NEW YORK LAW SCHOOL

NYLS Journal of Human Rights

Volume 13
Issue 2 *VOLUME XIII WINTER 1997 PART Two*

Article 3

Winter 1997

THE MANDATORY TESTING OF NEWBORNS FOR HIV: TOO MUCH, TOO LITTLE, TOO LATE

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NOTES

THE MANDATORY TESTING OF NEWBORNS FOR HIV: TOO MUCH, TOO LITTLE, TOO LATE

I. Introduction

In 1988, the Centers for Disease Control and Prevention ("CDC"), the National Institute of Child Health and Human Development, and 45 states[1] began an anonymous newborn Human Immunodeficiency Virus ("HIV") seroprevalence surveillance study.[2] This study measures the HIV infection rate of childbearing women in the United States, Puerto Rico, the Virgin Islands and the District of Columbia using dried blood which is collected for newborn screening.[3] The names of the mother and the newborn are removed from the newborn screening cards before the HIV test is performed, in accordance with guidelines promulgated by the CDC.[4] However, "demographic data such as the mother's age group, race and geographic region of residence

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[1] This study is also being conducted in the District of Columbia, Puerto Rico and the Virgin Islands. The five states not participating in the study are Idaho, Nebraska, North Dakota, South Dakota and Vermont. (Information obtained through a phone call to the CDC National AIDS Clearinghouse).

[2] *See* REPORT OF THE SUBCOMMITTEE ON NEWBORN HIV SCREENING OF THE NEW YORK STATE AIDS ADVISORY COUNCIL 2 (Feb. 10, 1994) (hereinafter A.A.C. SUBCOMMITTEE REPORT) ("Seroprevalence surveys based on tests for HIV antibodies in the blood, not AIDS symptoms, are a method to assess the extent of HIV infection in a given population or area.").

[3] *See* John M. Naber & David R. Johnson, *Mandatory HIV Testing Issues in State Newborn Screening Program*, 7 J.L. & HEALTH 55, 58 (1992-93).

[4] *Id.*; *see also* James Dao, *Mothers to Get AIDS Test Data Under Accord*, N.Y. TIMES, Oct. 10, 1995, at A1 (reporting that numbers and not names are attached to the vials of blood tested for HIV in New York's anonymous newborn screening program).

are retained" for purposes of statistical analysis and tracking of the incidence of HIV.[5] Despite the fact that it is the newborn's dried blood specimen that is tested, the current testing method utilized actually measures whether the mother is infected with HIV, not the newborn, because the test measures the presence of maternal antibodies in the newborn's blood.[6] In fact, a newborn's true HIV status often cannot be known for several months.[7] Perinatal transmission of HIV[8] accounts for eighty to ninety-five percent of pediatric Acquired Immunodeficiency Disease ("AIDS") cases.[9]

"New York uses the data from this survey to make informed decisions about allocation and funding of HIV prevention and treatment services for women, infants and families."[10] In New York State, between November 1987 and August 1993, a total of 10,333 newborns tested for HIV as part of the surveillance study received a positive result.[11] "Using the currently accepted transmission risk of fifteen to

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[5] Naber & Johnson, *supra* note 3, at 59.

[6] *Id.* ("These antibodies are produced in the mother in response to her HIV infection and cross through the placenta and into the blood of the fetus [and] remain . . . [there] . . . for up to eighteen months."). *See also* U.S. DEPT. OF HEALTH AND HUMAN SVCS., EVALUATION AND MANAGEMENT OF EARLY HIV INFECTION-CLINICAL PRACTICE GUIDELINE 83 (1994) (hereinafter U.S. DEPT. OF HEALTH AND HUMAN SVCS.).

[7] *See* U.S. DEPT. OF HEALTH AND HUMAN SVCS., *supra* note 6, at 83 (reporting that "[t]he median time to disappearance of maternal antibody in most studies is about 10 months, but antibody has been reported to persist for as long as 18 months").

[8] Transmission from a mother to her fetus or infant. The terms vertical transmission or mother-to-child transmission are also commonly used to indicate this method of HIV transmission. U.S. DEPT. OF HEALTH AND HUMAN SVCS., *supra* note 6, at 149.

[9] Srisakul C. Kliks et al., *Features of HIV-1 That Could Influence Maternal-Child Transmission*, 272 J. AMER. MED. ASSN. 467 (Aug. 10, 1994) (hereinafter *Features of HIV*); *see also U.S. Public Health Services Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women*, MORBIDITY AND MORTALITY WEEKLY REPORT, at 2 (July 7, 1995) (U.S. Centers for Disease Control and Prevention) (hereinafter *CDC-U.S. Public Health Service Recommendations*).

[10] *See* A.A.C. SUBCOMMITTEE REPORT, *supra* note 2, at 3.

[11] *Id.* at 7.

twenty-five percent,"[12] it is estimated that in New York State, an average of 1,800 newborn infants each year test positive for HIV,[13] of which 270 to 540 are actually infected with HIV.[14] This information was not disclosed to the newborns' parents because this was solely an epidemiological study that was conducted "blindly."[15] Concerned by the fact that parents and guardians were not informed of their child's HIV status, Assemblywoman Nettie Mayersohn[16] proposed legislation in the New York State Assembly, known as the "AIDS Baby Bill,"[17] that would have required the New York State Department of Health to:

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[12] *Id.* at 9; *see also generally* U.S. DEPT. OF HEALTH AND HUMAN SVCS, *supra* note 6. Transmission rates are between thirteen and thirty-nine percent. *Id.* Still other studies have shown transmission rates as low as twelve percent, while others have shown transmission rates as high as forty-five percent. *See, e.g., Features of HIV, supra* note 9, at 467.

[13] *See* A.A.C. SUBCOMMITTEE REPORT, *supra* note 2, at 6.

[14] *Id.*

[15] *See* Committee on HIV Prenatal/Newborn Testing, *Prenatal/Newborn HIV Testing*, 49 THE RECORD A.B.A.N.Y. 420 (May 1994) (hereinafter *Prenatal/Newborn HIV Testing).* "Blind" testing means that all personal identifiers are removed from the specimen being tested. *Id.*

[16] Assemblywoman Mayersohn is a Democratic legislator from the borough of Queens in New York City. It should be noted that Congressman Gary Ackerman (D-Queens) introduced similar legislation in the United States House of Representatives that would require all states to disclose the HIV status of newborns to parents or guardians. *See* Ian Fisher, *Lawmakers Agree on Testing Babies for the AIDS Virus*, N.Y. TIMES, May 1, 1996, at A1. After a nine-month stalemate, a compromise was reached on this issue as part of the re-authorization of the Ryan White Comprehensive AIDS Resource Emergency Act. *Id.* The agreement would "require doctors and other health care workers to advise pregnant women to be tested for HIV... but testing of children born to mothers whose HIV status is not known would become mandatory [in a state] if the number of infected children was not reduced by counseling alone by the year 2000." *Id.*

[17] New York State Assembly Bill No. 6747-C, 215th General Assembly (1993) (hereinafter "A.6747-C"). This bill has been amended several times: in June 1993, March 1994, April 1994, February 1995, April 1995, and most recently in June 1995. Jean R. Sternlight, *Mandatory Non-anonymous Testing of Newborns for HIV: Should it Ever Be Allowed?*, 27 J. MARSHALL L. REV. 373, 374 (1994). The most current version of the proposed AIDS Baby Bill is New York State Assembly Bill No. 6684-A, 218th General Assembly (1995) (hereinafter "A.6684-A"). *Id.* Companion legislation was introduced in the New York State Senate (S.5617-B) by Democratic State Senator Guy Valella of the Bronx. *Id.* The legislation was defeated. *Id.*

> disclose to the mother, prospective adoptive parents or the appropriate official of an authorized agency having the care, custody or guardianship of a newborn, confidential HIV related information obtained as a result of any testing done for any purpose whatsoever on such child, including epidemiological research .... If the mother of a newborn child cannot be located in order to receive such information, the father or the appropriate guardian of such child shall receive such notification.[18]

The level of support and opposition to this type of legislation is overwhelming.[19] Ninety-one members of the Assembly co-sponsored later legislation,[20] including both Democrats and Republicans, and their views ran the gamut from liberal to conservative.[21] The editorial boards of the major New York City newspapers, including the *Daily News*, the *New York Times*, and *New York Newsday*, expressed support for this legislation.[22] Various children's advocacy groups, such as the AIDS

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[18] *See* A. 6684-A (1995), *supra* note 17.

[19] Sternlight, *supra* note 17, at 374 (stating that the New York State Assembly narrowly defeated a proposed bill that would have permitted the non-anonymous testing of newborns and this bill created "fierce political controversy").

[20] *See* New York State Assembly Bill No. 4413, 216th General Assembly (1995). The primary sponsors of the "AIDS Baby Bill" were: Nettie Mayersohn (D-L)-Queens, Barbara M. Clark (D)-Queens, Brian M. McLaughlin (D)-Queens, Charles J. O'Shea (R-C)-Nassau, Alexander J. Gromack (D-C)-Rockland, Eric N. Vitaliano (D-C)-Richmond, Samuel Colman (D)-Rockland, Stephen B. Kaufman (D)-Bronx, and Audrey Pheffer (D-L)-Queens. They were joined by eighty-two of their colleagues in the Assembly. *Id.*

[21] *Id.*

[22] *Albany Flunks its AIDS Test*, DAILY NEWS (New York), Mar. 19, 1995, at 34; *Infant's Rights-Tell Mothers Their HIV Status* (editorial) NEWSDAY (New York), Mar. 17, 1995, at A36; *AIDS Babies Deserve Help, Now*, N.Y. TIMES, June 25, 1995, §4 at 14; Joyce Purnick,

Institute Committee on Children and Adolescents and the Association to Benefit Children, supported this bill.[23] The supporters of this legislation argued that it is crucial to identify these newborns so that they may receive appropriate medical care early on to prevent the occurrence of opportunistic infections and so that the mothers can be advised not to breastfeed.[24]

However, the AIDS Baby Bill faced vocal opposition from several medical and healthcare organizations:[25] doctors, such as Dr.

