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NEWBORN HIV SCREENING AND NEW YORK ASSEMBLY BILL NO. 6747-B: PRIVACY AND EQUAL PROTECTION OF PREGNANT WOMEN

I. Introduction

Since its earliest reported cases, already thirteen years ago,[1] the onslaught of the terminal condition known as acquired immunodeficiency syndrome (AIDS) has been relentless. Its worldwide cost cannot be understood through statistics alone; neither the thousands of human lives it has ended[2] nor the millions[3] it has made hopeless fully measure its toll. The AIDS epidemic is doubly fearsome: as it destroys lives and families and defies our medical capacity to provide a cure, it also strains our social capacity to respond to it fairly and effectively. As an ongoing and escalating pubic health disaster, AIDS remains misunderstood, its victims routinely mischaracterized and mistreated. Beyond the profound injury of the condition itself, AIDS victims struggle under the heavy weight of prejudice and fear. As it eludes the best hopes of science and medicine,[4] AIDS therefore raises a host of troubling legal, political, and ethical questions that leave society and its institutions wanting for answers.

Proposed New York Assembly Bill No. 6747-B[5] attempts to answer one of the most urgent problems of the current HIV/AIDS[6]

1. The first cases of what came to be called AIDS were reported in California in June of 1981. *The HIV/AIDS Epidemic: The First Ten Years*, MORBIDITY & MORTALITY WEEKLY REPORT, June 7, 1991, at 357 [hereinafter *The First Ten Years*].

2. As of June 1991, over 113,000 persons were reported to have died of AIDS. This represented almost two-thirds of the total reported cases. *Id.* at 359. AIDS is the second leading cause of death among men aged 25-44 and the fifth leading cause of death among women aged 15-44. *Id.* at 357.

3. The World Health Organization estimates that 8 to 10 million adults and one million children worldwide are HIV infected. *Id.* By the year 2000, 40 million persons may be infected with HIV. *Id.*

4. *See, e.g.*, Erik Eckholm, *HIV Negatives: AIDS Still Immune To the Onslaught of Medical Science*, N.Y. TIMES, Mar. 6, 1994, § IV, at 1.

5. N.Y. A.B. 6747-B (1993). The pertinent language of the bill can be found *infra*, part III.

6. The term "HIV/AIDS" is not used here to describe a specific medical condition, but rather to indicate the complicated spectrum of infection which begins with the HIV virus and ends with full blown AIDS. HIV infection can have a variety of debilitating outcomes, of which AIDS is the ultimate. The virus can be carried for years with no manifest symptoms, or decline can be precipitous. For a more thorough treatment of the complex medical dimensions of AIDS and HIV infection, see PAUL ALBERT ET AL., AIDS PRACTICE MANUAL (3d ed. 1992); MICHAEL CLOSEN ET AL.,

epidemic: pediatric AIDS.[7] The fierce and well-publicized debate it has engendered exposes not only our medical and social shortcomings in responding to the epidemic, but the legal and ethical dilemmas it has created as well.[8]

Pediatric AIDS is a particularly compelling target for legislative action for two reasons. First, children are typically perceived as the most innocent and helpless—and least threatening—of the disease's victims.[9] Second, this subset of the epidemic is among its fastest growing.[10] By the year 2000, twenty million children will be affected by HIV/AIDS.[11] In the United States, urban areas are at the center of this explosion.[12] New York, which accounted for one-third of all pediatric AIDS cases in the 1980's, reported 1,395 cases

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THE AIDS NUTSHELL (1990). The term HIV/AIDS as used in this Note is therefore meant to indicate both the medical and social realities of this "spectrum disease." *See* Ann Kurth & Margaret Hutchison, *Reproductive Health Policy and HIV: Where do Women Fit In?*, 1 PEDIATRIC AIDS AND HIV INFECTION: FETUS TO ADOLESCENT 121 (1990).

7. Pediatric AIDS was first recognized in 1983. Gwendolyn B. Scott et al., *Survival in Children with Perinatally Acquired Human Immunodeficiency Virus Type I Infection*, 321 NEW ENG. J. MED. 1791 (Dec. 28, 1989). Initially associated with general symptoms such as failure to thrive and various recurrent infections, both bacterial and opportunistic, HIV infection in children is now recognized as manifesting a broad array of clinical diseases in multiple systems. *Id.*

8. *See, e.g.*, Peter Hellman, *Suffer the Little Children: The Rising Storm Over the Law that Keeps HIV-Positive Newborns from Early Detection and Treatment*, N.Y. MAG., Feb. 21, 1994, at 26-32; *AIDS Babies Pay the Price*, N.Y. TIMES, Aug. 13, 1993, at A26 (editorial); *Infant's Rights: Give HIV Test Results to Mothers*, N.Y. NEWSDAY, June 10, 1993, at 46 (editorial).

9. For example, Assemblywoman Nettie Mayersohn, the leading proponent of Bill No. 6747-B, has opined that "[c]hildren are the silent, most vulnerable victims of AIDS." James Dao, *Bill Offered on Requiring AIDS Report*, N.Y. TIMES, Mar. 9, 1994, at B6.

10. *A Review of Epidemiologic Trends in HIV Infection of Women and Children*, 1 PEDIATRIC AIDS AND HIV INFECTION: FETUS TO ADOLESCENT 11 (1990). Whereas 95% of adult infection arises from voluntary behavior, pediatric HIV infection is thrust upon the infant. *Id.* An implicit appeal of treating pediatric AIDS is protecting the welfare of uninfected children attending school with and interacting in the community with the infected children.

11. This estimation includes ten million children the World Health Organization projects to be infected with HIV, and another ten million children who will lose one or both parents to AIDS. *The First Ten Years*, *supra* note 1, at 357.

12. Eighty-four percent of the pediatric AIDS cases in the United States occur in metropolitan areas with at least 500,000 people. Hermann Mendez & Jose Ernesto Jule, *Care of the Infant Born Exposed to Human Immunodefiency Virus*, 17 OBSTETRICS & GYNECOLOGY OF N. AMER. 637 (1990). Through the 1980's, New York City accounted for nearly one-third of pediatric AIDS cases nationwide. *See New York State Seroprevalence Project*, 81 AMER. J. PUB. HEALTH 10-11 (May 1991) (special supplement devoted to the New York seroprevalence testing program) [hereinafter *NY Seroprevalence Project*].

through 1993—87% of these in New York City.[13] These figures are expected to increase dramatically in the near future.[14]

Bill No. 6747-B would respond to pediatric AIDS by mandating HIV testing for all babies born in the state and requiring disclosure to all mothers whose babies test positive.[15] The bill's proponents in the legislature, as well as pediatricians, children's rights advocates, and others, argue that advances in medical treatment[16] that improve and prolong the quality of life of HIV-infected children justify an involuntary testing and disclosure mechanism.[17]

But the proposal has met serious opposition.[18] Most of this opposition is predicated on a peculiar feature of current newborn testing techniques: results are actually a more accurate indicator of

13. *Report of the Subcommittee on Newborn HIV Screening of the New York State AIDS Advisory Council* 5 (Feb. 10, 1994) [hereinafter *Newborn Screening Subcommittee Report*].

14. *See infra* notes 44-46 and accompanying text.

15. *See* Mireya Navarro, *Testing Newborns for AIDS Virus Raises Issue of Mothers' Privacy*, N.Y. TIMES, Aug. 8, 1993, at A1; Dao, *supra* note 9, at B6. The program currently in operation in New York state also provides for mandatory testing of newborns, but it is done anonymously and only for purposes of epidemiological research and efficient allocation of resources. *See infra* part III.A. When the term "mandatory testing" is applied to mothers in this Note, the author is referring to the affect of the bill and not its means. Testing would not actually be done directly on the mother. Instead sample blood (containing maternal antibodies) is drawn from the infant, as is done under the current program, but the results therefrom are indicative of the mother's status. *See id.*

16. Discussed *infra* part IVA.2.d.

17. *See* Dao, *supra* note 9, at B6; *see also Dissenting Comments on the Jan. 31, 1994 Report of the Subcommittee on Newborn Screening to the AIDS Advisory Council* (Feb. 4, 1994).

18. The history to date of Bill No. 6747-B is as follows. In June of 1993, Assemblywoman Nettie Mayersohn introduced the bill to the New York State Assembly. *Newborn Screening Subcommittee Report*, *supra* note 13, at 1. Her proposal was tabled, in a 10-9 vote, by the Assembly's Health Committee that month, *see* Navarro, *supra* note 15, at 44, pending the research and recommendations of a subcommittee to be appointed by the New York State AIDS Advisory Council. *Newborn Screening Subcommittee Report*, *supra* note 13, at 1. The Newborn Screening Subcommittee formed thereafter held five public meetings and a public hearing between September and December of 1993. *Id.* at 2. On February 10, 1994, the 24-member Newborn Screening Subcommittee voted, with four dissenters, to reject the proposal, advocating "strongly encourage" voluntary testing instead. *See id.* at iii. The AIDS Advisory Council adopted the subcommittee's recommendations on Feb. 24, 1994. *See* Mireya Navarro, *New York AIDS Panel Encourages Doctors to Test Pregnant Women*, NEW YORK TIMES, Feb. 25, 1994, at A1. Disregarding these recommendations, a bipartisan group of state legislators pressed ahead with Bill No. 6747-B on March 7. *See* Dao, *supra* note 9, at B6. As of the middle of April, the bill was still in Committee, with a vote expected later in the Spring. *Id.* More recently, a competing proposal, which stresses mandatory counseling and voluntary testing, has been introduced. Kevin Sack, *Bill to Require HIV Counseling for Pregnant Women Gains in Albany*, N.Y. TIMES, Apr. 1, 1994, at B5.

the mother's HIV status than the child's.[19] When a newborn tests positive, it means that the mother is HIV-infected, because the virus and its antibodies have been transferred to the newborn from the mother through the placenta sometime during pregnancy.[20] The effect of the bill, therefore is to impose mandatory HIV testing on all parturient[21] women. Currently, there is no compulsory HIV testing in New York for anyone, although federal law provides for testing without consent of federal prisoners, military personnel, and job corps applicants.[22] Bill No. 6747-B would therefore require amending Article 27-F of the New York Public Health Laws,[23] among the strictest AIDS confidentiality statutes in the United States. Put in effect on February 1, 1989, Article 27-F requires informed, written consent for any HIV-related test. Informed consent must be both preceded by personal counseling and followed by further post-test counseling.[24]

Although mandatory testing and disclosure to parturient women raises numerous legal problems,[25] the focus of this Note is limited to the possible infringement of the mother's constitutional rights to privacy and equal protection. Bill No. 6747-B cannot withstand a challenge brought under either Fourteenth Amendment aegis. Well-intentioned, the bill is nevertheless an unconstitutional manipulation of pregnancy as an occasion for invidious, unconstitutional governmental intervention.[26]

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19. *See* Dao, *supra* note 9, at B6; Navarro, supra *note* 15.

20. *See infra* notes 57-60 and accompanying text for a medical description of this process.

21. "Parturient" in this sense means "of or pertaining to giving birth." THE AMERICAN HERITAGE DICTIONARY 906 (2d ed. 1991).

22. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 23.

23. N.Y. PUB. HEALTH LAW art. 27-F (McKinney 1992).

24. *Id.* § 2781(1) ("A physician or other person authorized pursuant to law to order the performance of an HIV related test shall certify, in order for the performance of an HIV related test, that informed consent required by this section has been received prior to ordering such test by a laboratory or other facility.").

25. Among the legal arguments not addressed in this paper are other constitutional issues such as the Fourth Amendment's search and seizure protection and the Fourteenth Amendment's procedural due process protections; federal issues such as the Americans with Disabilities Act; state issues of confidentiality, disclosure, and consent (touched on tangentially), and the Family Court Act; criminal sanctions; and various tort issues such as the duty to disclose, duty to third persons, and child neglect. For a comprehensive treatment of the numerous areas where AIDS and the law intersect, see SCOTT BURRIS ET AL., AIDS LAW TODAY (1992).

26. A constitutional analysis of this issue is particularly important because there are 42 other states (plus Puerto Rico and the District of Columbia) which operate testing programs similar to that currently in place in New York. *See* J.P. Getchell et al., *HIV Screening of Newborns*, 49 BIOCHEM. MED. & METABOLIC BIO. 143, 145 (1993). Each of these states and territories runs a program similar to New York's, in

Part II of this paper briefly discusses the medical background of pediatric AIDS and HIV infection, particularly the epidemiology of HIV/AIDS in women and children. Part III describes New York's current HIV screening program and compares it to the changes proposed under Bill No. 6747-B. Part IV examines privacy issues, specifically infringement of the discrete rights of confidentiality and autonomy, and concludes that both are violated by the bill. Part V, focusing on gender and pregnancy discrimination, presents an equal protection argument likely to be raised against the proposal, and concludes that the bill violates the Equal Protection Clause as well. An alternative proposal—combining fully funded counseling and routinely recommended voluntary testing tied directly to family-oriented, follow-up care—is suggested in Part VI. In conclusion, this Note urges the New York State Assembly to reject Bill No. 6747-B, in light of its substantial and unconstitutional infringement of the rights of childbearing women and its inability to justify that infringement on medical or public policy grounds.

II. HIV Epidemiology in Women and Children

A. Women and HIV/AIDS

Because of its origins and early epidemiological profile,[27] AIDS is commonly perceived as an affliction of gay and intravenous drug using men. This lingering perception impedes progress against the disease and must be changed to reflect reality. AIDS only appears monolithic. In fact, the epidemic has splintered into diverse grains of society, threatening unforeseen segments of our population. Most significantly, "[t]he burden of [HIV] disease is shifting away from white males toward minority women."[28] The implications of this shift are profound: AIDS is now a serious threat to women, particularly to women of reproductive age and women of color, and to their babies. Despite the grave impact of this shift, women's needs are rarely the focus of public policy, prevention, research or

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that they are "unlinked," or anonymous, programs designed to trace and respond to the spread of HIV. *See infra* note 64. Passage of Bill No. 6747-B may encourage these states to enact similar mandatory testing and disclosure programs, thus directly affecting a large portion of our population.

