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RYAN WHITE CARE AMENDMENTS: MANDATORY HIV TESTING OF NEWBORNS AND A WOMAN'S RIGHT TO PRIVACY

*Catherine H. McCabe**

INTRODUCTION

Women of reproductive age comprise the fastest growing group infected with HIV in the United States today.¹ Not surprisingly the incidence of AIDS has increased among infants who contract the virus perinatally.² Currently 93 percent of all pediatric AIDS cases arise from vertical transmission of HIV, in which the HIV-infected mother passes the virus to her child.³ This mode of transmission may occur before birth through intrauterine infection, during delivery of the child, or potentially after birth via the mother's infected breast milk.⁴ Responding to this pediatric AIDS epidemic, state legislatures across the country have proposed mandatory HIV testing of all newborns and disclosure of HIV test results. Thus far only one state, New York, has enacted this type of legislation.⁵

The crisis surrounding HIV infected newborns has also attracted the notice of the federal government, which itself took measures toward mandating HIV testing of all newborns by enacting the Ryan White Comprehensive AIDS Resources Emergency (CARE) Amendments. The

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¹ Kevin J. Curnin, *Newborn HIV Screening and New York Assembly Bill No. 6747-B: Privacy and Equal Protection of Pregnant Women*, 21 *FORDHAM URB. L. J.* 857, 862 (1994). From 1985 to 1990, the number of women with AIDS practically doubled and currently, AIDS is the fifth leading cause of death among women of child-bearing age. These women usually contract HIV from having sexual intercourse with men who are infected with the virus or using intravenous drugs with needles that are contaminated.

² Karen L. Goldstein, *Balancing Risks and Rights: HIV Testing Regimes for Pregnant Women*, 4 *CORNELL J. L. & PUB. POL'Y* 609, 609-10 (1995). See also Curnin, *supra* note 1, at 863. Today, approximately 1500 to 2000 HIV-infected infants are born each year in the United States while only 3,199 cases were reported from 1982 to 1991.

³ Curnin, *supra* note 1, at 864.

⁴ *Id.*

⁵ See Curnin, *supra* note 1. See also Kevin Galvin, *Pregnant Women Targets of New HIV Testing Policy: House and Senate Agree to Delay Newborn Screening While Pushing It in Expectant Mothers*, S. F. *EXAMINER*, May 1, 1996, at A2.

CARE Amendments relate to the original CARE Act of 1990 providing for allocation of federal funding for HIV and AIDS treatment, as well as support services to states that adopt HIV testing of newborns. All states that implement programs requiring mandatory non-anonymous HIV testing will automatically be eligible for these federal funds.⁶ As expected, the program has created a great incentive for states to institute mandatory testing programs.

This article anticipates that the CARE Amendments will create a scheme of mandatory testing of all pregnant women and newborns among the states in order to ensure receipt of federal funds. It is the author's position, that although the Amendments are not *per se* unconstitutional, the CARE amendments are unconstitutional as applied by the states to HIV testing, since mandatory non-anonymous HIV testing of all newborns infringes upon each woman's right to privacy.

This article will first explore the political debate between the right of newborns to treatment versus the right of women to privacy. Second, the provisions of the CARE Amendments will be discussed. Next, the impact of the Amendments will be evaluated under both a substantive due process and an equal protection analysis. Finally, a less intrusive and more effective alternative solution to pediatric AIDS will be proposed.

BACKGROUND ON PEDIATRIC AIDS

Between early 1988 and May 1995, in order to track the prevalence of the HIV virus, the federal government anonymously tested all newborns in forty-five states for HIV.⁷ Because the HIV virus can be transmitted directly from an HIV-infected mother to the unborn fetus,⁸ a newborn's HIV-positive test result is indicative only of the mother's HIV status. In fact, current methods of testing newborns for HIV involve detecting the presence of maternal HIV antibodies in the newborns' blood that were transmitted through the placenta during pregnancy.⁹ Consequently, HIV

⁶ 42 U.S.C.A. § 300ff-37 (West Supp. 1991).

⁷ Galvin, *supra* note 5, at A2.

⁸ Jean R. Sternlight, *Mandatory Non-Anonymous Testing of Newborns for HIV: Should It Ever Be Allowed?*, 27 J. MARSHALL L. REV. 373, 376 (1994).

⁹ John M. Naber & David R. Johnson, *Mandatory HIV Testing Issues in State Newborn*

testing of newborns unavoidably reveals each mother's HIV status without her consent.

Due to the revealing nature of newborn blood testing, and pursuant to guidelines promulgated by the Centers for Disease Control and Prevention (CDC), all identifying information was removed from newborn blood samples prior to performance of the HIV tests. Information pertaining only to the mothers' age, race, and place of residence was retained.¹⁰ This testing scheme was discontinued in 1995 when Congress proposed identifying blood samples and disclosing test results to the mothers of the newborns and their physicians.¹¹

Congress' proposal to perform mandatory HIV testing on all newborns was prompted by the results of a 1994 study published in the *New England Journal of Medicine*.¹² The study demonstrated that HIV-positive, pregnant women can reduce the likelihood of passing HIV to their unborn child¹³ by taking the drug Zidovudine, commonly known as AZT or ZDV.¹⁴ This antiviral drug inhibits DNA replication of the HIV virus in the host cell, thereby decreasing the rate at which the HIV-infected individual's immune system is destroyed.¹⁵ The study involved a sample of pregnant women infected with HIV,¹⁶ one-half of whom were given the antiviral drug AZT while the other half were given a placebo.¹⁷ The results of the tests demonstrated that 25.5 percent of newborns whose mothers took the placebo were infected with HIV, whereas only 8.3 percent of newborns whose mothers took AZT were infected.¹⁸ Researchers concluded that by providing AZT treatment to pregnant

Scheduling Programs, 7 J. L. & HEALTH 55, 58 (1993).