When AIDS Testing Collides With Confidentiality, N.Y. TIMES, May 18, 1995, at B4; *Saving Babies-New York Should Start Telling Mothers When Their Newborns are at Risk of AIDS*, NEWSDAY, Mar. 20, 1995, at A26.

[23] *See Suit Seeks Results of Babies' AIDS Tests*, N.Y. TIMES, Mar. 15, 1995, at B2 (reporting that the Association to Benefit Children filed a lawsuit on March 14, 1995, to require New York State to inform mothers of the results of HIV tests performed on their newborns); *see generally* Dao, *supra* note 4 (noting that the settlement in the Association to Benefit Children lawsuit requires doctors to advise new mothers that HIV test results can be made available if consent forms are signed).

[24] *Id.*

[25] *See, e.g.*, Memorandum from The American College of Obstetricians and Gynecologists (June 28, 1994) (on file with *New York Law School Journal of Human Rights*) (opposing the bill because the purpose of the "blinded HIV research program . . . was not designed to nor does it provide the medical community and parents the information they need to diagnose and care for HIV infected women and infants[; it] was designed [to create] an epidemiologic database"); Letter from The Healthcare Association of New York State to James Klurfield, editor of NEWSDAY (June 14, 1994) (on file with *New York Law School Journal of Human Rights*) (opposing the bill because disclosing HIV test results to mothers will not accomplish the goal "to prevent or reduce AIDS transmission from mother to infant); Joint Memorandum of The American Academy of Pediatrics and The American College of Obstetricians and Gynecologists (Aug. 1995) (on file with *New York Law School Journal of Human Rights*) (opposing the bill because the "answer [to the AIDS epidemic] lies in an aggressive HIV education and counseling initiative, not in governmental medical protocols"); Testimony to the City Council by the New York Academy of Medicine (Sept. 29, 1995) (on file with *New York Law School Journal of Human Rights*) (opposing the bill because mandatory HIV testing of newborns only); Ruth Watson Lubic, General Director of Maternity Center Association, to Senator Michael J. Tully, New York State Senate, (Mar. 25, 1994) (on file with *New York Law School Journal of Human Rights*) (opposing the bill because counseling is the most effective way to reduce the spread of HIV and AIDS, not mandatory testing of newborns).

Lorraine Hale, who work with HIV-infected infants;[26] various women's advocacy groups;[27] as well as organizations committed to education and counseling regarding the AIDS virus.[28] These opponents argue that the "blind" testing which is now performed is for statistical purposes only and is not an accurate indicator of the HIV status of the newborn.[29] They argue further that the only definitive information that would be revealed by these tests is the HIV status of the mother, and that the disclosure of this information would weaken New York State's confidentiality and informed consent laws.[30]

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[26] Cindy Herrschaft, *Mayersohn, Dr. Hale in HIV Debate*, WESTERN QUEENS GAZETTE (New York), May 23, 1994, at 22 (reporting that Dr. Hale advocates voluntary HIV testing of pregnant women, but is concerned that mandatory testing would drive pregnant women away from much needed medical care).

[27] *See, e.g.*, Memorandum from the National Organization of Women, New York Chapter, (Feb. 28, 1994) (on file with *New York Law School Journal of Human Rights*) (opposing the bill because mandatory HIV testing denies women the "right to informed consent"); Memorandum from New York Task Force on Women and AIDS (Mar. 15, 1995) (on file with *New York Law School Journal of Human Rights*) (opposing the bill because the mandatory AIDS testing does not include counseling which will lead to "fewer women and children receiv[ing] the essential HIV-related care and services they need").

[28] *See, e.g.*, Memorandum from the New York AIDS Coalition [hereinafter Memorandum, NYAC] (on file with *New York Law School Journal of Human Rights*) (opposing the bill because testing newborn babies for HIV will only indicate whether the mother has HIV, not the baby); Testimony by Theresa M. McGovern, Executive Director, HIV Law Project (on file with *New York Law School Journal of Human Rights*) (opposing mandatory HIV testing because it "will drive women from care"); Testimony to Committee on Health, New York City Council, by Wendy Hoefler, Coordinator, Staten Island HIV CARE Network (on file with *New York Law School Journal of Human Rights)* (opposing mandatory HIV testing of newborns because it only reports if the mother is HIV positive and it violates the mother's "rights to voluntary consent under the New York State HIV Confidentiality Law"); Memorandum from seventy-four organizations (on file with *New York Law School Journal for Human Rights*) (opposing legislation A.4413/S.2704, requiring mandatory HIV testing of newborns, because it does not provide the necessary care and services for mother and newborn which are necessary to help reduce the spread of HIV).

[29] *See supra* notes 25-28; A.A.C. SUBCOMMITTEE REPORT, *supra* note 2, at 3.

[30] *See, e.g.*, Memorandum, NYAC, *supra* note 28 (arguing that "unblinding of the serosurvey amounts to mandatory testing of women who give birth in violation of their rights under New York State law to consent to HIV testing [while] no other group of individuals in New York is denied that right").

In 1993 "the New York State Assembly's Ad Hoc Task Force on AIDS invited Dr. David Rogers, Chair of the New York State AIDS Advisory Council, to appear before the Task Force to discuss the pros and cons of mandatory newborn screening."[31] As a result of Dr. Rogers' appearance, a blue ribbon panel was convened to examine the implications of the proposed AIDS Baby Bill.[32] The Subcommittee's report and recommendations, issued on February 10, 1994, advocated a policy of mandatory HIV counseling for all pregnant women and strongly encouraged voluntary testing for pregnant and post-partum women.[33] Based on the recommendations of the Subcommittee, Senator Michael Tully[34] introduced legislation that would require extensive and mandatory prenatal counseling to encourage a pregnant woman to be tested for HIV before birth and informed that if she does not have the financial resources to pay for such testing, it will be performed for free.[35] If a woman has not received prenatal care, she is to receive HIV counseling when she comes to the hospital to give birth.[36]

At no time did Senator Tully's legislation require mandatory testing.[37] It has been estimated that implementation of Senator Tully's legislation would have cost between seven and ten million dollars annually.[38] In contrast, it is unclear how much the AIDS Baby Bill will cost to implement because some have argued that the federal funds which are currently used for the "blind" seroprevalence study would no

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[31] A.A.C. SUBCOMMITTEE REPORT, *supra* note 2, at 1.

[32] *Id.* at 1-2. This panel became known as the Subcommittee on Newborn HIV Screening.

[33] *Id.* at 37-43.

[34] Michael Tully is a Republican New York State Senator from Roslyn, Long Island. *Thanks to Siris, State Senate Can't Hide Spending*, NEWSDAY, Dec. 8, 1994, at A38.

[35] New York State Senate Bill No.6775-A (1994). Senate Bill 6775-A was replaced by Assembly Bill 12248 which apparently died in the Senate Committee on Rules on July 3, 1994. (Available on LEXIS Bill Tracking at 1994 NY A.B. 12248).

[36] *Id.*

[37] New York Senate Bill 6775-A/Assembly Bill 12248 mandated that physicians must offer HIV testing and counseling to pregnant women, and perform these services if the mother wishes. Senate Bill 6775-A, 215th Gen. Assem., 2d Reg. Sess. (N.Y. 1994).

[38] *Prental/Newborn HIV Testing*, *supra* note 15, at 423.

longer be available if the tests were unblinded and the mothers were forced to submit to having their babies tested absent their informed consent.[39]

The issue of testing newborns caused a great deal of controversy in the New York State legislature. In fact, although the AIDS Baby Bill had many supporters in the New York State Senate and Assembly, the entire legislature failed to reach accord on the legislation for several years.[40] However, when the legislature once again addressed this issue during the 1995 legislative session, it resulted in overwhelming approval of the bill by the Senate Health committee as well as the entire Senate, but once again no accord was reached in the Assembly.[41] After several years of bitter debates on this issue, the New York State legislature passed the latest version of the AIDS Baby bill with virtually no fanfare as the 1996 legislative session came to a close.[42] The State Legislature

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[39] *Id.*; *see also* Linda Farber Post, Note, *Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?*, 16 CARDOZO L. REV. 169, n.190 (1994) (stating that "[u]nder the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, the awarding of federal grants is contingent upon the participating state having a policy of written, informed consent"). Therefore, unblinding these tests could put the federal funds that New York State receives for AIDS related programs in jeopardy. *But see* Ian Fisher, *Lawmakers Agree on Testing Babies for the AIDS Virus*, N.Y. TIMES, May 1, 1996, at A1. The article reports on the agreement reached by Congressional negotiators that would require the states to begin mandatory newborn HIV testing if the number of infected infants is not reduced. *Id.* The article goes on to state that "states that did not comply would risk losing Federal money under the Ryan White Act." *Id.* As a result, it remains unclear at this time what impact disclosure of newborn's HIV status will have on the level of Federal AIDS-related funding provided to New York State. *Id.*

[40] Richard Goldstein, *The Testing Mess*, THE VILLAGE VOICE (New York), July 19, 1994, at 12.

[41] Rebecca Blumenstein, *HIV Test of Tots Clears a Hurdle*, NEWSDAY, Mar. 15, 1995, at A19; *see also* Jim Dwyer, *The Privacy That Can Kill*, NEWSDAY, Mar. 15, 1995, at A2; *see also* Kevin Sack, *Senate Votes to Require Telling Mothers of HIV Results*, N.Y. TIMES, Apr. 5, 1995, at B4.

[42] N.Y. PUB. HEALTH LAW §2500-f (McKinney 1996). *See* Raymond Hernandez, *Parents to be Told HIV Status of Newborns*, N.Y. TIMES, June 27, 1996, at B5. Governor George E. Pataki signed the bill into law mandating health officials inform parents of the results of the HIV tests that were previously performed blindly. *Id.* This law also states that consent will

ultimately amended two sections of the New York State Public Health Law:

> §2500-f
> 1) In order to improve the health outcomes of newborns, and to improve access to care and treatment for newborns infected with or exposed to human immunodeficiency virus (HIV) and their mothers, the commissioner [of the Department of Health] shall establish a comprehensive program for the testing of newborns for the presence of human immunodeficiency virus and/or the presence of antibodies to such virus.
> 2) The commissioner shall promulgate regulations governing the implementation of the program required pursuant to subdivision one of this section, including the administration of testing, counseling, tracking, disclosure of test results pursuant to section twenty-seven hundred eighty-two of this chapter, follow-up reviews, and educational activities relating to such testing.[43]

The second part of the adopted AIDS Baby Bill removes the testing of newborns for HIV from the long-standing informed consent requirement for HIV testing in New York, embodied in section 2781 of the Public Health Law.[44]

The AIDS Baby Bill raises many important issues that must be considered. Mandatory HIV testing of newborns is a cause for great concern given the lack of absolute reliability in detecting HIV in newborns through the testing methods currently available,[45] and because

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no longer be needed before a newborn is tested, thus overturning New York's long-standing requirement of written consent before HIV testing. *Id.*

[43] N.Y. PUB. HEALTH LAW §2500-f (McKinney 1996).