27. For a general discussion of the natural history of AIDS, see *The First 10 Years*, *supra* note 1.

28. Mindy Tinkle et al., *HIV Disease and Pregnancy: Epidemiology, Pathogenesis, and Natural History*, 21 J. OF OBSTETRIC, GYNECOLOGIC & NEONATAL NURSES 86 (Mar./Apr. 1992).

treatment.[29] Three trends, however, dictate a need to refocus medical and societal views of AIDS and women.

First, women constitute the fastest growing subpopulation of the HIV epidemic.[30] Between 1985 and 1990, the incidence of AIDS in women in the United States nearly doubled;[31] between 1989 and 1990 alone, AIDS cases in women increased by 34%.[32] These women primarily contract HIV infection in one of two ways: having intercourse with an HIV-infected man or using intravenous drugs with a contaminated needle.[33] Indeed, women are four times as likely as men to contract HIV through heterosexual intercourse.[34]

Second, AIDS has a disproportionate impact on reproductive age women. It is the fifth leading cause of death among young women, and the number one cause of death among women age 20 to 40 in New York City.[35] Women in this age group constitute 77% of the female AIDS population.[36]

Third, AIDS has a similarly disproportionate impact on women of color,[37] particularly African-American and Hispanic women in

29. Joelle S. Weiss, *Controlling HIV-Positive Women's Procreative Destiny: A Critical Equal Protection Analysis*, 2 SETON HALL CONST. L.J. 643, 647 (1992)

30. *Id.* at 646-47. Between 1983 and 1990 the number of reported AIDS cases in women in New York increased 24 fold (from 174 to 4,194). *NY Seroprevalence Project*, *supra* note 12, at 19.

31. *AIDS Rate Among U.S. Women Nearly Doubled in Five Years*, AIDS POL'Y & L., June 26, 1991, at 9. The figures increased from 6.6% to 11.5%. *Id.*

32. Tinkle, *supra* note 28, at 87. As of December of 1991, there were 21,225 reported AIDS cases among adult women in the United States. Arlene Butz et al., *HIV-Infected Women and Infants: Social and Health Factors Impeding Utilization of Care*, 38 J. OF NURSE MIDWIFERY 103 (Mar./Apr. 1993) (special issue). AIDS is the eighth leading killer of women in the United States. Tedd V. Ellerbrock et al., *Epidemiology of Women with AIDS in the United States, 1981 through 1990 a Comparison with Heterosexual Men with AIDS*, 265 JAMA 2971 (1991). It is further estimated that 140,000 women are infected with HIV, *U.S. Public Health Service National Conference: Women and HIV Infection*, CLINICAL COURIER, Aug. 1991, at 1. Other estimates put that figure as high as one in every 800 women. Martha Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402, 406 (1993).

33. Sheldon Landesman, *HIV Infection in Women: An Overview*, SEMINARS IN PERINATOLOGY, Feb. 1989, at 2. While most infections occur through contaminated needles (51%), a rising number occurs through heterosexual transmission (33%). Tinkle, *supra* note 28, at 87. The Newborn Screening Subcommittee puts this figure at 75%. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 5.

34. Mary E. Guinan & Ann Hardy, *Women and AIDS: The Future is Grim*, 42 JAMA 157 (1987).

35. Butz, *supra* note 32, at 103.

36. HIV/AIDS SURVEILLANCE REP. 12 (Aug. 1991).

37. Almost 83% of women with AIDS are also women of color; 52% Afro-American and 30.6% Hispanic. *Newborn Screening Committee Report*, *supra* note 13, at 5.

poor urban neighborhoods.[38] A minority female is more than twice as likely than a white woman to become HIV-infected.[39] In 1988, AIDS killed African-American women at nine times the rate it killed white women.[40] Nationally, it remains the number one killer of African-American women;[41] in New York City, AIDS is the leading killer of Hispanic women.[42]

B. Newborns and Vertical Transmission

The shift in AIDS demographics has bleak implications for urban minority children. Because perinatal transmission (from the mother to the fetus or infant) accounts for 93% of pediatric AIDS cases,[43] the spread of HIV-infection among newborns mirrors its spread among childbearing women. The number of reported cases of pediatric AIDS has increased dramatically: between 1982 and 1991, only 3,199 cases were reported to the CDC;[44] today, it is estimated that 1,500 to 2,000 HIV-infected children nationwide are born every year.[45] This surge in HIV-infected children, tied indirectly to the explosion in intravenous drug use in inner cities, is expected to "skyrocket" even further.[46]

As merciless as it is in adults, AIDS is even more brutal in newborns, who have not had the time to develop protective antibodies before their immune system is assaulted by HIV.[47] When in-

38. Weiss, *supra* note 29, at 649 ("[T]he demographic distribution of HIV-infected women highlights stark geographic, ethnic, and economic patterns."). "At present, the group of persons diagnosed with HIV spectrum disease who die the fastest are women with AIDS, especially urban, low-income black and latina women." Kurth & Hutchison, *supra* note 6, at 121.

39. Butz, *supra* note 32, at 103.

40. *AIDS in Women—United States*, 265 JAMA 23 (1991).

41. Vicki Alexander, *Black Women and HIV/AIDS*, SIECUS REP., Dec. 1990-Jan. 1991, at 8.

42. Miguelina Maldonado, *Latinas and HIV/AIDS Implications for the 90s*, SIECUS REP., Dec. 1990-Jan. 1991, at 11.

43. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 5.

44. HIV/AIDS SURVEILLANCE, *supra* note 36, at 9. Over half of these children have already died. *Id.* at 13.

45. *Center for Disease Control, Special Report, Pediatric HIV Infection on the Increase*, HIV/AIDS PREVENTION, July 1991, at 2 [hereinafter *Pediatric HIV Infection*].

46. Weiss, *supra* note 29, at 653 (noting a projected increase of 10,000-20,000 cases in the United States in the next few years. The World Health Organization has estimated a fifteen-fold increase, from 700,000 in 1990 to 10 million in 2000); Peter Lamptey & William R. Finger, *The Next AIDS Crisis: Babies Born with HIV*, S.F. CHRON., Nov. 30, 1990, at A31. Pediatric AIDS is already the ninth leading killer of children between one and four. *Pediatric HIV Infection*, *supra* note 45, at 2.

47. Tinkle, *supra* note 28, at 88. In adults, the common opportunistic, AIDS-defining diseases include pneumocystis carinii pneumonia (PCP), candidiasis of the esophagus and lungs, persistent fulminating herpes simplex infection, cytomegalovirus

fection strikes, it is fast and ruthless, manifesting itself in one or several opportunistic diseases.[48] The younger the child is when symptoms appear, the shorter the survival period.[49] The median age for *presenting* with symptoms of HIV infection is 8-9 months.[50] The average survival time after diagnosis is nine months, with 90% dying within five years and one-fifth within a year.[51]

Ninety-three percent of the children who develop pediatric AIDS acquire the virus perinatally,[52] through "vertical transmission"—the passing of HIV from mother to child.[53] Vertical transmission can occur before birth (via intrauterine infection), during birth (via exposure to contaminated blood during delivery), or possibly after birth (via breastfeeding).[54] In 1990, 87% of all pediatric AIDS cases began with prenatal, in utero HIV infection.[55] Nevertheless, much remains unknown about vertical transmission, including a way to prevent it.[56]

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in organs other than the liver, spleen, or lymph nodes; toxoplasmosis of the brain; disseminated tuberculosis; Kaposi's sarcoma; and lymphoma of the brain. *Id.* at 90 (citations omitted). Pediatric AIDS does not include Kaposi's sarcoma, but PCP is particularly deadly in children. The manifestation of HIV infection in children involves multiple organ systems, progressive clinical deterioration, and severe immune dysfunction; opportunistic infections and secondary cancers follow; opportunistic infections include chronic parotitis, lymphocytic interstitial pneumonitis, and serious recurrent bacterial infections (meningitis, pneumonia, osteomyelitis, septic arthritis, septicemia). Mendez & Jule, *supra* note 12, at 638.

48. *See generally*, Scott et al., *supra* note 7 (discussing these diseases and the average rates of infection and survival).

49. *Id.* at 1791.

50. *Id.*; *see also* Mendez & Jule, *supra* note 12, at 638.

51. *See A Review of Epidemiologic Trends in HIV Infection of Women and Children*, *in* 1 PEDIATRIC AIDS AND HIV INFECTION: FETUS TO ADOLESCENT 11 (1990).

52. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 5. For a thorough, recent synopsis of routes of vertical transmission, see Richard R. Viscarello et al., *Is the Risk of Perinatal Transmission of Human Immunodeficiency Virus Increased by the Intrapartum Use of Spiral Electrodes or Fetal Scalp pH Sampling?*, 170 AM. J. OBSTET. GYNECOLOGY 740 (1994).

53. *See generally* Peggy Weintrub et al., *Use of Polymerase Chain Reaction for the Early Detection of HIV Infection in the Infants of HIV-Seropositive Women*, 5 AIDS 881 (1991); Marguerite Pappaioanou et al., *HIV Seroprevalence Surveys of Childbearing Women—Objectives, Methods, and Uses of the Data*, 105 PUB. HEALTH REPS. 147 (Mar./Apr. 1990) [hereinafter *Objectives, Methods, and Data*].

54. The exact nature and magnitude of the dangers of breastfeeding by HIV-positive women are not well understood. *See infra* notes 171-79 and accompanying text.

55. *Pediatric HIV Infection*, *supra* note 45, at 2; *see* Vicki M. Mays & Susan D. Cochran, *Issues in the Perception of AIDS Risk and Risk Reduction Activities by Black and Hispanic/Latinas Women*, 43 AMER. PSYCHOLOGIST 949 (1988).

56. An important new finding, however, has revealed a breakthrough in the prevention, or the deterrence, of perinatal HIV transmission. *See* Lawrence K. Altman, *In Major Finding, Drug Curbs H.I.V. Infection in Newborns*, N.Y. TIMES, Feb. 21, 1994, at A1. A federally financed study conducted in France and the United States

Although all children who are born to HIV-positive women will test positive for the virus immediately after birth, only 25% will in fact turn out to be actually HIV-infected, the remaining three-fourths will "seroconvert" by shirking off their mothers' antibodies while presenting none of their own.[57] What occurs *in utero* is the transfer to the child, through the placenta, of the mother's antibodies and possibly the virus itself.[58] Thus, the only certain indication of a positive newborn test is that the mother is infected. There is a window period of approximately twelve months when it is impossible to tell which infants are truly infected and that are presenting maternal antibodies which will later disappear in an otherwise healthy baby.[59] During this window period, perhaps the most accurate description of these babies is "antibody-positive."[60] New

has revealed that AZT, the drug previously most successful in treating the symptoms of adult AIDS and HIV infection, can successfully prevent transmission of the virus from infected mothers to newborns. *Id.* The CDC has called the finding one " 'of major public health importance.' " *Id.* In the study, 26% of the HIV-infected newborns whose mothers were treated with a placebo during pernancy were infected, whereas only 8% of those newborns whose mothers were treated with AZT were infected. *Id.* at A13. Medically, the impact of this finding is enormous. Since HIV-infection is incurable, the best course is to prevent pediatric AIDS by blocking transmission. Legally, however, this finding will only shift the terms of the debate. Instead of focusing on post-natal testing and medical intervention, the focus will be on prenatal testing. In terms of Bill No. 6747-B, the finding would seem to undermine its utility. If AZT can prevent pediatric AIDS, or a high percentage of cases, governmental efforts should be focused on prenatal counseling and voluntary testing rather than after-the-fact compulsory testing. For a discussion of the legislative impact of this breakthrough, see *infra* part VI.

57. Twenty-five percent is at the top end of the currently accepted transmission risk rates. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 9. Because so little is known about vertical transmission, and because transmission rates vary from country to country and state to state, there are divergent estimates of the vertical transmission rate. *See* Mendez & Jule, *supra* note 12, at 638 (20-40%); Tinkle et al., *supra* note 28, at 28 (25-35%); Weintrub, *supra* note 53, at 881 (25-60%); Antonio V. Sison & John L. Sever, *HIV-1 Infections in Pregnancy and Perinatal Transmission of HIV-1: Current Issues*, 3 PEDIATRIC AIDS & HIV INFECTION: FETUS TO ADOLESCENT 5 (1992) (15-30%; 12.9%).

58. Mendez & Jule, *supra* note 12, at 645-46.

59. *Id.* at 646. The window period frustrates the usefulness of the proposed testing procedure because immediate identification of the infant as antibody positive does not indicate an affirmative course of action, it only alerts vigilant health care providers to the possibility of infection. The inadequacy of current testing techniques has prompted considerable research, as scientists work to discover new methods or improve existing ones. The most promising hope for a test that more accurately and more quickly reflects the true status of the neonate is the polymerase chain reaction test. *See* Tinkle et al., *supra* note 28, at 89. Further frustrating both this effort and the New York proposal is the sparsity of knowledge about vertical transmission in general. *See generally, id.*; C. Everett Koop, *Inaugural Editorial*, *in* 1 PEDIATRIC AIDS AND HIV INFECTION: FETUS TO ADOLESCENT 7 (1990).

60. Kurth & Hutchison, *supra* note 6, at 121.

York's current testing program circumvents the uncertainty of the window period by tracking only the rates of transmission of the mother's antibodies, thus casting a wide net over high-risk areas rather than targeting specific infants for acute care.

