely used brand of the drug zidovudine, which is also known as ZDV. See CDC Guidelines, *supra* note 12, at ii. Zidovudine is referred to as AZT throughout the text.

²³ See Edward M. Connor et al., *Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment*, 331 NEW ENG. J. MED. 1173 (1994) (presenting the findings of Clinical Trial 076). In Clinical Trial 076, 8.3% of infants who had been treated with AZT during prenatal, perinatal and postnatal phases were HIV-infected at 18 months, whereas 25.5% of infants who had not been treated with AZT were infected at 18 months. *Id.* These statistics evidence that without AZT treatment, approximately one quarter of infants born to HIV-infected mothers become infected with HIV.

²⁴ *Perinatal transmission* is commonly defined as the transmission of HIV from mother to child that occurs before, during or after birth. See DORLAND'S ILLUSTRATED MED. DICTIONARY 1511 (27th ed. 1988).

²⁵ See CDC Guidelines, *supra* note 12, at 1. The CDC includes in its numerous recommendations that: "[h]ealth-care providers should ensure that all pregnant women are counseled and encouraged to be tested for HIV infection"; "HIV testing of pregnant women and their infants should be voluntary"; "[h]ealth-care providers should counsel and offer HIV testing to women as early in the pregnancy as possible so that informed and timely therapeutic and reproductive decisions can be made"; "[u]ninfected pregnant women who continue to practice high-risk behaviors . . . should be encouraged to avoid further exposure to HIV"; "[t]he prevalence of HIV infection may be higher in women who have not received prenatal care" and "[t]hese women should be assessed promptly for HIV infection"; "HIV-infected pregnant women should receive counseling," including an "assessment of the potential for negative effects resulting from HIV infection (e.g., discrimination, domestic violence, and psychological difficulties)"; counseling should include advice concerning options for medication and assistance in identifying and referral for support networks; and there be adequate provisions for follow-up for HIV-infected women and their

lines intentionally rejected mandatory testing because it is coercive and encourages women to avoid prenatal care.²⁶

In 1996, Congress for the first time addressed the issue of mandatory HIV testing of newborns and pregnant women by amending the Comprehensive AIDS Resources Emergency Act, popularly known as the Ryan White CARE Act, which was enacted in 1990 to provide emergency funding for cities that are disproportionately affected by the AIDS epidemic.²⁷ These amendments are aimed at reducing the number of HIV-infected infants²⁸ and

children when necessary. CDC Guidelines, *supra* note 12, at 8-11.

²⁶ The CDC states the following policy reasons:

Data from universal, routine HIV counseling and voluntary testing programs in several areas indicate that high test-acceptance levels can be achieved without mandating testing. Mandatory testing may increase the potential for negative consequences of HIV testing and result in some women avoiding prenatal care altogether. In addition, mandatory testing may adversely affect the patient-provider relationship by placing the provider in an enforcing rather than facilitating role. Providers must act as facilitators to adequately assist women in making decisions regarding HIV testing and ZDV [AZT] preventive therapy. Although few studies have addressed the issue of acceptance of HIV testing, higher levels of acceptance have been found in clinics where testing is voluntary but recommended by the health-care provider than in clinics that use a nondirective approach to HIV testing (i.e., [sic] patients are told the test is available, but testing is neither encouraged nor discouraged).

CDC Guidelines, *supra* note 12, at 6 [citations omitted].

²⁷ 42 U.S.C. §§ 300ff-33, -37 (1996). The Act seeks to improve the quality and availability of care for communities affected by HIV, to provide early intervention services such as counseling and testing and to offer primary care. See 42 U.S.C. § 300 *et seq.* (1990). The Act is the federal government's primary response to the AIDS epidemic and the funds it authorizes are crucial to state AIDS programs. See Christina Kent, *States Pushed to Test Newborns for HIV*, AM. MED. NEWS, May 27, 1996, at 1 (quoting a state official who said: "In many states, the only source of money for AIDS is Ryan White.").

²⁸ See 42 U.S.C. § 300ff-33. Congress stated in its findings that "[r]esearch studies and statewide clinical experiences have demonstrated that administration of anti-retroviral medication during pregnancy can significantly reduce the transmission of [HIV] from an infected mother to her baby." *Id.* Congress also pointed out that HIV testing, "without access to such counseling, treatment, and services will not improve the health of the woman or the child." *Id.*

require all states to conform to the amended Act or risk losing federal financing available under the Act.²⁹

Specifically, the amendments required that states adopt the CDC guidelines recommending HIV counseling and voluntary testing of all pregnant women by September 1996.³⁰ At that time, the CDC implemented a reporting system in order for states to determine the annual rate of AIDS cases resulting from perinatal transmission.³¹ In the latter half of 1998, the CDC must publish a determination of whether mandatory testing of newborns or pregnant women is a routine practice nationwide.³² If the CDC determines that mandatory testing is a nationwide practice, a state will lose its funding unless it can show one of the following: 1) a 50% reduction in the rate of new AIDS cases as a result of perinatal transmission as compared to 1993 rates; 2) at least 95% of women in the state who have been to at least two prenatal visits have volunteered for HIV testing; or 3) the state has enacted or promulgated mandatory HIV testing requirements for newborns or pregnant women.³³

States unwilling to implement mandatory testing face a heavy burden of showing that either 95% of pregnant women are consenting to testing,³⁴ or that there has been a 50% reduction in

²⁹ See *id.* § 300ff-33(b) (declaring that a state "shall not be eligible to receive assistance for HIV counseling and testing" until certification of compliance with the amendments is provided).

³⁰ See *id.* § 300ff-33(a) ("[A] State shall, not later than 120 days after May 20, 1996, certify to the Secretary that such State has in effect regulations or measures to adopt the guidelines issued by the [CDC] concerning recommendations for [HIV] counseling and voluntary testing for pregnant women."). Congress has authorized a total of \$10 million per year through the year 2000 in order to assist the states in carrying out this mandate. See *id.* § 300ff-33(c)(2).

³¹ See *id.* § 300ff-34.

³² See *id.* §§ 300ff-34, -35.

³³ See *id.* § 300ff-34(e)(2).

³⁴ In theory, it is conceivable that 95% of pregnant women, if aggressively and appropriately counseled, would voluntarily agree to an HIV test. In fact, according to state health officials, one such counseling program at Harlem Hospital resulted in 95% of pregnant women volunteering to test for HIV. See Navarro, *supra* note 14, at A1. At Grady Hospital in Atlanta, 96% of approximately 3600 women agreed to be tested as part of their prenatal care. See Shelton, *supra* note 21, at 23. Despite these successes, proponents of mandatory testing assume that pregnant women do not want to know their HIV status or that

the rate of HIV-positive newborns. Although this showing will only be required if the CDC determines that mandatory testing is a routine practice nationwide, such a determination may be likely because the Act itself encourages mandatory testing policies.³⁵ Under the amendments, states can avoid the potential burden by immediately adopting mandatory testing.³⁶ Thus, while the amendments appear to give the states time and discretion in determining whether to adopt mandatory testing, states are in fact encouraged to enact mandatory testing laws immediately, in order to avoid having to grapple with adopting aggressive counseling policies and reducing the rate of new AIDS cases among newborns.³⁷

of their children. *See Post, supra* note 1, at 197 (stating that the New York bill for mandatory testing of newborns "appears predicated on the assumption that women will refuse to be tested voluntarily" and that "[i]mplicit in the bill's language and legislative intent is the notion that coercion is the only way to get women to do what is in their children's best interest"); Shelton, *supra* note 21, at 23 (noting that women have not been adequately counseled to test for HIV, but are being blamed for not seeking testing); *infra* notes 146-55 and accompanying text (discussing the ways in which the government and community have historically failed to adequately address the needs of women with HIV and have subsequently punished women by increasing the regulation of their bodies). It is likely that the assumption that women are unwilling to be tested or do not care about their children is motivated in part by race and class bias, because low-income women and women of color are most affected by HIV and mandatory testing. *See Post, supra* note 1, at 197 n.181.

³⁵ *See Kent, supra* note 27, at 1 (exploring the possible impact of the 1996 amendments and noting the confusion and controversy that the amendments have caused).

³⁶ *See* 42 U.S.C. § 300ff-37 (providing that any state that establishes mandatory HIV testing prior to or after May 20, 1996 will not lose its funding). Aimee Berenson, legislative counsel for AIDS Action Council, fears that in light of the 1996 amendments, "state legislatures will implement mandatory testing programs in order to protect themselves against the possible loss of vital Ryan White CARE Act dollars." Kent, *supra* note 27, at 1.

³⁷ In discussing the Ryan White amendments, Berenson states that the "language of this compromise presents Washington double-speak at its worst." Kent, *supra* note 27, at 1. While the Ryan White legislation appears to support counseling and voluntary testing, it enables mandatory testing approaches as a simple alternative, which takes away the incentive to establish strong and effective voluntary programs. The 1996 amendments amount to a shoddy

Since the Ryan White amendments were passed in 1996, New York has already initiated mandatory HIV testing of all newborns.³⁸ While the debate over mandatory HIV testing for newborns had been raging in New York for years,³⁹ the 1996

compromise that makes little sense.

³⁸ New York instituted mandatory testing of newborns by amending its Public Health Law to exempt childbearing women and newborns from its confidentiality and consent requirements, and to require the promulgation of regulations that would mandate the testing of all newborns and parental notification of the results. See N.Y. PUB. HEALTH LAW §§ 2500-f, 2781-6(d) (McKinney 1996). New York was the first state nationwide to enact a law requiring the mandatory HIV testing of newborns. See Hentoff, *supra* note 6, at 8 (arguing that the New York law is justified because it enables HIV-infected infants to gain access to health care and treatment). Under New York's program, which has been in effect since February 1, 1997, newborns are tested for HIV at birth and hospitals attempt to track down the mothers of HIV-exposed infants several weeks after they leave the hospital. See Lynda Richardson, *Critics Say Mothers Get Little Help After H.I.V. Notification*, N.Y. TIMES, June 16, 1997, at B1. If and when the mothers are found, they "are simply told they are H.I.V. positive and given the names of programs they can turn to." *Id.* at B2 (quoting Marie St. Cyr, Executive Director of Iris House, a social service agency for HIV-infected poor women in East Harlem). Because some hospitals are poorly administering the program, some mothers are not even informed that the infant is being tested and receive little or no counseling. See *id.* at B1-B2. When the program began in February, a telephone information line concerning mandatory testing was initiated. See *id.* at B2. As of June 1997, the hotline received about 60 complaints. See *id.*

³⁹ The bill to mandate testing of newborns, proposed by Nettie Mayersohn, a Democratic Assembly Member from Flushing, was stalled in the New York Assembly's Health Committee for over three years before it was made law. See Nettie Mayersohn, *HIV Mothers Need to Know*, N.Y. NEWSDAY, Jan. 28, 1994, at 54. During this period, the issue of mandatory HIV testing of newborns was hotly contested in the press. See, e.g., Buchenholz, *supra* note 8, at 37 (arguing that invasion of a mother's privacy "is morally justified where lives are at stake"); Nat Hentoff, *The Shame of Sheldon Silver*, VILLAGE VOICE, Aug. 1, 1995, at 18 (arguing that Speaker of the Assembly Sheldon Silver should be ashamed for blocking the bill "that would have saved lives"); Mayersohn, *supra*, at 54 (proposing that an alleged 85 to 91% voluntary testing success rate for Health Department counseling and testing initiatives "is a fantasy"); Anna Quindlen, *Public & Private; The Baby Bill*, N.Y. TIMES, June 8, 1994, at A25 (remarking that mandatory testing "seems so right at first blush," but that it is a complicated policy decision which is opposed by many AIDS providers who

amendments apparently prompted the passage of the New York law.⁴⁰ Because New York often initiates legislative and judicial

understand the detrimental effects on women and children); Tayler, *supra* note 9, at A4 (noting criticisms of Pataki's plan to mandate testing).

The mandatory testing issue was also contested in the courtroom. See Raymond Hernandez, *Pataki's Plan to Offer Results of HIV Tests Is Assailed*, N.Y. TIMES, Oct. 11, 1995, at B2 [hereinafter Hernandez, *Pataki's Plan*] (discussing a court settlement which resulted in Governor Pataki agreeing to promulgate regulations for mandatory testing). Impatient with the Assembly's failure to enact the amendment to the Public Health Law, the Association to Benefit Children brought suit against Governor Pataki in April 1995 in an effort to compel the Governor to institute mandatory HIV testing for newborns by executive order or regulations. See *id.* As it was clear that Pataki himself wanted a mandatory testing law or regulation, over thirty opponents of mandatory HIV testing, including HIV Law Project, Housing Works and other local AIDS service organizations, intervened as defendants. See *Attorney General Vacco Agrees to Violate Existing State Law to Mandate HIV Testing of All Women Giving Birth*, Press Advisory, Oct. 9, 1995, at 1 (on file with the *Journal of Law and Policy*). With the intervenors being effectively excluded from all settlement negotiations, the case was settled and the Governor agreed to promulgate regulations through the Department of Health. See *id.*; Hernandez, *Pataki's Plan*, *supra*, at B2. Commissioner of the Department of Health, Barbara DeBuono, subsequently promulgated regulations and a new lawsuit was brought, with many of the former intervenors as plaintiffs, to enjoin the regulations. See Tayler, *supra* note 9, at A4. As this suit was being successfully litigated, the 1996 Ryan White amendments were passed and Democratic party members of the State Assembly, most notably Speaker of the Assembly Sheldon Silver, who had long been opposed to the bill, caved in to political election year pressures and pushed the bill through. See Raymond Hernandez, *Pataki and Lawmakers Agree on Plan for Testing Newborns for AIDS Virus*, N.Y. TIMES, June 6, 1996, at B8 [hereinafter Hernandez, *Pataki and Lawmakers*]. Sheldon Silver had previously been credited with blocking the passage of the mandatory testing for newborns legislation. See Terry McGovern, *Scarlet Letters*, CITY LIMITS, Aug.-Sept. 1995, at 33 (arguing that mandatory testing "will have a devastating effect on mothers and children").