[44] *Id.*.

[45] *See infra* notes 81-93, and accompanying text.

of the civil liberty issues that are involved.[46] Furthermore, the fact that the tests currently used and available can only definitively disclose the mother's HIV status[47] raises a plethora of legal and constitutional issues.[48] This Note is an attempt to address each of these issues and the various implications of the AIDS Baby Bill. The second part of this Note will be an overview of the prevalence of HIV in women and children, a discussion of maternal-fetal transmission of HIV, and a summary of the current testing available for the detection of the HIV infection[49] The third part of this Note discusses the issues raised by mandatory versus voluntary testing programs, the issues raised by newborn screening programs in general, and the role that informed consent plays in these type of programs.[50] The fourth part of this Note discusses the various legal and constitutional issues raised by the mandatory testing and disclosure of the HIV status of newborns.[51] This Note concludes with recommendations based on the issues raised in the previous sections. The most urgent recommendation is that if the New York State legislature is truly concerned with reducing the rate of perinatal HIV transmission, it must strive to adequately fund prenatal counseling, education, and AZT treatment programs to ensure that HIV positive women are provided with the most effective means to prevent

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[46] Doe v. Roe, 526 N.Y.S.2d 718, 721 (1988). Because of the

> lack of absolute reliability, potential ostracization, the threat to civil liberties and psychic harm which may occur from mandatory testing... the United States Surgeon General, the United States Public Health Service, the American Medical Association, and most state and local health departments including New York's all oppose mandatory HIV testing. *Id.*

[47] *See supra* notes 6 and 7, and accompanying text.

[48] *See infra* Section IV.

[49] *See infra* Section II.

[50] *See infra* Section III.

[51] *See infra* Section IV.

the transmission of this fatal disease to their unborn children.[52]

II. The Prevalence of HIV/AIDS in Women and Newborns

AIDS is caused by a virus called Human Immunodeficiency Virus (HIV).[53] The virus attaches to lymphocytes, which are a type of white blood cell essential to the body's immune system.[54] The specific lymphocyte attacked is known as the "CD4" cell or the "T4 helper" cell.[55] When a person becomes infected with HIV, his or her number of CD4 cells begins to decline, thus permitting increased replication of the HIV.[56] The incidence of AIDS in the United States is growing fastest among women.[57] AIDS became the fourth leading cause of death among all women in the United States between the ages of twenty-five and forty-four in 1993, and is now the leading cause of death among women in 15 of the 135 largest cities in the United States.[58] Many women infected with HIV acquire the disease through intravenous drug

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[52] *See infra* Section IV.

[53] *See* U.S. DEPT. OF HEALTH AND HUMAN SVCS., *supra* note 6, at 145; *see also* Steven Eisenstat, *An Analysis of the Rationality of Mandatory Testing for the HIV Antibody: Balancing the Governmental Public Health Interests with the Individual's Privacy Interest*, 52 U. PITT. L. REV. 327, 329 (1991).

[54] *See* Eisenstat, *supra* note 53, at 329. "[A]s the disease progresses, opportunistic diseases attack the body, further wearing down the body. Pneumocystis carinii pneumonia ("PCP") and Karposi's sarcoma are the most frequent examples of opportunistic infections and unusual cancers that invade the body." *Id.*

[55] *See* U.S. DEPT. OF HEALTH AND HUMAN SVCS., *supra* note 6, at 141. "[A]s HIV infected individual's CD4 cells decline, the risk of developing opportunistic infections increases. The trend of several consecutive CD4 counts is more important than any one measurement." *Id.*

[56] *Id.*

[57] *See CDC-U.S. Public Health Service Recommendation*, *supra* note 9, at 1.

[58] Lawrence K. Altman, *AIDS is Now the Leading Killer of Americans From 25 to 44*, N.Y. TIMES, Jan. 31, 1995, at C7.

use.[59] In addition, a woman's chances of contracting HIV through heterosexual intercourse is more than four times greater than that of a man's.[60] It has been estimated that nearly eighty-five percent of the AIDS cases reported in women in the United States occur in women of childbearing age.[61] As a result, AIDS is also increasing rapidly among children.[62]

In the United States, minorities such as African-Americans and Hispanics currently account for almost three-fourths of the population infected with HIV,[63] and since perinatal transmission accounts for eighty to ninety-five percent of pediatric AIDS cases,[64] the majority of children infected with HIV are also members of racial and ethnic minorities.[65]

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[59] Josephine Gittler & Sharon Rennert, *HIV Infection Among Women and Children and AntidiscriminationLaws: An Overview*, 77 IOWA L. REV. 1313, 1314 (1992) (discussing that the sharing of drug injection equipment contaminated with HIV infected blood is responsible for one-half of new reported HIV cases in women); *see also CDC-U.S. Public Health Service Recommendati ons supra* note 9, at 2 (reporting that approximately half of all AIDS cases among women have been attributed to intravenous drug use).

[60] Joelle S. Weiss, *Controlling HIV Positive Women's Procreative Destiny: A Critical Equal Protection Analysis*, 2 SETON HALL CONST. L.J. 643, 647 (1992); *see also* Altman, *supra* note 58 (stating that in 1992, heterosexual transmission became the leading route of transmission of HIV in women).

[61] *See* Division for HIV/AIDS, Center for Infectious Diseases, Centers for Disease Control and Prevention, *Aids in Women—United States*, 265 JAMA 23 (1991) (hereinafter *AIDS in Women*) (defining childbearing age as between the ages of 15 and 44).

[62] Suzanne Sangree, *Control of Childbearing by HIV Positive Women: Some Emerging Legal Policies*, 41 BUFF. L. REV. 309, 311 (1993). *But see Fewer Infants Acquire AIDS From Mothers*, N.Y. TIMES, Nov. 22, 1996, at A16 (reporting the encouraging news that Federal health officials from the Centers for Disease Control and Prevention found that the number of newborns contracting AIDS from their mothers actually dropped 27 percent from 1992 to 1995).

[63] *See* Gittler & Rennert, *supra* note 59, at 1314. Weiss, *supra* note 60, at 649-50; *see also CDC-U.S. Public Health Service Recommendations*, *supra* note 9, at 2.

[64] *See supra* note 9, and accompanying text.

[65] *See CDC-U.S. Public Health Service Recommendations*, *supra* note 9, at 2 (stating that "in 1991, HIV infection was the second leading cause of death among black children 1-4 years of age in New Jersey, Massachusetts, New York, and Florida, and among Hispanic children in this age group in New York").

Medical professionals believe that perinatal infection can occur either during gestation,[66] or intrapartum,[67] as well as postpartum via breastfeeding.[68] Although an HIV positive woman will always pass HIV antibodies to her newborn, approximately one-third or less of all babies born to HIV positive mothers will actually develop the virus.[69] In fact, less than one percent of all newborn babies are estimated to be HIV infected.[70]

Since, as stated above, the majority of women infected with HIV are of childbearing age,[71] public health officials remain committed to reducing the rate of perinatal transmission of the disease.[72] In fact, in December, 1985, the CDC officially prescribed that HIV positive women and AIDS infected women should "be advised to consider delaying pregnancy until more is known about perinatal transmission of the virus."[73] However, given the current medical data regarding the actual transmission rate from mother to child, it is clear that this

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[66] Gestation is defined as pregnancy. STEDMAN'S MEDICAL DICTIONARY 643 (25th ed. 1990).

[67] Intrapartum refers to the periods during labor and delivery or childbirth. *Id.* at 796.

[68] Postpartum refers to the period after childbirth. *Id.* at 1246. *See CDC-U.S. Public Health Service Recommendations supra* note 9, at 3 ("HIV can be transmitted from an infected women to her fetus or newborn during pregnancy, during labor and delivery, and during the postpartum period (through breastfeeding) although the percentage of infections transmitted during each of these intervals is not precisely known.").

[69] *See supra* notes 6 and 7, and accompanying text. Although all infants born to HIV infected mothers will test positive for HIV at birth due to the presence of maternal antibodies in their bloodstream, within 15 to 18 months of birth, up to 70 percent of these infants will no longer test positive. U.S. DEPT. OF HEALTH AND HUMAN SVCS., *supra* note 6, at 81. Approximately 25 to 30 percent of these infants will actually be infected with HIV. *Id.*

[70] Kathryn Boockvar, *Beyond Survival: The Procreative Rights of Women With HIV*, 14 B.C. THIRD WORLD L.J. 1, 30 (1994).

[71] *See* Altman, *supra* note 58, and accompanying text.

[72] *See AIDS in Women, supra* note 61.

[73] Weiss, *supra* note 60, at 645.

directive is not necessary.[74] Furthermore, in a federal study involving 477 pregnant women infected with HIV, half the women were given AZT[75] and the other half a placebo.[76] Researchers found that just 8.3 percent of the babies born to the women who took AZT were infected with the virus, while 25.5 percent of the babies born to those women taking placebos were infected.[77] Based largely on the results of this study, the CDC issued new recommendations and guidelines in July 1995 that advocated HIV counseling for all pregnant women by their health care providers and voluntary testing of pregnant women and their infants based upon their informed consent.[78]

The blinded New York State newborn HIV seroprevalence study was "designed for the collection of aggregate numbers to create an epidemiological database only."[79] Furthermore, antibody tests,[80] while

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[74] *See supra* note 12, and accompanying text, indicating the rate of maternal-fetal transmission is no more than forty-five percent and possibly as low as twelve percent; *see also Fewer Infants Acquire AIDS From Mothers*, N.Y. TIMES, Nov. 22, 1996, at A16 (reporting that a study by the CDC has shown that ninety percent of children with AIDS were infected prenatally, but that this number is decreasing).