III. New York's Current Testing Program and Bill No. 6747-B'S Proposed Changes

A. New York's Current Testing Program

New York was one of the first states to cooperate with a national seroprevalence[61] testing program initiated in 1987.[62] The seroprevalence program is designed to trace and predict the epidemiological trends of HIV infection in New York in order to implement more effective strategies for dealing with the AIDS epidemic.[63] The state already tested for seven inherited metabolic disorders, using a heelstick blood sample taken from the infant.[64] Piggybacked on routine testing, HIV screening necessitated no

61. Serologic testing, first developed in 1985, detects the presence of HIV-1 antibodies in the blood. Neil J. Hoxie et al., *HIV-1 Among Childbearing Women and Newborns in Wisconsin*, WISC. MED. J., Nov. 1990, at 627. Seroprevalence refers to the per capita rate at which the AIDS virus is found in the blood samples of a given population group.

62. Forty-two states, Puerto Rico, and the District of Columbia, and 39 metropolitan areas participate in an ongoing HIV "national sentinel surveillance system" operated under the auspices of the Center for Disease Control. Marguerite Pappaioanou et al., *The Family of HIV Seroprevalence Surveys: Objectives, Methods, and Uses of Sentinel Surveillance for HIV in the United States*, 105 PUB. HEALTH REP. 113, 113 (1990); *see also* J.P. Getchell et al., *supra* note 26, at 143. Known as the "CDC family of HIV seroprevalence surveys," this system enlists the assistance of state and local health departments, federal agencies, blood collection agencies, and medical research institutions in an effort to assist health officials in allocating resources and developing strategies for HIV prevention and health-care programs. Pappaioanou, *supra* at 113-14. For a definitive account of the New York seroprevalence project, see *NY Seroprevalence Project*, *supra* note 12. For a technical account of HIV epidemiologic surveillance surveys, see generally *Objectives, Methods, and Data*, *supra* note 53.

63. New York's willingness to undertake the seroprevalence project is understandable: it leads the nation in AIDS reporting, with nearly 30,000 cases (resulting in 18,239 deaths) through March 31, 1990 representing almost one-fourth of all cases nationwide; of these, 84% are New York City residents; in New York City, AIDS is the number one killer of males 30 to 49, the number one killer of females between 20 and 39, and the number two killer of males between 20 and 39; statewide there were 648 cases of pediatric AIDS as of March 31, 1990, accounting for almost a third of all cases in the United States. *See NY Seroprevalence Project*, *supra* note 12, at 10-11.

64. *See id.* at 12. These disorders include phenyketonuria (PKU), congenital hyperthyroidism, and maple sugar urine disease. *See Objectives, Methods, and Data*, *supra* note 53, at 149. Five other "window" groups were also selected for blind HIV screening: prisoners, family planning clinic clients, runaway and homeless adolescents, sexually transmitted disease clinic clients and intravenous drug users. *See NY Seroprevalence Project*, *supra* note 12, at 9, 12.

newly invasive procedures. Unlike routine testing, however, HIV screening is "blinded," meaning all personal identifiers are removed from the blood sample except the age of the mother, the race/ethnicity of the infant, and the zip code of the hospital.[65] This information is linked to the test result through a mutually assigned random number fed through a data base.[66]

Most importantly, the seroprevalence program operates within the strict parameters for the confidentiality of AIDS information established by Article 27-F.[67] Because the program is primarily a research device, with no means of accessing confidential information, it necessitates neither the informed consent nor counseling services required by Article 27-F.

The results of the New York program dramatically confirm the shift of the AIDS epidemic to urban, minority, reproductive-age women.[68]

- The overall seroprevalence rate in New York State was .66%,[69] or more than eight times higher than the national median of .08%, with a New York City rate of 1.24%.[70]
- In some zip code areas, as many as 1 in 22 childbearing women were HIV-infected.[71]
- 87% of the seropositives in the state and 89.3% in the city were African-American or Hispanic.[72]
- Nearly 90% of all pediatric AIDS cases were African-American or Hispanic.[73]
- The sharpest increase over this period was in young women: the 14-year-old seroprevalence rate was .16% (1 in 624); by age 24, it jumped to 1.41% (1 in 71).[74]

B. Changes Proposed by Bill No. 6747-B

Assembly Bill No. 6747-B would amend Article 27-F and change the goals and the methods of New York's current testing program. The goal of tracking the demographic profile HIV infection would

65. *See NY Seroprevalence Project, supra* note 12, at 9, 12.
66. *Id.* at 15.
67. *See supra* notes 23-24.
68. The study covered 96.3% of all births in New York from November 30, 1987 through March 31, 1990. *NY Seroprevalence Project, supra* note 12, at 9.
69. This rate has since dipped to 0.59%. *Id.* at 7-8.
70. *Id.* at 16, 20.
71. *Id.* at 18.
72. *Id.* at 16.
73. *Id.* at 56.
74. *Id.* at 16.

be replaced by the goal of maximizing treatment opportunities for infants who are antibody-positive. The current anonymous testing procedure would be replaced by a mandatory testing and disclosure formula.

The wording of Bill No. 6747-B, in pertinent part, is as follows:

> Section 1. Section 2782 of the public health law is amended by adding a new subdivision 10 to read as follows:
>
> The department shall disclose to the mother . . . of a newborn child confidential HIV related information obtained as a result of any testing done for any purpose whatsoever on such child . . . .[75]

Proponents of the bill argue that the current New York seroprevalence program does not go far enough to protect children born to HIV-infected mothers and that insistence on anonymity ignores the baby's "right to survive."[76] The bill's primary sponsor, Assemblywoman Nettie Mayersohn of Queens, asserts that it is medically and ethically unjustifiable *not to inform* a mother that her child has tested positive simply to preserve her own right to privacy.[77] Maternal privacy is said to be subordinate to the newborn's right to life-prolonging treatment, or if the newborn is not actually infected, to its right not to become inadvertently infected by an uninformed mother who transmits HIV through her breastmilk.[78] The infant beneficiaries of Bill No. 6747-B can therefore be divided into two groups: the one-fourth of positive newborns who actually are infected and could therefore benefit from acute care, and the remaining three-fourths of newborns who

75. Bill No. 6747-B, which originally called for disclosure to both parents, also provides for disclosure to prospective adoptive parents, to officials of agencies having the care, custody or guardianship of the child, and, in cases where the mother "cannot be located," to the father or guardian of the newborn. These provisions raise substantial legal issues—primarily in terms of the privacy of the mother and the infant and the biological family—and policy issues (providing the best opportunities for adoption and care within overburdened child resources facilities) that are beyond the scope of this Note but nevertheless would also undermine the effectiveness of the bill. *See e.g.*, Navarro, *supra* note 15, at 44; D. Marianne Brower Blair, *Lifting the Genealogical Veil: A Blueprint for Legislative Reform of the Disclosure of Health-Related Information in Adoption*, 70 N.C. L. REV. 681 (1992). Recent changes made in Bill No. 6747-B also provide for (1) five million dollars to provide assistance to newborns testing positive and their family, "provided that the commissioner of health is authorized to transfer and deposit this amount," and for (2) grants to be made to programs serving HIV infected children and their families,"within amounts available therefor." N.Y. ASSEMBLY BILL No. 6747-B, §§ 3-4.

76. Nettie Mayersohn, *It's A Baby, Not A Statistic, Stupid*, NEWS FROM ASSEMBLYWOMAN NETTIE MAYERSOHN, at 2 (July 1993).

77. *Id.*

78. *Id.*

only test positive and should therefore avoid inadvertent infection after birth via breastfeeding.

Although Bill No. 6747-B has been popularly publicized as an "unblinding" of the current seroprevalence screening program,[79] it is really an entirely new mechanism. "Unblinding" the current program means not that women will have the opportunity to find out about their status, but that they will have no choice but to do so. Under this unprecedented proposal, a newborn will be tested as it currently is, only the personal identifiers will not be stripped from its blood sample. When the results become available, the mother who returns with her child for pediatric care will be confronted with them.

IV. The Right to Privacy and Mandatory Testing and Disclosure

The right to privacy is an elusive constitutional freedom.[80] It is frequently traced to "the right to be let alone."[81] More recently, the United States Supreme Court has enunciated the right to be free from "unwanted governmental intrusions into one's privacy,"[82] and "unwarranted governmental intrusion into matters . . . fundamentally affecting a person."[83] In *Planned Parenthood v. Casey*,[84] a recent case which signaled a new and as yet unclear di-

79. *See id.*; *see also AIDS Babies Pay the Price*, N.Y. TIMES, Aug. 13, 1993, at A26 (editorial); *Infants Rights: Give Test Results to Mothers*, N.Y. NEWSDAY, June 10, 1993, at 46 (editorial).

80. *See* Roe v. Wade, 410 U.S. 113, 152 (1973). Justice Blackmun, writing for the Court in *Roe*, acknowledged the difficult line-drawing implicit in carving out a right to privacy when he wrote that "[t]he Constitution does not *explicitly* mention any right of privacy. In a line of decisions, however, going back perhaps as far as . . . (1891), the Court has recognized that a right of personal privacy, or a guarantee of certain areas or zones of privacy, *does exist* under the Constitution." *Id.* (emphasis added).

81. Warren & Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 195 (1890) (borrowing the phrasing of T. Cooley, A TREATISE ON THE LAW OF TORTS 29 (2d ed. 1888)). This phrase was most memorably used by Justice Brandeis, in *Olmstead v. United States*, when he wrote that the Founding Fathers "conferred, as against the Government, the right to be let alone—the most comprehensive of rights and the right most valued by civilized men." 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting). However often it is cited by courts and commentators as an early echo of the constitutional right to privacy, the privacy alluded to by Warren and Brandeis actually speaks not to the Constitution but to principles of tort law. Nevertheless, in *Olmstead*, it could be argued that Brandeis, obviously aware of this distinction, consciously imported this concept of privacy into the constitutional domain.

82. Stanley v. Georgia, 394 U.S. 557, 564 (1969).

83. Eisenstadt v. Baird, 405 U.S. 438, 453 (1972).

84. 112 S. Ct. 2791 (1992) (stating that the Constitution limits the state's right to interfere with an individual's most basic decisions about family and parenthood).

rection in the Court's jurisprudence on this issue, privacy was broadly described in terms of "substantive liberties"[85] that should not be subjected by the state to an "undue burden."[86] No matter how it is described, privacy is rooted in the doctrine of modern substantive due process[87]—the Court's recognition of constitutional safeguards against state infringement of certain fundamental freedoms.[88]

Two distinct strands within the right to privacy have been identified.[89] The first, less controversial strand is *confidentiality*, or the

85. *Id.* at 2808.

86. *Id.* at 2819.

87. *See*, 2 RONALD R. ROTUNDA ET AL., TREATISE ON CONSTITUTIONAL LAW: SUBSTANTIVE AND PROCEDURAL (1986); LAWRENCE H. TRIBE, AMERICAN CONSTITUTIONAL LAW, § 15-1 (2d ed. 1988). For a criticism of this doctrine, see, Thomas I. Emerson, *Justices in Search of a Doctrine*, 64 MICH. L. REV. 219 (1965). The Due Process Clause of the Fourteenth Amendment states that no state shall "deprive any person of life, liberty, or property, without due process of law . . ." U.S. CONST. amend. XIV, § 1. The Supreme Court adopted a substantive due process doctrine when it began to recognize the right of privacy as a protected "liberty" interest under the clause. This doctrine has since been used to invalidate federal and state legislation that infringes privacy on the basis of the legislation's substance rather than its procedure. *See, e.g.*, Zablocki v. Redhail, 434 U.S. 374 (1978) (marriage); Roe v. Wade, 410 U.S. 113 (1973) (abortion); Eisenstadt v. Baird, 405 U.S. 438 (1972) (contraception); Loving v. Virginia, 388 U.S. 1 (1967) (family and parenthood); Skinner v. Oklahoma, 316 U.S. 535 (1942) (family and parenthood); Pierce v. Society of Sisters, 268 U.S. 510 (1925) (childbearing); *see also Casey*, 112 S. Ct. at 2805 (noting "a promise of the Constitution that there is a realm of personal liberty which the government may not enter," and which is not restricted to the express rights of the Bill of Rights nor to those private practices protected at the time of the Fourteenth Amendment's ratification).

88. *See* CASS R. SUNSTEIN ET AL., CONSTITUTIONAL LAW ch. VI: Implied Fundamental Rights, § F, Modern Substantive Due Process: Privacy, Personhood, and Family, at 908. In 1923, with Myers v. Nebraska, 262 U.S. 390, and in 1925, with Pierce v. Society of Sisters, 268 U.S. 510, the Court formally began an expansive reading of Constitutionally protected, but unenumerated, liberties. "[T]he "liberty" guaranteed by the due process clause of the fourteenth amendment denotes not merely freedom from bodily restraint, but also the right of the individual to contract, to engage in any of the common occupations of life, to acquire useful knowledge, to marry, to establish a home and bring up children, to worship God according to the dictates of his own conscience, and generally to enjoy those privileges long recognized at common law as essential to the orderly pursuit of happiness by free men." *Meyers*, 262 U.S. at 393; *see also* Calder v. Bull, 3 U.S. 386, 387 (1798) (arguing a theory of natural law in which "[t]here are certain vital principles in our free Republican governments, which will determine and over-rule an apparent and flagrant abuse of legislative power.") (Chase, J., dissenting); Corfield v. Coryell, 6 Fed. Cas. 546 (Cir. Ct. E.D. Pa. 1823) (J. Bushrod Washington) (describing a broad range of interests which are "fundamental; which belong, of right, to the citizens of all free governments.").