⁴⁰ When Governor Pataki and the New York State Assembly agreed to enact mandatory testing of newborns, the *New York Times* wrote:

The unexpected agreement reached today was largely prompted by recent Congressional efforts to require states to begin mandatory H.I.V. testing of newborns—with the results disclosed to parents—unless state health officials can reduce the number of infected infants born in the next few years.

Both the House and the Senate passed a law last month that would cut off Federal money for AIDS treatment to states that fail to comply

trends in the rest of the country, it is likely other states will take New York's lead and also enact statutes providing for mandatory HIV testing of infants or pregnant women.⁴¹

II. MANDATORY HIV TESTING DOES NOT PROTECT THE FETUS OR THE NEWBORN AND DRIVES WOMEN FROM CARE

Many experts believe that mandatory testing and similar coercive medical policies discourage women from seeking medical care.⁴² This is particularly unfortunate because HIV infection may

with the requirements. Over all, New York receives more than \$150 million a year from the Federal Government to treat people with AIDS under the Ryan White act.

Hernandez, *Pataki and Lawmakers*, *supra* note 39, at B8.

⁴¹ Theresa McGovern, Legal Director of the HIV Law Project in New York, believes that other states around the country have been closely watching what happens in New York on this issue and that other states unfortunately will follow what New York has done. *See* Shelton, *supra* note 21, at 23 (interviewing McGovern). The HIV Law Project is now suing New York State over the mandatory HIV testing of newborns law, because it has been "implemented in a slipshod fashion, offering little support and poor counseling to the most vulnerable women." Richardson, *supra* note 38, at B4.

⁴² Martha Field writes:

Even apart from issues of the rights of women who would be tested, a powerful argument against imposing testing on particular groups, like pregnant women, is that testing will not work to slow the spread of HIV, or to accomplish any other legitimate government purpose. Not only is universal precautions a more effective approach than the vain effort to sort the population into infected and uninfected segments, but also the attempt to impose testing on women who do not want it will be counterproductive. If forced testing becomes part of prenatal care, it will drive pregnant women who do not want to be tested away from the other components of prenatal care as well. . . . If testing is a condition of admission to the hospital, when women learn of that fact, then women who do not want to be tested will simply give birth elsewhere under less safe conditions.

Field, *supra* note 4, at 422.

Dr. Alfred J. Saah, Associate Professor of Epidemiology and Infectious Diseases at Johns Hopkins University, writes:

The American Medical Association's [AMA] decision to recommend mandatory H.I.V. testing in pregnant women . . . is shameful. For it

be most prevalent in those women who already lack access to medical care, including prenatal care.⁴³ The first question raised, therefore, is whether a policy that mandates testing of pregnant women will actually reach those likely to be infected. Furthermore, mandatory testing of women who are able to obtain some form of prenatal care, and of infants, does not guarantee access to HIV-related medical care and treatment in the future.⁴⁴ In fact, one recent study found that White people with HIV in New York City

does not mandate treatment, which is the only way to reduce transmission to newborns. If H.I.V. infection were a benign condition without social, medical or employment consequences, testing could be done with impunity. But in the absence of universal health care and given that H.I.V. predominates in poor communities, mandatory testing becomes another obstacle to obtaining prenatal care.

Alfred J. Saah, *Forced H.I.V. Testing*, N.Y. TIMES, July 2, 1996, at A14 (responding to the AMA's decision to endorse mandatory HIV testing of all pregnant women). See *Doctors Back AIDS Tests for Pregnant Women*, N.Y. TIMES, June 28, 1996, at A20 (noting that the resolution of the AMA's policy-making House of Delegates was passed by a very close vote of 185 to 181).

The New York courts have also acknowledged the potential danger of coercive medical policies by ruling in favor of the position that "the voluntary cooperation of high-risk individuals [in public health programs] . . . would be chilled by the threat of mandatory testing despite assurances of confidentiality." *Matter of New York State Soc'y of Surgeons v. Axelrod*, 555 N.Y.S.2d 911, 914 (App. Div., 3d Dep't 1990) (upholding the dismissal of a petition requesting that AIDS be designated as a communicable and sexually transmitted disease), *aff'd* 572 N.E.2d 605 (N.Y. 1991).

⁴³ See *HIV Testing and Counseling for Women: An Update*, CONSULTANT, May 1996, at 1049, 1050 (citing a study which found that the "prevalence of HIV infection may be higher in women who have not received prenatal care than in those who have received such care").

⁴⁴ One study in New York City found that identified HIV-exposed infants may actually be receiving less medical care than infants who do not test positive for HIV. See Betty Levin et al., *Treatment Choices for Infants in the Neonatal Intensive Care Unit at Risk for AIDS*, 265 JAMA 2976 (1991). In addition, mere HIV testing and identification does not necessarily ensure the future provision of adequate medical care as there is no universal health care system in this country. See Nan D. Hunter, *Complications of Gender: Women and HIV Disease*, in AIDS AGENDA: EMERGING ISSUES IN CIVIL RIGHTS 5, 23-26 (Nan D. Hunter & William B. Rubenstein eds., 1992) (discussing the unlikelihood that many HIV-infected infants will receive adequate medical care).

"are much more likely than [B]lack and Hispanic people to have access to powerful new drugs that have revolutionized AIDS treatment," which is especially unfortunate given that Black and Hispanic individuals are "considered most in need of advanced treatments."⁴⁵

Proponents of mandatory testing argue that because most HIV-infected pregnant women have no access to prenatal care, newborn testing is sometimes the only opportunity to identify HIV-positive infants.⁴⁶ In addition, proponents assert that the results of Clinical Trial 076⁴⁷ and the increasing success of new drug therapies warrant compulsory testing of newborns.⁴⁸ Although the relative success of the new therapies does strengthen proponents' arguments, the extent to which infants benefit from new therapies is exaggerated.

First, the new drug therapies, commonly referred to as triple combination therapies or drug cocktails, do not benefit infants as they do adults.⁴⁹ Although there are eleven government-approved drugs used in combination therapies for adults, there are only six for children.⁵⁰ In addition, children may tend to fail a particular

⁴⁵ Lynda Richardson, *White Patients Have More Access to New AIDS Drugs, A Survey Shows*, N.Y. TIMES, July 27, 1997, § 1, at 25.

⁴⁶ See Ruth R. Faden et al., *HIV Infection, Pregnant Women, and Newborns: A Policy Proposal for Information and Testing*, in AIDS, WOMEN, AND THE NEXT GENERATION 331, 335-36 (Ruth R. Faden et al. eds., 1991) (stating that many commentators justify mandatory HIV testing for newborns on the grounds that such testing provides the last chance to identify a potentially infected newborn before all pregnancy and birth-related medical care is completed and explaining why this argument does not justify mandatory HIV testing of newborns).

⁴⁷ See Connor, *supra* note 23, at 1173 (stating the findings of the study).

⁴⁸ See Richardson, *supra* note 15, at A1 (stating that some advocates and health professionals are now proposing that "[s]uccessful new drug therapies make early detection and treatment more important" and that privacy concerns may now be outweighed by improvements in available treatments).

⁴⁹ See Sheryl Gay Stolberg, *A Revolution in AIDS Drugs Excludes the Tiniest Patients*, N.Y. TIMES, Sept. 8, 1997, at A1. In early 1996, it was found that three-drug regimens combining older drugs such as AZT, 3TC and ddi with new drugs called *protease inhibitors* can prolong life and most effectively combat HIV. See *id.* at A1, A14.

⁵⁰ See *id.*

drug regimen more quickly than adults because they are very likely to miss doses due to vomiting, spitting up or otherwise refusing the medicine and because doctors are uncertain about the appropriate dosages for children.⁵¹ Moreover, newborns have missed out on the benefits of new drugs almost entirely because protease inhibitors, which are drugs that are essential to the triple combination therapies, have not been approved for children under two years of age.⁵²

Second, the administration of the new drugs to children may create serious health risks. As discussed above, doctors are uncertain about proper drug dosages for children. Administering an improper dosage of protease inhibitors may have "dire consequences" for the child.⁵³ Moreover, the National Institute of Health recently reported a study's finding that AZT causes cancer in baby mice whose mothers are administered AZT during pregnancy.⁵⁴ The *Times* reported that a study "found high doses of AZT increased certain types of cancer in baby mice, including an eight-fold increased risk of lung cancer in males. And 17 percent of the female mice developed rare reproductive tumors, a

⁵¹ See *id.* One mother thought that her child was taking the pills religiously, only to find that the pills were being hidden under a radiator. See *id.*

⁵² See *id.* It is suggested that mandatory testing is justified because patients benefit the most when the triple combination therapies are administered very early in the HIV infection, which, for perinatal transmissions, would be just after birth. However, only some newborns, who are enrolled in clinical trials, have access to protease inhibitors. See *id.*

⁵³ *Id.* The *New York Times* recently reported: "Dosing information for protease inhibitors is still sketchy in children, both because the drugs have been studied much more thoroughly in adults and because young people metabolize them differently. That has left doctors playing a guessing game with potentially dire consequences. Too much medication could harm a child. Too little could create a mutant strain of H.I.V., saddling young patients with an illness that resists future treatment." *Id.* Dr. Ross McKinney, who specializes in pediatric AIDS at Duke University Medical Center, says that he only prescribes protease inhibitors to children "when we are really up against a wall . . . using them broadly is simply to invite disaster." *Id.*

⁵⁴ See *Panel Urges Caution in Use of AIDS Drug*, N.Y. TIMES, Jan. 15, 1997, at A16.

type similar to those caused by the drug DES that women once took to prevent miscarriages.”⁵⁵

Third, Clinical Trial 076 only determined that HIV transmission is preventable when AZT is administered throughout the entire reproductive cycle: to pregnant women before birth and during birth, and to the newborn postnatally.⁵⁶ This study did not determine that administering AZT postnatally will decrease the chances of HIV infection in newborns.⁵⁷ Therefore, testing of newborns will show that a mother is HIV-infected and that her infant has been HIV-exposed, but the advantages of early detection and early administration of AZT are lost where there is only post-natal identification of HIV exposure or infection.⁵⁸ Proponents of mandatory testing therefore misrepresent the capability and risks of current medical therapies when they insist that testing newborns or pregnant women will save babies' lives.⁵⁹

In addition to economic obstacles to health care and the highly questionable benefits of treatment for HIV-positive infants,

⁵⁵ *Id.* After this article appeared in the *Times*, some advocates issued a press release claiming that the Pataki administration has failed to appropriately inform pregnant women of the potential health risks posed by AZT therapy. See *Women Charge Pataki Administration with Concealing Dangers of AZT; Demand Government Disclosure of Cancer Risk to HIV-Negative Children Posed by AIDS Treatment During Pregnancy*, Press Release, Jan. 23, 1997 (on file with the *Journal of Law and Policy*).

⁵⁶ See Connor, *supra* note 23, at 1173 (stating that according to Clinical Trial 076, the effectiveness of AZT depends on administration early in the pregnancy); *HIV Testing and Counseling for Women: An Update*, *supra* note 43, at 1050 (“The effectiveness of [AZT] therapy depends on diagnosis of HIV infection before or during early pregnancy.”).

⁵⁷ See Connor, *supra* note 23, at 1173.

⁵⁸ See Richard Goldstein, *Spare the Mother, Save the Child: The State Is Considering a New Policy on HIV Testing that Promotes Prenatal Screening But Preserves Parental Consent*, VILLAGE VOICE, June 7, 1994, at 24 (discussing what can and cannot be done for infants identified as HIV-exposed). It should be noted that infants who are seriously ill at birth are generally given appropriate medical care, whether or not they have been exposed to HIV.

⁵⁹ Dr. McKinney comments that although many adults are experiencing terrific results from new treatments, “none of us are perceiving that we are getting the same results in kids,” and “[i]nfected kids are getting left behind.” Stolberg, *supra* note 49, at A1, A14.

mandatory testing creates significant psychological obstacles for women attempting to access care and treatment. If pregnant women know they will be forced to get an HIV test, they may turn away from the health care system and forego prenatal care altogether:

The spread of HIV can be reduced only through the willingness of individuals to avoid unsafe sexual and needle-sharing behavior. This introduction of compulsory screening may have the reverse effect of causing persons vulnerable to HIV to avoid coming forward for testing, counseling, and treatment. If the public health strategy is to encourage as many people as possible to receive education and counseling, then the use of measures that can be regarded as controlling or punitive might be counterproductive.⁶⁰

In addition, women who are subjected to coercive testing may be driven away from seeking medical treatment in the future because coercive testing creates an environment of distrust and does not foster necessary cooperative relationships between medical providers and patients.⁶¹

Mandatory testing undermines the positive psychological effects of pre- and post-test counseling.⁶² Pre-test counseling can assist an

⁶⁰ Gostin, *supra* note 16, at 15. See also Field, *supra* note 4, at 422-23 (stating that coercive HIV testing harms public health because women will be driven from prenatal care).

⁶¹ Post, *supra* note 1, at 181-82. Post writes:

Aggressive and sustained counseling for women before and after birth is widely considered to be the most effective method of getting women to be tested voluntarily and then securing their cooperation in behavior modification. Most health care professionals believe that involving women as active partners, rather than simply informing them of their HIV serostatus, leads to successful health care management.

Post, *supra* note 1, at 181-82.