[75] *See* PHYSICIAN'S DESK REFERENCE 802 (49th ed. 1995) (defining Zidovudine (AZT) as an anti-viral medication that operates by inhibiting the replication of HIV within the body).

[76] Provisional Committee on Pediatric AIDS, *Perinatal Human Immunodeficiency Virus Testing*, 95 PEDIATRICS 303, 304 (Feb. 1995); *see also* Gina Kolata, *Discovery That AIDS Can Be Prevented in Babies Raises Debate on Mandatory Testing*, N.Y. TIMES, Nov. 3, 1994, at B14.

[77] *See* Kolata, *supra* note 76.

[78] *See CDC-U.S. Health Service Recommendations, supra* note 9, at 8-11.

[79] *See* A.A.C. SUBCOMMITTEE REPORT, *supra* note 2, at 3 (stating that the survey is "an epidemiological research study, not a public health screening program"); *see also* John G. Boyce, *Letters to the Editor-Encourage Pregnant Women to be Tested for HIV*, NEWSDAY, June 30, 1993, at A43 (stating that it is estimated that currently not all infants in New York State are even tested due to inadequate specimen collections, and advocating the prenatal period as the appropriate time for medical intervention to decrease the transmission of HIV from mother to child).

[80] *See* U.S. DEPT. OF HEALTH & HUMAN SVCS., *supra* note 6, at 140. Antibodies are "proteins in the blood or secretory fluids that tag and help remove or neutralize bacteria, viruses, and other harmful toxins." *Id.* Antibodies are "members of a class of proteins

appropriate for adults, are not accurate indicators of the HIV infection in infants until they are fifteen to eighteen months old.[81] Therefore, it would be inappropriate to inform mothers of the results of these inconclusive tests.[82] There are several tests currently being developed and evaluated which are expected to be able to diagnose HIV infection earlier in infants, however, these tests are not yet available for ordinary clinical use.[83] Other tests that are currently available for early diagnosis of HIV infection in infants include viral cultures,[84] polymerase chain reaction (PCR)[85] and Immunoglobulin G (IgG).[86] However, these tests also are not yet able to accurately diagnose HIV infection in infants until months after they are born and, furthermore, they are expensive to perform.[87]

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known as immunoglobulins, which are produced and secreted by B-lymphocytes in response to stimulation by antigens," and an antigen is "any foreign substance that evokes an immune response when introduced into the body." *Id.*

[81] *See Polymerase Chain Reaction in Children with HIV Infection*, AM. FAM. PHYSICIAN 2371 (1992) (stating that children born to HIV infected mothers may retain maternal antibodies for up to 15 months thereby "making diagnosis by conventional antibody based enzyme-linked immunoabsorbent assay (ELISA) or Western Blot techniques unreliable").

[82] *See* Anna Quindlen, *The Baby Bill-But What About the Mothers*, N.Y. TIMES, June 8, 1994, at A25 (stating that all "infants whose mothers are HIV positive initially test positive . . . [however] . . . perhaps 80 percent will eventually be HIV negative").

[83] *See* U.S. DEPT. OF HEALTH AND HUMAN SVCS., *supra* note 6, at 85.

[84] *Id.* at 83 (stating that viral cultures "remain the standard test for diagnosis of HIV infection in early infancy" and should be repeated over time to confirm any diagnosis).

[85] *Id.* at 150. PCR is "a laboratory technique that employs molecular biology technology to identify the nucleic acid sequence of HIV in the cells of an infected individual . . . that is a useful technique for early detection of perinatally infected infants." *Id.*; *see also Polymerase Chain Reaction in Children with HIV*, *supra* note 81, at 2371 (concluding that PCR is a reliable HIV test for infants and encouraging repeated testing over time).

[86] U.S. DEPT. OF HEALTH & HUMAN SVCS., *supra* note 6, at 146. IgG is "a protein produced by plasma cells derived from B-lymphocytes and found in the blood and other body tissues." *Id.* Increased levels are found in persons with HIV infection and this particular protein crosses the placenta, unlike other proteins which do not. *Id.*

[87] *Id.* at 83-84.

III. Mandatory Testing

Several states have enacted legislation requiring the mandatory testing of childbearing women for HIV.[88] Opponents of mandatory HIV testing programs argue that "mandatory testing proposals have arisen largely as a public response, characterized by fear, frustration and anger at the disease itself, and at those who have been infected."[89] Mandatory HIV testing policies aimed at newborns are especially troublesome because, as stated above, such tests only definitively reveal a mother's antibody status.[90] The two tests that are currently used to detect HIV antibodies are a screening ELISA[91] and a confirmatory Western Blot analysis.[92] Because the ELISA test lacks specificity and can result in positive reactions in persons who are not infected with the virus ("false positives"), a Western Blot test is performed as the confirmatory testing

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[88] Sangree, *supra* note 62, at 356-57 (stating that both "Florida and Delaware require that all pregnant women be tested for HIV regardless of their consent"). Both states require prenatal blood testing for sexually transmissible diseases (DEL. CODE ANN. tit. 16, § 711 (1992 & Supp. 1996), FLA. STAT. ANN. § 384.31 (West 1992 & Supp. 1997), and both states include HIV in their definitions of a sexually transmitted disease (DEL. CODE ANN. tit. 16 § 1202 (c)(5) (1993 & Supp. 1996), FLA. STAT. ANN. § 384.23 (West 1993 & Supp. 1997)). *But see* New York State Soc. of Surgeons v. Axelrod, 77 N.Y.2d 677 (N.Y. 1991) (upholding the New York State Health Commissioner's decision not to define HIV as a sexually transmissible disease subject to contact tracing and mandatory testing).

[89] Eisenstat, *supra* note 53, at 327.

[90] *See* U.S. DEPT. OF HEALTH & HUMAN SVCS., *supra* note 6, and accompanying text (stating that although every infant born to an HIV positive woman will carry the HIV antibody up to the eighteenth month of life, with a median time of ten months, only approximately twenty-five to thirty percent, or perhaps even less, will actually develop HIV).

[91] New York State Bar Ass'n., *Report of the Special Committee on AIDS and the Law*, at 17 (Oct. 1993) (hereinafter *N.Y.S. Bar Assn. Report*) (describing ELISA, or enzyme-linked immunoabsorbent assay, as "a test in which viral proteins (antigens) from disrupted viral particles are attached to a solid matrix. Antibodies, if present in the serum of a patient, attach to the virus proteins and are then detected by other reagents"); *see also* AIDS LAW AND POLICY 29 (Arthur L. Leonard et al., eds. 1995).

[92] *Id.* ("[I]n the Western Blot procedure, the viral proteins are purified and separated before the serum is added, so binding to specific proteins can be identified. A positive Western Blot is usually defined by the presence of multiple reactions.").

method.[93] As stated in Section II, several tests have recently been developed that can determine, at an earlier point in time, whether a newborn is actually infected with HIV, although still not reliably until several months after birth.[94]

Proponents of mandatory newborn testing argue that it is vital to test all newborns so that proper medical treatment may be administered immediately to those infants testing positive for HIV.[95] Such treatment includes the administering of AZT as well as prophylaxis treatment of pneumocystis carinii pneumonia (PCP).[96] However, medical professionals have found that AZT can actually produce some "severe toxic effects."[97] Because there is currently no accurate testing method that will reliably demonstrate the presence of the HIV infection in newborns,[98] nor a treatment available that will cure or prevent the occurrence of HIV in newborns,[99] it seems absurd to legislate mandatory disclosure of a newborn's HIV status based on the argument of the need

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[93] *Id.*

[94] *See* U.S. DEPT. OF HEALTH & HUMAN SVCS., *supra* note 6, at 84-85. These tests include polymerase chain reaction and detection of infant produced, HIV specific antibodies of the IgA and/or the IgM classes. *Id.*

[95] *See* A.4413, and accompanying memorandum in support; *see also* notes 18-26, and accompanying text.

[96] *CDC-U.S. Public Health Services Recommendations*, *supra* note 9, at 5 (stating that "PCP is the most common opportunistic infection in children with AIDS and is often fatal").

[97] Martha A. Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402, 427 (citing a study in the New England Journal of Medicine that found "AZT . . . treatment-associated toxic effects, including nausea, headaches, myalgins and anemia"); *see also* U.S. DEPT. OF HEALTH & HUMAN SVCS., *supra* note 6, at 89 (stating that some of the toxic effects seen include anemia, neutropenia, neuropathy/myopathy, headaches and hyperactivity); *see also* Naber and Johnson, *supra* note 3, at 63 (stating that "currently physicians are reluctant to treat newborns who merely show the presence of their mother's HIV antibody because of the serious side effects of anti-AIDS drugs").

[98] *See supra* notes 81-93, and accompanying text.

[99] *See* Leonardo Renna, Note, *New York State's Proposal to Unblind HIV Testing for Newborns: A Necessary Step in Addressing a Critical Problem*, 60 BROOK. L. REV. 407, 415-17 (1994) (stating that "[a]lthough there is as yet no cure for HIV, there are a variety of treatments today that will enhance the length and quality of an infected child's life").

for immediate treatment.[100] However, since there has been success in reducing the transmission rate of HIV perinatally,[101] it seems more appropriate for the legislature to focus on funding prenatal HIV education and counseling programs, as well as programs in which pregnant women with HIV are given the opportunity to receive AZT, in order to reduce the transmission rate from mother-to-child.[102]

A. Informed Consent

The premise behind the concept of informed consent is to allow individuals to exercise their free will in making important decisions regarding their medical treatment and care.[103] Most states follow the common law doctrine of informed consent, thus requiring consent which is "knowing, voluntary and competent," before the administration of health care or the performance of medical testing.[104] In fact, the Supreme Court in *Cruzan v. Director, Mo. Dept. of Health*[105] held that the right to make one's own medical decisions is protected by the Constitution,[106] and that "the notion of bodily integrity has been embodied in the requirement that informed consent is generally required for medical treatment."[107]

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[100] *But see Fewer Infants Acquire AIDS from Mothers*, *supra* note 74 (stating that HIV positive mothers who take AZT reduce the chances of transmitting HIV to their babies).