89. *See* Whalen v. Roe, 429 U.S. 589, 599-600 (1977); Nixon v. Adm'r of Services, 433 U.S. 425, 458 (1977); *see also* Blair, *supra* note 75, at 688; Gretta J. Heaney, *The Constitutional Right of Informational Privacy: Does it Protect Children Suffering from AIDS?*, 14 FORDHAM URB. L.J. 927, 929 (1986).

"individual interest in avoiding disclosure of personal matters."[90] The second strand, recently revisited by the Court in *Casey*, is *autonomy*, or "independence in making certain kinds of important decisions."[91] At least until *Casey*, autonomy issues have traditionally been subject to strict scrutiny analysis, which requires that any governmental action infringing on a fundamental right be narrowly tailored to meet a compelling governmental interest.[92] In contrast, confidentiality issues have traditionally received a less stringent balancing test analysis, which weighs the state interest advanced against the personal infringement incurred.[93]

Although most analyses of mandatory HIV testing focus solely on confidentiality,[94] a testing scheme predicated on a woman's decision to give birth implicitly burdens her autonomous decision-making as well.[95] Therefore, both tests are applied below.

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90. *Whalen*, 429 U.S. at 599.

91. *Id.* at 599-600.

92. *See, e.g.*, Carey v. Population Services, 431 U.S. 678, 686 (1977); Zablocki v. Redhail, 433 U.S. 374, 388 (1978); *Roe*, 410 U.S. at 155 ("Where certain 'fundamental rights' are involved, the Court had held that regulation limiting these rights may be justified only by a 'compelling state interest,' and that legislative enactments must be narrowly tailored to express only the legitimate state interest at stake.") (citations omitted). Strict scrutiny is also applied under an Equal Protection analysis to classifications on the basis of race, alienage, or national origin. *See* Frontiero v. Richardson, 411 U.S. 677, 688 (1978) (race, alienage, and national origin are suspect classifications); Korematsu v. United States, 323 U.S. 314, 316 (1944) (applying the "most rigid scrutiny" to the internment of Japanese-Americans in California during World War II).

93. *See* Nixon v. Adm'r of Services, 433 U.S. 425 (1977); Whalen v. Roe, 429 U.S. 589 (1977). A balancing test avoids the "severity" of strict scrutiny and the "leniency" of rational relationship test. Heaney, *supra* note 89, at 945. A balancing test may also avoid the "political arbitrariness" of determining a "compelling" state interest and thereby "allows the government to perform its functions effectively while safeguarding the sanctity of vital privacy interests." *Id.* at 945-46.

94. *See, e.g.*, Heaney, *supra* note 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 (1991); Steven Eisenstadt, *An Analysis of the Rationality of Mandatory Testing to the HIV Antibody: Balancing the Governmental Public Health Interests with the Individual's Privacy Interest*, 52 U. PITT. L. REV. 327 (1991). For an comprehensive and recent treatment of the confidentiality of HIV-related information, focusing particularly on new threats to three levels of protection—statutory protection of HIV-related information, statutory protection of medical information, and constitutional and common law privacy rights—and suggesting ways in which they can be reinforced against the current trend of aggressive public health intervention, see Roger Doughty, *The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic*, 82 CAL. L. REV. 113 (1994).

95. *See infra* part III.B. (discussing autonomy).

A. Confidentiality: Weighing the Scope of the Intrusion against the Interests Advanced

1. Privacy Denied: A Constitutional Balancing Test

Clarifying both confidentiality and autonomy precedent, *Whalen v. Roe*[96] expressly recognized both strands as elements of constitutionally protected privacy.[97] *Whalen* addressed a New York statute that required that the names of persons using certain prescription drugs be recorded with the State.[98] Physicians and patients who challenged the statute argued that disclosure to the State of private, medical information both violated their confidentiality and deprived them of their right to acquire, use, or dispense such medications.[99] The Court weighed the individual's interests in nondisclosure and autonomy against the State's "broad latitude in experimenting with possible solutions to problems of vital local concern,"[100] before finding that the statute did not "pose a sufficiently grievous threat to either interest to establish a constitutional violation."[101]

Later in the same term, in *Nixon v. Administrator of General Services*,[102] the Court reiterated *Whalen's* recognition of the individual's interest in non-disclosure and formally enunciated the balancing test introduced in the earlier case. Under this test, the purpose of the challenged statute and the public interest served by it must be weighed against the scope and extent of its intrusion on individual privacy.[103]

Although a balancing test is necessarily a "delicate task of weighing competing interests,"[104] several criteria have emerged

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96. 429 U.S. 589 (1977).

97. *Id.* at 598-99. ("The cases sometimes characterized as protecting "privacy" have in fact involved at least two different kinds of 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.") (footnotes omitted).

98. 429 U.S. at 589.

99. *Id.* at 602.

100. *Id.* at 597.

101. *Id.* at 600. *Whalen* is distinguishable not only for the nature of its intrusion, but because the Court relied in making its decision on two elements absent from Bill No. 6747-B: (1) the disclosures were not "significantly different" from those already required by law, and (2) it could not be said that "any individual has been deprived of the right to decide independently." *Id.* at 602.

102. 433 U.S. 425 (1977) (rejecting former President Nixon's privacy challenge to a federal law that authorized the seizure and screening of his documents and tape recordings).

103. *Id.* at 458.

104. United States v. Westinghouse, 638 F.2d 570, 578 (3d Cir. 1980).

from the Circuit Courts to guide its implementation.[105] The *Whalen-Nixon* balancing test has been interpreted by the Third Circuit as sanctioning disclosures regarding "past medical history, present illness, or the fact of treatment" in those circumstances where "the government has advanced a need to acquire the information to develop treatment programs or control threats to public health."[106] However, although the individual's right to control access to personal matters is not absolute, the State must still demonstrate that "the societal interest in disclosure outweighs the privacy interest on the specific facts of the case."[107] The D.C. Circuit has held that the standard by which the right to nondisclosure is to be protected requires examining "the need for intrusion against its severity."[108] The Fifth Circuit has held that the standard for judging the lawfulness of intrusive legislation requires comparing "the interest it serves against those it hinders."[109] The D.C. Circuit has also determined that Supreme Court precedent mandates that "all lawful privacy intrusions must be narrowly drawn" and "reasonably related in scope to the justification for their initiation."[110] Finally, the 9th Circuit has held that the burden on the State to justify an infringement of informational privacy increases with the sensitivity of the information disclosed and the severity of the intrusion.[111]

In *United States v. Westinghouse*,[112] in which the State sought access to certain employee medical records, the Third Circuit suggested that the following factors should be considered "in deciding whether an intrusion into an individual's privacy is justified:"[113] (1) the type of record requested, (2) the information that is contained or may be contained in the record, (3) the potential for harm in any subsequent non-consensual disclosure, (4) the injury from disclo-

105. *But see* J.P. v. DeSanti, 653 F.2d 1080 (6th Cir. 1981) (finding no constitutional right of nondisclosure in juvenile social histories prepared by State).

106. *Westinghouse*, 638 F.2d at 578.

107. *Id.*

108. Tavoulareas v. Washington Post Co., 724 F.2d 1010, 1019 (D.C. Cir. 1984) (discussing the evolution of the right to confidentiality in Supreme Court and Circuit Court jurisprudence).

109. Plante v. Gonzalez, 575 F.2d 1119 (5th Cir. 1978), *cert. denied*, 439 U.S. 1129 (1979).

110. *Tavoulareas*, 724 F.2d at 1023 (citing Terry v. Ohio, 392 U.S. 1, 29 (1968)).

111. Thorne v. City of El Segundo, 726 F.2d 459, 469 (9th Cir.), *cert. denied*, 469 U.S. 979 (1983).

112. 638 F.2d 570 (3d Cir. 1980) (denying an employer the right to refuse the National Institute for Occupational Safety and Health access to its employees health records, but requiring prior notice from the Institute to permit employees to raise personal privacy claims).

113. *Id.* at 578.

sure 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. Under these standards, Bill No. 6747-B does not pass constitutional scrutiny.

2. *Bill No. 6747-B's Infringement of Individual Privacy is not Outweighed by the Public Interest it Serves*

It cannot be reasonably argued that the state lacks an interest in protecting the public against the spread of HIV infection.[114] Even an important interest, however, is not by itself dispositive in a balancing test, which is contingent on the means chosen to reach this end and the burden those means place on the individual. This implicitly requires assessing how well the governmental purpose is served by the means selected. Were it otherwise, the overwhelming weight of the AIDS crisis would smother whatever right to privacy was offered against it, regardless of the substantive merits of the state proposal.[115]

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114. Before even proceeding to a balancing test, it must be shown that the information at issue constitutes a "personal matter" as required by *Whalen*. It is generally agreed, particularly in more recent case law, that one's medical condition, including one's HIV status, qualifies as a "personal matter." *See, e.g.*, United States v. Westinghouse Elec. Corp., 638 F.2d 570, 577 (3d Cir. 1980) (medical information is part of that "private enclave where [the individual] may lead a private life" and "there can be no question that an employee's medical record, which may contain intimate facts of a personal nature, are well within the ambit of materials entitled to privacy protection) (citation omitted); Woods v. White, 689 F. Supp. 874, 876 (W.D. Wis. 1988), *aff'd*, 899 F.2d 17 (7th Cir. 1990) ("[I]t is difficult to argue that information about [AIDS or HIV status] is not information of the most personal kind, or that an individual would not have an interest in protecting against the dissemination of such information."). New York courts have also held that medical and HIV status constitutes confidential information. *See* Doe v. Coughlin, 697 F. Supp. 1234, 1237 (N.D.N.Y. 1988) (acknowledging a right to privacy in preventing the non-consensual disclosure of one's medical condition or diagnosis); Doe v. Roe, 526 N.Y.S.2d 718, 724 (Sup. Ct. 1988) ("Existing regulations and laws, as well as the stated policy of responsible Health Department and health officials demonstrate a public policy militating strongly against court interference in the confidentiality of existing records, and unalterably opposed to judicially coerced non-voluntary testing.").

115. One New York court has shown model sensitivity to the context in which mandatory testing is put:

> The question is, therefore, what standard must be met, or what showing made before an involuntary AIDS test can be compelled. Before this question can be addressed, the present level of knowledge concerning AIDS and AIDS testing, as well as special problems such testing raises, relevant case law and clearly expressed public policy must all be reviewed and considered.

Doe, 526 N.Y.S.2d at 720.

Although the courts review public health statutes under a presumption of validity,[116] an unjustified statutory intrusion will be struck down, particularly when it impairs privacy and when a *less restrictive method* can achieve the same objective.[117] This principle is well stated in *Wong Wai v. Williamson*,[118] in which a city ordinance aimed at stopping the bubonic plague required that all Chinese residents be innoculated:

> If the legislature, in the interests of the public health, enacts a law, and thereby interferes with the personal rights of 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 substance of the thing involved, and will not be controlled by mere forms.[119]

The "object in view" of Bill No. 6747-B is not simply HIV testing and disclosure. These are a means to an end and not an end themselves. The purpose of the proposal is to bring immediate, improved medical care to more AIDS-threatened babies than currently receive it. But this purpose is fatally undermined by the means chosen to achieve it. A mandatory testing and disclosure scheme will not provide for enough immediate, improved care of infants to justify its substantial invasion of their mothers' privacy. Several pragmatic factors combine to undermine the likelihood of Bill No. 6747-B's success and contribute to its failure of a constitutional balancing test: (1) fear of discrimination and care avoidance; (2) the absence of direct linkage to follow-up care; (3) alienation of the mother; (4) the uncertain relationship between early identification and improved care; (5) the misapplication of a traditional pub-

116. *See, e.g.*, Moore v. Draper, 57 So. 2d 648 (Fla. 1952) (tuberculosis statute); Kirk v. Wyman, 65 S.E. 387 (S.C. 1909) (leprosy regulations).

117. *See, e.g.*, Wong Wai v. Williamson, 103 F. 1 (C.C.N.D. Cal. 1900) (plague regulations); New York State Ass'n for Retarded Children v. Carey, 612 F.2d 644 (2d Cir. 1979) (hepatitis B school plan); Hershberg v. City of Barbourville, 133 S.W. 985 (Ky. 1911) (smoking ordinance). *See generally*, Comment, *The Constitutional Rights of Aids Carriers*, 99 HARV. L. REV. 1274 (1986); Closen, *supra* note 94, at 465 ("[A] court will invalidate a health and welfare statute in which the substance of the law is not genuinely related to, or is not really appropriate to, the accomplishment of its health or welfare goal (i.e., other, less objectionable methods are just as likely to achieve the desired purpose).").

118. 103 F. 1 (N.D. Cal. 1900).

119. *Wong Wai*, 103 F. at 7 (emphasis added)(citation omitted); *see also* Jew Ho v. Williamson, 103 F. 10, 22 (N.D. Cal. 1900) (invalidating quarantining of San Francisco Asians because, *inter alia*, it would not prevent the spread of the bubonic plague).

lic health care solution to a non-traditional public health problem; and (6) the viability of a superior alternative.

a. Discrimination and Care Avoidance

The absence of a provision in Bill No. 6747-B for a general disclosure or public dissemination of the mother's status does not mean that the discrimination which accompanies AIDS is irrelevant to these mothers or to the purpose of the bill. On the contrary, there is a likely, significant social fallout from mandatory screening that seriously reduces the bill's effectiveness. Although Bill No. 6747-B does not create the physical suffering or the social discrimination that attend AIDS, its effectiveness will be undermined by the fact that mothers unwilling to be forced into confronting either reality will avoid mandatory testing or resist cooperating with positive results.

Two lines of argument suggest that societal factors are irrelevant when balancing the bill's intrusiveness against its benefits. The first posits that there is no privacy invasion at all because the only person to whom the testing results are disclosed is the same person to whom they are confidential. The second posits that even though there is a privacy invasion, it is not terribly intrusive, and not public, because results are disclosed confidentially and kept between the State and the mother.