¹⁰ Galvin, *supra* note 5, at A2.

¹² John Schwartz, *AIDS Testing Urged in All Pregnancies; Drug "Breakthrough" Prompted Policy Shift*, WASH. POST, July 7, 1995, at A1.

¹³ The AIDS Clinical Trials Group (ACTG) Protocol 076. Howard Minkoff & Anne Willoughby, *Pediatric HIV Disease, Zidovudine in Pregnancy, and Unblinding Heelstick Surveys: Reframing the Debate on Prenatal HIV Testing*, 274 JAMA 1165 (1995).

¹⁴ Schwartz, *supra* note 12, at A1.

¹⁵ Michael A. Grizzi, *Recent Developments: Compelled Antiviral Treatment of HIV Positive Pregnant Women*, 5 UCLA WOMEN'S L. J. 473, 481 (1995).

¹⁶ Schwartz, *supra* note 12, at A1.

¹⁷ *Id.*

¹⁸ *Id.*

mothers and their infants, as many as two-thirds of the infants otherwise infected might avoid contracting HIV.¹⁹

Following Congress' proposal to start mandatory HIV testing, a political debate ensued over whether the rights of newborn children to treatment were more important than the right of a pregnant woman to protect her privacy.²⁰ Proponents of unblinded, mandatory HIV testing of newborns asserted that the purpose of the legislation was to protect public health, as well as to identify and provide treatment for HIV-positive newborns.²¹ Supporters further contended that HIV transmission would be prevented by informing women of their HIV-positive status and encouraging them to refrain from engaging in high risk behaviors, such as unprotected sexual intercourse or breastfeeding.²² Additionally, proponents maintained that early identification of HIV-positive newborns would afford health care providers the opportunity to provide treatment for the infected newborns which would most likely both lengthen and enhance the quality of their lives.²³

Opponents of mandatory testing argued that compulsory HIV testing of newborns and disclosure of the resultant information violates a woman's constitutional right to privacy since her HIV status is inevitably revealed. Although the fundamental right to privacy is not set forth explicitly in the United States Constitution, the Supreme Court has clarified the privacy debate. First, in the 1965 case of *Griswold v. Connecticut*, the Court found that the Bill of Rights implies a "penumbra" or "zone" of privacy encompassing the right of married individuals to use contraceptives.²⁴ A few years later in *Roe v. Wade*, the Supreme Court recognized the right of privacy as encompassed in the concept of personal liberty under the Fourteenth Amendment of the United States

¹⁹ *Id.*

²⁰ Christina Kent, *States Pushed to Test Newborns for HIV (Reauthorization of 1990 Ryan White CARE Act)*, AM. MED. NEWS, May 27, 1996, at 1.

²¹ Suzanne M. Malloy, *Mandatory HIV Screening of Newborns: A Proposition Whose Time Has Not Yet Come*, 45 AM. U. L. REV. 1185, 1204 (1996).

²² *Id.* at 1210.

²³ *Id.*

²⁴ *Griswold v. Connecticut*, 381 U.S. 479 (1965).

Constitution, and found it to include a woman's decision to obtain an abortion without governmental interference.²⁵

More directly on point is the 1977 case of *Whalen v. Roe*, where the Court considered whether an individual's right to privacy concerning personal information is protected by the Fourteenth Amendment.²⁶ In *Whalen*, the Court employed a balancing approach and upheld a New York State statute requiring physicians to disclose information regarding the identification of individuals receiving certain prescription drugs.²⁷ Despite the fact the *Whalen* Court held the state's interest in gathering information concerning drug usage outweighed the prescription drug users' privacy interest, the Court recognized that medical information pertaining to the physician-patient relationship is included within the right to privacy.²⁸ The *Whalen* Court, in particular, found at least two types of privacy interests, "One is the individual interest in avoiding disclosure of personal matters, and another is the interest in independence in making certain kinds of important decisions."²⁹ It is this first strand of privacy that is implicated by non-anonymous HIV testing programs.

In addition to acknowledging that individuals have a privacy right in medical records, various federal courts have also concluded that individuals have a specific right to privacy in nondisclosure of their HIV or AIDS status. The Second Circuit, for example, recently held in *Doe v. City of New York* that individuals have a fundamental right to privacy concerning the confidentiality of their HIV status.³⁰ In *Doe*, the City of New York disclosed information to the public regarding the settlement of a discrimination claim against Delta Airlines based on the plaintiff's HIV-positive status.³¹ Similarly, in *Nolley v. County of Erie*, the Western District Court of New York evaluated the constitutionality of a correctional facility's policy of labeling HIV-positive inmates'

²⁵ *Roe v. Wade*, 410 U.S. 113, 152-153 (1973).

²⁶ *Whalen v. Roe*, 429 U.S. 589 (1977).

²⁷ *Id.*

²⁸ *Id.* See also *Mann v. Univ. of Cincinnati*, 824 F. Supp. 1190 (S.D. Ohio 1993) (holding that patient's medical records are protected by constitutional right to privacy and such information could not be disclosed during discovery without patient's consent or valid court order).