[101] *See supra* note 69-74, and accompanying text.

[102] *See Perinatal Human Immunodeficiency Virus Testing*, *supra* note 76, at 306.

[103] Sangree, *supra* note 62, at 364; Field, *supra* note 97, at 407.

[104] Sangree, *supra* note 62, at 362.

[105] 497 U.S. 261 (1990).

[106] *Id.* at 278 (1990) ("[A] constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.").

[107] *Id.* at 270 (holding that "the logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment"); *see also in re* A.C., 573 A.2d 1235, 1244 (D.C. 1990). The court held that a mother could not be compelled to undergo a Caesarean section for the benefit of her unborn baby without her

Because of the significance of the information revealed through HIV testing, thirty states have enacted statutes requiring that physicians obtain specific informed consent before performing an HIV antibody test.[108] Several of the leading healthcare organizations in the United States agree that specific informed consent must be procured before testing for HIV.[109] Because the law generally "regards children as incompetent to consent to decisions on medical treatment, and grants decision making authority to someone else, usually the parent[s] or legal

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consent because "the right to accept or forego medical treatment is of constitutional magnitude." *Id.* at 1237.

[108] Sangree, *supra* note 62, at 367, 446. In fact, it has been argued that the "psychological impact of learning that one is HIV-positive has been compared to receiving a death sentence." *Roe*, 526 N.Y.S.2d at 722.

The following states have enacted statutes which require informed consent prior to conducting an HIV antibody test: ALA. CODE SEC. 22-11A-51 (1991 & Supp. 1996), ARIZ. REV. STAT. ANN. § 366-663 (1993 & Supp. 1996), CAL. HEALTH & SAFETY CODE § 199.22 (West 1990 & Supp. 1997), CONN. GE. STAT. ANN. § 19a-582 (West 1993 & Supp. 1996), DEL. CODE ANN. tit. 16, § 1202 (1995), D.C. CODE ANN. § 35-226 (1993 & Supp. 1996), FLA. STAT. ANN. § 381.004 (West 1993 & Supp. 1997), ILL. STAT. ANN. ch. 1111/2 para. 7304 (Smith-Hurd 1991 & Supp. 1996), IND. CODE ANN. § 16-1-9.5-2.5 (Burns 1993 & Supp. 1996), LA. REV. STAT. ANN. § 40:1 300.13 (West 1992 & Supp. 1997), ME. REV. STAT. ANN. tit. 5, § 19203-A (West 1989 & Supp. 1996), MD. HEALTH-GEN. LAWS ANN. § 18-336 (b) (1) (1989), MASS. GEN. LAWS ANN. ch. 111, § 70F (West 1992), MICH. COMP. LAWS ANN. § 333.5133 (2) (West Supp. 1991), MINN. STAT. ANN. § 144.765 (West 1989 & Supp. 1997), MISS. CODE ANN. § 41-41-16 (1993), MONT. CODE ANN. § 50-16-1007 (1995), N.H. REV. STAT. ANN. § 141-F:5 (1993), N.M. STAT. ANN. § 24-2B-2 (Michie 1996), N.Y. PUB. HEALTH LAW § 2781 (McKinney 1996), N.D. CENT. CODE 23-07.5-01,-02 (1991 & Supp. 1995), OHIO REV. CODE ANN. § 3701.242 (Baldwin Supp. 1995), OR. REV. STAT. §§ 433.045, 433.075 (1995), PA. STAT. ANN. tit. 35, § 7605 (a), § 7606, § 7608 (Supp. 1993), R.I. GEN. LAWS § 23-6-12 (1996), TEX. HEALTH & SAFETY CODE ANN. § 81.105 (West 1992), VT. STAT. ANN. tit. 18, § 1128(a) (1996), VA. CODE ANN. § 32.1-37.2 (Michie 1992 & Supp. 1996), W. VA. CODE § 16-3C-2 (1995), WIS. STAT. ANN. § 146.025 (2) (West Supp. 1991).

[109] Sangree, *supra* note 62, at 368. The American Public Health Association, the American Medical Association Center on Children and the Law, and the National Academy of Science's National Institute of Health have advocated this procurement. *Id.*

guardian,"[110] it should be left up to a mother to decide, for her child, whether the HIV screening test should be administered and the results revealed.[111] No mother should be *forced* to learn the results of an inconclusive test that has been performed on her child without her consent.

The New York statutes related to HIV testing provide that no person shall order the performance of an HIV-related test without first receiving the written, informed consent of the test subject who must have capacity to consent.[112] When the person lacks capacity to consent, a person who is authorized by law to give such consent must do so before the testing can be done.[113] This statute further provides that the results of such test shall be confidential and shall not be subject to disclosure except under the most limited circumstances.[114]

The preference in New York State for voluntary, as opposed to coercive, measures to control the spread of HIV was supported by the holding in *New York State Society of Surgeons v. Axelrod.*[115] In that case, the New York State Court of Appeals concluded that the Health Commissioner's decision not to designate HIV as a communicable

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[110] Sharon Rennert, *AIDS/HIV and Confidentiality-Model Policies and Procedures*, A.B.A. COMM'N. ON THE MENTALLY DISABLED AND CTR. ON CHILDREN & THE LAW (1991).

[111] *Id.* See Matter of Hofbauer, 393 N.E.2d 1009, 1013 (N.Y. 1989) (holding that "great deference must be accorded to a parent's choice as to mode of medical treatment to be undertaken and the physician selected"); Matter of Corey L. v. Martin L, 380 N.E.2d 266, 271 (N.Y. 1978) (holding that the "filial bond is one of the strongest, yet most delicate, and inviolable of all relationships"); Prince v. Massachusetts, 321 U.S. 158, 165 (1944) (holding "that the custody, care and nurture of the child reside first in the parents").

[112] N.Y. PUB. HEALTH LAW § 2781(1) (McKinney 1996).

[113] *Id.*

[114] *Id.* at (2)(c); *see also Roe,* 526 N.Y.S.2d at 725 (holding that involuntary testing for the AIDS virus could only be ordered in civil litigation upon "the most stringent test—that is, a showing of compelling need").

[115] 572 N.Y.S.2d 605, 608 (N.Y. 1991) (upholding the Commissioner of the Health and State Public Health Council's decision not to designate HIV as a sexually transmitted disease, because such a designation would have triggered mandatory reporting, contact tracing, isolation, quarantine and patient testing).

disease was a rational public health policy based on the concern by the Commissioner that mandatory testing and contact tracing would discourage infected persons from cooperating with public health officials.[116] The decision to treat HIV differently from other diseases results from the "discrimination, stigmatization and hysteria" HIV infected individuals face.[117] However, the enactment of the AIDS Baby Bill has removed the protection of New York's long-standing informed consent requirement prior to HIV testing of postpartum women and newborns because the bill contains a provision stating that consent will no longer be required when a newborn is tested.[118]

B. Newborn Screening Programs

Screening programs aimed at the detection of diseases in newborns are not a recent development.[119] In fact, over the past thirty years, various newborn screening programs have been developed after careful consideration of the legal, medical, scientific and social policy implications associated with the development of such programs.[120]

> There are generally five criteria to be satisfied before a disease is considered appropriate for newborn screening: (1) the disease must be well-defined and serious

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[116] *Id.* at 609.

[117] *Roe*, 526 N.Y.S.2d at 726.

[118] Raymond Hernandez, *Parents to be Told HIV Status of Newborns*, N.Y. TIMES, June 27, 1996, at B5; *see also* N.Y. PUB. HEALTH LAW. § 2781(6)(d) (stating that the requirement of informed consent prior to HIV testing embodied in section 2781 shall not apply to newborn HIV testing).

[119] Naber & Johnson, *supra* note 3, at 56; *see also* Katherine L. Acuff and Ruth R. Faden, *A History of Prenatal and Newborn Screening Programs: Lessons for the Future, in AIDS*, WOMEN AND THE NEXT GENERATION 59 (Ruth R. Faden et. al., eds. 1991).

[120] Naber & Johnson, *supra* note 3, at 55.

> enough to justify mass screening; (2) there must be an accurate testing method available; (3) the cost of the test must be reasonable; (4) there must be available treatment for the disorder; and (5) there must be adequate medical management facilities to refer infants for confirmatory diagnosis and treatment.[121]

The mandatory testing of newborns for HIV explicitly fails to satisfy several of these criterion. First, there is currently no testing method available that can detect HIV in newborns with 100 percent accuracy and it is unclear what the cost would be if an accurate test were developed.[122] Second, there is currently no treatment available that effectively prevents occurrence of the disease in newborns.[123] Finally, New York lacks adequate medical management facilities to refer infants for confirmatory diagnosis and treatment of the many opportunistic infections that accompany HIV, the majority of whom are born to indigent mothers.[124]

In New York State, newborns are routinely screened for seven diseases at birth:[125] phenylketonuria (PKU),[126] branched chain

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[121] *Id.* at 57.

[122] *See* U.S. DEPT. OF HEALTH & HUMAN SVCS., *supra* note 6, at 83-85.

[123] *See* Field, *supra* note 97, at 427. Prophylaxis treatments merely help to prevent PCP, the most lethal complication of pediatric AIDS. *Id.* However, this treatment fails to prevent HIV from progressing to full blown AIDS. *Id. But See* Renna *supra* note 99, at 415-17 (stating that "although there is [currently] no cure for HIV infection, there are a variety of treatments today that will [prolong] the [length] and quality of life of an infected child").

[124] Sangree, *supra* note 62, at 314 (discussing that because the majority of HIV infected babies are born to indigent mothers, this results in an economic burden on the state where they reside).