The first argument is easily refuted. Although it represents a common paradigm,[120] direct disclosure by the State to a third party is not a necessary predicate to an invasion of privacy. Simply the taking and recording by state agencies of personal matters is sufficient to infringe individual privacy. Such was the case, for example, in *Whalen* and *Westinghouse*, where the State sought access to already existing personal records for governmental purposes which did not entail sharing the information with other parties. Additionally, the circumstances of Bill No. 6747-B are more intrusive that in either *Whalen* or *Westinghouse* in that mandatory screening of newborns (1) creates a State program which not only collects personal information, but discloses this newly collected information through health care providers who are necessarily made aware of

120. *See, e.g.*, Doe v. City of Cleveland, 788 F. Supp. 979 (N.D. Ohio 1991) (disclosure of individual's HIV status by police to neighbors); Carter v. Broadlawns Med. Cen., 667 F. Supp. 1269, 1282 (S.D. Iowa 1987), *cert. denied*, 489 U.S. 1096 (1989) (disclosure of individual's HIV status by hospital to chaplain); Doe v. Coughlin, 697 F. Supp. 1234 (N.D.N.Y. 1988) (disclosure of individual's HIV status by prison to prisoners).

the mother's status,[121] and (2) provides not simply for accessing already recorded personal information, but for obtaining previously unrecorded personal information from nonconsenting persons. A third way to refute this argument is to conceive of the mother as both the testee from whom personal information is taken, and the third party to whom that information is revealed. This conception is supported by the state's own approach to the issue. In Bill No. 6747-B, the mother is treated as a carrier whose rights are subordinate to the newborn's for purposes of testing, but as a caregiver whose decision-making is crucial to improved care for purposes of treatment. The ends and means of the bill itself treat the mother as separable individuals, the one from whom confidential information is taken and the one to whom it is given.

As to the second argument, no one seriously suggests that there is any real guarantee of confidentiality in such a statewide, institutionalized testing scheme as is proposed. It is widely acknowledged by care providers and hospital administrators,[122] legal commentators,[123] and advocacy groups[124] that problems with leakage and dissemination of confidential medical information are endemic.[125] Furthermore, even if disclosure through intentional or careless leakage were not inevitable, societal disclosure would still be

121. It is also likely that within the close environment of a health care center or hospital HIV ward more than a single caregiver will be made aware of the mother's status. This group could include administrators, clerks, secretaries, nurses, doctors, midwives, and other patients. Alternatively, the common, third party privacy paradigm may be satisfied by viewing the hospital as taking confidential information from the mother and disclosing it to the State and her caregiver.

122. *Hearing of the Newborn Screening Subcommittee, New York State AIDS Advisory Council* (Nov. 9, 1993) (Comments by Dr. Allan Rosenfeld, Dean of Columbia University School of Public Health, calling the supposed confidentiality of hospital records a "farce").

123. *See* Michael Closen et al., *AIDS: Testing Democracy—Irrational Responses to the Public Health Crisis and the Need for Privacy in Serologic Testing*, 19 J. MARSHALL L. REV. 835, 888 ("[T]here are no effective guarantees as to the confidentiality of test results or the purposes to which results may be put."); Field, *supra* note 32, at 409-10 (citing not only inherent systemic leaks and an absence of safeguards, but external pressures to release data from courts, employers, insurers, family, etc.: "the reality may be that it is difficult to maintain total confidentiality once a person is found to be HIV positive").

124. *Hearing of the Newborn Screening Subcommittee, New York State AIDS Advisory Council* (Nov. 8, 1993) (testimony of Terry Maroney, New York City Gay and Lesbian Anti-Violence Project).

125. *See* AIDS PRACTICE MANUAL, *supra* note 6, § 3.2. ("[C]onfidential HIV testing may not be all that the term suggests."); *see also* Doe v. Roe, 526 N.Y.S.2d 718, 723 (Sup. Ct. 1988) ("The State and City have demonstrated a similar concern for the confidentiality of records of persons already tested and found to be infected with AIDS.").

forced upon any mother who actively seeks improved care for her child. It would be exceedingly difficult to respond appropriately to a positive test result and still maintain confidentiality. Here are just some of the ways in which a mother who conscientiously responds to a positive result would publicly betray her HIV-positive status:

(1) By modifying and monitoring her behavior and her child's, by adjusting dietary and sleeping habits and by administering a regular course of medication, and by maintaining a healthy household, a mother is unlikely to be able to hide her condition from her family or (potentially abusive) spouse.

(2) By pursuing treatment for herself and her child through routine visits several days a week to a community hospital or health care center would presumably also betray her circumstance to neighbors and friends, or to anyone interested enough to scrutinize the clinic's clients.

(3) Even if the mother could conceal from her immediate community both her and her child's status and still provide for improved care, she would not be able to conceal it from insurance companies, employers, health maintenance organizations, and other institutions which now routinely inquire of applicants what their status is or if they have been AIDS tested.[126] These mothers would then be put in a situation where they would have to lie to maintain their privacy or risk losing their insurance coverage, job, or home.[127]

(4) Even for the mother who does not pursue a course of treatment, there is a substantial risk of exposure to third parties, namely to the fathers. Not only does Bill No. 6747-B provide for disclosure to the father if the mother "cannot be located,"[128] but under Article 27-F of the New York Public Health Law, a physician may notify a partner of an HIV-positive person if the physician "reasonably believes that: disclosure is medically appropriate; the partner is at significant risk; and the HIV-positive patient will not inform the partner."[129]

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126. *See* Field, *supra* note 32, at 409-10.

127. *See id.* at 410. Field notes a Fifth Circuit case in which the court held that ERISA does not prohibit an employer from reducing an existing insurance policy from a $1,000,000 lifetime medical benefit to a $5,000 benefit after an employee with AIDS filed for reimbursement. *Id.* at 410 n.29 (citing McGann v. H & H Music Co., 946 F.2d 401 (5th Cir. 1991), *cert. denied*, 113 S. Ct. 482 (1992)).

128. *See supra* note 75.

129. NEW YORK STATE DEP'T OF HEALTH, QUESTIONS AND ANSWERS ABOUT THE NEW YORK STATE CONFIDENTIALITY LAW (1989).

In both *Whalen* and *Nixon*, the Supreme Court has noted the difference in intrusiveness between those disclosures made only to the State and those made to the public. The latter type of disclosure increases the burden on the State to justify its infringing legislation.[130] A public as opposed to governmental dissemination of confidential information has been considered by at least one Circuit Court to be a "severe" intrusion that can only be justified by a "compelling interest."[131] This analysis, although instructive, is attenuated when the public disclosure is only indirectly forced by the State.

Because the burden on the state to justify an infringement of informational privacy increases with the sensitivity of the information disclosed and the severity of the intrusion,[132] it is critical to consider the unique medical and social significance of AIDS when attempting to justify mandatory HIV screening. Diagnosis with HIV is a matter of great privacy. It is hard to imagine a medical disclosure more serious or sensitive than infection with the AIDS virus, the precursor to an incurable and invariably fatal disease. The trauma of that disclosure is only partially accounted for by its severe physical implications.[133] Perhaps the more brutal aspect of an HIV/AIDS diagnosis is the inevitable stigma and discrimination that accompany it.

Even if the positively diagnosed mother is able herself to accept and respond positively to her diagnosis, greater society has proven far less willing to do so. AIDS victims and persons known to be HIV-positive are routinely subject to direct and indirect discrimination in many forms.[134] Major areas of discrimination are hous-

130. Tavoulareas v. Washington Post Co., 724 F.2d 1010, 1020 (D.C. Cir. 1984).

131. *Id.* at 1023 (citing *Whalen*, 429 U.S. at 606 (Brennan, J., concurring) ("Broad dissemination by state officials of [personal] information . . . would presumably be justified only by compelling state interests.")).

132. *See supra* note 111 and accompanying text.

133. For example, two of the primary opportunistic diseases which afflict AIDS victims are Kaposi's sarcoma and pneumocystis carinii pneumonia. The former is a rare form of severely disfiguring cancer, producing blue-black skin blotches and lesions and accompanied by severe weight loss. People with HIV/AIDS may also suffer from profound fatigue, profuse night sweating, oral thrush, persistent fevers, swollen lymph nodes, digestive tract infections, loss of appetite, tuberculosis, shingles, headaches, emotional upset, dementia and other health disorders. Science, unable to cure HIV/AIDS, has only been able to treat its symptoms, thus prolonging life and indirectly exposing patients to a growing list of opportunistic infections. JARVIS ET AL., *supra* note 6, at 6-7, 14-17, 19, 22-23.

134. *See generally* Eisenstadt, *supra* note 94, at 364-69. An extensive survey published in 1990, typical of the national mood, revealed that whereas over four-fifths of those surveyed believed that those who contracted AIDS through blood transfusions

ing, insurance, employment, education (particularly against children), and health care.[135] Compounding the fear of losing one's job, apartment, or insurance is the daily humiliation and isolation caused by general fear, ignorance, misperception and prejudice.[136] Like the physical toll, the social costs of AIDS are opportunistic and persistent; and the stress to one's psyche and spirit is profound.[137] The impact on poor, minority, childbearing women

should be treated with compassion, less than one-half of those polled believed that persons infected through homosexual activity, intravenous drug use, or sexual relations with an intravenous drug user should be treated with compassion. Renee Graham, *Most Favor Bigger U.S. Role in AIDS Fight*, BOSTON GLOBE, June 17, 1990, at 1.

135. *See* Closen et al., *supra* note 123, at 927-28. Discrimination is also manifest in the various legislative and private efforts proposed to combat the epidemic, such as mandatory tattooing, exclusionary zoning, identification cards, and quarantining. *Id.* at 838-39. Many of the more extreme suggestions are motivated by homophobia. *Id.* Sterilization has also been offered as an alternative means of containment. Field, *supra* note 32, at 417. Criminalizing the transfer of HIV has recently become a popular response. *See* Richard T. Andrias, *Urban Criminal Justice: Has the Response to the HIV Epidemic Been "Fair?"*, 20 FORDHAM URB. L.J. 497 (1993); Scott H. Isaacman, *Are We Outlawing Motherhood for HIV-Infected Women?*, 22 LOY. U. CHI. L.J. 479 (1991); Deborah Wieczorkowski Wanamaker, *From Mother to Child . . . A Criminal Pregnancy: Should Criminalization of the Prenatal Transfer of AIDS/HIV be the Next Step in the Battle Against this Deadly Epidemic?*, 97 DICK. L. REV. 383 (1993); Louise M. Chan, Note, *S.O.S. From the Womb: A Call for New York Legislation Criminalizing Drug Use During Pregnancy*, 21 FORDHAM URB. L.J. 199 (1994). *But see* Jennifer Mone, *Has Connecticut Thrown Out the Baby with the Bath Water? Termination of Parental Rights and In re Valerie D.*, 19 FORDHAM URB. L.J. 535 (1992) (arguing that State protection of the best interests of the child neither necessitates pitting the welfare of the child against the rights of the mother nor justifies termination of parental rights).

136. The discriminatory effects of AIDS have not been lost on the courts. "A person who has been involuntarily tested for AIDS and receives a positive result may suffer a number of possible injuries. Perhaps first and foremost among these is the danger of stigmatization and ostracism which may result." *Doe*, 526 N.Y.S.2d at 721 (citing American Med. Ass'n Bd. of Trustees, *Prevention and Control of Acquired Immunodeficiency Syndrome: An Interim Report*, 258 JAMA 2097, 2098 (1987)).

137. *See* Closen, *supra* note 123, at 875 n.172 ("[T]he trauma of learning about a positive antibody result can be psychologically devastating."); *see also* Marshall Forstein, *Understanding the Psychological Impact of AIDS: The Other Epidemic*, 4 NEW ENG. J. PUB. POL'Y 159 (1988); *Hearings before the Newborn Screening Committee* (Nov. 8, 1993) (testimonies of Eleanor Mitchell and Phyllis Sharpe, HIV-infected mothers of newborns). *See generally* AIDS PRACTICE MANUAL, § 1.2 (*Psychological and Social Concerns of People with HIV*).

may be particularly harsh,[138] as pregnancy becomes a particularly vulnerable occasion for unwanted intrusion.[139]

Not only would parturient women be forced to confront the medical and social realities of AIDS, which is a substantial burden in itself, but experts fear that these realities will cause some pregnant women to shun prenatal care and hospital births rather than risk being exposed.[140] "Care avoidance" is the term used to describe this unfortunate cycle, which exists predominantly among disadvantaged women who may already have reasons to distrust institutional authority.[141] These are the same populations among which seroprevalence rates are highest.[142] Mandatory testing and the consequent fear of exposure will increase care avoidance among those women who do not wish to be tested for AIDS. Thus, not only does care avoidance lead to increased infant mortality rates (because women who do not want to be tested give birth under less safe conditions), but it will undermine the goal of Bill No. 6747-B by preventing the children most at-risk from being tested.

Although the risk of care avoidance is not as significant a factor here as it is in the context of drug-addicted parturient women who

138. "[E]vidence suggests that poor, minority women risk the devastation of their personal and family relationships, the loss of social and medical services, the loss of control of their own medical decisions, and even the loss of their children." *Working Group on HIV Testing of Women and Newborns: A Policy Proposal for Information and Testing*, 264 JAMA 2416, 2418 (1990).

139. "The stigma of a positive HIV antibody test—loss of employment, insurance, housing, and other economic or social harm—provides another reason for women who suspect they are infected with HIV to avoid routine prenatal screening." Taunya Lovell Banks, *Women and AIDS—Racism, Sexism, and Classism*, 17 N.Y.U. REV. L. & SOC. CHANGE 351, 370 (1990).