⁶² Counseling can educate the patient about "the meaning of a positive and negative test, the known routes of transmission, and [for pregnant women] the estimated risk of perinatal HIV transmission." Nancy E. Kass, *Reproductive Decision Making in the Context of HIV: The Case for Nondirective Counseling*, in AIDS, WOMEN, AND THE NEXT GENERATION, *supra* note 46, at 308, 312. Counseling should also involve discussions of safer-sex practices and the use of clean needles for intravenous drug users.

individual in coming to her own decision to be tested and help prepare the counselee for a positive test result. Post-test counseling is important even for those who test negative because it can encourage them to continue safer sex and drug practices and negate the tendency of the uninfected to assume that they are immune. When the counselee is HIV-infected, post-test counseling can provide crucial psychological support and direct the counselee to further counseling and medical care. This may also include "determining and facilitating a patient's ability to tap her own support system and typical coping mechanisms."⁶³

Involuntary testing creates an antagonistic relationship between medical provider and patient and eliminates the opportunity for conscious decision-making that cooperative counseling provides. Under mandatory testing, women, with little or no counseling or support from health providers, will be forced into an array of social problems which are best endured only after making a thoughtful and conscious decision to have an HIV test. The social risks of being identified as HIV-positive include the loss of employment and housing, isolation from spouses, friends and family, and difficulty in obtaining medical insurance.⁶⁴ Women are also subject to an increased risk of domestic violence after testing positive.⁶⁵ Aggressive counseling and voluntary testing of pregnant

⁶³ Kass, *supra* note 62, at 312. If a decision must be made about terminating or initiating pregnancy, "it is crucial to sort out the counselee's values and feelings in regard to the decision." Kass, *supra* note 62, at 312. See generally CDC Guidelines, *supra* note 12, at 1 (discussing counseling and testing strategies and objectives).

⁶⁴ See Post, *supra* note 1, at 179 n.67. In addition, health care professionals have refused to treat HIV-infected individuals, employers try to fire HIV-infected employees and some have advocated for the quarantine of infected persons. See Peter H. Berge, *Setting Limits on Involuntary HIV Antibody Testing Under Rule 35 and State Independent Medical Examination Statutes*, 44 FLA. L. REV. 767, 780-81 (1992). Current protections from these kinds of discrimination are inadequate. See Banks, *supra* note 21, at 370-71 (discussing the social and economic stigma of identified HIV infection).

⁶⁵ See Karen L. Goldstein, Note, *Balancing Risks and Rights: HIV Testing Regimes for Pregnant Women*, 4 CORNELL J.L. & PUB. POL'Y 609, 620 (1995). Unfortunately, the 1996 amendments to the Ryan White CARE Act also include a provision that requires all states to make a "good faith effort to notify the

women is therefore the more effective policy choice because it will more wholly suit the health needs of HIV-infected women.⁶⁶

The emotional health of women may be even more seriously threatened by mandatory testing of newborns. If a newborn tests positive for HIV antibodies it is automatically known that the mother is HIV-positive.⁶⁷ Therefore, administering an HIV test to a newborn without the mother's consent has a similar effect on the mother as does the forcible administration of an HIV test to a pregnant woman. However, the adverse psychological effect on the mother may be heightened because she may be suffering from postpartum depression⁶⁸ and is certainly adapting to her new life

spouse of a known HIV-infected patient that such spouse may have been exposed to [HIV] and should seek testing." 42 U.S.C. § 300ff-27a. If an informed spouse or partner perceives that a woman is HIV-positive because of sexual infidelity or drug use, a woman may face the risk of physical violence and loss of economic support for herself and her children. See Post, *supra* note 1, at 197 n.179.

⁶⁶ See generally CDC Guidelines, *supra* note 12, at 1 (recommending aggressive strategies of counseling and voluntary testing for pregnant women and rejecting mandatory HIV testing initiatives).

⁶⁷ See *HIV Infection, Pregnant Women, and Newborns: A Policy Proposal for Information and Testing*, 264 JAMA 2416 (1991). Many infants born to HIV-infected mothers will test positive for HIV antibodies, which they have acquired from the mother. See CDC Guidelines, *supra* note 12, at 7. This positive antibody test shows that the newborn has been exposed to HIV, but does not mean that the newborn is infected with HIV. See CDC Guidelines, *supra* note 12, at 7. Using only the ELISA test, which is the most widely used and inexpensive HIV test in this country, laboratories cannot determine that an infant is infected with HIV until around 18 months of age, when the infant's system is cleared of all maternal antibodies. See CDC Guidelines, *supra* note 12, at 7. The relatively new and much more expensive PCR test can more definitively identify the virus in infants shortly after birth. See CDC Guidelines, *supra* note 12, at 7.

⁶⁸ Postpartum depression occurs in 8 to 20% of women after birth. See Lori A. Button, Comment, *Postpartum Psychosis: The Birth of a New Defense?*, 6 T.M. COOLEY L. REV. 323, 324 (1989). The symptoms of this moderate to extreme depression can include mood swings, delusions, suicidal ideation, lack of concentration, insomnia, psychotic episodes, panic attacks and negative feelings toward the infant. See AMERICAN PSYCHIATRIC ASSOCIATION, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 386-87 (4th ed. 1994). Fifty to eighty percent of women experience a more temporary and less severe postpartum disorder, known as *maternity blues* or *baby blues*, which is

as a mother. In addition, the new mother will be less able to keep the HIV infection a private matter as she struggles to cope with this news. One attorney, who represents low-income women infected with HIV, recalls asking her clients how they would have responded had they learned of their HIV status after birth pursuant to a mandatory testing of newborns scheme.⁶⁹ “[O]ne replied that she might have killed herself. Others said they would never have returned to the hospital for fear that their children would be taken away.”⁷⁰ Thus, the concern that coercive HIV testing will drive women from care is also present when the newborn, and not the pregnant woman, is mandatorily tested for HIV.

Driving women from health care hurts infants and mothers. Infants do not obtain medical treatment on their own. If mothers are alienated from the health care system, their children, likewise, will not receive the medical care they need.⁷¹ Thus, proponents of

characterized by tearfulness, insomnia, anxiety and mild depression. See Button, *supra*, at 324.

⁶⁹ McGovern, *supra* note 39, at 33.

⁷⁰ McGovern, *supra* note 39, at 33.

⁷¹ Dr. Michael T. Mennuti, the Chairman of the American College of Obstetricians and Gynecologists’s Committee on Obstetric Practice, states that when “‘HIV testing is mandatory in an office or clinic setting, individuals simply stop going to that physician or clinic.’” Kent, *supra* note 27, at 1 (quoting Dr. Mennuti). “‘This was highlighted most recently in New York, where women with HIV stated that they would not seek care from physicians who required HIV testing at prenatal care clinics. Unfortunately, the stigma attached to HIV in certain communities still precludes many women from seeking out their HIV status.’” Kent, *supra* note 27, at 1 (quoting Dr. Mennuti). Discussing similar problems with mandatory HIV testing, Dr. Robert J. Simonds writes:

Prenatal care, treatment for HIV infection, and zidovudine treatment to reduce perinatal transmission all require frequent interactions and an ongoing collaborative relationship between an HIV-infected woman and her health care professional. Mandatory testing programs may jeopardize these interactions and this relationship. Some women fear HIV testing because they are unprepared to face their test results or are concerned about lack of confidentiality, stigmatization, or other negative consequences of being diagnosed with HIV infection. If prenatal testing is mandatory, some women may not seek prenatal care to avoid being tested or not continue prenatal care to avoid receiving test results, thus missing opportunities not only for preventing perinatal

mandatory testing cannot honestly argue that infants do not suffer from coercive testing policies or that infants can only gain attention and care under mandatory testing policies.

Proponents also argue that forced testing leads to behavioral changes which benefit both the woman and the fetus.⁷² Their position is that HIV-infected pregnant women who know of their HIV status will seek medical treatment and counseling, make changes in sexual practices and drug use, alter their general personal health choices,⁷³ and maybe decide not to become pregnant or to terminate a pregnancy.⁷⁴ This reasoning is flawed because there is no evidence that a person will "make more rational decisions about behavior change if [she] is informed about [her] serological status,"⁷⁵ especially when frightening information about HIV-infection is unexpectedly thrust upon an individual who has not even consented to a test.

For example, there are many reasons why an HIV-infected woman might decide to bear a child. "Many women may feel pressure from the great value society places upon women to reproduce, and may feel that bearing a child can improve their community status. Some commentators have observed that this

transmission but also for receiving other benefits of prenatal care. Furthermore, testing against their patients' wishes would transform clinicians from advocates for their patients to enforcers of legal mandates. The supportive environment needed to successfully initiate and maintain prenatal and HIV care likely would be compromised when the patient-physician relationship begins under the threat of such measures.

Robert J. Simonds et al., *Preventing Perinatal HIV Transmission*, 276 JAMA 779 (1996) (letter to the editor).

⁷² See McKenna, *supra* note 15, at 147 (stating that "because knowledge can actually make a difference in a pregnant woman's choices and behavior, she has a right, and an obligation, to know if she is infected").

⁷³ See McKenna, *supra* note 15, at 147.

⁷⁴ See Grizzi, *supra* note 20, at 484.

⁷⁵ Gostin, *supra* note 16, at 15. In other contexts it is acknowledged that individuals do not necessarily change their behavior simply because they have medical information concerning the potential detrimental effects of certain practices, such as cigarette smoking.

pressure may be especially strong in minority cultures."⁷⁶ In addition, women who are chemically dependent may experience motherhood as a boost to their self-esteem; others may want to leave behind a legacy; still others may be in denial about their condition or may actually be very healthy.⁷⁷ There is also no obvious answer to the question of whether it is ethical for women who know they are HIV-infected to choose to bear children: fewer than 8.3% of infants born to HIV-infected mothers will actually be HIV-infected if the mother is administered AZT, and fewer than 25.5% of infants born without AZT therapy will be infected.⁷⁸ Thus, proponents have failed to show how mandatory testing leads to behavioral changes which benefit the women and fetus. To the contrary, coercive and unexpected HIV testing may result in greater stress and psychological damage to a pregnant woman or a new mother who learns of her HIV infection in this manner.⁷⁹

In addition, it should not be assumed that mandatory testing will necessarily result in HIV-infected women and children taking AZT. Infected women and children may lack access to drug treatments.⁸⁰ Furthermore, HIV-infected women may choose not to engage in a program of AZT therapy and decline to place their children on AZT. Many HIV-infected individuals have made a reasoned and educated decision not to take AZT because of its high levels of toxicity, its side effects and unknown dangers.⁸¹ Because

⁷⁶ Grizzi, *supra* note 20, at 485.

⁷⁷ See Grizzi, *supra* note 20, at 485-86.

⁷⁸ See Connor, *supra* note 23, at 1176. See also HIV, AIDS AND CHILDBEARING (Ruth R. Faden & Nancy E. Kass eds., 1996) (challenging the assumption that HIV-positive women should not have children).

⁷⁹ See Gostin, *supra* note 16, at 15.

⁸⁰ See Richardson, *supra* note 45, § 1, at 25 (noting that Black and Hispanic populations in New York City do not have the same access to AIDS treatments that Whites do, despite the fact that HIV infection is growing in the Black and Hispanic communities).

⁸¹ The CDC notes that although Clinical Trial 076 indicated that AZT therapy can have substantial benefits for the infants of HIV-infected pregnant women, the trial also presented a few unresolved issues. See CDC Guidelines, *supra* note 12, at 4. These issues include questions about the long-term safety of AZT for mothers and infants, the effectiveness of AZT for women who have different clinical characteristics than trial participants and the probability of

the long-term effects of AZT on mothers, fetuses and infants are unknown, a childbearing woman's decision to refuse AZT therapy should be respected.⁸²

Finally, mandatory testing proponents make assumptions about behavior and lifestyle which are ignorant of race, class and gender difference. Knowledge of HIV status may affect poor women and women of color differently than it affects, for instance, middle-class white men. For the middle-class white man, becoming HIV-positive may be the ultimate crisis of his life. For women who have suffered from poverty and racism throughout their lives, HIV infection may be just one more obstacle to overcome. While the middle-class white man will likely be able to invest in extensive counseling, support groups, medical care and dietary programs, low-income women have overwhelming economic and social barriers to overcome, in addition to psychological barriers. Because so many additional obstacles have already been placed in the way of low-income women and women of color, it is simply outrageous to drive the women most at risk for HIV away from care with coercive policies which are justified on grounds that are irrelevant to their lives.⁸³ Women need cooperation and understanding in

individuals' adherence to strict regimens for the administration of AZT. See CDC Guidelines, *supra* note 12, at 4.

⁸² See CDC Guidelines, *supra* note 12, at 4, 10. The CDC states:

The PHS recommendations for [AZT] therapy emphasize that HIV-infected pregnant women should be informed of both benefits and potential risks when making decisions to receive [AZT] therapy. Discussions of treatment options should be noncoercive—the final decision to accept or reject [AZT] treatment is the responsibility of the woman. Decisions concerning treatment can be complex and adherence to therapy, if accepted, can be difficult; therefore, good rapport and a trusting relationship should be established between the health-care provider and the HIV-infected woman.

CDC Guidelines, *supra* note 12, at 4.

⁸³ Judith Figueroa, a clinic administrator at St. Luke's-Roosevelt Hospital Center in Manhattan, states: "Mandatory testing is not the way to go. I feel that there has to be another creative way of distributing this information. Because you're going to drive these women underground. You really are." John Riley, *Focus On: Mandatory AIDS Tests: Pain of Knowing: Doctor, Clinician Disagree on Testing Moms, Newborns*, N.Y. NEWSDAY, Aug. 25, 1993, at 15 (quoting

order to cope with this virus, not paternalistic health and social policies.