[125] N.Y. PUB. HEALTH LAW § 2500-a (McKinney 1994 & Supp. 1996).

ketonuria,[127] homocystinuria,[128] galactosemia,[129] homozygous sickle cell disease,[130] hypothyroidism,[131] and biotinidase deficiency.[132] In addition, tests to detect hepatitis B and syphilis are performed at a pregnant woman's first prenatal examination and, if a woman has not had prenatal care, such testing is performed at the time that she gives birth.[133] However, the presence of syphilis and hepatitis B in a newborn is distinguishable from the presence of HIV in a newborn in that effective treatments exist to prevent the child from ultimately developing either

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[126] PKU is a congenital deficiency of phenylalanine 4-monooxygenase causing inadequate formation of tyrosine, elevation of serum phenylalanine, urinary excretion of phenylpyruvic acid, and accumulation of phenylalanine and its metabolites that produce brain damage resulting in severe mental retardation, often with seizures, and other neurologic abnormalities. STEDMAN'S MEDICAL DICTIONARY 1185 (25th ed. 1990).

[127] Branched Chain Ketonuria is called the maple syrup urine disease. *Id.* at 824. Ketonuria is an enhanced urinary excretion of Ketone bodies. *Id.*

[128] Homocystinuria is a disorder characterized by excretion of homocystine in urine, mental retardation, ectopia lentis, sparse blond hair, genu valgum, convulsive tendency, failure to thrive, thromboembolic episodes, and fatty changes of liver. *Id.* at 722.

[129] Galactosemia is an inborn error of galactose metabolism due to a congenital enzyme deficiency; patients exhibit nutritional failure, hepatosplenomegaly with cirrhosis, cataracts, mental retardation, etc. *Id.* at 620.

[130] Sickle cell anemia is called crescent cell anemia. *Id.* at 74. It is an inherited anemia characterized by the presence of crescent or sickle-shaped erythrocytes and by accelerated hemolysis, due to substitution of a single amino acid in the sixth position of the beta chain of hemoglobin. *Id.* Homozygous means having identical genes at one or more paved loci in homologous chromosomes. *Id.* at 723.

[131] Hypothyroidism is characterized by a diminished production of thyroid hormone leading to thyroid insufficiency. STEDMAN'S MEDICAL DICTIONARY 755.

[132] Biotinidase deficiency is an insufficient amount of the enzyme that catalyzes the hydrolises of biotin amide, biocytin, and other compounds of biotin to biotin. *Id.* at 188; *see also Prenatal/Newborn HIV Testing*, *supra* note 15, at 427 (stating that these diseases all have "serious medical consequences" if left undiagnosed and untreated; and that these diseases are distinguishable from HIV in that there are diagnostic tests available to reliably detect them, and that "early diagnosis and/or treatment offers the promise of significantly improving the infant's condition").

[133] *Id.* at 430 (stating that testing for syphilis and hepatitis B at the time of birth are usually performed on a sample of blood taken from the umbilical cord).

syphilis or hepatitis B.[134] Many leading AIDS experts and organizations, and most state and local health departments, including New York's, oppose mandatory, involuntary testing for HIV.[135] In fact, the National Academy of Sciences' Institute of Medicine has argued that "routine screening of newborns is unjustified because the tests are inconclusive in newborns and . . . because using newborn HIV screening to identify infected mothers would . . . mean that postpartum women would currently be the only civilian, non-institutionalized adult population not given the opportunity to consent or refuse HIV testing."[136] Moreover, many HIV health care experts contend that voluntary counseling and education programs are more effective in combatting the spread of AIDS than coercive measures.[137]

Based on the results of the federal study involving the administration of AZT to HIV infected pregnant women,[138] which revealed that the risk of transmission from mother to child was reduced by almost 70 percent for those women who took AZT prenatally,[139] it is clear that the prenatal period should be the focus of medical intervention in the form of counseling, education and AZT treatment programs for

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[134] *Id.*

[135] *See* Naber & Johnson, *supra* note 3, at 63-64 (discussing the positions of the National Academy of Sciences' Institute of Medicine and the American Academy of Pediatrics Task Force on Pediatric AIDS that informed consent should be obtained prior to newborn HIV screening); *see also* Sangree, *supra* note 62, at 368 (stating that such organizations include the American Public Health Association, the American Medical Association Commission on the Mentally Disabled, the American Medical Association Center on Children and the Law and the National Academy of Science Institute of Medicine). *See* Sangree, *supra* note 62, at 367, 447 (listing all of the states that have informed consent requirements for HIV testing). *Roe*, 526 N.Y.S.2d at 721 (stating that the New York State Department of Health opposes mandatory, non-voluntary testing for HIV).

[136] Naber & Johnson, *supra* note 3, at 63.

[137] *See* Sangree, *supra* note 62, at 335-36; *see also* Larry Gostin, *The Politics of AIDS: Compulsory State Powers, Public Health, and Civil Liberties*, 49 OHIO ST. L.J., 1017, 1019 (1989); *Perinatal Human Immunodeficiency Virus Testing*, *supra* note 76, at 306; *U.S. Public Health Service-CDC Recommendations*, *supra* note 9, at 8-11.

[138] *See supra* notes 78-79, and accompanying text.

[139] *Id.*

HIV-infected women and their newborns.[140] If legislators and public health officials are truly concerned with reducing the rate of perinatal HIV transmission and saving lives, they should focus their efforts and resources on the prenatal period.[141] Further, as stated above, there are distinct benefits to explaining the risks of perinatal HIV transmission in the context of counseling and education, as opposed to the reporting of an inaccurate statistical finding, received too late to prevent the transmission of the HIV infection, as the AIDS Baby Bill requires.[142]

New York State has undertaken two successful voluntary prenatal HIV testing programs[143] resulting in approximately 46 percent of HIV-infected pregnant women learning their HIV status prior to delivery,[144] with rates as high as 90 percent achieved at Harlem Hospital Center.[145] These studies indicate that women who are properly educated and counseled regarding the transmission of HIV to their children are willing to learn their HIV status.[146] Further, given the success of AZT during pregnancy in reducing the rate of perinatal transmission,[147] it stands to reason that if pregnant women are educated and counseled regarding this benefit and are given the opportunity to partake in AZT treatment programs during their pregnancy, more women will opt to

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[140] *Id.*

[141] *See Perinatal Human Immunodeficiency Virus Testing*, *supra* note 76, at 306.

[142] *See, e.g.*, Geoffrey F. Proud, *Encourage Pregnant Women to be Tested for HIV—Letters to the Editor*, NEWSDAY, June 30, 1994, at A43.

[143] *See* A.A.C. SUBCOMMITTEE REPORT, *supra* note 2, at 31-32 (these programs are called the Obstetrical Initiative and the Prenatal Care Assistance Program).

[144] *Id.* at 31-32.

[145] *Id.*

[146] *Id.*; *see also* Kevin J. Curnin, Note, *Newborn HIV Screening and New York Assembly Bill No. 6747-B: Privacy and Equal Protection of Women*, 21 FORDHAM URB. L.J. 857, 895 (1994) (citing a study conducted at John Hopkins University that found acceptance rates for voluntary HIV testing by pregnant women of 96 percent in hospitals and 85 percent in clinics in Baltimore).

[147] *See supra* notes 78-79 and accompanying text.

learn their HIV status during pregnancy, when knowledge of such status and treatment with AZT can have a real impact on reducing the rate of transmission of this disease to their newborns.

The AIDS Baby Bill does not address the issue of *prenatal* counseling and education regarding risk behaviors associated with transmission, nor does it address the issue of treatment with AZT during pregnancy to prevent the transmission of the disease altogether.[148] In contrast, the Tully bill[149] required extensive and mandatory prenatal counseling to encourage pregnant women to be tested for HIV before giving birth, but did not mandate testing at any time, and further provided that if a woman had not received any prenatal care, she was to receive HIV-related counseling when she came to the hospital to give birth.[150]

C. Arguments Surrounding Mandatory Disclosure of HIV Test Results

Before a state legislates the mandatory disclosure of the HIV status of a woman and her newborn, there must be a compelling interest in such disclosure, and this interest must be significant enough to outweigh the mother's right to refuse to submit to such testing.[151] Interests articulated for mandatory HIV testing include tracking the incidence of the disease and preventing its transmission. States

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[148] *See* N.Y. PUB. HEALTH LAW § 2500-f (McKinney 1996) (discussing a "comprehensive program for the testing of newborns for HIV" and that the Commissioner of Health "promulgate regulations governing the administration of testing, counseling, tracking, disclosure of test results . . . follow-up reviews and educational activities relating to such testing").

[149] New York State Senate Bill No. 6775-A (1994).

[150] *Prenatal/Newborn HIV Testing*, *supra* note 15, at 423.

[151] *See* Sangree, *supra* note 62, at 440 (stating that the Fourth Amendment only permits mandatory HIV testing when state interests clearly outweigh an individual's privacy interests).

interested in tracking the incidence of HIV infection among women and their children, for statistical purposes and in order to make programmatic funding decisions, can do so in an anonymous manner by removing all personal identifiers.[152] Therefore, this would not represent a reason so compelling as to outweigh a mother's privacy interests.

The governmental interest of reducing perinatal HIV transmission is not furthered by a legislative scheme mandating involuntary HIV testing of newborns.[153] "Mandatory testing of newborns represents an infringement upon the fundamental rights of the mother, which can be justified only by evidence that the testing will result in therapy of substantive benefit to the newborn."[154] Moreover, other less intrusive measures may be more successful at reducing HIV transmission.[155] Such measures include counseling, education, voluntary testing and prenatal AZT treatment programs, all of which should be made widely available.[156] Women testing positive should be counseled regarding the significance of an HIV diagnosis and informed of the options available to them to help reduce the risk of transmitting the disease to their children (i.e., AZT treatment during pregnancy).[157] A further argument against imposing testing on particular groups, such as pregnant women and their newborns, is that it may drive women who do not wish to know their HIV status away from much needed medical

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[152] *See, e.g.*, A.C.C. SUBCOMMITTEE REPORT, *supra* note 2 (the seroprevalence study is an excellent example of an anonymous tool for measuring the incidence of HIV infection in women and their newborns).

[153] *See* Eisenstat, *supra* note 53, at 365 (stating that "the governmental interests ostensibly served by mandatory testing are in fact not furthered by such testing").

[154] *Prenatal/Newborn HIV Testing*, *supra* note 15, at 446 (stating that this evidence does not currently exist with regard to HIV infected newborns).

[155] *See* Eisenstat, *supra* note 53, at 355-56 (stating that education and counseling, along with the promise of AZT treatments, will likely encourage many individuals to consent to the test and enlist their further cooperation).