140. *See* Kathleen Nolan, *Human Immunodeficiency Virus Infection, Women, and Pregnancy*, 17 OBSTETRICS & GYNECOLOGY CLINICS OF N. AMER. 651, 658 (1990); Field, *supra* note 32, at 422; Isaacman, *supra* note 135, at 482. *See generally Hearings before the Newborn Screening Subcommittee* (Nov. 8-9, 1993).

141. *See* Isaacman, *supra* note 135, at 481-82. These women fear accusations that they are unfit for motherhood, that they have abused the child, and that they are drug-abusers. *Id.* Some also fear, therefore, that their child will be taken from them and put in foster care; others may be living in this country illegally or are otherwise deterred by language, cultural, educational barriers. *See Hearing before the Newborn Screening Subcommittee* (Nov. 8, 1993) (Testimonies of Dr. Carola Marte of Beth Israel Medical Center—"stigmatization in the health care system is given as the primary reason for not seeking or for refusing HIV care"; David M. Abramson, MPH, of Columbia School of Public Health—relating to barriers to HIV care, "[t]he overriding concern expressed by these women was fear"; and Shannon Cain, Executive Director, Women's Health Education Project—mandatory HIV screening "could drive pregnant women further away from getting crucial prenatal care, not to mention make them hesitant to go to the hospital when it comes time to give birth").

142. *See supra* part II.A. (discussing the demographics of HIV-infection in women).

fear criminal or civil penalties for the intra-uterine transfer of illicit substances,[143] it is nevertheless a factor to weigh in the balance.[144]

The absence from Bill No. 6747-B of a provision for pre-test or post-disclosure counseling highlights its slight regard for the mother's privacy. Counseling could at least in part prepare at-risk mothers for the immediate and longterm difficulties that disclosure will entail. Instead, there is no preparation, education, or instruction, only the grim news of infection for both mother and, perhaps, child. This slight regard for the impact of disclosure on the mother runs counter to the doctrine of informed consent,[145] the protective laws in place in New York and many other states,[146] and the widely

143. *See, e.g.*, Isaacman, *supra* note 135.

144. A lesson can be learned from Illinois' experiment with a mandatory AIDS test as a prerequisite to attaining a marriage license. Proposed in January of 1988, the bill was repealed in September of 1989. Rather than submit to forced testing, hundreds of couples traveled to neighboring states to get their licenses. *See* George Papajohn & Charles Mount, *Illinois Licenses Soar After repeal of AIDS Test Law*, CHI. TRIB., Oct. 11, 1989, at 2.

145. For a general discussion of the doctrine, see FAY A. ROZOKOVSKY, CONSENT TO TREATMENT: A PRACTICAL GUIDE, §§ 11.0-11.11 (2d ed. 1990 & Supp. 1992). Informed consent, which derives from principals of tort rather than constitutional law, is central to issues of medical privacy. Broadly recognized by the states and the medical community, it has been embraced by the Supreme Court as well. *See* Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 270 (1990) ("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."). Some states, however, have selectively rejected the doctrine in certain circumstances, including pregnancy, see FLA. STAT. ANN. §§ 384.23(3), 384.31 (West Supp. 1992), and parental consent, see R.I. GEN. LAWS § 23-6-14(a) (1989 & Supp. 1993) (testing without consent at discretion of health care provider on any patient less than one year old); N.C. GEN. STAT. § 130A-148(h) (1989 & Supp. 1991) (testing without consent when there is a reasonable suspicion that a minor has AIDS or is HIV-infected). Confidentiality laws and informed consent are meant to encourage persons to seek care and reveal to caregivers the full circumstance of their illness without fear of betrayal to third persons or fear of receiving unwanted treatment. *See* ROZOVSKY, *supra*, at 740; Candace C. Gauthier, *HIV Testing and Confidentiality*, 2 BIOLAW 349, 351 (Mar.-Apr. 1990) (special section); *see also* Troyen A. Brennan, *AIDS and the Limits of Confidentiality*, 4 J. GEN. INTERNAL MED. 242 (1988). Exceptions to informed consent undermine the trust between at-risk women and caregivers that is crucial to improving access to care.

146. *See* Albert et al., *supra* note 6, at § 3.4(2). "Many states have now enacted legislation that specifically protects the confidentiality of HIV-related information. *The adoption of these statutes reflects the widespread acceptance of a public health strategy that encourages voluntary HIV antibody testing, and hence requires protection from harm for those who choose to be tested.*" *Id.* (footnote omitted and emphasis added). In addition to Art. 27-F of the Public Health Law, New York has in place other confidentiality-protective laws. *See* N.Y. PUB. HEALTH LAW § 2780(9) (McKinney Supp. 1990) (requiring fully-informed written consent and specification of the time, purpose, and recipient(s) of disclosure); N.Y. PUB. HEALTH LAW § 2781 (McKinney Supp. 1991), 1988 N.Y. Laws 9265-A § 2781(3), and N.Y. PUB. HEALTH LAW

accepted public health policy which informs those laws.[147] This head-in-the-sand pursuit of its goal handicaps the bill's effectiveness by increasing the likelihood of care avoidance by those most in need of care.

b. No Linkage to Care

Bill No. 6747-B offers no provision and no legislative strategy for providing the kind of follow-up care which disclosure is intended to facilitate. The bill thus raises, without answering, the question of how care will occur for the hundreds of new babies identified as antibody positive.

Identification merely begins the process of providing improved care. To surprise unprepared mothers with the doubly traumatic news that they are HIV-positive and their baby may also be will not necessarily lead to better treatment for their children. Particularly in an inner city environment, many obstacles stand in the way of that outcome. Linkage to care is hardly automatic.

First, there is already a scarcity of adequate counseling and services for those inflicted with HIV/AIDS, especially women.[148] Fear and discrimination are not stilled by the Hippocratic Oath, and

§ 2781(6), 2783 (McKinney Supp. 1991) (civil penalties plus misdemeanor for willful violations of confidentiality).

147. Not only does Bill No. 6747-B undermine the medical purpose behind informed consent, it also defies a trend in New York to shore this doctrine against further erosion. Since the late 1980's, "[t]he clear position of state and city health officials has been a virtually complete ban on involuntary testing for the HIV virus." Doe v. Roe, 526 N.Y.S.2d 718, 723. The legislature intended Article 27-F of the Public Health Law to "provid[e] *additional protection* of the confidentiality of HIV related information . . . [and] to encourage the expansion of *voluntary confidential testing* for the human immunodeficiency virus (HIV) so that the individuals may come forward, learn their health status, *make decisions* regarding the appropriate treatment, and *change the behavior* that puts them and others at risk of infection. The legislature also recognizes that strong confidentiality protections can limit *the risk of discrimination and the harm to an individual's interest in privacy* that unauthorized disclosure of HIV related information can cause. It is the intent of the legislature that *exceptions to the general rule of confidentiality of HIV related information be strictly construed.*" N.Y. PUB. HEALTH LAW § 2780 (McKinney 1993) (quoting § 1, L. 1988, c. 584, eff. Feb. 1, 1989) (emphasis added). This legislative rationale—stressing voluntary cooperation and behavioral change over the discriminatory risks of forced testing and disclosure—mirrors the argument against mandatory newborn screening.

148. *Hearing before the Newborn Screening Subcommittee, New York State AIDS Advisory Council* (Nov. 8-9, 1993); *see also* Arlene M. Butz et al., *HIV-Infected Women and Infants: Social and Health Factors Impeding Utilization of Health Care*, 38 J. NURSE-MIDWIFERY. 103 (1993); Carol Levine & Nancy Neveloff Dubler, *HIV and Childbearing: Uncertain Risks and Bitter Realities: The Reproductive Choices of HIV-infected Women*, 68 MILBANK Q. 321, 339 (1990) ("Access to health care in the inner cities varies from limited to nonexistent.").

there is rather an unfortunate withdrawal even within the medical community from the HIV/AIDS population.[149] In addition, there is a lack of funding for and organization of AIDS-related services.[150] As a result, the medical community dedicated on a daily basis to providing acute care is overwhelmed by the number of cases requiring acute care.[151] Without direct linkage to care, which requires an expansion of available services, those infants who are identified as at risk may find improved care unavailable.

Second, the proper response to a positive diagnosis is by no means obvious or simple. Without close supervision, improved care becomes a matter of guesswork. Treatment of newborn HIV-infection requires of the mother long-term, consistent, informed, behavioral change. In addition to looking after her own health and household, the infected mother may have to administer a regular, intense course of medication to the child, arrange for regular visits to a health care provider and follow the prescribed daily regimen, maintain a strict vigil over the infant's diet, general symptoms and behavior, and, in short, successfully modify her own behavior and

149. The stories of doctors and institutions turning their back on AIDS/HIV-inflicted patients are many. A typical story was related by Jeffrey Reynolds, representing the Long Island Association for AIDS Care, Inc., in his testimony before the Newborn Screening Committee, on Nov. 8, 1993. Mr. Reynolds told of recent efforts by the Association to contact doctors who would be willing to take AIDS/HIV referrals. Of the 13 contacted, 12 doctors said they would not take referrals, and one said to call "if things got bad." This phenomenon was confirmed recently by New York City Councilman, Thomas Duane, in an address at Fordham Law School on Nov. 10, 1993, entitled *Recent AIDS Legislation.* Mr. Duane, who represents a district that includes much of liberal Greenwich Village, noted that "even there" professional intolerance was unavoidable. For example, of 5,800 dentists surveyed nationwide, less than a third expressed a willingness to treat AIDS patients. Bruce Lambert, *Experts Fault Doctors on AIDS Efforts*, N.Y. TIMES, Apr. 23, 1990, at D3 ("Nine years into the AIDS epidemic, most of the nation's physicians still are failing to take part in the fight to treat and control the deadly disease, many health expert say"). This discrimination has persisted despite the state and federal anti-discrimination legislation it has necessitated, such as the Americans with Disabilities Act of 1990 ("ADA"). 42 U.S.C. §§ 12101-12189 (1990). The ADA prohibits discrimination against persons with disabilities, including AIDS or HIV infection (and, in some jurisdictions, those perceived to be HIV-infected). 104 Stat. 267, Pub. L. No. 101-336, 1990 U.S.C.C.A.N. (1990).

150. The Newborn Screening Subcommittee, citing "severe obstacles to the provision of timely medical, mental health, and supportive social services," *Newborn Screening Subcommittee Report, supra* note 13, at 21-22, called the existing network of programs "inaccessible, fragmented, or overburdened." *Id.* at 33.

151. The consensus among the Newborn Screening Committee was that current urban services were understaffed and overburdened. In the words of Co-Chair Dr. Carolyn Britton, addressing the 16-member committee on the availability of acute HIV/AIDS care in the New York City: "This is it. *We are it.*" *Hearing of the Newborn Screening Subcommittee, New York State AIDS Advisory Council* (Nov. 9, 1993).

regulate her household so as to reduce or eliminate any extraneous risks to her child's (or her children's[152]) health. Frequently, she must accomplish this under disadvantaged circumstances, and in the shadow of normally discriminatory attitudes towards her social and physical circumstance.

Third, current testing procedures raise unanswered questions about the nature and timing of disclosure itself, which is the crucial link between testing and care. Under the most commonly used form of newborn testing,[153] results are usually not returned to the hospital for several weeks.[154] Under new testing procedures that are gaining favor for their ability to more accurately identify the infant's actual status,[155] results still take from several days to several weeks to return, and some of these tests are not even useful until the newborn is several months old.[156] The net result is that the mother and child will already have been discharged from the hospital by the time results are available. This time lapse raises its own set of unanswered questions. How will a mother be notified of her results and will that means be compassionate and practical? Will all mothers even be reachable at their given addresses? If a mother does not respond to a mailed notice, what other measures will be taken? If a mother does not seek pediatric care at the same hospital at which she gave birth, will her treating physician know of her status or the infant's? If the mother does not respond at all, will she be subject to further State action? If inadequately answered, these details about notice could seriously impair the goal of improved care for HIV-positive infants.

Finally, without explicit linkage to care the mother may not overcome her own unwillingness to face her condition and the stigma it carries. Even her willingness to seek care for her child may be compromised by distrust of a test for which she was unprepared, or

152. Depending on when she contracted the virus, the HIV-positive parturient woman may have vertically passed it to previous children who may also be infected.

153. The routine infant HIV antibody test is the enzyme-linked immunosorbent assay ("ELISA") test. Tinkle et al., *supra* note 28, at 88. The ELISA test is often confirmed by a Western Blot test. *Id.* at 88-89.

154. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 4 (HIV test results take about one month).

155. *See* Field, *supra* note 32, at 424-25 n.82. These tests are the HIV Culture test, the Polymerase Chain Reaction, the P-24 Antigen test, and the IGA Antibody test. *Id.*; *see also Newborn Screening Subcommittee Report*, *supra* note 13, Appendix F (Current Procedures for Newborn Congenital Disease Screening).