²⁹ *Id.* at 599-600.

³⁰ *Doe v. City of New York*, 15 F.3d 264 (2nd Cir. 1994).

³¹ Goldstein, *supra* note 2, at 632.

possessions, thereby necessarily revealing their HIV-positive status to others.³² The *Nolley* court invalidated this policy, reasoning that prisoners have a constitutional right to privacy in unjustified disclosure of their HIV status.³³ Finally, the court in *Doe v. City of Cleveland* also concluded that arrestees have a constitutional right to privacy regarding nondisclosure of AIDS information.³⁴

An individuals' right to privacy and confidentiality in medical records, however, is not absolute. Disclosure of information, for example, may be warranted by public concerns such as developing treatment programs to control threats to public health.³⁵ A footnote in *Whalen* is illustrative of this point, the deciding court stating: "reporting requirements relating to venereal disease, child abuse, injuries caused by deadly weapons, and certifications of fetal death" could be sufficient to justify disclosure.³⁶ As a result, courts since *Whalen* have engaged in a three-way balancing test by weighing the individuals' right to privacy and confidentiality against the governmental interest in obtaining and utilizing personal data as well as the societal interest in disclosure of information.³⁷

This balancing test has since been employed in several significant decisions. For example, in *United States v. Westinghouse Elec. Corp.* the Third Circuit held governmental interest in obtaining information related to a hazardous work site outweighed any individuals' privacy interests.³⁸

³² *Nolley v. County of Erie*, 776 F. Supp. 715 (W.D.N.Y. 1991).

³³ *Id.* at 729-31. See also *Doe v. Town of Plymouth*, 825 F. Supp. 1102 (D. Mass. 1993) (holding that plaintiff had constitutional right to privacy including nondisclosure of her HIV status after police officer revealed her HIV-positive status to others upon discovering a bottle of AZT in her purse).

³⁴ *Doe v. City of Cleveland*, 788 F. Supp. 979, 985 (N.D. Ohio 1991).

³⁵ *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 578 (3rd Cir. 1980).

³⁶ *Whalen v. Roe*, 429 U.S. 589, 602 n.29 (1977).

³⁷ *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 578 (3rd Cir. 1980).

³⁸ *Id.* The federal government ordered an employer to produce its employees' medical records under a *subpoena duces tecum* through the Occupational Safety and Health Agency (OSHA) in order to investigate a potentially hazardous work area. The *Westinghouse* court considered the following seven factors in balancing these competing interests: (1) "the type of record requested;" (2) "the information it does or might contain;" (3) "the potential for harm in any subsequent nonconsensual disclosure;" (4) "the injury from disclosure to the relationship in which the record was generated;" (5) "the adequacy of safeguards to prevent unauthorized disclosure;" (6) "the degree of need for access;" and (7) "whether there is an express statutory mandate, articulated public policy, or other recognizable public interest militating toward access."

Likewise in *Nixon v. Administrator of Gen. Servs.*,³⁹ the Supreme Court used the balancing test to conclude that the Presidential Recordings and Materials Preservation Act did not impermissibly infringe upon President Nixon's privacy interests. The *Nixon* Court found the former President's privacy interest in his personal communications was outweighed by the public interest in subjecting the materials to archival screening.⁴⁰ Finally, in *United States Dep't of Justice v. Reporters Committee for Freedom of the Press*, the Supreme Court balanced the public interest in disclosure of information against the individual's privacy interest.⁴¹ In this case, the Court held disclosure of the contents of the Federal Bureau of Investigation's (FBI) criminal identification records to a third party constituted unwarranted invasion of personal privacy under the Freedom of Information Act.⁴²

The controversy over a woman's right to privacy, versus a newborns' right to treatment, can be evaluated under a similar balancing test by weighing the interest of women in nondisclosure of their HIV status against governmental interest in protecting public health and providing treatment to HIV-positive newborns. Upon consideration of these competing interests, the House still chose to pass the bill requiring mandatory testing of all newborns, and the Senate also recommended expansion of voluntary testing and counseling for pregnant women.⁴³ In an attempt to compromise with both the House and the Senate, positions Congress reauthorized the Ryan White CARE Act.⁴⁴

³⁹ *Nixon v. Administrator of Gen. Servs.*, 433 U.S. 425 (1977).

⁴⁰ *Id.* The Supreme Court reached this conclusion based upon facts including the limited intrusion of the screening process, the President's status as a public figure, the President's lack of expectation of privacy in the materials, and the need for comprehensive screening.

⁴¹ *United States Dep't of Justice v. Reporters Committee for Freedom of the Press*, 489 U.S. 749 (1989).

⁴² *Id.*

⁴³ Kent, *supra* note 20, at 1.