[156] *See Perinatal Human Immunodeficiency Virus Testing*, *supra* note 76, at 306 (recommending various methods to reduce HIV transmission).

[157] *Id.*

care.[158]

It has also been argued by some that "mandatory testing eviscerates a woman's right to make her own medical decisions and medical decisions concerning her newborn, and requires instead that she submit to medical decisions made by the state."[159] Currently, no compelling reason exists that justifies mandating the infringement of a mother's right to decide when and if she must learn her HIV status and that of her newborn.

As this section illustrates, any legislative scheme aimed at mandatory testing, as opposed to counseling, education and voluntary testing, has the potential for forcing women away from much needed medical care at a critical stage.[160] Furthermore, "when a program both fails to effectuate the purpose which underlies its implementation, and simultaneously invades significantly upon the privacy of the individuals it affects, the program is not rational and should not be adopted."[161] For the reasons stated above, allowing women to make an informed and educated choice regarding learning their HIV status and that of their child is better public policy than forcing their HIV results on them. This would also more effectively further the goal of reducing the rate of perinatal HIV infection.

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[158] *See* Field, *supra* note 97, at 422 (noting that "[i]f 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"); *see also Perinatal Human Immunodeficiency Virus Testing*, *supra* note 76, at 305 (stating that "in several settings in which HIV counseling and *voluntary* testing have been routinely offered to all prenatal patients, no measurable decrease in women seeking prenatal care has been observed") (emphasis added).

[159] Field, *supra* note 97, at 412.

[160] *See* Eisenstat, *supra* note 53, at 342 (stating that mandatory testing programs, absent informed consent, run the risk of reducing the patient's cooperation which, in turn, reduces the testing program's effectiveness in preventing further HIV transmission).

[161] *Id.* at 365.

III. Legal and Constitutional Issues Surrounding Mandatory HIV Testing

A. Privacy

The Constitution has been interpreted as conferring on individuals a fundamental right to privacy in landmark cases such as *Griswold v. Connecticut*[162] and *Roe v. Wade*.[163] In addition, the Supreme Court has held that the decision to have a child is a fundamental right subject to protection.[164] Therefore it could be inferred that a legislative scheme mandating the testing of newborns for HIV, thus revealing their mother's status, "would invoke the fundamental right to privacy because [such] testing would be triggered by a woman's decision to have a child."[165] Although judicial deference is usually given to statutes intended to protect the health and welfare of the citizenry,[166] a public health statute would not be upheld if it is found that such statute fails to advance the goal underlying its enactment.[167]

> If the legislature, in the interests of public health, enacts a law, and thereby interferes with the personal rights of

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[162] 381 U.S. 479, 495 (1965) (holding that specific guarantees in the Bill of Rights have penumbras formed by emanations from those guarantees that help give them life and substance creating guaranteed zones of privacy).

[163] 410 U.S. 113, 152 (1973) (holding that the right of personal privacy or guarantee of certain areas or zones of privacy exists under the Constitution).

[164] *See* Boockvar, *supra* note 70, at 22 (citing Carey v. Population Svcs. Int'l, 431 U.S. 678, 686 (1977)) (holding that the ability to decide whether to "bear or beget" a child is a fundamental right); *see also* Cleveland Bd. of Educ. v. LaFleur, 414 U.S. 632, 639-40 (1974) (holding that the freedom of personal choice in family matters is protected by the Due Process Clause of the Fourteenth Amendment).

[165] Sangree, *supra* note 62, at 415.

[166] *See* Eisenstat, *supra* note 53, at 339; *see also* Michigan Dep't of State Police v. Sitz, 496 U.S. 444 (1990)

[167] Eisenstat, *supra* note 53, at 339.

> an individual, destroys or impairs his liberty or property—it then under such circumstances, becomes the duty of the courts to review such legislation, and determine whether it in reality relates to, and is appropriate to secure the object in view; and in such an examination the court will look to the significance of the testing, and will not be controlled by mere forms.[168]

The violation of a fundamental right as a result of a legislative enactment cannot be justified unless the government can establish that there exists a compelling state interest, and that the legislative scheme enacted is the least intrusive and restrictive means for doing so.[169] It would appear that the state interest underlying the testing of newborns for HIV would include preventing the spread of the disease and ensuring treatment for those infected.[170] However, mandatory testing of newborns neither prevents nor cures AIDS in a tested newborn or its mother[171] and, further, the AIDS Baby Bill fails to allocate sufficient funding to ensure adequate care and treatment for those testing HIV positive.[172] Therefore, the AIDS Baby Bill explicitly fails to further the legitimate state interest of preventing the spread of AIDS.

Further, a statute affecting a fundamental right will only be

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[168] *Id.* at 339 (quoting Wong Wai v. Williamson, 103 F.2d 1, 7 (N.D. Cal. 1990)).

[169] Boockvar, *supra* note 70, at 26.

[170] *See* A.4413, and accompanying Memorandum in Support; *see also* Boockvar, *supra* note 70, at 31.

[171] *See* Suzanne M. Malloy, *Mandatory HIV Screening of Newborns: A Proposition Whose Time Has Not Yet Come*, 45 AM. U.L. REV. 1185, 1190 (1996); Maia E. Scott, *Tests for Pediatric AIDS: Are We Failing Our Children?*, 3 VA. J. SOC. POL'Y & L. 217, 238 (1995).

[172] *See* Malloy, *supra* note 171, at 1213 (discussing how legislation that mandates HIV testing will be unsuccessful unless it "bear[s] the burden of demonstrating that a child who tests positive will receive such treatment").

upheld if it can withstand the strict scrutiny test.[173] The factors that must be weighed in determining whether a woman and her newborn's fundamental privacy rights are outweighed by a greater state public health interest include "the availability of effective treatment, prevalence of the disorder, rates of transmission, and severity of the illness."[174] In applying these criteria to the AIDS Baby Bill, it is helpful to consider the following statistics:

> [t]here were 36,325 reported cases of AIDS in women as of June 1993 and a total of 4,121 cases of pediatric AIDS related to a mother with or at risk of HIV infection. It is estimated that 5 to 70 seropositive infants are born per 10,000 births, in other words, approximately 0.05 to 0.7 percent of all babies born to all mothers will become HIV infected. These statistical differences play an important role in determining the balance between public health needs and women's privacy.[175]

These statistics, along with the recent announcement by the CDC that the number of infants contracting AIDS from their mothers declined 27 percent from 1992 to 1995,[176] indicate that the prevalence of HIV in this population and the incidence of perinatal transmission do not appear

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[173] *See* Boockvar, *supra* note 70, at 25; *see also* BLACK'S LAW DICTIONARY 1427 (6th ed. 1992) (defining strict scrutiny as "[a] measure which is found to affect adversely a fundamental right will be subject to 'strict scrutiny' which requires the state to establish that it has a compelling interest justifying the law and that the distinctions created by law are necessary to further some governmental purpose.").

[174] Boockvar, *supra* note 70, at 26.

[175] *Id.* at 29 (stating that the CDC estimates that between 1989 and 1990, 0.15 percent of all childbearing women nationwide were HIV positive); *see also Fewer Infants Acquire AIDS From Mothers*, *supra* note 74.

[176] *See Fewer Infants Acquire AIDS From Mothers*, *supra* note 74.

sufficient to outweigh the mother's privacy interests.[177] Furthermore, because there is no lifesaving treatment or cure currently available, nor any financial commitment by the legislature to appropriate sufficient funding to ensure the care and treatment of HIV-infected newborns and their mothers, the mandatory testing of newborns does not effectuate the goal of preventing the spread of AIDS.[178] Because the public health arguments for mandatory disclosure of a newborn's HIV status are weak, more weight should be given to women's privacy rights.[179] Testing newborns for HIV does not sufficiently address the goal of reducing the transmission of the disease to mandate forced invasion of a woman's privacy rights.

B. Search and Seizure

The current method utilized by New York State for newborn HIV screening involves the collection of a blood specimen from the newborn, usually taken from its umbilical cord.[180] The Supreme Court has determined that an involuntary blood test constitutes a search and

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[177] *See* Ana O. Dumois, *The Case Against Mandatory Newborn Screening for HIV Antibodies*, 20 J. COMMUNITY HEALTH 143 (1995). The Working Group on HIV Testing of Pregnant Women and Newborns issued its report "recogniz[ing] that [the] 'screening of pregnant women raises profound moral, legal and policy issues. . . . In our view, a policy of mandatory screening . . . is not justified in the current situation on traditional public health criteria or other grounds.'" *Id.* at 147.

[178] *But see* Deborah L. Shelton, *Is it Time . . . . (for Mandatory HIV Testing of Pregnant Women)*, 39 AM. MED. NEWS 23, 24 (1996) (stating that the "National Institutes of Health AIDS Clinical Trial Group . . . demonstrated . . . that . . . AZT reduced maternal-fetal HIV transmission by about two-thirds . . . "); *see also* Howard Minkoff & Anne Willoughby, *Pediatric HIV Disease, Zidovudine in Pregnancy, and Unblinding Heelstick Surveys: Reframing the Debate on Prenatal HIV Testing*, 274 JAMA 1165, 1171 (1995) (noting that "75% of the offspring of infected mothers are not and have never been at risk of infection").

[179] *See generally* Curnin, *supra* note 146.

[180] *See* A.A.C. SUBCOMMITTEE REPORT, *supra* note 2, at 4; *see also supra* note 3, and accompanying text.

seizure within the scope of the Fourth Amendment.[181] Therefore, a compelling reason must be shown that warrants disregarding a person's right to be free from bodily intrusion as significant as testing a newborn's blood for HIV, which only definitively reveals its mother's HIV status absent her informed consent.[182]

Most would argue that a state's interest in protecting a child's life and health is always compelling.[183] In determining whether the state's interest may override privacy and liberty interests, "courts generally have considered the following factors: the importance of the competing interest, the seriousness and scope of the restriction, the sensitivity of the information disclosed, and whether the restriction is sufficiently narrowly tailored to meet the compelling state interest."[184] In the situation of HIV testing of newborns and the disclosure of the test results to their mothers, the competing interests are the protection of the child's health and the mother's privacy rights.[185] The information disclosed is as sensitive as it gets,[186] and the newborn HIV testing program is not sufficiently tailored to meet the state's interest in preventing the spread of the disease or in protecting the child's health because it fails to effectuate that goal.[187] As a result, in the context of newborn HIV testing, the state's interest does not outweigh the mother's privacy interests because the HIV testing of newborns is performed too late to achieve the goal of reducing the transmission risk and to have any

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[181] *See* Schmerber v. California, 384 U.S. 757 (1966); Skinner v. Railway Labor Executives' Assn. 489 U.S. 602 (1989).