156. *See* Field, *supra* note 32, at 424-25 n.82. These tests are the HIV Culture test, the Polymerase Chain Reaction, the P-24 Antigen test, and the IGA Antibody test. *Id.*; *see also Newborn Screening Subcommittee Report*, *supra* note 13, App. F (Current Procedures for Newborn Congenital Disease Screening).

by the 75% chance that her child is not in fact infected. Bill No. 6747-B's means do not realistically provide for its goal. The bill assumes that the common response to mandatory testing and disclosure will be the one that it implicitly demands—willing cooperation and fully informed behavioral change. In the real world, this assumption carries little weight.[157] Given the history of discrimination against persons with HIV/AIDS, its imperviousness to a cure, and the slim chance that the newborn will test positive—and even if it does, the 75% chance that it will seroconvert— it is clear that the ineffectiveness of the bill in remedying the problem it addresses renders it unreasonable in light of the privacy intrusion imposed by it. Without encouragement and information, and without the support to overcome the social stigma and physical debilitation of HIV-infection, behavioral change should not be assumed; and without care, forced disclosure is a profound burden without the promise of any benefit.

c. Bill No. 6747-B Unneccesarily Alienates the Mother

Mandatory testing reflects a policy that ignores the needs and views of the mother. In rushing to the cause of the newborn, the bill characterizes the mother in one harsh light: as a carrier in a chain of infection.[158] This narrow legislative conceptualization is unnecessary, unfair, and ultimately counter productive, because the success of the bill is contingent upon fully recognizing and empowering the mother as a care provider.[159]

157. *See* Field, *supra* note 32, at 413. Contrary to the presumption of increased precaution, persons mentally unprepared for disclosure of their status often engage in erratic, violent, self-destructive behavior. *Id.* Closen argues that even voluntary testing labors under"[t]he unspoken but fallacious rationale behind voluntary testing for [HIV] antibodies is that the person, once he or she learns that test result, will engage in some type of behavior modification." Closen, *supra* note 123, at 876. In the case of HIV-positive mothers of the positive newborn, however, the real fear is not self-destructive behavior but a lack of voluntary cooperation. It is hoped that voluntary testing and peer counseling linked to services will prepare the mother to place the needs of the child first. *See infra* part IV.A.2.f. (discussing the willingness of peer-counseled mothers to cooperate).

158. *See, e.g.,* Kurth & Hutchison, *supra* note 6, at 121.

159. Simply conceptualizing the mother as a carrier—as a source or vector of infection—has the further unfortunate result of putting the rights of the mother and the rights of the baby in conflict. The issue here, in terms of the law and ethics, should not be whose rights come first or whose rights are more important. In treatment as in birth, the mother and child should be treated as a unit. Improvements in family health care are made not by dividing the family unit, but by strengthening the internal and external apparatus which support it. *But see* Mayersohn, *supra* note 76, at 2 ("In any event, any reasonable person would argue that the baby's right to survive must be our first concern.").

Ironically, the mother's confidentiality and autonomy,[160] ignored by the state for purposes of testing and disclosure, become indispensable for purposes of improved treatment. At testing, the mother's interest in confidentiality is secondary; at disclosure, her privacy and the discrimination to which she will likely be subjected is also disregarded; but when it comes time to act on the results, the once transparent mother is again recognized and called upon to cooperate with the State by providing the care and supervision that it cannot. Although willing to step over the mother at the moment of birth for the sake of the child, the State must thereafter, for the sake of the child, step back and invite the mother to reassume the role it had usurped.[161]

A mother's voluntary decision-making and her privacy in so deciding provide the child's best hope for improved care. The real work of Bill No. 6747-B can only be achieved by a mother who is much more than a carrier. It is the mother who must bring the child for follow-up care, who must follow the caregiver's regimen, who must keep a healthy and loving home and respond to her child's changing condition. For the state to conceptualize and treat the mother one way when exercising its power, but rely on her in a completely different way when setting its goals, is political expediency. When the decision-making of the mother *after* disclosure is the key to the success of the state's intervention, her decision-making *before* testing should not be ignored.[162]

d. Questionable Benefits of Early Detection and Treatment

Questions concerning the benefits of early detection of HIV-infection in newborns further compromise the interests served by Bill No. 6747-B. While there is a clear consensus that early identifica-

160. *See infra* part III.B. (discussing autonomy).

161. *See Newborn Screening Subcommittee Report, supra* note 13, at 20 ("[T]he infected child's health and well being are usually directly dependent on his or her mother's health and well being.").

162. Whatever means are used to combat pediatric AIDS, it should not degrade, alienate, or isolate the mother. Voluntary testing is promising because it treats the mother as an ally rather than an adversary in the crusade for improved newborn care. As Dr. Britton noted at the Nov. 9 public hearing of the Newborn Screening Committee, the most effective care of the newborn and the family exposed to HIV/AIDS will occur in a supportive, loving environment. Her comments echo those of a legal scholar describing the essence of privacy. "To respect, love, trust, feel affection for others and to regard ourselves as the objects of love, trust and affection is at the heart of our notion of ourselves as persons among persons, and privacy is the necessary atmosphere for these attitudes and actions, as oxygen is for combustion." Charles Fried, *Privacy*, 77 YALE L.J. 475, 477-78 (1968).

tion of possibly infected newborns is itself desirable,[163] there is no consensus as to how to use early test results. There are two preliminary constraints on the utility of follow-up care: (1) there is no cure for HIV infection or pediatric AIDS, and (2) three-fourths of antibody-positive newborns are not infected and have nothing to gain from medical treatment. In addition, there are too many medical uncertainties to assume that an early identification of an antibody-positive newborn will of itself trigger improved care, especially the kind of immediate, acute care that proponents of the bill stress.

Because of the turnaround time required in current testing procedures no treatment is truly immediate. The normal lapse, simply for returning test results and not for actually notifying the mother or getting the newborn to a care facility, is several weeks; and studies show that it can take another *several months* before the parent of a positively tested child can be reached.[164] Therefore, although immediate care is stressed by proponents of the bill, delay in disclosure may neutralize the usefulness of "early" detection. Early treatment is crucial because HIV infection generally progresses faster in infants than in adults,[165] manifesting itself in opportunistic diseases as early as one week after birth.[166] Because of the shortened incubation period, prophylactic or antiretroviral treatment to prevent the onset of opportunistic diseases must occur as soon as possible.[167] This is especially true for the most deadly of the pediatric AIDS killers, *pneumocystis carinii pneumonia* ("PCP").[168] In one study, PCP presented itself at a median age of five months, with a median survival time thereafter of only one month.[169]

A second variable to be weighed when balancing the benefits of early medical treatment against the invasiveness of forced disclo-

163. *See, e.g.*, Mendez & Jule, *supra* note 12, at 637.

164. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 31 ("It often takes longer than a 13-week tracing period to reach a parent and requires a variety of strategies.").

165. *See generally* Scott et al., *supra* note 7.

166. *Id.* at 1792.

167. "In particular, there is only a short period during which antiviral treatment or other effective prophylactic measures can be initiated before the onset of clinical disease. This emphasizes the importance of early recognition of HIV-1 infection in children to permit early and effective treatment." *Id.* at 1795. In Scott's study, the majority of children diagnosed with HIV-associated diseases were under one year of age. *Id.* at 1792. The younger the child at diagnosis, the shorter the survival time. *Id.* at 1794.

168. *See* Field, *supra* note 32, at 430 (PCP is "the major lethal complication of pediatric HIV infection.").

169. *See* Scott, *supra* note 7, at 1791.

sure is the eventual seroconversion of three-fourths of those newborns who test positive. These children are not in fact infected, and just as healthy as any child born to a non-HIV-positive mother. There is therefore no benefit to these children from immediate, acute care. In fact there is a risk that highly toxic treatments can harm uninfected infants.[170] Proponents of the bill argue, however, that the benefit of early detection for uninfected newborns is that mothers made aware of their own status will not postnatally infect that child through contaminated breastmilk.[171] This argument is not persuasive. Although some studies have found the AIDS virus in breastmilk, and although some health organizations advise HIV-infected women not to breastfeed,[172] the medical data on transmission via breastmilk to non-infected children is inconclusive.[173] "Human immunodeficiency virus type 1 (HIV-1) has been detected in breast milk by both culture and polymerase chain reaction (PCR). However, this finding does not necessarily mean that breastfeeding is a route of transmission."[174] Transmission via breastmilk was first reported in 1985 in Australia; over the next five years, eight cases were reported, none in the United States.[175] Transmission may be more likely in postnatally infected mothers, who would not be detected by newborn screening tests.[176] While the CDC has recommended that women who are HIV-infected not breastfeed, "the relative importance of breast-feeding as a route of mother-to-child HIV-I transmission remains to be identified" and should be weighed against the benefits of breastfeeding.[177] Irrespective of the unproven benefits of avoiding breastfeeding, the need for forced testing and disclosure is further undermined by a demonstrated willingness of women who choose to breastfeed to

170. *See* Field, *supra* note 32, at 427. Some aggressive treatment, particularly AZT treatment, can be severely toxic "[t]hus, it is both dangerous and wholly without benefit to those infants who are not infected but still test positive." *Id.*

171. This course of action is highly touted by Assemblywoman Mayersohn in her advocacy of Bill No. 6747-B. *See* Mayersohn, *supra* note 76, at 1-2.

172. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 14. The New York State Department of Health recommends that infected women be counseled not to breastfeed. *Id.*

173. *See, e.g.*, Richard E. Stiehm & Peter Vink, *Transmission of Human Immunodeficiency Virus Infection by Breast-Feeding*, 118 J. OF PEDIATRICS 410 (Mar. 1990).

174. D.T. Dunn et al., *Risk of Human Immunodeficiency Virus Type 1 Transmission Through Breastfeeding*, 340 LANCET 585 (Sept. 1992).

175. Stiehm & Vink, *supra* note 173, at 410.

176. Dunn et al., *supra* note 174, at 585.

177. Martino et al., *HIV-I Transmission Through Breast-Milk: Appraisal of Risk According to Duration of Feeding*, 6 AIDS INST. 991, 995 (June 3, 1993).

submit to voluntary testing.[178] There is no extensive data on the subject, but at least one unpublished study has shown that women in high-risk areas face numerous obstacles to breastfeeding and are less likely to do so.[179] In addition, breastfeeding normally starts immediately after birth, and yet normal test results are not available until several weeks after, thus negating their prophylactic purpose for three-fourths of the positive newborns. If the usefulness of not breastfeeding is uncertain, if few mothers in high-risk areas tend to breastfeed, if those who do tend to breastfeed also tend to agree to voluntary testing, and if those mothers for whom the results could make a difference do not receive them until after breastfeeding has begun, then a primary rationale behind the bill is substantially negated.

A third variable involves uncertainties of prophylactic treatment for antibody-positive newborns in general. While the primary medical advantages of early treatment are not disputed,[180] there is disagreement among primary caregivers as to when and how treatment should be administered to positively tested newborns. While some caregivers may treat every newborn who tests positive with an aggressive course of prophylactic treatment, many will refrain from acting on the basis of test results alone.[181] These doctors, although put on notice to the newborn's status, will nevertheless hold off treatment of the asymptomatic infant until infection is corroborated by a second source, such as symptomatic infection, documentation of actual infection, or a sufficiently low CD4 lymphocyte count.[182] Thus, although the initial infant screening is useful for putting the caregiver on notice and for prompting frequent immunologic and virologic monitoring, primary acute care is predicated

178. *See* Kathleen Nolan, *Human Immunodeficiency Virus Infection, Women, and Pregnancy*, 17 OBSTETRICS & GYNECOLOGY CLINICS OF N. AM. 651, 655 (Sept. 1990).

179. *See Obstacles to Breastfeeding* (Systems Approach to Nutrition for Children (SANC) Study done at Columbia School of Public Health in Spring of 1992).

180. The most important treatment benefits arising from early detection are: (1) prophylactic or retroviral therapy with AZT (Zidovudine) (to minimize the effects of the virus on the various organs and systems of the body); (2) immunologic and virologic monitoring (to alter immunization schedules and procedures so as not to provide opportunities for infection, and to monitor and respond to changes in the infant's health); (3) PCP prophylaxsis (to reduce the likelihood or mitigate the effects of pneumocystis carinii pneumonia, perhaps the most dangerous of the pediatric opportunistic HIV diseases); and (4) administration of intravenous immune globulin (to bolster natural defenses). *See, e.g.*, Mark Kleine et al., *A National Survey on the Care of Infants and Children with Human Immunodeficiency Virus Infection*, 118 J. PEDIATRICS 817, 820-21 (May 1991).

181. *Id.*

182. *Id.* at 820.

not on testing but on reliable case-by-case confirmation.[183] Ethical and medical uncertainties account for some of the hesitation in pursuing an aggressive course of treatment solely on the basis of newborn screening results. Acute care is inhibited by the perception that neonatal HIV infection is a fatal condition, and that even optimal care cannot provide a cure.[184] Treatment may ease some symptoms, forestall or prevent opportunistic disease, or perhaps only prolong a pain-filled life.[185] For these and other reasons, aggressive treatment is not always recommended by physicians.[186]

Although less is known about treatment of infant infection than adult infection, this gap is narrowing. As more is known about the nature of vertical transmission,[187] as more accurate and faster diagnostic techniques are developed, and as more effective treatment is perfected, the medical benefits of early detection will be more likely to outweigh its intrusiveness. Today, however, the medical advantages, when put in context, are significantly restricted.

e. Bill No. 6747-B Applies the Wrong Model

Bill No. 6747-B is conceptually and practically flawed by its application of a traditional public health intervention solution to a problem that does not fit a traditional public health intervention model.[188] The lack of an immediate and dramatic treatment, the impossibility of a definitive newborn diagnosis, the profound stigma attached to AIDS, the absence of direct linkage to care, and the inherent complications of early treatment[189] make newborn

183. *See Newborn Screening Subcommittee Report*, *supra* note 13, at 17 ("[I]t appears that factors other than lack of knowledge of HIV status may also be responsible for the fact that PCP prophylaxix is not available to all infected children.").

184. Betty Wolder Levin et al., *Treatment Choice for Infants in the Neonatal Intensive Care Unit at Risk for AIDS*, 265 JAMA 2976, 2978 (1991).