⁴⁴ *Id.*

THE RYAN WHITE CARE ACT

The Ryan White CARE Act of 1990⁴⁵ provides grants to assist states, cities, and hospitals in offering treatment and support services for individuals infected with HIV and those suffering from AIDS.⁴⁶ Reauthorization of the Act will allocate \$738 million in 1997, an increase from \$632 million allocated last year.⁴⁷ Under the CARE Amendments, states which demonstrate they have adopted the CDC guidelines regarding HIV counseling and voluntary testing for pregnant women will be eligible for federal funding.⁴⁸

In order to assist states in meeting the CDC's guidelines, the Amendments provide that \$10 million will be available each year from 1996 through the year 2000, with priority given to states demonstrating the highest rates of HIV infection among pregnant women.⁴⁹ Specifically, funding will be provided to the states for the following purposes:

- (1) HIV counseling for pregnant women;
- (2) prenatal care for pregnant women at high risk of contracting HIV;
- (3) voluntary HIV testing for pregnant women;

⁴⁵ 42 U.S.C.A. § 300ff (West Supp. 1991). "The purpose of the Act is to provide emergency assistance to localities that are disproportionately affected by the Human Immunodeficiency Virus epidemic and to make financial assistance available to States and other public or private nonprofit entities to provide for the development, organization, coordination and operation of more effective and cost efficient systems for the delivery of essential services to individuals and families with HIV disease."

⁴⁶ See, John Boehner, *Ryan White CARE Act Amendments-Conference Report*, Gov't Press Releases, FED'L DOCUMENT CLEARING HOUSE, INC., May 1, 1996. The Act was named in honor of a hemophiliac boy who acquired HIV through a blood transfusion at the age of 12; See also Josephine Gittler & Sharon Rennert, *HIV Infection Among Women and Children and Antidiscrimination Laws: An Overview*, 77 IOWA L. REV. 1313, 1321 & 1388 n.33 (1992). Ryan was subsequently prohibited from attending seventh grade at a public school in his hometown of Kokomo, Indiana. Until his death at age eighteen in 1990, he and his family successfully fought for AIDS awareness, contributing to public understanding of and compassion for individuals living with HIV and AIDS.

⁴⁷ Curt Anderson, *Ryan White Bill Compromise Means More AIDS Dollars for Rural Areas*, ASSOCIATED PRESS POL. SERV., May 1, 1996.

⁴⁸ 42 U.S.C.A. § 300ff-33(a), (b) (West Supp. 1991).

⁴⁹ 42 U.S.C.A. § 300ff-33(c)(2), (3) (West Supp. 1991). Rates would be determined by CDC statistics.

- (4) costs incurred while attempting to meet CDC guidelines and/or implementing mandatory HIV testing of newborns.⁵⁰

As a prerequisite to funding, states must determine on a yearly basis the prevalence of perinatal AIDS transmission within their state.⁵¹ Additionally, states are required to evaluate the possible causes of perinatal transmission including:⁵²

- (1) failure of current prenatal HIV counseling and testing programs to meet the guidelines issued by the CDC;
- (2) unavailable or inaccessible treatment programs; or
- (3) the refusal of pregnant women to undergo treatment.⁵³

Pursuant to the CARE Amendments, in September 1998 the Secretary of Health and Human Services (Secretary) will assess whether non-anonymous mandatory HIV testing of newborns has become a common practice among the states.⁵⁴ The HIV testing scheme entails disclosure of test results to the newborns' biological mothers (or legal guardians) and the newborns' health care providers.⁵⁵ In addition to testing newborns, the CARE Amendments provide that prenatal test results will also be revealed to the pregnant woman and her physician.⁵⁶ In either case, the Amendments require that the mother then be provided with HIV counseling.⁵⁷

Once mandatory HIV testing has become a routine practice, as determined by the Secretary, each state will then be required to demonstrate attainment of one of the following three goals by March of 2000:⁵⁸

⁵⁰ 42 U.S.C.A. § 300ff-33(c)(1) (West Supp. 1991).

⁵¹ 42 U.S.C.A. § 300ff-34(a) (West Supp. 1991).

⁵² 42 U.S.C.A. § 300ff-34(b) (West Supp. 1991).

⁵³ *Id.*

⁵⁴ Kent, *supra* note 20, at 1.

⁵⁵ 42 U.S.C.A. § 300ff-35(2) (West Supp. 1991).

⁵⁶ 42 U.S.C.A. § 300ff-35(3) (West Supp. 1991).

⁵⁷ 42 U.S.C.A. § 300ff-35(4) (West Supp. 1991).

⁵⁸ *Id.*

- (1) a 50 percent reduction in the rate of new cases of AIDS as a result of perinatal transmission as compared to the rate of such cases reported in 1993;⁵⁹
- (2) HIV testing of at least 95 percent of women in the state who have received at least two prenatal visits prior to thirty-four weeks gestation with a health care provider or provider group;⁶⁰ or
- (3) mandatory HIV testing of all newborns whose mothers have not undergone prenatal HIV testing, and disclosure of the resultant information.⁶¹ If a state does not reach one of the above goals, it must institute a program equivalent to the third goal requiring mandatory HIV testing of all newborns, or otherwise forfeit funding provided under the Amendments.⁶²

ASSESSING THE CONSTITUTIONALITY OF THE CARE AMENDMENTS

When assessing the constitutionality of public health statutes, in this case the Ryan White CARE Amendments, courts review under a presumption of validity. However, public health statutes that infringe upon a fundamental right, however, are more likely to be invalidated.⁶³ Under a substantive due process analysis, strict judicial scrutiny must be applied to the Amendments, since they interfere with a fundamental right to privacy, namely "the individual interest in avoiding disclosure of personal matters."⁶⁴ According to this heightened standard of review, a statute may be upheld only if found necessary to attain a compelling governmental interests.⁶⁵ Moreover, the means of attaining this interest must be

⁵⁹ 42 U.S.C.A. § 300ff-34(e)(A) (West Supp. 1991). Since reported AIDS cases were readily available, these statistics were used to estimate the prevalence of HIV-infected infants, although states could rely on available HIV data instead. States with less than ten cases would use a comparable measure.