A policy of aggressive HIV counseling and voluntary HIV testing of pregnant women will more adequately address the interests of women and infants than will mandatory testing.⁸⁴ Rather than spending federal and state funds on mandatory testing, federal and state governments should be funding programs which educate the public about HIV transmission, bring pregnant women into care and provide free counseling and medical care to infected individuals.⁸⁵ Programs that combine mandatory, aggressive

Judith Figueroa). Figueroa, who counsels women at risk for HIV before and after they give birth, "sees the panic that testing can arouse among the largely poor and minority women who use St. Luke's." *Id.*

⁸⁴ Anna Quindlen writes:

The idea that a woman, postpartum, would forge ahead heroically after being informed that her kid may be mortally ill and she herself is a goner would make for a swell television movie. But it is not, says Dr. Mitchell [who runs a clinic at Harlem Hospital], real life.

Real life is talking to her patients at every visit about H.I.V. testing, just as she talks about nutrition and smoking and drugs. It is explaining to them what being positive would mean and what kind of help is available to them and their babies. It is follow-up, outreach and persistence.

And it works. Close to 90 percent of the women in the Harlem Hospital program agree to be tested, and nearly all infected babies are in care. "We create trust," Dr. Mitchell says. "You cannot tell someone that they are H.I.V. positive out of a clear blue sky."

Quindlen, *supra* note 39, at A25.

⁸⁵ Some analysts have determined that it is more cost-effective to perform counseling and voluntary testing than it is to conduct mandatory testing. See Gostin, *supra* note 16, at 14-16. Gostin states:

The personal and economic costs engendered by a program of compulsory screening are likely to be disproportionate to the marginal public health benefit. The objective of a screening is to obtain shifts in behavior and early treatment among groups most vulnerable to HIV infection. This objective can be achieved in a more effective and less restrictive way through a comprehensive, voluntary program of public health education and professional testing and counseling services. Those inclined to seek treatment and behavior control are likely to respond to cost-free, readily available education and services. Such a voluntary program would achieve the same public health advantages as

counseling and voluntary testing of pregnant women are the more effective alternative to policies of mandatory testing.

Despite the huge success of Harlem Hospital's aggressive counseling program, which resulted in almost 90% of women volunteering for an HIV test after being counseled about HIV,⁸⁶ states have made little effort to really attempt counseling and voluntary testing programs. Terry McGovern, Legal Director of the HIV Law Project, states that many women she has spoken with "were never offered counseling and testing."⁸⁷ Some dismiss voluntary testing programs on the assumption that "women will refuse to be tested voluntarily, even after they have been informed of the risks and benefits HIV testing holds for them and their children."⁸⁸ Others minimize Harlem Hospital's high success rate with voluntary testing initiatives by portraying it as truly exceptional and impossible to duplicate.⁸⁹ What mandatory testing proponents fail to realize is that even with mandatory testing, adequate pre- and post-test counseling must still be performed, and it is not more cost-effective to institute mandatory testing than it is

a mandatory program without the significant detriments of the widespread use of compulsion.

Gostin, *supra* note 16, at 16. One study has concluded that programs involving counseling and voluntary testing of pregnant women and subsequent AZT treatment for those identified as HIV-infected reduce the overall costs of pediatric AIDS cases. See Gorsky, *supra* note 21, at 335 (calculating "the annual cost of HIV counseling and voluntary testing for pregnant women and the cost of [AZT] treatment for HIV-infected women and their infants" and finding that this intervention saved costs in medical care because of the resulting decrease in pediatric HIV infections).

⁸⁶ See Quindlen, *supra* note 39, at A25.

⁸⁷ McGovern, *supra* note 39, at 33.

⁸⁸ Post, *supra* note 1, at 197 ("Implicit [in mandatory testing initiatives] is the notion that coercion is the only way to get women to do what is in their children's best interest. This assumption . . . has been explicitly rejected by maternal and pediatric health care professionals."). See also Simonds, *supra* note 71, at 779 (arguing that an "often unspoken tenet of arguments and policies favoring mandatory prenatal HIV testing is that many women will not be tested if testing is voluntary").

⁸⁹ See Goldstein, *supra* note 65, at 622 (stating that proponents "suggest that [Harlem Hospital's] long-established, flexible program is incompatible with the more administratively-oriented environment of conventional hospitals").

to counsel women affected by HIV.⁹⁰ Proponents of mandatory testing have rejected the approach of aggressive counseling and voluntary testing before it has even been attempted in a large-scale initiative.⁹¹ Instead, they punish and blame women for the failure of government and health providers to aggressively counsel pregnant women about HIV tests.⁹²

The federal action taken in the amendments to the Ryan White CARE Act has granted opponents of mandatory testing some time to continue fighting this issue on the state level.⁹³ During this crucial time, opponents of mandatory testing need to re-frame the debate by focusing not on the respective rights of women and fetuses, but on the public health reasons which support voluntary and confidential pre- and post-natal care, and on exposing the problematic assumptions behind mandatory HIV testing laws.

III. RIGHTS TALK IN THE MANDATORY TESTING DEBATE

Unfortunately, the public debate around mandatory testing has not done justice to these complex issues. While opponents have made great attempts to show that mandatory testing is harmful to families and a destructive public health policy,⁹⁴ proponents have

⁹⁰ See *supra* note 85 (citing studies of the cost-effectiveness of mandatory testing).

⁹¹ See Shelton, *supra* note 21, at 23 (quoting McGovern).

⁹² See *infra* notes 146-55 and accompanying text (discussing the ways that women affected by HIV have been abandoned throughout the history of the AIDS epidemic).

⁹³ See *supra* notes 27-37 and accompanying text (discussing the 1996 amendments to the Ryan White CARE Act).

⁹⁴ From discussions with lawyers working to oppose mandatory testing, I have learned that opponents have made enormous efforts to take the public discussion of this issue away from rights-centered rhetoric. This is also evident from many articles that oppose mandatory testing on public policy grounds and do not rely solely on rights arguments. See, e.g., Elizabeth A. Cooper, *Why Mandatory HIV Testing of Pregnant Women and Newborns Must Fail: A Legal, Historical, and Public Policy Analysis*, 3 CARDOZO WOMEN'S L.J. 13, 22-26 (1996); Field, *supra* note 4; Theresa M. McGovern, *Mandatory HIV Testing and Treating of Child-Bearing Women: An Unnatural, Illegal, and Unsound Approach*, 28 COLUM. HUM. RTS. L. REV. 469 (1997). Although proponents assert that opponents are only concerned about women's rights, most opponents detail the

very effectively constructed this issue as one that involves women's and children's *rights*. This is both a testament to proponents' political savvy and to the predominance of rights ideology in our culture. Within the public sphere, there is little discussion about the actual impact of mandatory testing on HIV-infected women and children. The public health and social problems involved are publicly presented as a more simple question: are the rights of a woman or the rights of the fetus and infant paramount? This focus reflects a cultural preoccupation with evaluating the relative rights of women and infants, which, for example, is also articulated in public debates about abortion and fetal endangerment prosecutions.⁹⁵

The purpose of this section is not to analyze whose rights are legally paramount, or which rights are protected or guaranteed by law.⁹⁶ Rather, it seeks to illuminate how the debate around

deleterious effects of mandatory testing on women and children and assert rights arguments only as part of a legal analysis. Therefore, rather than arguing that opponents have placed the focus on rights, I want to show that rights claims in the public debate tend to overshadow more complicated, substantive contentions concerning the problems of mandatory testing. My project also is to illustrate how rights discourse has to a large extent produced and determined the terms of the mandatory testing debate so that arguments against mandatory testing are made more difficult. I would even contend that rights and individualist ideology provide the context for the development of mandatory testing policies.

⁹⁵ See *supra* note 11 (noting the plethora of recent news stories about fetal endangerment prosecutions and mothers suspected of murdering their infants).

⁹⁶ Several authors have explored whether mandatory testing violates constitutional and statutory rights. See, e.g., Colin Crawford, *An Argument for Universal Pediatric HIV Testing, Counseling and Treatment*, 3 CARDOZO WOMEN'S L.J. 31, 40 (1996) (arguing that state interest in protecting public health, especially in light of the increasing availability of effective new treatments, may override constitutional concerns); Field, *supra* note 4, at 411-13 (arguing that mandatory testing violates the 14th Amendment's protection of women's privacy); Grizzi, *supra* note 20, at 484-500 (discussing the extent of a mother's right to refuse medical treatment); McKenna, *supra* note 15, at 133 (arguing that pregnant women have a right to refuse medical intervention); Post, *supra* note 1, at 226 (evaluating a proposed mandatory testing scheme in New York, which later became law in modified form, and concluding that the proposed law carried "the potential for significant infringement of a woman's constitutionally protected rights").

mandatory testing is one in which a colloquial and popular notion of "rights" is deployed, in addition to legal notions of rights, in order to support each of the opposing positions.⁹⁷

The mandatory testing issue is framed as one that pits fetal and children's rights against women's rights, or welfare of the child against women's rights.⁹⁸ Both proponents and opponents of mandatory testing use the language of rights to legitimate their arguments and appeal to common sense. Although opponents have sought to show how this issue is about families and public health policy, the public has focused primarily on opponents' legal arguments that mandatory testing violates constitutional and statutory rights of women, especially privacy, equal protection and procreative rights and patients' rights under informed consent laws.⁹⁹ The constitutional right to privacy that is asserted in

⁹⁷ Section IV discusses the way that this focus on rights has precluded the pursuit of more holistic and less oppositional approaches to the issue and questions the efficacy of using rights rhetoric to oppose mandatory testing.

⁹⁸ See Paris R. Baldacci, *An Introduction to "Mandatory HIV Screening of Newborns: A Child's Welfare in Conflict with its Mother's Constitutional Rights?" - False Dichotomies Make Bad Law*, 3 CARDOZO WOMEN'S L.J. 1, 5 (1996). Professor Baldacci of Cardozo School of Law states:

discussion of the legal, political, medical, and public health policy implications of recent medical developments regarding HIV treatment of newborns is, indeed, all too frequently articulated in terms of a necessary and inevitable conflict between the child's medical welfare and his or her mother's constitutional rights of privacy and autonomous informed choice regarding medical testing and treatment.

Id. at 5. See also Navarro, *supra* note 14, at A1 ("A growing effort in New York State to identify and quickly treat children infected with H.I.V. has led to a struggle over how to reconcile the health needs of the children with the right to privacy of their mothers."); Post, *supra* note 1, at 170-71 ("Because it involves the health of newborns and the rights of women, this issue predictably has come to be framed in terms of maternal-child rights."); Riley, *supra* note 83, at 15 (stating that the mandatory HIV testing debate "ultimately pits the health of the babies against the rights of their mothers").

⁹⁹ See *supra* note 96 (citing law review articles addressing the legal rights implicated by mandatory testing); Kathryn Boockvar, *Beyond Survival: The Procreative Rights of Women with HIV*, 14 B.C. THIRD WORLD L.J. 1, 4, 21-41 (1994) (arguing that women should not be "screened, prosecuted, or punished for perinatal transfer of HIV" because such initiatives "violate women's constitu-

opponents' legal arguments derives primarily from the Supreme Court cases *Griswold v. Connecticut*,¹⁰⁰ *Eisenstadt v. Baird*¹⁰¹ and *Roe v. Wade*.¹⁰² Opponents also derive from these constitutional privacy rights less legalistic and more popular and colloquial "rights." For instance, one author has written of a woman's "right not to know" about her HIV infection,¹⁰³ "right of personal autonomy,"¹⁰⁴ "right to develop . . . individuality"¹⁰⁵ and "right to make her own medical decisions,"¹⁰⁶ and questioned whether there is a "right to object even to learning the truth."¹⁰⁷ Thus, when making legal arguments, opponents of mandatory testing attest to rights that are grounded both in constitutional doctrine and a derivative, popular rhetoric of rights.

tional rights of liberty and privacy" and "work against sensible public policies rather than accomplishing legitimate state goals"); Julie D. Levinson, Note, *While Ignorance May Not Be Bliss, It Is a Mother's Right: Constitutional Implications of Testing Newborn Babies for HIV*, 3 CARDOZO WOMEN'S L.J. 71 (1996) (arguing that mandatory HIV testing violates women's rights under the Equal Protection Clause of the Fourteenth Amendment and privacy and procreative rights); Catherine H. McCabe, *Ryan White CARE Amendments: Mandatory HIV Testing of Newborns and a Woman's Right to Privacy*, 1 DEPAUL J. HEALTH CARE L. 373 (1996) (arguing that the 1996 amendments to the Ryan White Care Act, if applied by the states in mandatory testing schemes, violate women's constitutional right of privacy); Post, *supra* note 1, at 199-226 (arguing that the state must choose public health measures that will infringe on individual rights as little as possible and that mandatory testing measures violate women's constitutional rights to privacy and equal protection); Sangree, *supra* note 18, at 316, 362-441 (demonstrating how the "coercive control over childbearing and HIV testing infringes upon various basic individual rights").

¹⁰⁰ 381 U.S. 479 (1965) (recognizing a right to marital privacy as falling within the penumbra of the Bill of Rights).

¹⁰¹ 405 U.S. 438 (1972) (employing equal protection doctrine to expand *Griswold's* right to privacy to include individual procreative privacy rights).

¹⁰² 410 U.S. 113 (1973) (holding that the Fourteenth Amendment's substantive due process doctrine requires that the right of personal privacy include a woman's right to have an abortion).

¹⁰³ Field, *supra* note 4, at 411.

¹⁰⁴ Field, *supra* note 4, at 412.

¹⁰⁵ Field, *supra* note 4, at 412.

¹⁰⁶ Field, *supra* note 4, at 412.

¹⁰⁷ Field, *supra* note 4, at 409.