[182] *Roe*, 526 N.Y.S.2d at 722 (quoting Winston v. Lee, 470 U.S. 753 (1985)).

[183] *Prenatal/Newborn HIV Testing*, *supra* note 15, at 445.

[184] *Id.*

[185] *Id.*

[186] *Roe*, 526 N.Y.S.2d at 722.

[187] *See* Minkoff & Willoughby, *supra* note 178, at 1170 (stating that "[i]f the purpose of mandatory testing is universal perinatal therapy, then treatment as well would have to be mandated [because]. . . taking away maternal rights without ensuring benefits would be illogical and indefensible").

impact in preventing the child from actually developing HIV.

C. Equal Protection

The Equal protection Clause of the U.S. Constitution states that

> [n]o state shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any state deprive any person of life, liberty, or property without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.[188]

The Supreme Court has developed a three-tiered approach to analyzing claims based on equal protection grounds.[189] The Court generally employs its lowest standard of review, that of "mere rationality," when analyzing claims related to economic and social welfare interests.[190] A "middle-tier review" is often applied to cases "involving gender and illegitimacy" with the Court requiring that "an action must be substantially related to the achievement of an important governmental end" to survive this standard of review.[191] Finally, the Court applies "strict scrutiny" to cases involving a "suspect class" or "fundamental right."[192] "[U]nder the strict scrutiny test . . . a compelling state interest

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[188] U.S. CONST. amend XIV.

[189] *See* Weiss, *supra* note 60, at 677 (noting the approach the Court currently uses to analyze equal protection claims).

[190] *Id.*

[191] *Id.* at 677-78.

[192] *Id.*; *see also* BLACK'S LAW DICTIONARY 1427 (6th ed. 1992) (noting that a "[m]easure which is found to affect adversely a fundamental right will be subject to 'strict scrutiny' which requires the state to establish that it has a compelling interest justifying the law and that the distinctions created by law are necessary to further some governmental purpose")

must be achieved through narrowly tailored means."[193]

As stated earlier, the Supreme Court has deemed privacy to be a "fundamental right."[194] The mandatory testing of newborns and resultant disclosure of their mother's HIV status involves fundamental privacy rights that demand the application of strict scrutiny. Application of this test to the AIDS Baby Bill requires the State of New York to show that this legislative scheme is the most narrowly tailored method of furthering the compelling state interest of reducing perinatal AIDS transmission. The State would fail in its effort to satisfy this burden because this legislation does not adequately effectuate the purpose of reducing the rate of perinatal HIV transmission because it is performed too late to achieve this noble goal. Further, more effective approaches to reducing the rate of transmission currently exist that could be implemented by the State including: prenatal education and counseling programs with voluntary testing and a program that offers women the opportunity to take AZT during pregnancy to reduce the risk of transmission to their newborns.[195]

As stated earlier, the National Academy of Sciences' Institute of Medicine has argued that "routine screening of newborns is unjustified because the tests are inconclusive in newborns and . . . because using newborn HIV screening to identify infected mothers would . . . mean that postpartum women would currently be the only, civilian, non-institutionalized adult population not given the opportunity to consent

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(citations omitted).

[193] *See* Curnin, *supra* note 146, at 899 ("Where certain 'fundamental rights' are involved, the Court has held that regulation limiting these rights may be justified only by a 'compelling state interest' and that legislative enactments must be narrowly drawn to express only the legitimate state interest at stake."). (Citing the Court's holding in *Wade*, 410 U.S. at 155).

[194] *See Griswold*, 381 U.S. at 479 (Goldberg, J., concurring) (noting "the right of privacy is a fundamental personal right . . ."); *Wade*, 410 U.S. at 152 (holding that while "the Constitution does not explicitly mention any right of privacy," the Court has recognized the "right of personal privacy" and "zones of privacy" in various cases).

[195] *See* Curnin, *supra* note 146, at 899 (discussing that voluntary programs with counseling successfully avoid the invasion of a woman's privacy right).

or refuse HIV testing."[196] This results in a discriminatory effect on child bearing women and newborns and denies them the equal protection guarantees embodied in the Fourteenth Amendment.[197] Any legislative scheme that results in discrimination against the persons it purports to protect should not be upheld.

IV. Conclusions and Recommendations

The AIDS Baby Bill was clearly not the best approach for the legislature to take if it was truly serious about preventing the transmission of HIV and saving lives. Any mandatory HIV testing program for infants raises numerous legal issues.[198] By revealing the results of the newborn's HIV test, the only information revealed with 100 percent accuracy is the HIV status of the mother.[199] This forced disclosure goes against women's privacy rights and their right to bodily integrity.[200] The effect of this legislation, forcing only childbearing women to learn their HIV status, is discriminatory against all women and particularly minority women who are infected with HIV at greater

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[196] Naber & Johnson, *supra* note 3, at 63.

[197] *See* Curnin, *supra* note 146, at 906 (arguing that "[d]iscrimination predicated on pregnancy for purposes of HIV testing also constitutes a violation of the Equal Protection Clause"); *see also* Thomas Maier, *Doomed By Diagnosis, Study: HIV Babies May Get Less Care*, NEWSDAY, Nov. 13, 1995, at 59 (reporting that a nationwide survey showed that "[b]abies with the AIDS virus may suffer discrimination from doctors once their status is known and may be less likely to get life-saving surgery and medical treatments than other children").

[198] *See supra* Section III (discussing legal issues surrounding mandatory HIV testing).

[199] *See* U.S. DEPT. OF HEALTH AND HUMAN SERVICES, *supra* note 6, at 82 (noting that infants infected with HIV "cannot be differentiated from uninfected infants on the basis of clinical and immunologic parameters," so routing HIV testing should be made part of regular pediatric care). *But see* Field, *supra*, note 97, at 425 (pointing out that most "HIV-infected infants can be identified by the time they are three to six months old").

[200] *See supra* Section III.A.

rates.[201] The negative impact that this legislation will have on women, especially women of racial and ethnic minorities, is extreme. Childbearing women would become the only non-institutionalized persons forced to learn their HIV status.[202]

If a treatment or cure for HIV were available, the State might be able to demonstrate a compelling state interest in identifying these newborns. But currently there is no cure and the only treatment that is available will prevent the infant from developing PCP, but cannot protect the child from succumbing to one of the many other opportunistic infections that strike newborns with HIV.[203] Therefore, the benefits available at this time are simply too tenuous to outweigh the burdens that will be caused by this mandatory newborn HIV testing program.

Finally, and most importantly, the results of the federal study in which AZT was administered to HIV positive pregnant women shows that the focal point in reducing HIV transmission should, and must, be during pregnancy.[204] Thus, testing for HIV after the child is born is just too late to be of any value. The study found that by administering AZT during pregnancy and childbirth, the rate of HIV transmission was reduced from over twenty-five percent down to eight percent.[205] At

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[201] *See* EPIDEMIOLOGY PROGRAM OFFICE, CENTERS FOR DISEASE CONTROL, PUBLIC HEALTH SERV., U.S. DEPT. OF HEALTH AND HUMAN SERVICES, *U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women*, 44 MORBIDITY AND MORTALITY WEEKLY REPORT, at 2 (1995) (explaining that "Blacks and Hispanics have been disproportionately affected by the HIV epidemic").

[202] *See* Naber & Johnson, *supra* note 3, at 63 (noting that routinely conducting HIV screening of newborns would mean that child-bearing women "would be the only civilian, non-institutionalized adult population not given the opportunity to consent to or refuse HIV testing") (citations omitted).

[203] *See* Field, *supra* note 97, at 429 (stating that for newborns who are and are not infected, "access to medical care is by no means guaranteed").

[204] *See Perinatal Human Immunodeficiency Virus Testing*, *supra* note 76, at 304 (noting that there are medical benefits to women and infants of early HIV testing).

[205] *Id.*

present this is the only point at which transmission from mother to child can be prevented. Further, recently released statistics indicate that the rate of perinatal transmission is declining significantly as a result of women taking AZT during pregnancy and delivery.[206] Childbearing women should be educated and counseled regarding the risks of HIV transmission to their babies, and presented with the option of AZT treatment to reduce the probability of transmission. Such education and counseling programs must be sufficiently funded and undertaken by professionals who truly have the best interests of both the mother and child in mind. These programs, administered in conjunction with providing AZT to those pregnant women who request it, will be much more effective in preventing the spread of HIV than the forced disclosure of inconclusive test results, which is exactly what will occur in New York under the AIDS Baby Bill. The enactment of the AIDS Baby Bill has the potential of scaring away pregnant women from seeking much needed prenatal care.[207] Surely this is not the result the New York State legislature desires. If the legislature is truly concerned with reducing the rate of perinatal HIV transmission, it must develop an alternative legislative scheme that adequately funds counseling, educational and prenatal AZT treatment programs.[208] Legislators need to take a proactive rather than a reactive stance. The legislature must take a comprehensive approach to ensuring that HIV positive women are provided with the most effective means to prevent the spread of this

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[206] *See Fewer Infants Acquired AIDS From Mothers*, N.Y. TIMES, *supra* note 74 (stating that the number of newborns who were infected with AIDS from their mothers dropped 27 percent from 1992 to 1995, with the Centers for Disease Control attributing the decrease in HIV-infected women to AZT).

[207] *See supra* note 160, and accompanying text.

[208] *See, e.g.*, Jessie Mangaliman, *Plea For Law on HIV Babies*, NEWSDAY, Apr. 5, 1995, at A39 (discussing that "[t]he state and federal Centers for Disease Control have established guidelines recommending voluntary testing of pregnant women, and the use of AZT . . .").

deadly disease to their unborn children. Otherwise they are just engaging in political posturing and that has never, and will never, save the life of any baby.

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