⁶⁰ 42 U.S.C.A. § 300ff-34(e)(B) (West Supp. 1991).

⁶¹ Kent, *supra* note 20, at 1.

⁶² *Id.*

⁶³ Curnin, *supra* note 1, at 875

⁶⁴ Michael Closen, Robert Gamrath, & Dem Hopkins, *Mandatory Premarital HIV Testing: Political Exploitation of the AIDS Epidemic*, 69 TUL. L. REV. 71, 102 (1994).

⁶⁵ *Id.*

narrowly tailored and constitute the least restrictive mode of achieving the stated goals.⁶⁶

Prior case law offers some guidance, but little certainty, on this privacy issue. For example, although the *Whalen* Court found governmental interest in information pertaining to prescription drug usage outweighed an individuals' right to privacy, revealing a pregnant woman's HIV status has potentially more harmful consequences. Furthermore, HIV testing cannot be fairly characterized as "routine" and, thus, is not analogous to the records at issue in *Westinghouse*, which pertained to routine tests such as "X-rays, blood tests, pulmonary function tests, [and] hearing and visual tests."⁶⁷ Non-anonymous HIV testing is clearly distinguishable from both prescription drug identification and routine tests due to the likelihood of discrimination and stigmatization; consequently, a pregnant woman's HIV status should be afforded greater protection and should not be made public information by the government.

A similar conclusion was reached by the court in *Hawaii Psychiatric Soc'y v. Ariyoshi*, which similarly distinguished *Whalen*⁶⁸ holding that disclosure of patients' files and psychological profiles violated patients' rights to privacy.⁶⁹ The *Ariyoshi* court found, unlike the *Whalen* court, that the type of information at issue had a unique personal character and involved "most intimate thoughts and emotions, as well as descriptions of conduct that may be embarrassing or illegal."⁷⁰ Likewise, a woman's HIV status is unique as compared to other personal information, because AIDS is distinguished from other diseases by its incurable nature, the means of infection, and fear and stigma associated with the disease.

Notwithstanding the important governmental interest in protecting public health and providing treatment for HIV-positive newborns, the CARE Amendments are still unconstitutional in light of the severe consequences -- violating all women's right to privacy. Several factors demonstrate that mandatory HIV testing legislation is not sufficiently

⁶⁶ *Id.*

⁶⁷ *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 579 (3rd Cir. 1980).

⁶⁸ *See generally Hawaii Psychiatric Soc'y v. Ariyoshi*, 481 F. Supp. 1028 (D. Hawaii, 1979).

⁶⁹ *Id.*

⁷⁰ *Id.*

narrowly tailored to attain the purported goals of a substantive due process analysis including:

- (1) The Amendments may cause discrimination and avoidance of prenatal care;
- (2) the uncertainty of HIV test results; and
- (3) disputable benefits of HIV treatment programs.

Discrimination and Stigmatization of Mothers and Newborns

HIV-positive test results will undoubtedly subject mothers and newborns to stigmatization and discrimination by the general population. It is well known that victims of HIV and AIDS continue to be negatively stereotyped and stigmatized,⁷¹ primarily due to the fact that HIV and AIDS were initially more prevalent among disfavored segments of the population, including homosexuals, intravenous drug addicts, prostitutes, promiscuous individuals, and indigent minority groups.⁷² Current statistics indicate that more than 70 percent of women with AIDS are African-American or Latina⁷³ and, therefore, targeting these minority women who are concentrated mostly in poverty-stricken inner cities, would further contribute to discrimination against these women.

The stigmatization associated with HIV and AIDS may also result in loss of employment opportunities for infected individuals, housing availability, and the support of friends and family.⁷⁴ The disclosure of an HIV-positive test result could cause individuals to lose health insurance coverage⁷⁵ even though the CARE Amendments explicitly prohibits insurers from discontinuing policies based on HIV status⁷⁶ However, the

⁷¹ *Id.* at 83.

⁷² *Id.* See also Closen, Gamrath & Hopkins, *supra* note 65, at 84. Some individuals further contribute to the stigmatization of individuals suffering from HIV and/or AIDS by broadcasting their theory that HIV and AIDS are a form of God's retribution on individuals engaging in "sinful" behaviors, which they contend includes homosexuality, substance abuse, prostitution, and adultery/pre-marital sex.

⁷³ Taunya Lovell Banks, *Women and AIDS—Racism, Sexism, and Classism*, 17 N.B. REV. L. & SOC. CHANGE 351, 351 (1990).

⁷⁴ Closen et al., *supra* note 64, at 104.