Proponents also offer legalistic rights arguments. It is argued that when there is no mandatory testing requirement, fetal and children's rights are violated.¹⁰⁸ Another tactic of proponents is to argue that mandatory testing protects women's rights because a mother has a "right to know" that she and her infant are infected and that mothers will in fact *gain* new rights under mandatory testing laws.¹⁰⁹

Proponents utilize a popular notion of rights to bolster their arguments, much more so than opponents of mandatory testing.

¹⁰⁸ Dr. Keith Krasinski of Bellevue Hospital states: "'Every child must be identified for HIV at birth so that he or she can be treated. To do less is discrimination in its cruelest form.'" Hentoff, *supra* note 6, at 8 (quoting Dr. Krasinski). Gretchen Buchenholz, Director of the Association to Benefit Children, argues that the failure to mandatorily test infants violates infants' constitutional rights:

[The state] is obligated to perform and disclose results of HIV tests so appropriate treatment may be provided. Failure to do so violates the U.S. and New York constitutions' equal protection clauses, and the state's constitutional obligation to care for the needy. This sacrifice of defenseless children on the altar of political expediency and special interests can no longer be tolerated.

Buchenholz, *supra* note 8, at 37. Buchenholz wrote another article in the *New York Daily News* concerning infants' "rights" to HIV identification that was entitled *HIV Babies Have Rights, Too*. Buchenholz, *supra* note 7, at 15C.

¹⁰⁹ See Hentoff, *supra* note 6, at 8 (discussing remarks by Dr. Arthur Ammann, Professor of Pediatrics at the University of Southern California). Juliet McKenna writes: "Mandatory testing [of pregnant women] is warranted by a woman's own right to be aware of her HIV status, apart from any interest that may be asserted on behalf of the fetus or the public health." McKenna, *supra* note 15, at 134.

An article announcing Pataki's regulations for the testing of all newborns was entitled *New Rights for Moms in HIV Tests*. Tayler, *supra* note 9, at A4. In describing the former New York screening program in which all infants were anonymously screened for HIV for epidemiological purposes, the *New York Times* wrote that parents could not learn of the results. See Hernandez, *Pataki's Plan to Offer Results of H.I.V. Tests is Assailed*, *supra* note 39, at B2. This characterization of the screening program implies that parents were somehow cheated of their right to know their child's HIV status, even though parental knowledge of HIV infection was not the purpose of the blinded screening and even though any parent can always volunteer for an HIV test or request that their child be tested.

Proponents mock women's rights by arguing that a mother does not have a "right to remain ignorant."¹¹⁰ In addition, some proponents irresponsibly attempt to harness conservative distaste for civil libertarians, feminists and gay rights advocates by claiming that it is primarily these groups that motivate opposition to mandatory testing.¹¹¹

Members of Congress also debated the clashing rights of women and infants when they considered the amendments to the Ryan White CARE Act. Representative Gary Ackerman [D-N.Y.], an advocate of mandatory HIV testing for newborns in cases where the mother has not been tested for HIV, stated in a floor debate:

Some have advocated that the mother has a right to privacy, and in testing the child we have inadvertently or deliberately tested the mother to determine her status, and that the mother has a right to remain ignorant of her status if she so chooses. That may be so, but the child has a right to live.

In this complex and complicated society, so often rights conflict. . . . Certainly if the right of the child to survive is more important than the constitutional right of freedom

¹¹⁰ See *infra* note 112 and accompanying text (remarks of Rep. Ackerman).

¹¹¹ For example, in referring to New York's mandatory testing debate, proponent Nat Hentoff writes: "'The parents and kids are pawns in somebody else's game.' And that game is financed by these groups with money for lobbyists in Albany while the most at-risk black, Latina, and white kids are without such resources." Hentoff, *supra* note 6, at 8 (quoting Dr. Stephen Nicholas, the medical director of a residential program for children with AIDS). Hentoff describes these wealthy interests as the Gay Men's Health Crisis, the ACLU, and "some feminists and medical societies." Hentoff, *supra* note 6, at 8.

By characterizing opponents of mandatory testing as only civil libertarians and feminists, Hentoff ignores that many of mandatory testing's fiercest opponents are also not-for-profit AIDS service providers, who for many years have advocated for and represented the communities who will be most impacted by mandatory testing. HIV Law Project, which provides free legal services to low-income individuals with HIV and AIDS, Housing Works, which also assists low-income people living with HIV, and approximately 30 other organizations and individual women filed an action in New York to attack Pataki's mandatory testing regulations. See *Attorney General Vacco Agrees to Violate Existing State Law to Mandate HIV Testing of All Women Giving Birth*, *supra* note 39.

of religion, certainly it is equally important as the mother's right to remain ignorant.¹¹²

Representative Patsy Mink [D-Haw.] responded: "I question whether or not we can accomplish [reduced incidences of vertical transmission of HIV] by simply mandating testing. Mandatory testing violates the civil liberties of the woman and may produce the opposite response by driving them out of medical care."¹¹³

Proponents of mandatory testing successfully minimized opponents' focus on public health and families and pushed rights-based analysis to the forefront. In the Congressional forum as well as in public speech, the mandatory testing debate is constructed as an argument about whose rights are paramount. The following section argues that contemporary rights discourse by its nature overshadows attempts to address substantive policy issues and fails to foster a discursive and political environment conducive to the creation of policy that can help prevent perinatal HIV transmission and enable access to care for women and children.

IV. RIGHTS DISCOURSE, INDIVIDUALISM AND OPPOSITION

The discourse of rights¹¹⁴ obscures the intricacies of mandatory testing, eliminates consideration of how women and their

¹¹² 141 Cong. Rec. H9050-05, H9059-60 (1995).

¹¹³ *Id.* at H9061.

¹¹⁴ Rights discourse has been critiqued by Critical Legal Studies ("CLS") texts. See generally Peter Gabel & Duncan Kennedy, *Roll Over Beethoven*, 36 STAN. L. REV. 1 (1984) (engaging in a now infamous dialogue about the difficulties with critique of rights and other CLS polemics); Mark Tushnet, *The Critique of Rights*, 47 SMU L. REV. 23 (1993) (outlining the problems with rights discourses). Others have also articulated a critique of rights. See generally MARY ANN GLENDON, *RIGHTS TALK: THE IMPOVERISHMENT OF POLITICAL DISCOURSE* xi, xii (1991) (arguing that "our distinctive current rights dialect . . . frequently works against the conditions required for the pursuit of dignified living" and advocating for a renewal of "our strong rights tradition"); LEGAL RIGHTS: HISTORICAL AND PHILOSOPHICAL PERSPECTIVES (Austin Sarat & Thomas R. Kearns eds., 1996) (providing a collection of essays on rights from varied perspectives); Matthew A. Ritter, "Human Rights": *Would You Recognize One If You Saw One? A Philosophical Hearing of International Rights Talk*, 27 CAL. W. INT'L L.J. 265 (1997) (discussing rights in the international context).

children are actually affected by mandatory testing and conceals the failure of government and the community to adequately address the needs of women and children affected by HIV.¹¹⁵ Instead of enabling the community to confront the particular problems that women face in terms of access to prevention services, education, counseling and medical care, rights discourses focus the public's attention on abstract notions and rhetoric¹¹⁶ and construct an opposition between women and their children. Conferring a right becomes an end in itself.¹¹⁷ Rights rhetoric creates the impression

¹¹⁵ See *infra* notes 146-55 and accompanying text (providing some examples of how women, especially low-income women and women of color, have been abandoned by government and health care providers throughout the AIDS epidemic).

¹¹⁶ Some CLS theorists attack rights on the grounds that they are illusory, vacuous diversions which prevent government, lawyers and the public from seriously analyzing the issues at hand. See Gabel & Kennedy, *supra* note 114, at 33-34. CLS theorist Peter Gabel states:

Exactly what people don't need is their rights. What they need are the actual forms of social life that have to be created through the building of movements that can overcome illusions about the nature of what is political, like the illusion that there is an entity called the state, that people possess rights. It may be necessary to use the rights argument in the course of political struggle, in order to make gains. But the thing to be understood is the extent to which it is enervating to use it. It's a diversion from true political language, political modes of communication about the nature of reality and what it is that people are trying to achieve

Gabel & Kennedy, *supra* note 114, at 33.

¹¹⁷ See Gabel & Kennedy, *supra* note 114, at 39. CLS theorist Duncan Kennedy illustrates this point with a hypothetical situation where a progressive group wants to picket inside a shopping center, but the police tell them they have no right to picket. Gabel & Kennedy, *supra* note 114, at 27. If the issue is litigated in court, the progressives will argue that the shopping center is partly public property, and therefore there is a First Amendment right to picket inside. Gabel & Kennedy, *supra* note 114, at 27. Kennedy goes on to say: "The problem with rights analysis [is that it] leads you to believe in the power of saying things like: 'Well, the shopping center is private property.' It leads you to think that you've said something when you say that the shopping center is private property. It's mainly a problem of vacuity." Gabel & Kennedy, *supra* note 114, at 39. Gabel says that this does not mean that such a case should not be litigated; rather, "you keep your eye on power and not on rights." Gabel & Kennedy,

that the mandatory testing issue will be solved once we determine whose rights are more important.¹¹⁸

supra note 114, at 36. Rights are a diversion because, according to Gabel, they are merely “shared, imaginary attributes that the group attributes to its members that don’t in fact exist. It’s a hallucination.” Gabel & Kennedy, *supra* note 114, at 34.

¹¹⁸ The CLS critique of rights reflects a broader CLS critique of law. One of the primary contentions of CLS is that law depoliticizes and removes “crucial issues from the public agenda.” *THE POLITICS OF LAW: A PROGRESSIVE CRITIQUE* 5 (David Kairys ed., rev. ed. 1990). The law is able to appear as free from political motivation and value judgments because it is “depicted as separate from—and ‘above’—politics, economics, culture, and the values or preferences of judges.” *Id.* at 1. See also HILAIRE MCCOUBREY & NIGEL D. WHITE, *TEXTBOOK ON JURISPRUDENCE* 223 (1993) (explaining that under the CLS approach, contract law, for instance, “serves the ideological function of reinforcing the conception that law is neutral, self-contained, that it cannot be challenged and that it is the product of reasoned analysis”). Deconstruction and CLS teach that, in fact, law is both constitutive of and constructed by society and is not separable from the “social totality.” *THE POLITICS OF LAW*, *supra*, at 6 (“[T]he law is not simply an armed receptacle for values and priorities determined elsewhere; it is part of a complex social totality in which it constitutes as well as is constituted, shapes as well as is shaped.”).

Where society presumes that law is objective, CLS “has traditionally aspired to show how legal orders systematically reflect, generate, and/or reinforce poverty, class inequality, and patriarchal, homophobic, and racial domination.” Karl E. Klare, *Critical Theory and Labor Relations Law*, in *THE POLITICS OF LAW*, *supra*, at 61, 65. For Roberto Unger, who has written some of the seminal CLS texts, “legal adjudication is purely arbitrary and used for political purposes to further the needs of the powerful and persuasive in society.” MCCOUBREY & WHITE, *supra*, at 226. Rand Rosenblatt illustrates this concept with the problem of welfare rights:

[The] denial of governmental, and more generally social responsibility with respect to poverty and other human needs, like the similar denial of responsibility for racism and its effects . . . enhances the economic power of the relatively well-off, preserves the myth that the market operates fairly, neutrally, and apolitically, and reinforces the idea that those who do not succeed economically have no moral or legal claims on the community and only themselves to blame.

Rand E. Rosenblatt, *Social Duties and the Problem of Rights in the American Welfare State*, in *THE POLITICS OF LAW*, *supra*, at 90, 92.

Rights, because of their self-referential and abstract qualities, serve to distract attention away from the politicized nature of the law and the economic

This section examines the effects that rights discourses have on the mandatory testing debate: how the popular conception and use of rights diminish the potency of asserting a right; how assertions of fetal rights are used to usurp the rights of women; how rights reproduce individualistic ideologies which compel the opposition between woman, child and fetus and place blame on women for larger societal problems; and how rights conceal the discriminatory and racist impetus behind mandatory testing policies. This section concludes that rights discourse does not positively inform the debate on whether mandatory testing is effective public health policy and beneficial for women and children. Those who oppose mandatory testing should continue trying to shift the focus from rights and expose mandatory testing as a policy which does not truly assist women and children affected by HIV and AIDS and masks government's ongoing failure to appropriately address the needs of affected women and children.

A. The Changing Landscape of Rights: Rights in Popular Culture; Counter-Rights; Privacy Rights

The prevalence of rights talk in our popular and political culture has enabled and legitimized the utilization of fetal and children's rights as a counter to assertions of women's rights. Contemporary culture conflates wants and needs with rights; when we feel we have identified something that we deserve, we use the language of rights.¹¹⁹ In commenting on the proliferation of rights talk,

and social consequences of conferring rights themselves. For instance, in the mandatory testing debate, it is presumed that determining who has the greater right, woman or child, will solve the question of whether mandatory testing is an acceptable and effective policy. The preoccupation with rights forecloses the possibility of confronting the actual or potential impact of mandatory testing on women and children and then determining whether it is acceptable policy.

¹¹⁹ See David Ray Papke, *Understanding "Rights" in Contemporary American Discourse*, 2 MICH. J. RACE & L. 521 (1997) (reviewing LEGAL RIGHTS: HISTORICAL AND PHILOSOPHICAL PERSPECTIVES, *supra* note 114); Jeremy Waldron, *Rights and Needs: The Myth of Disjunction*, in LEGAL RIGHTS: HISTORICAL AND PHILOSOPHICAL PERSPECTIVES, *supra* note 114, at 87 (exploring the relationship between the language of rights and the language of needs).