⁷⁵ *Id.*

⁷⁶ 42 U.S.C.A. § 300ff-35(5)(A) (West Supp. 1991).

exception is if individuals misrepresent their HIV status when applying for health insurance.⁷⁷ In any event, insurance companies are still able to discontinue coverage simply by offering another reason for no longer insuring the HIV-positive patients⁷⁸ and, more surprisingly, insurers may still be entitled to alter the terms of HIV-positive individuals' insurance plans.⁷⁹ Finally, in addition to social and institutional discrimination, it is likely that HIV-positive newborns may be abandoned by their mothers, thereby causing the infants to suffer additional discrimination in the context of adoption and foster homes.⁸⁰

The potential stigma and discrimination against individuals living with HIV or AIDS may further provide incentive for pregnant women to avoid prenatal care altogether, thereby contravening the purpose of the CARE legislation. Additionally, when a pregnant woman realizes that HIV testing is a prerequisite to hospital admission, she may choose to have her baby delivered elsewhere under unsafe conditions, particularly if she is at high risk for HIV infection.⁸¹

Proponents of CARE legislation argue that any infringement upon a woman's right to privacy in non-anonymous testing is minimal, and that societal discrimination is unlikely since the results of the HIV tests are revealed only to the newborn's mother, the physician, and the government.⁸² However, this argument fails to take into account the fact that dissemination of confidential medical information occurs frequently.⁸³ Moreover, mothers who seek treatment for their infants or themselves, would most likely not be able to hide their HIV-positive status.⁸⁴

⁷⁷ 42 U.S.C.A. § 300ff-35(5)(B) (West Supp. 1991).

⁷⁸ *Id.*

⁷⁹ 42 U.S.C.A. § 300ff-35(5)(C) (West Supp. 1991). The Act provides that "subparagraph (A) does not apply to any reasonable alteration in the terms of health insurance for an individual with HIV disease that would have been made if the individual had a serious disease other than HIV disease."

⁸⁰ Martha A. Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402, 429 (1993).

⁸¹ *Id.* at 422.

⁸² Curin, *supra* note 1, at 876.

⁸³ *Id.* at 877.

⁸⁴ *Id.* at 877-78.

Inaccuracy of HIV Test Results

Second, the CARE Amendments are not narrowly tailored enough, since the legislation presumes highly accurate HIV test results even though only 25 percent of infants who test positive for HIV are found to be actually infected.⁸⁵ The rest of the infants “seroconvert” or shed their mothers’ HIV antibodies, while their own bodies produce none.⁸⁶ During this window period that lasts approximately twelve months, the “true” HIV-positive infants are indistinguishable from the “false” HIV-positive infants. An HIV-positive test result, however, is definitively indicative of the mothers’ HIV-positive status.⁸⁷

HIV test results can also be inaccurate as a result of errors that may occur at any point during the testing process. Testing materials themselves may be faulty⁸⁸ and HIV test results can also be inaccurate if laboratory technicians’ fail to follow a sound two-part testing procedure. The first part of the testing procedure involves an enzyme-linked immunoabsorbent assay (ELISA) test, an overly sensitive test that reduces a large quantity of blood samples to a smaller number of potentially HIV-infected samples.⁸⁹ After the initial ELISA screening, the more expensive and less sensitive Western Blot test is conducted.⁹⁰ Only when both of these tests are performed correctly does the accuracy of detecting the “true” HIV-contaminated blood samples exceed 99 percent.⁹¹ The ELISA test alone, however, will also detect false positives and individuals will likely be informed incorrectly that they have tested HIV-positive.⁹²

⁸⁵ *Id.* at 865.

⁸⁶ *Id.* at 865.

⁸⁷ Kevin J. Curnin, *Newborn HIV Screening and New York Assembly Bill No. 6747-B: Privacy and Equal Protection of Pregnant Women*, 21 *FORDHAM URB L. J.* 857, 865 (1994).

⁸⁸ Closen, et al., *supra* note 65, at 91.

⁸⁹ Michael L. Closen, *Mandatory Disclosure of HIV Blood Test Results to the Individuals Tested: A Matter of Personal Choice Neglected*, 22 *LOY. U. CHI. L. J.* 445, 449 (1991).

⁹⁰ *Id.*

⁹¹ Closen et al., *supra* note 64, at 91.

⁹² Closen, *supra* note 89, at 449.

Debatable Benefit Of Treatment Programs

The benefits of treatment programs are debatable, largely because the HIV tests employed today render immediate treatment of HIV-positive newborns impractical. Because infection manifests quickly in newborns, treatment must be immediate to be effective.⁹³ Under current procedures, several weeks may lapse before laboratory test results are available; and an additional period of time, possibly lasting several months, may pass while efforts are made to contact the newborns' mother or guardian.⁹⁴ Additionally, an HIV-positive woman could unknowingly infect her newborn infant through breastfeeding after being discharged from the hospital when test results are not yet available.⁹⁵

The effectiveness of antiviral drugs is also quite limited since the drugs only decrease the rate at which HIV replicates, rather than destroying the virus or terminating DNA replication altogether.⁹⁶ Patients may also develop immunity to the drugs, necessarily reducing the drugs' effectiveness, and often require physicians to alternate treatment among different antiviral drugs.⁹⁷ Long-term side effects of antiviral drugs are not yet known, but these drugs are often accompanied by a variety of intolerable side effects including anemia, peripheral neuropathy, and headaches.⁹⁸ Side effects are of particular concern for three-quarters of the HIV-positive infants who will derive no benefit from treatment since they eventually shed their mothers' antibodies eventually.⁹⁹ For this reason, many physicians refrain from treating HIV-positive newborns based solely on an HIV-positive test result.¹⁰⁰ In fact, many physicians wait until the HIV-positive test results are corroborated by symptoms of infection or an

⁹³ Curmin, *supra* note 1, at 888.

⁹⁴ *Id.*

⁹⁵ *Id.* at 890. The results of medical studies concerning transmission from mother to infant through breast milk are inconclusive. An occurrence of this type of transmission was first documented in Australia in 1985 and over a period of five years. Only eight cases were reported thereafter.

⁹⁶ Grizzi, *supra* note 15, at 481.

⁹⁷ *Id.* at 482.

⁹⁸ *Id.*

⁹⁹ Curmin, *supra* note 1, at 889.

¹⁰⁰ Naber & Johnson, *supra* note 9, at 62.

extremely low CD4 lymphocyte count before treating the newborn with any antiviral drugs at all.¹⁰¹

CARE Amendments Violate Privacy Rights

In light of the stigmatization and discrimination associated with HIV and AIDS, the danger that pregnant women will avoid prenatal care, the inaccuracy of test results, and the questionable benefits of current treatment programs, legislation requiring non-anonymous HIV testing of all newborns is not sufficiently narrowly tailored. Therefore, the Amendments are violative of the Substantive Due Process Clause of the Fourteenth Amendment.

When a statutory classification impacts a fundamental right (in this instance, the right to privacy), the identical strict scrutiny test discussed above for substantive due process is applied under an equal protection analysis, regardless of whether the classification itself is "suspect." Under a strict scrutiny standard, a statutory classification will be upheld only if the classification is necessary to achieve a compelling government interest. By requiring HIV testing of all newborns, the CARE Amendments necessarily impose HIV testing on all women who give birth, resulting in creation of a class based on gender. Accordingly, in order to prevail on an equal protection challenge based on sex discrimination, opponents of the CARE legislation must demonstrate purposeful and deliberate legislative discrimination, rather than merely a discriminatory effect.¹⁰²

¹⁰¹ Curnin, *supra* note 1, at 890.

¹⁰² *Washington v. Davis*, 426 U.S. 229 (1976) (holding purposeful discrimination must be proven before an equal protection racial discrimination claim will prevail, although racial impact may be taken into account in ascertaining intent). *See also* *Personnel Admin'r of Mass. v. Feeney*, 442 U.S. 256 (1979) (holding the state's preference for veterans in civil service positions was not violative of equal protection despite the fact that over 98 percent of the Massachusetts veterans were men since a significant number of male non-veterans were also affected. The Court stated the statute would not be deemed unconstitutional unless it was demonstrated that the legislature acted because of—and not merely "in spite of," the discriminatory effect on women).

Purposeful discrimination, may be proven in three ways:

- (1) by demonstrating the statute is discriminatory according to its explicit terms;¹⁰³
- (2) by showing the statute, although neutral on its face, is administered in a discriminatory manner;¹⁰⁴ or
- (3) by demonstrating the statute, although neutral on its face and as applied, was originally enacted with a discriminatory purpose as shown by circumstantial evidence such as legislative history, legislators' statements, or discriminatory impact.¹⁰⁵

Notwithstanding the fact that the mandatory HIV testing scheme is facially neutral since all newborns are tested,¹⁰⁶ the Amendments are discriminatory in their implementation because they discriminate based on gender. This is true because HIV testing of newborns only reveals the mother's HIV status and not the father's. Even assuming arguendo that the legislation is neutral on its face and as applied, the legislation inevitably constitutes invidious gender discrimination in consideration of circumstantial evidence. For instance, women have been politically, economically, and socially discriminated against in the past.¹⁰⁷ Further, as long as reproductive differences, which are immutable characteristics and unrelated to an individual's ability to contribute to society, are not recognized as falling under the Equal Protection Clause, a woman's

¹⁰³ See *Strauder v. West*, 100 U.S. 303 (1880) (holding that a statute stating that "all white male persons who are twenty-one years of age who are citizens of this State shall be eligible to serve as jurors" was facially discriminatory against African-Americans and thus, unconstitutional under the Equal Protection).

¹⁰⁴ See *Yick Wo v. Hopkins*, 118 U.S. 356 (1886) (holding that a facially neutral ordinance was violative of equal protection when permits issued pursuant to the statute were given to all except one non-Chinese applicant while none were issued to nearly 200 Chinese applicants).

¹⁰⁵ See *Rogers v. Lodge*, 458 U.S. 613 (1982) (holding that although the voting system of electing the Board of Commissioners was facially neutral and not originally enacted for a discriminatory purpose, the statute was violative of equal protection since it was maintained by the state legislature for discriminatory purposes and had a discriminatory impact on the African-American citizens).

¹⁰⁶ Linda Farber Post, *Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?*, 16 CARDOZO L. REV. 169, 219 (1994).

¹⁰⁷ Joelle S. Weiss, *Controlling HIV-Positive Women's Procreative Destiny: A Critical Equal Protection Analysis*, 2 SETON HALL CONST. L. J. 642, 711 (1992).

procreative capacity will continue to be exploited, thereby encouraging and justifying male supremacy.¹⁰⁸

At least one Supreme Court decision appears to be an obstacle to such an equal protection challenge. In *Geduldig v. Aiello*,¹⁰⁹ the Court found a state insurance system that denied coverage for certain pregnancy-related disabilities did not constitute gender discrimination in violation of the Equal Protection Clause of the Fourteenth Amendment.¹¹⁰ Although *Geduldig* has rarely been relied upon as precedent,¹¹¹ the few cases that have followed it have narrowly construed its holding, such as in *Bray v. Alexandria Women's Health Clinic*,¹¹² where *Geduldig* was cited for the proposition that distinctions based on pregnancy did not constitute *ipso facto* gender classifications.