Professor David Ray Papke¹²⁰ alludes to a recent hit song, *Passionate Kisses*, where the singer demands passionate kisses and states, "Give me what I deserve because it's my right."¹²¹ Another interesting example of popular rights talk is a satiric moment in the movie *Scream*¹²² when a reporter asks actress Neve Campbell, "So how does it feel to be almost brutally butchered? People want to know—they have a right to know."¹²³ Not only do we commonly express our desires and needs with the language of rights, but there is also a "tendency to frame nearly every social controversy in terms of a clash of rights," which "impedes compromise, mutual understanding, and the discovery of common ground."¹²⁴ In the political context, this clash of rights is exemplified by the mandatory HIV testing debate and other issues where women's rights are countered with the rights of children and fetuses.

One effect of the proliferation of rights talk in popular discourse is that the effect of asserting a right has been dissipated.¹²⁵ Although those who historically have been subordinated, such as certain racial and ethnic groups, women and gays and lesbians, have used rights discourse progressively in the twentieth century to strip away the forms and instruments of their subordination, or in the popularly preferred terms, to achieve greater "equality," the rhetoric of rights is now employed by those groups who have enjoyed the privilege of dominance for many centuries.¹²⁶ In fact, it has been suggested that the rhetoric of rights

¹²⁰ Professor of Law and the Liberal Arts, Indiana University at Indianapolis.

¹²¹ MARY-CHAPIN CARPENTER, *Passionate Kisses*, on COME ON COME ON (Columbia Records 1992). See Papke, *supra* note 119, at 521.

¹²² SCREAM (Dimension Films 1996).

¹²³ *Id.*

¹²⁴ Glendon, *supra* note 114, at xi (using the example of "a woman's right to her own body vs. a fetus's right to life"). Professor Mary Ann Glendon notes that "the catalog of individual liberties expands without much consideration of the ends to which they are oriented, their relationship to one another, to corresponding responsibilities, or to the general welfare." Glendon, *supra* note 114, at xi.

¹²⁵ See Tushnet, *supra* note 114, at 32 (arguing that rights have been weakened and have taken on the lesser stature of policies).

¹²⁶ See Tushnet, *supra* note 114, at 33.

at this point may be more useful to anti-progressives than progressives.¹²⁷

Tushnet describes the proliferation of rights rhetoric in terms of the deployment of “counter-rights,”¹²⁸ and explains the emergence of “counter-rights” as follows:

When a court recognizes a claim as a legal right, and particularly as a constitutional right, it treats the claim as really important: Rights outweigh ordinary policy concerns, for example. People on the other side of the issue then have to respond. They can say, as they often do, that the court made a mistake. But, at least in the short run, that may not be a promising strategy. Instead, they can argue that, although the court found a right on the other side (and so overrode mere policy objections), it did not consider whether that right was countered by some other right. That is, the rhetoric of rights generates a rhetoric of counter-rights. Against the right to choose, the right to life is deployed; against affirmative action, the language of discrimination against white men begins to be used.¹²⁹

Because in a given dispute rights are deemed paramount to policy considerations, the most effective way to oppose a right is to claim

¹²⁷ See Tushnet, *supra* note 114, at 33. Mark Tushnet, Carmack Waterhouse Professor of Constitutional Law, Georgetown University Law Center, writes:

[I]f the rhetoric of rights in our culture is individualistic (and if that sort of individualism is anti-progressive in today's circumstances), conservatives are more likely than progressives to find the rhetoric of rights helpful. For example, conservatives have used the rhetoric of rights to obstruct progressive regulation of property and—in a directly related field—to challenge campaign finance regulation on the ground that it violates free speech rights. On this view, progressive victories are likely to be short-term only; in the longer run the individualism of rights-rhetoric will stabilize existing social relations rather than transform them.

Tushnet, *supra* note 114, at 33.

¹²⁸ See Tushnet, *supra* note 114, at 31 (coining the term “counter-rights” and explaining that counter-rights emerge when a claimed right is opposed with a countervailing right).

¹²⁹ Tushnet, *supra* note 114, at 31.

a counter-right.¹³⁰ Although Tushnet explains the use of counter-rights in the litigation context, the same dialectic occurs in popular discourse. As a result, the language of rights has become deprived of its special power and significance:

[Powerful rights] claims are needed because they are asserted on behalf of those previously excluded from serious consideration; having been excluded before, these groups not only should be allowed to take part in ordinary politics, they should receive special consideration because of their prior exclusion. As rights proliferate and generate counter-rights, the special force attached to the language of rights dissipates. The distinction between rights and mere policies weakens, and proponents of rights-claims become just another interest group in the ordinary play of politics.¹³¹

The use of the language of rights to express wants and needs, and the expansion in the use of rights rhetoric for polemics that might have traditionally been centered in policy and not rights, have deflated the power of asserting a right. Rights assertions are now routine testimonials, not exceptional claims.

In the mandatory testing context, proponents were quick to assert that fetal rights are implicated and fetal rights override women's rights in this context because the health of an infant is more important than protecting women's privacy.¹³² This has resulted in a public debate that is predominantly focused on rights; we are now embroiled in a meaningless dialectic which can only reify maternal rights and fetal rights. There is no result in this circular discourse: it is a stalemate, it is without conclusion or resolution and it is meaningless. The only apparent response to a rights assertion is, "So what? This one has a right, too." Because women's rights are not as special as they once were, assertions of fetal rights are being taken very seriously as rights which place

¹³⁰ See Tushnet, *supra* note 114, at 31.

¹³¹ Tushnet, *supra* note 114, at 32.

¹³² See *supra* note 108 (quoting authors who believe that the failure to mandatorily test newborns violates children's rights); Crawford, *supra* note 96, at 40.

limits on women's rights.¹³³ The mandatory testing debate, and of course the abortion debate, forcefully demonstrate that rights claims by women and pro-choice advocates are not perceived to carry the same weight that they once did.

It is interesting to note that privacy rights, specifically, are currently suffering from attack. The *New York Times* recently reported that because of new medical advances, some former advocates for special privacy rights for people with AIDS have changed their minds and begun to press for increased reporting of HIV cases and mandatory testing.¹³⁴ Some attribute this shift away from privacy interests to the change in AIDS demographics, arguing that the political power of white gay men enabled them to successfully assert privacy rights when that population was the focal point of the epidemic.¹³⁵ Terry McGovern says she should have predicted that privacy protections would slip away when the epidemic shifted to low-income women and women of color.¹³⁶

The potential loss of the privacy battle also seems rooted in a "wider backlash against the idea of privacy" in our postmodern, mass media culture.¹³⁷ However, the cultural movement away

¹³³ See *supra* note 11 (discussing the increased use of fetal rights rhetoric in the abortion debate and in fetal endangerment prosecutions).

¹³⁴ Richardson, *supra* note 15, at A1, B4 ("The cloak of privacy that has long set AIDS apart from other infectious diseases, like tuberculosis and syphilis, is beginning to be pierced, with lawmakers, health officials and even some advocates for people with the disease pushing for more testing and the mandatory reporting of those who are infected with H.I.V.").

¹³⁵ See Richardson, *supra* note 15, at B4 (quoting statements by Professor Ronald Bayer, Columbia University School of Public Health, and Theresa McGovern).

¹³⁶ See Richardson, *supra* note 15, at B4 (quoting McGovern).

¹³⁷ Adam Phillips, *Grief on Demand*, N.Y. TIMES, Sept. 7, 1997, at E17. In commenting on the recent death of Diana, Princess of Wales, and the British peoples' demand that the Queen express some emotion in public, a psychoanalyst made some remarks that shed light on the state of privacy today:

Christianity may have democratized privacy with the idea of the soul; everyone has this secret essence. But privacy has traditionally been the sign of privilege and power. The affluent have a lot to protect. The poor, however, are overexposed to everything—sickness, hunger, need. Indeed, it is part of the cultural legacy of the West to equate privacy with what we value most.

from privacy need not be a damaging course, if we can adapt. As discussed in the next subsection, privacy protections have not been granted without costs, and it may actually benefit women to abandon privacy arguments in favor of other polemics that can achieve similar ends.

If we want to truly address the complexities of the mandatory testing issue, we must adjust to these shifts in the discursive and cultural landscape of rights and privacy. Opponents of mandatory testing must continue asking the question whether mandatory testing benefits women and children affected by HIV and AIDS and fighting proponents' focus on rights.

B. Rights and Individualism: Separating HIV-Positive Pregnant and Childbearing Women from Community, Fetus and Child and Assigning Blame to Women

An additional problem with rights discourse is that it is historically individualistic.¹³⁸ The individualism that is promoted has two effects that are relevant here: individualism precludes us from perceiving HIV-infection in women as a communal and

Today, privacy—that is, family life—is considered a haven in a heartless world. Indeed, it has become increasingly clear that our idealizing of private life is a sign of our despair about political life.

We are addicted to publicity now because we have a lingering doubt that there may be no such thing as privacy; that the protection privacy affords might be a protection racket for those who can afford it. It's as though we are not sure what privacy is for anymore.

Id.

¹³⁸ See Glendon, *supra* note 114, at 47-61 (providing a historical analysis of the development of rights as an individualistic discourse). Glendon writes:

When, in our legal and political discourse, we pay homage to radical autonomy and self-sufficiency we are not speaking the language of the frontier or of the Founders. Nor are we using the second languages we still employ (to varying degrees) in the neighborhood, in religious communities, or around the kitchen table. We are adopting, rather, the language and images of certain philosophers and lawyers [such as J.S. Mill] who, initially at least, were not proposing the product for general consumption.

Glendon, *supra* note 114, at 75.

societal problem¹³⁹ and contributes to a perceived opposition between woman and fetus or child.¹⁴⁰

It was Karl Marx who first noted the individualistic quality of the rights of life, liberty and property.¹⁴¹ Indeed, rights discourse "perceives the individual as separated from the community and prevents individuals from understanding how they are dependent on one another—how every individual is linked to every other."¹⁴² Glendon states that "American rights dialect" pays "extraordinary homage to independence and self-sufficiency, based on an image of

¹³⁹ See Glendon, *supra* note 114, at 48. Tushnet states:

Rights-claims are individualistic . . . not because of something inherent in the concept of rights, but rather because of the historical development of the language of rights. The central image of "rights" in our culture is, as MacKinnon's critique suggests, of a sphere within which each of us can do what he or she pleases. This image, in turn, reinforces the distinction between law and politics that is itself subject to challenge from critical legal studies. Politics is the domain of pure will or preference, not subject to discussion and deliberation except as each individual chooses to be influenced by others. Rights—or law—protect the domain in which political preferences are formed. If, however, a critic believes that making politics truly social is an important task, it might be important as well to fight an ideology, the ideology of rights, that leads people to think of themselves as disconnected from others in important ways.

Tushnet, *supra* note 114, at 27 (citing Catherine A. MacKinnon, *Reflections on Sex Equality Under Law*, 100 YALE L.J. 1281 (1991)).

¹⁴⁰ See Baldacci, *supra* note 98, at 5-11 (discussing how the mandatory testing debate has presumed an opposition between woman and fetus or child).

¹⁴¹ See Glendon, *supra* note 114, at 47-48. Marx wrote that in eighteenth century France and North America, the notion of liberty idealized "man regarded as an isolated monad, withdrawn into himself." Karl Marx, *On the Jewish Question* (1843), reprinted in THE MARX-ENGELS READER 26, 42 (Robert C. Tucker ed., 2d ed. 1978); see Glendon, *supra* note 114, at 47. Perceiving rights to produce separation between individual and community, Marx wrote: "Let us notice first of all that the so-called *rights of man*, as distinct from the *rights of the citizen*, are simply the rights of a *member of civil society*, that is, of egoistic man, of man separated from other men and from the community." Marx, *supra*, at 42.

¹⁴² Renata Salecl, *Rights in Psychoanalytic and Feminist Perspective*, 16 CARDOZO L. REV. 1121, 1125 n.8 (1995) (explaining the position of CLS theorists).

the rights-bearer as a self-determining, unencumbered, individual, a being connected to others only by choice."¹⁴³ Our culture of individualism, and the belief that we live in a society of free choice and self-determination,¹⁴⁴ typically leads us to the conclusion that *all* we need to do is make sure people have their rights. We are comforted by the conferring of rights because an individual with vested rights is perceived to be sufficiently protected: the community has satisfied its responsibilities to the individual.

In the mandatory testing debate, society looks to confer a right on either the woman or the fetus or child. However, if policy is determined solely by conferring rights, the more important analysis of whether a policy is effective is overlooked. This short-cut, of determining rights rather than analyzing policy, allows policy-makers to ignore community and government denial of responsibility for women and children affected by HIV.

Proponents of mandatory testing seek to more heavily regulate women's bodies and take away their "choices" because proponents have determined that HIV-positive women are infected and suffering from poverty because they have not been responsible. However, the assumption upon which mandatory testing is based, that women have somehow failed, and will continue to fail, themselves and their infants,¹⁴⁵ is made with complete ignorance to the ways in which women affected by AIDS have been abandoned by community and government since the beginning of this epidemic.

¹⁴³ Glendon, *supra* note 114, at 48.

¹⁴⁴ Marxist theory suggests that the very concept of "self-determination" is encumbered by the theory of ideology. See Louis Althusser, *Ideology and Ideological State Apparatuses (Notes towards an Investigation)*, in *LENIN AND PHILOSOPHY AND OTHER ESSAYS* 127 (Ben Brewster trans., 1971). Althusser discusses the fallaciousness of a philosophy of unencumbered "freedom," as he describes the inescapability of the human subject from an over-arching ideological frame which has its roots in capitalism, a global structure that negates the "individual" through commodification. See *id.*; 1 KARL MARX, *Chapter One: Commodities*, in *CAPITAL* (1867), reprinted in *THE MARX-ENGELS READER*, *supra* note 141, at 302.