Numerous other cases have echoed similar finding to *Geduldig*. In *General Elec. Co. v. Gilbert*, for example, the Supreme Court found an employer's disability benefits plan was not violative of Title VII of the Civil Rights Act of 1964 and did not constitute gender discrimination, even though the plan did not cover pregnancy-related disabilities.¹¹³ Additionally, in *Weinberger v. Salfi* the Supreme Court held a Social Security Act provision was constitutional even though the provision denied insurance benefits to surviving wives and stepchildren whose familial relationship with deceased wage earner was less than nine months.¹¹⁴

However, neither the Supreme Court nor the lower courts have ever expressly held that pregnancy discrimination can never constitute gender discrimination.¹¹⁵ As long as the *Geduldig* holding is interpreted as permitting men and women to be treated differently based on women's reproductive capacity, women will never be afforded equal protection under the law since only similarly situated individuals are entitled to such

¹⁰⁸ *Id.* at 713-14.

¹⁰⁹ *Geduldig v. Aiello*, 417 U.S. 484 (1974).

¹¹⁰ *Id.*

¹¹¹ *Id.*

¹¹² *Bray v. Alexandria Women's Health Clinic*, 506 U.S. ____ (1976) (holding that antiabortion protesters did not invidiously discriminate against women in general).

¹¹³ *General Elec. Co. v. Gilbert*, 429 U.S. 125 (1976).

¹¹⁴ *Weinberger v. Salfi*, 422 U.S. 749 (1975).

¹¹⁵ *Curnin*, *supra* note 1, at 910.

constitutional guarantees.¹¹⁶ Thus, it would be a significant decision for programs requiring non-anonymous HIV testing of newborns to be invalidated, since these programs discriminate based on gender.

Strict scrutiny under equal protection of the CARE Amendments demonstrates that HIV testing is not necessary to serve any compelling governmental interests. Taking into account the previous discussion pertaining to the discrimination and stigma associated with HIV and AIDS, the potential avoidance of prenatal care, the inaccuracy of test results and the debatable benefits of treatment programs, the Amendments are clearly an unjustified infringement upon a pregnant woman's right to privacy.

In addition to due process and equal protection violations, non-anonymous HIV testing of newborns necessarily reveals the HIV status of their mothers. This revelation could lead to questions concerning the "fitness" of HIV-infected women for marriage and parenthood, potentially resulting in such drastic measures as mandatory HIV testing of all women, criminalization of the transmission of HIV from mother to fetus, coerced abortions, or compulsory sterilizations.¹¹⁷ Possible adverse consequences of the Amendments are even more pronounced upon consideration of the "slippery slope," potentially leading to mandatory testing for a variety of other conditions and traits detectable from blood samples.¹¹⁸

AN ALTERNATIVE TO MANDATORY TESTING

The potential constitutional and logistical complications posed by the CARE Amendments can be completely avoided because the Amendments are not necessary to control the pediatric AIDS crisis. In fact, far less drastic measures are available.

One alternative is to repeal the provision making federal funding contingent upon whether the states achieve at least one of the three goals specified in the Act. Instead, voluntary, anonymous testing should be encouraged, and there should be additional focus on education and pre- and post-natal counseling specific to HIV and AIDS. This alternative

¹¹⁶ Weiss, *supra* note 108, at 700.

¹¹⁷ *Id.* at 660.

¹¹⁸ Field, *supra* note 80, at 435.

scheme to mandatory testing is more likely to succeed since women who choose to be tested for HIV are more apt to seek follow-up care and to make the behavioral changes recommended by their health care providers.¹¹⁹

Since physicians today are inadequately prepared to provide HIV counseling, specially trained HIV counselors should be made available¹²⁰ to provide pregnant women with written materials and/or videos explaining the nature of HIV. In addition, these counselors could explain to patients how the virus is transmitted, help interpret test results, and provide information on available treatment programs and reproductive options.¹²¹ Further, any education and counseling provided should be tailored toward individual needs, and be based upon each woman's individual education level as well as her cultural and linguistic backgrounds.¹²² The focus of the counseling should be on prevention, the benefits of HIV testing, and the availability of support services.¹²³

Education and counseling have already proven effective, as demonstrated by the increasing number of women who agree to voluntary testing and by the decreasing incidence of HIV infection. The New York State Health Department, for instance, recently reported that 85 to 91 percent of women who were provided with education and counseling chose to test voluntarily for HIV.¹²⁴ Additionally, several gay communities have documented a decrease in the incidence of new HIV cases, which has been attributed to the effectiveness of recently implemented educational programs.¹²⁵

CONCLUSION

The Ryan White CARE Amendments will ultimately coerce states to adopt mandatory, non-anonymous HIV testing statutes in an effort to prevent the state's loss of federal funding. Consequently, any effort to

¹¹⁹ Curnin, *supra* note 1, at 894.

¹²⁰ Ram Yoge, *Prenatal Testing Can Curb AIDS in Children*, CHI. TRIB., July 28, 1996, at 6.

¹²¹ *Id.*

¹²² Post, *supra* note 106, at 122.

¹²³ *Id.*

¹²⁴ Malloy, *supra* note 21, at 1213.

¹²⁵ Closen et al., *supra* note 64, at 90.

comply with the guidelines pursuant to the Act will result in unnecessary infringement upon the individual privacy rights of all women. Since other less intrusive and more effective means of addressing the pediatric AIDS epidemic are available, mandatory HIV testing of newborns is violative of the Substantive Due Process and Equal Protection Clauses of the United States Constitution and should be discontinued.