¹⁴⁵ See *supra* notes 86-91 and accompanying text (discussing the assumption that childbearing women will not voluntarily test for HIV).

For example, there has been a general lack of medical attention to the impact of AIDS on women and those living in poverty.¹⁴⁶ Throughout the 1980s, the CDC definition of AIDS, which is used to determine access to subsidized medical care and disability benefits, did not include the symptoms and diseases of AIDS that most commonly occur in people living in poverty and in women but not in men.¹⁴⁷ It was not until a class action lawsuit was brought against the government that the AIDS definition was changed to include diseases commonly found in women with AIDS and the financially disadvantaged.¹⁴⁸ Before the definition was changed, many women and poor people died of AIDS without ever meeting the CDC definition and without ever receiving needed benefits.

In addition, many HIV-positive women are excluded from clinical trials because it is feared that the differences in women's

¹⁴⁶ See McKenna, *supra* note 15, at 137. McKenna states:

Since its discovery in 1981, AIDS has been considered primarily a disease of gay men. Despite radical shifts in the demographics of the populations affected by AIDS, and the fact that the rate of HIV infection is growing most rapidly in women, this popular misperception still persists. As a result, physicians may be less likely to be alert to early symptoms of HIV infection in women or to counsel their female patients vigorously

McKenna, *supra* note 15, at 137.

¹⁴⁷ See Theresa M. McGovern, *S.P. v. Sullivan: The Effort to Broaden the Social Security Administration's Definition of AIDS*, 21 FORDHAM URB. L.J. 1083, 1087 (1994) (comparing the most typical symptoms of gay white men with the symptoms of women and those living in poverty). For example, those living in poverty tend to suffer from extreme, new forms of tuberculosis. See *id.* at 1087 n.25. Women with AIDS frequently suffer from gynecological problems such as pelvic inflammatory disease, cervical cancer and chronic yeast infections. See McKenna, *supra* note 15, at 137.

¹⁴⁸ See *S.P. v. Sullivan*, No. 90 Civ. 6294 (S.D.N.Y. Feb. 9, 1996) (approving a stipulation and order of settlement). HIV Law Project, the same organization that is currently fighting mandatory testing in the courts, served as lead counsel for the plaintiffs. The new AIDS definition, promulgated by the Social Security Administration, took effect on July 1, 1993. See generally McGovern, *supra* note 147 (reviewing the history of *S.P. v. Sullivan*).

bodies (as compared to men) will confuse results.¹⁴⁹ Women are also excluded from clinical trials on the grounds that they may become pregnant and that the potential effects on a fetus are unknown.¹⁵⁰ This failure to include women in clinical trials has several unfortunate effects, including the fact that drugs that have not been tested on women may not be safe or effective for women, and that women have fewer opportunities to become one of those clinical trial participants who have access to the latest, most effective drugs, free of cost.¹⁵¹ Furthermore, recent studies have shown that communities of color are not receiving the same education about AIDS or access to the latest treatments, such as the triple combination drug therapies.¹⁵²

Although proponents of mandatory testing argue that women must be coerced because they have failed to voluntarily seek HIV testing, the evidence indicates that for many years, few women were encouraged to seek testing by their medical providers or public health authorities:

¹⁴⁹ See McKenna, *supra* note 15, at 137 n.55; Mary Anne Bobinski, *Women and HIV: A Gender-Based Analysis of a Disease and Its Legal Regulation*, 3 TEX. J. WOMEN & L. 7 (1994).

¹⁵⁰ See Hunter, *supra* note 44, at 14, 15 ("Drug manufacturers and investigators justify the exclusion of women by their fear of liability for *in utero* injuries, which could be the basis for claims by children born with congenital anomalies."). However, Professor Hunter of Brooklyn Law School notes that "existing principles of law provide that manufacturers of experimental drugs are protected from strict liability for harm caused by the drug, provided that they have adequately warned and obtained consent from test subjects." Hunter, *supra* note 44, at 15. The existing law thus calls into question the necessity of drug companies' policy of excluding women. In addition, there is nothing stopping drug companies from conducting pre-trial testing to investigate potential harms to fetuses, as they do other pre-trial investigations, except for apathy and greed.

¹⁵¹ Although deaths among women with HIV are up 3%, deaths among men are down 15%. See *At-Risk Populations Experts Gather to Explore Why American Women Are Fastest Growing Group With HIV*, AIDS WKLY. PLUS, May 19, 1997, available in 1997 WL 11006391. Despite the changing epidemiologic data, women only constitute 12% of clinical trial participants. See *id.*

¹⁵² See *Minorities Miss Out on AIDS Survival Increase: Campaign Pushes Education for Patients, Providers*, AIDS ALERT, May 1, 1997, at 55 (referring to statements made by former U.S. Surgeon General Joycelyn Elders).

the irony is that women have not been protected by the health system. Public health authorities were slow to warn women they were at risk for HIV . . . and many of her clients only learned they were infected after they developed opportunistic infections or their babies became sick.

"Now, what's happening in New York state and across the country is that medical providers are blaming their failure (to counsel) on these women. Agreeing to be tested has less to do with lack of consent and more to do with not being offered the test."¹⁵³

A 1988 survey revealed that only 15% of patients recalled talking to their doctor about AIDS, and that 72% of the reported discussions were initiated by the patient.¹⁵⁴ In 1991, the same survey resulted in 19% of patients reporting discussions with their doctors about AIDS, of which 51% were initiated by the patient.¹⁵⁵ Despite the past problems that providers have had in expressing the need for HIV testing to their patients, especially to populations other than gay men, mandatory testing proponents assume that any failure to seek testing by pregnant women is the result of women's *refusal* to test.

Recent studies show the contrary. Between 1992 and 1995, the number of perinatal transmissions dropped 27%.¹⁵⁶ The CDC attributed this decrease to Public Health Service recommendations that pregnant women be tested for HIV and that HIV-infected pregnant women take AZT therapy.¹⁵⁷ The obvious conclusion to be drawn is that once pregnant women were informed of the need for them to seek HIV testing, women have done so voluntarily, and voluntary testing has led to decreases in perinatal transmissions. The decrease can certainly not be attributed to mandatory testing because no mandatory testing programs existed until 1997. In

¹⁵³ Shelton, *supra* note 21, at 23 (quoting Terry McGovern).

¹⁵⁴ See Shelton, *supra* note 21, at 23 (referring to a survey based on a national random sample of 2,000 patients which was published in the *American Journal of Public Health* in April 1990).

¹⁵⁵ See Shelton, *supra* note 21, at 23.

¹⁵⁶ See *Fewer Infants Acquire AIDS from Mothers*, N.Y. TIMES, Nov. 22, 1996, at A20.

¹⁵⁷ See *id.*

addition, use of AZT by HIV-infected pregnant women rose from 17 to 80% as a result of CDC recommendations.¹⁵⁸ Despite increasingly powerful evidence that voluntary counseling and testing programs work, mandatory testing proponents still assume that coercive regulation is necessary.

The push for greater regulation of HIV-positive childbearing women must be partly motivated by the assumption that women infected with HIV are irresponsible, bad mothers who do not care for their fetuses and infants. This perception reflects racist stereotypes. The moral judgments imposed on low-income women and women of color who are pregnant and HIV-infected derive from a history of general devaluation of Black motherhood and mothers with little or no income.¹⁵⁹ The problems of HIV-infection, drug addiction, poverty and lack of access to medical care are often characterized as the private failures of poor women and women of color.¹⁶⁰ As a result, larger social issues that need to be addressed by those outside the Black, Hispanic and other affected communities are obscured.

¹⁵⁸ See *id.*

¹⁵⁹ See Dorothy E. Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy*, 104 HARV. L. REV. 1419, 1437-40 (1991). Enslaved African-American women were perceived as sexual objects to be raped and abused, whose only purpose was to work and produce more slaves. See *id.* Dorothy Roberts, Professor of Law at Rutgers, Newark, discusses the common slave-owner practice of whipping pregnant women while they were lying face down in the dirt, with a hole that was dug out just large enough for their stomachs in order that the fetus would not be injured. See *id.* at 1438. Roberts writes that this "serves as a powerful metaphor for the evils of a fetal protection policy that denies the humanity of the mother." *Id.*

Such racist attitudes continue today when we look at the present disproportionate removal of black children from their mothers' custody and sterilization abuses. See *id.* at 1440-44. Regarding the widespread practices of coerced and non-consensual sterilization practices on women of color, Roberts notes that, in effect, "sterilization is the only publicly-funded birth control method readily available to poor women of color." *Id.* at 1444. Court ordered medical procedures in general are performed disproportionately on pregnant women of color. See *id.* at 1457 n.197.

¹⁶⁰ See Lisa C. Ikemoto, *The Code of Perfect Pregnancy: At the Intersection of the Ideology of Motherhood, The Practice of Defaulting to Science, and the Interventionist Mindset of Law*, 53 OHIO ST. L.J. 1205, 1211-22 (1992).

Similar to the separation between women and the larger community, rights discourse instills a separateness between woman and fetus.¹⁶¹ A right is "something to which one has a just claim: as . . . the power or privilege to which one is justly entitled."¹⁶² Rights give license to do something against something or someone else; rights are tempered only by other rights.¹⁶³ In the mandatory testing context, policy analysts debate who has a right to protection and autonomy: does the woman have a right of privacy and choice, or does the child have a right to identification of HIV and treatment?¹⁶⁴ Within this opposition, the woman is perceived to be in a position of power, and the fetus or child is perceived as an innocent victim who must be protected.¹⁶⁵ This limited discourse precludes consideration of policies that might aid both woman and child without placing them in opposition. However, the two-patient model "is being accepted with little consideration being given to the potential harm of describing pregnancy as the source of conflict."¹⁶⁶

¹⁶¹ A historically earlier model for the maternal-fetus relationship was one of interdependence, which was reflected in the law because fetuses had very few legal interests. *See id.* at 1293. This began to change with the sonogram and other technological advances which have enabled physicians to view the fetus as a separate patient. *See id.*

¹⁶² MERRIAM-WEBSTER'S COLLEGIATE DICTIONARY 1008 (10th ed. 1995).

¹⁶³ *See* Tushnet, *supra* note 114, at 31; *supra* notes 128-31 and accompanying text (discussing counter-rights).

¹⁶⁴ Professor Lisa Ikemoto of Loyola Law School, Los Angeles, notes that the two-patient model promotes conflict and opposition. *See* Ikemoto, *supra* note 160, at 1293-94 ("The important point is that once the two-patient model is accepted, conflict is assumed to be inevitable. This conflict is a cultural construct, not the result of 'pure science.'").

¹⁶⁵ *See* Ikemoto, *supra* note 160, at 1293-94.

¹⁶⁶ *See* Ikemoto, *supra* note 160, at 1293-94. In discussing the proliferation of criminal prosecutions for fetal-endangerment, one author writes:

Rights discourse evinces an adversarial, individualistic perspective of social interaction that distorts the maternal-fetal relationship by forcing women to see their fetuses as things which curtail their own rights. Fetal rights discourse places the duty to promote infant well-being, a responsibility which belongs to the community as well as to individuals, upon individual pregnant women alone. Arguing that a fetus has a right to be born healthy deflects attention from underlying questions

The discourse of fetal rights and the constructed opposition between mother and fetus have emerged as a way of explaining and addressing what is really a larger social problem. Ikemoto states that the ideology of the "good mother," who is white, "noble," "benign" and "self-sacrificing," has enabled the dominant culture to ignore the obstacles that low-income women and women of color face because of their impoverishment, race and social status and to script social and economic oppression as the private failures of irresponsible mothers.¹⁶⁷ Because low-income women and women of color are seen as not conforming with the traditional icon of white, middle-class motherhood, they are punished for their perceived ineptitude,¹⁶⁸ even though they do not have the same access to economic, medical and social support as their white middle-class counterparts.¹⁶⁹ Ikemoto writes:

Women of color, those who live in poverty, and those made outsiders by virtue of cultural or religious practices

of social policy. By setting the problems of infant addiction and mortality in a framework specific to individual women, rights discourse obscures the statistical reality that fetal rights practices have counter-productive results.

Deborah J. Krauss, *Regulating Women's Bodies: The Adverse Effect of Fetal Rights Theory on Childbirth Decisions and Women of Color*, 26 HARV. C.R.-C.L. L. REV. 523, 544 (1991).

¹⁶⁷ Ikemoto, *supra* note 160, at 1211-12. Ikemoto writes:

Social problems, then, could be explained as a failure in the private sphere—the failure to sustain motherhood as an institution, and the failure of individual women to meet the standards of the calling. As a result, fear of social disorder has often been expressed by regulating women as mothers. That is, society responds to problems in ways that elaborate upon the ideology of motherhood. One traditional way of regulating women is fairly straightforward—by promulgating laws that restrict women to the private sphere roles of mother and wife.

Ikemoto, *supra* note 160, at 1211-12.

¹⁶⁸ The punishment is the increased regulation of their bodies and of motherhood in general. See Ikemoto, *supra* note 160, at 1211-12.

¹⁶⁹ See Ikemoto, *supra* note 160, at 1207. See also Roberts, *supra* note 159, at 1422 ("[Poor women of color] are the least likely to obtain adequate prenatal care, the most vulnerable to government monitoring, and the least able to conform to the white, middle-class standard of motherhood. They are therefore the primary targets of government control.").

are stigmatized by the dominant society and are never presumed good mothers, as are white middle- and upper-class women. In addition, even while outsider women are subject to the white-middle-class-good-mother standard, direct and indirect state actions expressing patriarchal norms deprive these women of the material, political, and social resources to conform to [that standard].¹⁷⁰

The discourse of rights thus serves to further obscure gender and racial subordination by positing an individual, without context or community, to sink or swim on her own, regardless of the numerous obstacles that dominant culture and ill-conceived political and regulatory schemes have placed in her way.

Despite the failure of the government and community to adequately educate women about AIDS and to provide access to medical care for impoverished women, and despite the success rates of voluntary counseling and testing programs, proponents of mandatory testing assume that pregnant women with HIV are to blame for their situation,¹⁷¹ cannot be trusted to make medical decisions with the help of counseling, and, consequently, should be treated like incompetents and subjected to government intervention. Where women and AIDS are concerned, the responsibility of the community is erased, women are presumed guilty despite history and evidence to the contrary, and the problem of fetal health is placed on women alone.¹⁷² Given the history of women and AIDS, it is a great injustice to ignore the discrimination and obstacles that have been placed in the way of HIV-positive women and to make policy decisions based on who has a greater right, woman or child.

Proponents of forced testing inaccurately characterize opponents' arguments as being centered around women's privacy rights. This is an effective tactic because privacy rights may perpetuate an ideology which promotes the isolation and abandonment of women

¹⁷⁰ Ikemoto, *supra* note 160, at 1207.

¹⁷¹ See *supra* notes 86-91 and accompanying text (discussing proponents' assumption that women will not voluntarily test for HIV, despite the success of aggressive counseling and testing programs).

¹⁷² See Krauss, *supra* note 166, at 544.

with HIV. Glendon asserts that "[n]o aspect of American rights discourse more tellingly illustrates the isolated character of the rights-bearer than our protean right of privacy."¹⁷³ While privacy rights initially sprung from a tradition of limited government,¹⁷⁴ privacy rights in the American liberal tradition have evolved into "the right to enjoy life" and "the right to be let alone."¹⁷⁵ It is Glendon's contention that women and other disenfranchised groups are not served by these privacy rights:

By exalting autonomy to the degree we do, we systematically slight the very young, the severely ill or disabled, the frail elderly, as well as those who care for them—and impair their own ability to be free and independent in so doing. Our insistence, even in divorce law, that self-sufficiency should be the goal for everyone, in practice leaves women bearing the brunt of responsibility for children and other persons in need of care, while running the main risk of family dissolution.¹⁷⁶

Glendon provides a dark and sobering example of the double-edged sword of privacy rights with an allusion to the epitome of women's privacy rights litigation, *Roe v. Wade*:¹⁷⁷

In *Roe*, Justice Blackmun had stated reassuringly that the pregnant woman was not to be 'isolated' in her privacy. But when the Court faced the issue head-on in actual cases concerning whether abortion funding should be available to her, or whether states could require women seeking abortions to be provided with information regarding alternatives such as adoption, or assistance available to them if they wished to bring the pregnancy to term, the paradigm of the lone rights-bearer prevailed.¹⁷⁸

¹⁷³ Glendon, *supra* note 114, at 48.

¹⁷⁴ See Glendon, *supra* note 114, at 49 (discussing the writings of Blackstone).

¹⁷⁵ Glendon, *supra* note 114, at 51-52 (quoting Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 197 (1890)).

¹⁷⁶ Glendon, *supra* note 114, at 74-75.

¹⁷⁷ 410 U.S. 113 (1973).

¹⁷⁸ Glendon, *supra* note 114, at 59.

Glendon notes that Norma McCorvey, also known as "Jane Roe," won her privacy right—the right to a legal abortion—but then truly was "let alone."¹⁷⁹ "No one, apparently, had been willing to help her either to have the abortion she desired, or to keep and raise the child who was eventually born. While the litigation was still pending, she surrendered the infant for adoption. Years later, she was fruitlessly searching for her son or daughter"¹⁸⁰

V. BEYOND RIGHTS?

Because the power of asserting a right has been weakened by the popular proliferation of rights language and because rights discourse has served to isolate HIV-infected women from society and their infants and helped to rationalize coercive regulatory policy, the focus on maternal and fetal rights in the mandatory testing debate has greatly assisted proponents in realizing their goal of the nationwide adoption of mandatory testing. The question remains: can we speak of abandoning rights discourses which have historically provided people of color and women with some legal protection from discrimination? Because rights discourses have been employed to fight racism and other forms of systematic disempowerment of specific groups of people, the critique of rights has been attacked by Critical Race Theorists.¹⁸¹

Professor Kimberle Crenshaw of UCLA Law School writes that the "trashing" of rights discourses "may have the unintended consequence of disempowering the racially oppressed while leaving

¹⁷⁹ See Glendon, *supra* note 114, at 58 (discussing McCorvey's personal history and famous venture into the American justice system).

¹⁸⁰ Glendon, *supra* note 114, at 58.

¹⁸¹ See generally PATRICIA J. WILLIAMS, *THE ALCHEMY OF RACE AND RIGHTS* (1991) (arguing that CLS's abandonment of rights in favor of a discourse of *needs* is insufficient); Kimberle W. Crenshaw, *Race, Reform, and Retrenchment: Transformation and Legitimation in Antidiscrimination Law*, 101 HARV. L. REV. 1331 (1988) (criticizing the CLS view of rights and arguing that African-Americans cannot afford to abandon rights arguments). For a collection of works by Critical Race Theorists, see *CRITICAL RACE THEORY: THE CUTTING EDGE* (Richard Delgado ed., 1995).

white supremacy basically untouched.”¹⁸² Crenshaw argues that the focus of Critical Legal Studies¹⁸³ on ideologically-induced *consent* to discourses that legitimate the domination and subordination of marginalized people, such as rights discourses, underemphasizes a more material coercion that is occurring through racial domination.¹⁸⁴ “[C]onsensus and coercion can be understood together: ideology convinces one group that the coercive domination of another is legitimate.”¹⁸⁵

Crenshaw acknowledges the problematic effects of relying on rights discourses. She writes that “the Critics are correct in observing that, despite [the gains of the civil rights movement], engaging in rights discourse has helped to deradicalize and co-opt the challenge in the current period, in which racial oppression continues to flourish behind the screen of racial equality.”¹⁸⁶ However, because African-Americans cannot afford to abandon rights as a primary method of “self-defense,” Crenshaw suggests that African-Americans must find ways to continue using rights in

¹⁸² Crenshaw, *supra* note 181, at 1357-58.

¹⁸³ See *supra* notes 114-18 and accompanying text (discussing the CLS critique of rights and CLS theories of law).

¹⁸⁴ Crenshaw, *supra* note 181, at 1358.

¹⁸⁵ Crenshaw, *supra* note 181, at 1358. For Crenshaw it is significant that African-Americans were originally excluded from the discourse of rights altogether. The civil rights movement was radical because of the very proposition that African-Americans should have rights and it was only with the civil rights movement that Whites were forced to respond to Black demands. See Crenshaw, *supra* note 181, at 1359, 1366.

¹⁸⁶ Crenshaw, *supra* note 181, at 1370. The utility of using legal forums for redressing racial domination, inequality and discrimination has been questionable since the Supreme Court decided *Washington v. Davis*, 426 U.S. 229 (1976) (establishing that the mere showing of a law's disproportionate effect on minorities is not sufficient to trigger strict scrutiny). *Davis'* requirement that a challenged law have a discriminatory purpose has greatly limited the availability of legal redress against laws that disfavor people of color, especially as facially discriminatory laws and express racism have diminished in favor of a highly institutionalized, more covert racism. See generally Charles R. Lawrence III, *The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism*, 39 STAN. L. REV. 317 (1987) (discussing unconscious racism and the doctrine of discriminatory purpose and proposing an alternative means of evaluating laws that foster racial discrimination).

the waging of political struggles, but minimize the detrimental effects of engaging in a discourse that inherently legitimates the established order.¹⁸⁷ Crenshaw concludes that "Blacks are ultimately presented with a dilemma: liberal reform both transforms and legitimates. Even though legal ideology absorbs, redefines, and limits the language of protest, African-Americans cannot ignore the power of legal ideology to counter some of the most repressive aspects of racial domination."¹⁸⁸

Ultimately, it may not be possible to limit the use of rights discourse to when it is politically expedient, or to minimize the detrimental effects of rights discourse when it is wielded. The teachings of French philosopher Michel Foucault suggest that rights discourse is an integral and inseparable part of the relations of power; it is therefore futile to engage in a discourse that merely perpetuates the same power relations.¹⁸⁹ "The subject becomes part of [a legal-discursive] game when it articulates its relation to power in the apparently neutral language of fundamental rights and freedoms."¹⁹⁰ In addition, some feminists propose that the indi-

¹⁸⁷ See Crenshaw, *supra* note 181, at 1387.

¹⁸⁸ Crenshaw, *supra* note 181, at 1370.

¹⁸⁹ See Salecl, *supra* note 142, at 1122 (discussing the theories of Foucault and other theorists working within Foucauldian frameworks); see generally 1 MICHEL FOUCAULT, THE HISTORY OF SEXUALITY: AN INTRODUCTION (Robert Hurley trans., Vintage Books 1990) (1976). The Foucauldian position is that "in resisting unjust laws, there is no need to appeal to some universal idea of human rights because it is unproductive to judge power relations in terms that are part of the relations of power." Salecl, *supra* note 142, at 1122. Under this theory, when rights are invoked they merely "justify a strategy of power in a specific legal-discursive game." Salecl, *supra* note 142, at 1122. These aspects of Foucauldian theory are somewhat consistent with Kennedy and Gabel's belief that rights discourse diverts attention from power relations and the exercise of dominion and control. See Gabel & Kennedy, *supra* note 114, at 36 (stating that we need to monitor power, and not rights).

Mandatory testing arguments framed in terms of rights and counter-rights divert attention from the exercise of dominion over the bodies of low-income women and women of color and shift attention, instead, to the respective rights of the woman and fetus. Proponents of mandatory testing have forced the public into a "legal-discursive game" that precludes interrogation of mandatory testing as a public health policy. See Salecl, *supra* note 142, at 1122.

¹⁹⁰ Salecl, *supra* note 142, at 1122.

vidual subject of rights discourse is inherently masculine; working from a rights framework will not promote change but inevitably subject women to subordination and control.¹⁹¹ According to this analysis, rights discourses reify and legitimate a system of domination and subordination, and any use of rights, successful or not for a particular problem, will ultimately only reaffirm the established order.

Because rights discourse is so deeply ideological it is unlikely that rights can be employed only at strategic moments so as to escape legitimizing the established order. It is also unlikely that rights discourse is going to be abandoned, in the mandatory testing debate or anywhere else, and it is questionable whether outsider groups can afford to abandon rights and risk further subordination. The problem of rights feels insurmountable.

Patricia Williams, Professor of Law at Columbia Law School, offers some interesting comments in her discussion of the CLS critique of rights. Williams writes that CLS theorists have urged the abandonment of rights and merely replaced rights discourse with a discourse of *needs*.¹⁹² That is, CLS theorists propose that the best alternative to asserting rights is to argue that the disadvantaged and marginalized *need* housing, assistance, and so on. Williams' response to this is that African-Americans have fruitlessly expressed their needs for centuries:

Such statements . . . about the relative utility of needs over rights discourse overlook that blacks have been describing their needs for generations. They overlook a long history of legislation *against* the self-described needs of black people. While it is no longer against the law to

¹⁹¹ Many feminist theorists posit that, in history and language, women are excluded from philosophies of "human rights," which are essentially men's rights. See Salecl, *supra* note 142, at 1126. These schools of feminism expose the individualism of rights and the masculinity of the unitary subject. Salecl, *supra* note 142, at 1126-27. Under this kind of feminist analysis, the notion of the unitary subject fails to account for women, who are "not essentially, necessarily, inevitably, invariably, always, and forever separate from other human beings: women, distinctively, are quite clearly 'connected' to another human life when pregnant." Salecl, *supra* note 142, at 1127.

¹⁹² Williams, *supra* note 181, at 146-53.

teach black people to read, there is still within the national psyche a deep, self-replicating strain of denial of the urgent need for a literate black population. ('*They're* not intellectual,' '*They can't* . . .') In housing, in employment, in public and private life, it is the same story: the undesired needs of black people transform them into those-without-desire. ('*They're* lazy,' '*They don't want to* . . .')

For blacks, describing needs has been a dismal failure as political activity. It has succeeded only as a literary achievement.¹⁹³

Williams proposes that the struggle is not to abandon rights or create statements about need, but rather "to find a political mechanism that can confront the *denial* of need."¹⁹⁴

Rights discourse has structured and confined the terms of the mandatory testing debate so that the public can only perceive the mandatory testing issue in very limited ways. The task before us is to continue to recognize the limitations of rights discourse and attempt to counteract its tendencies to isolate and blame women, people of color and the poor. Perhaps the goal of defeating mandatory testing policies may be reached partly by challenging assumptions about HIV-affected women and children and exposing social failures to support women affected by HIV.

CONCLUSION

By exposing the erroneous assumption that fetal health is protected by mandatory testing and by uncovering the damaging effects of coercive testing, opponents of mandatory testing can more effectively argue against this destructive policy. In the opposition to mandatory testing, the solutions cannot be found in a public debate about rights and counter-rights. Opponents of any form of mandatory HIV testing of infants and pregnant women need to continue trying to reframe the current discourse around this problem. In the debates to come, we must concentrate our resources on characterizing mandatory HIV testing as bad public health

¹⁹³ Williams, *supra* note 181, at 151 (emphasis in original).

¹⁹⁴ Williams, *supra* note 181, at 152 (emphasis in original).

policy, exposing the false assumptions behind the “save the babies” rhetoric, and demonstrating how low-income women and women of color are abandoned by government and scapegoated for larger social problems.