185. *Id.*

186. *Id.* In one survey conducted in six neonatal intensive care units in New York City, respondent physicians said that even if there were a definitive HIV test available, they would withhold treatment because an infected newborn's quality of life, is so diminished by the pain and suffering which accompany infection. Other respondents, however, said they would pursue an aggressive course of treatment even when it was uncertain that the infant was infected, because (1) the infant could become infected, (2) the infant could survive a long time without infection, (3) a better quality of life could be achieved, and (4) life could be prolonged until a cure was found. *Id.*

187. *See* Altman, *supra* note 56, at A1; also discussed *infra* part VI.

188. *See* Nolan, *supra* note 178, at 656; *Neonatal HIV Screening: Is Good Ethics Bad Practice?*, 1 PEDIATRIC AIDS AND HIV INFECTION: FETUS TO ADOLESCENT 71, 73 (1990) [hereinafter *Good Ethics/Bad Practice*].

189. It is impossible to ignore that HIV/AIDS *is* different from any other disease, medically, socially, and even legally. *See* Doe v. Roe, 526 N.Y.S. 2d 718, 722 (Sup. Ct. N.Y. County 1988) ("While there is no consensus under what circumstance the ex-

HIV screening radically unlike routine screening and intervention for other treatable metabolic disorders such as PKU (phenylketonuria), hyperthyroidism, or maple-syrup urine disease, or treatable infectious diseases such as hepatitis B or syphilis.[190]

A traditional public health model such as mandatory vaccinations of schoolchildren for certain communicable diseases[191] is based on an "infectious disease paradigm" in which health officials identify a specific disease and take effective steps to prevent its spread in the public.[192] This model relies on the assumption that the proven prevention of harm to oneself and others will find universal acceptance.[193] The intrusiveness of a public health model is primarily justified by its ability to offer fast and effective treatment and/or prevention. Mandatory testing and disclosure of parturient women offers neither and "work[s] best in circumstances where parents can be expected to be grateful for screening results that *cause little harm* and at the same time allow *obviously beneficial interventions*."[194] Similarly, the public health model is "most easily justified when safe and effective interventions to prevent disease transmission are available and when the spread of the disease to a large number of persons is expected."[195] Newborn HIV screening does not promise prevention, nor does it involve large numbers of persons.

Distinguished from the traditional public health model are family planning and genetics models concerned with parental responsibility.[196] As opposed to the emphatic mandate underlying the public health model, family planning and genetic models lack a clear intervention solution and therefore "emphasize individual choice; the norms of promoting autonomy and 'value neutrality'

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traordinary remedy [of] involuntary testing should take place, it is clear that the medical, psychosocial, and legal ramifications of such testing *place it on an entirely different plane* than other, non-invasive or minimally invasive procedures.") (emphasis added).

190. *Good Ethics/Bad Practice*, *supra* note 188, at 73; *see also* Field, *supra* note 32, at 427 (calling PKU "the paradigm for a procedure to which parents cannot effectively withhold consent" and differentiating PKU from HIV screening).

191. *See, e.g.*, N.Y. PUB. HEALTH LAW § 2164(9) (McKinney 1993) (mandatory vaccination of schoolchildren).

192. Nolan, *supra* note 178, at 656.

193. *Id.*

194. *Good Ethics/Bad Practice*, *supra* note 188, at 73 (emphasis added).

195. Nolan, *supra* note 178, at 656. In contrast, the genetic screening model "has been adopted in situations where, despite heavy burdens from disease, effective interventions are lacking and the risk of transmission is relatively low, either in terms of the risk to the individual or in terms of the total number of individuals likely to be exposed." *Id.*

196. *Id.*

reflect a respect for the ethical ambiguities generated by the delicate array of competing values encountered."[197] Because newborn HIV screening is far closer to a family planning or genetics model than the traditional public health model, its purpose is not well served by a mandatory program.[198]

Finally, a public health model intervention does not rely on ongoing, voluntary participation. Bill No. 6747-B, however, would represent a meaningless intrusion if it failed to inspire serious long-term cooperation.

f. Voluntary Cooperation is a Superior Alternative

When balancing the state interest advanced by a statute which infringes on individual privacy, a court will consider the existence of alternative, less intrusive means to the same end;[199] when such an alternative exists, it will weigh heavily against the state's choice of the more restrictive statute.[200] There is a clear alternative to mandatory newborn screening which is both less invasive and more likely to succeed: voluntary testing tied to peer counseling.

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197. *Id.* Newborn screening is further distinguishable from traditional intervention models in that it implicates the rights of the mother rather than those of the subject actually tested.

198. Nolan also argues in *Good Ethics/Bad Practice*, *supra* note 188, that HIV screening of newborns is closer to the genetic model than the public health model.

> The closest analogies for neonatal HIV screening would be screening for such conditions as cystic fibrosis or sickle cell anemia, in which treatment does not cure or correct the underlying conditions but may improve quality of life or, in some instances diminish morbidity and mortality. It is worth noting that only a few states have opted to conduct routine neonatal screening for these conditions, despite their severity, prevalence, and relatively non-stigmatizing character.

Good Ethics/Bad Practice, *supra* note 188, at 73. Nolan concludes that,

> [n]ecessity [of care], however, must be defined with reference to specific diagnostic and management needs of the individual children, not to a vague desire to identify and thereby benefit all infants at risk. Until effective therapies become available for asymptomatic HIV-infected children, early identification cannot be deemed essential, and involuntary approaches cannot be justified.

Id. at 73; *see also* ROBERT ROOT-BERNSTEIN, RETHINKING AIDS: THE TRAGIC COST OF PREMATURE CONSENSUS (1993). Root-Bernstein criticizes the medical establishment's tunnel vision approach to HIV/AIDS research and calls instead for a new, "multidisciplinary" approach that views AIDS as a social disease that cannot be understood purely in medical, biological, or laboratory terms.

199. *See* discussion of *Wong Wai v. Williamson* and other cases, *supra* notes 117-19 and accompanying text.

200. Dunn v. Blumstein, 405 U.S. 330, 343 (1972); Griswold v. Connecticut, 381 U.S. 479, 485 (1965); Aptheker v. Secretary of State, 378 U.S. 500 (1964); Shelton v. Tucker, 364 U.S. 479, 488 (1960); Cullen v. Fliegner, 1994 WL 59923 (2d Cir. Feb. 28, 1994); Black v. Beame, 550 F.2d 815, 817 (2d Cir. 1977).

The argument for voluntary screening is straightforward. In removing Bill No. 6747-B's offense against privacy—there is no invasion of the mother's right to confidentiality when she agrees to be tested—a voluntary program simultaneously increases the likelihood of improved care for the newborn. It does this by removing the obstacles inherent in a mandatory approach. Soliciting informed cooperation from the mother, through pre- and post-natal counseling, reduces the likelihood of care avoidance,[201] increases the likelihood of cooperation with test results and follow-up care, avoids alienation of the mother, and maximizes the likelihood of positive, voluntary behavioral change. The mother who agrees to be tested, who is adequately prepared to receive and respond appropriately to her results, has already weighed the burdens of testing against its benefits and chosen to pursue treatment should it become necessary. A mother who cooperates with testing, who has been prepared for a positive disclosure and educated on how to respond, is more likely to engage in the behavioral modifications needed to improve the lives of her child, herself, and her family.

Proponents of Bill No. 6747-B argue that the voluntary approach has failed,[202] but as Dr. Carolyn Britton, Co-Chair of the New York State AIDS Advisory Council Subcommittee on Newborn Screening, has perceptively noted, we must ask what "failure" means before dismissing voluntary programs. Mandatory testing advocates urge that failure means that only a small percentage of parturient mothers submit voluntarily to testing.[203] In fact, under the current system, which does not even routinely encourage voluntary testing,[204] approximately one-half of all HIV-infected women already consent to testing.[205] If active encouragement of testing were pursued through peer counseling at all hospitals, the voluntary cooperation rate is likely to rise significantly.

In Harlem Hospital, for example, where a highly concentrated at-risk population is served, voluntary counseling achieves cooperation rates around 95%.[206] This is an extraordinarily high and encouraging rate which exceeds even the most optimistic predictions

201. However, for those women who would avoid prenatal care regardless, the presence of prenatal counseling would make no difference. It is estimated that 10% of childbearing women receive no prenatal care. *See* Navarro, *supra* note 15, at A44.

202. Mayersohn, *supra* note 76, at 3 ("[T]here is no evidence that counseling and voluntary testing initiatives have been successful.").

203. *Id.*

204. *See* Navarro, *supra* note 18, at B4.

205. *See* Navarro, *supra* note 15, at A44.

206. *Id.*

for an involuntary system.[207] Unfortunately, and despite its success, it is among the only fully-staffed, fully-funded programs in the city. There is nothing to indicate that the Harlem program cannot be duplicated, and the effort to do so could begin with increasing staffing and funding in all hospitals and initiating a program of routine pre- and post-natal counseling that strongly encourages testing.

Harlem's is not the only success story. Other sites indicate that enhanced attention to education and pretest counseling result in increased cooperation with screening efforts. A study done at the Johns Hopkins Hospital in Baltimore revealed that acceptance rates for voluntary HIV testing were 96% in hospitals and 85% in sexually transmitted disease clinics.[208] And there are other less dramatic, relative successes. In one understaffed program at a major inner-city hospital, seven counselors working with 50 pregnant women a day achieved a 55% compliance rate, a figure matched by 17% of New York City hospitals.[209] In another understaffed program, 75-80% of parturient mothers were tested within three months of delivery.[210]

The appeal of a mandatory approach is the promise of improved care for all at-risk newborns. Unfortunately, Bill No. 6747-B's results would not keep pace with this promise. In contrast, the realistic promise of voluntary testing, as Harlem Hospital's experience indicates, is far more encouraging—without invading the mother's privacy.

None of these considerations—discrimination, care avoidance, no linkage to care, alienation of the mother, compromised early identification benefits, wrong health model—could on its own render Bill No. 6747-B unconstitutional, but cumulatively, and especially in light of the superior, less intrusive alternative of strongly encouraged and counseled voluntary testing, they so undermine the governmental purpose of the bill that it is clearly outweighed by the individual burdens it would cause.

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207. Because of the obstacles discussed in this part of the Note, 100% compliance is not a realistic goal even in a compulsory scheme.

208. Thomas C. Quinn, *Screening for HIV Infection—Benefits and Costs*, NEW ENG. J. MED. 486, 487-88 (Aug. 13, 1992). The latter figure represents a 20% increase in a two-year period. *Id.* at 488.

209. *Hearing of Newborn Screening Subcommittee, New York State AIDS Advisory Council* (Nov. 30, 1993) (Comments of Dr. Allan Rosenfield, Dean of Columbia School of Public Health and Newborn Screening Committee member).

210. *Hearing of Newborn Screening Subcommittee, New York State AIDS Advisory Council* (Nov. 8, 1993) (Comments of Dr. Kieth Krasinski, pediatrician and Newborn Screening Committee member).

B. Autonomy: Strict Scrutiny of Governmental Intrusion

As varied as governmental responses to HIV/AIDS have been, Bill No. 6747-B is unique in that it alone is predicated entirely on the occurrence of a discrete biological event, the birth of a child. This perhaps is part of its political allure: infants are seen as the most innocent and helpless, and least threatening, of HIV/AIDS victims. But the fact that the proposed testing scheme is premised on birth and the mother's decision to take her fetus to term has a more significant legal meaning. Unlike other mandatory testing schemes, Bill No. 6747-B implicates the second strand of privacy identified in *Whalen*, namely autonomy, or "independence in making certain kinds of important decisions."[211]

This kind of privacy, which has also been called the right to self-determination and is perhaps best characterized as a liberty,[212] has a rich and varied constitutional heritage. It has been rooted by the Supreme Court in the First,[213] Fourth and Fifth,[214] and Ninth Amendments,[215] and the penumbras of the Bill of Rights.[216] Today, it is secured by the Court in the Due Process Clause of the Fourteenth Amendment.[217]

Only those rights which are "fundamental" or "implicit in the concept of ordered liberty" are included under the constitutional guarantee of individual privacy.[218] Fundamental rights are parsed

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211. *Whalen*, 429 U.S. at 599-600. For a related study on the various factors that influence the decision-making process of a pregnant HIV-positive woman choosing whether to continue her pregnancy, see Kurth & Hutchison, *supra* note 6, at 122.

212. *See* Planned Parenthood v. Casey, 112 S. Ct. 2791 (1992), discussed *infra* part IV.C.1.; *see also, e.g.*, Cleveland Bd. of Educ. v. Lafleur, 414 U.S. 632, 639-40 (1974) ("This Court has long recognized that freedom of personal choice in matters of marriage and family life is one of the liberties protected by the Due Process Clause of the Fourteenth Amendment.").

213. Stanley v. Georgia, 394 U.S. 557, 564 (1969).

214. Terry v. Ohio, 392 U.S. 1, 8-9 (1968); Katz v. United States 389 U.S. 347, 350 (1967).

215. Griswold v. Connecticut, 381 U.S. 479, 486-87 (1965) (Goldberg, J., concurring).

216. *Id.* at 484-85.

217. *See* Roe v. Wade, 410 U.S. 113, 152-53 (1973) ("This right of privacy, whether it be founded in the Fourteenth Amendment's concept of personal liberty and restrictions upon state action, *as we feel it* is . . .") (emphasis added); *see also* Meyer v. Nebraska, 262 U.S. 390, 399 (1923).

218. *Griswold*, 381 U.S. at 499-502 (Harlan, J., concurring). Justice Harlan, in his influential concurrence in *Griswold*, argues that the justification for extending the fundamental protection of the Due Process Clause of the Fourteenth Amendment beyond those rights explicitly assured by the letter or penumbra of the Bill of Rights is found in our tradition of adherence to those basic values "implicit in the concept of ordered liberty," a concept originally enunciated by Justice Cardozo in Palko v. Connecticut, 302 U.S. 319, 325 (1937).

into several discrete "zones of privacy."[219] These zones include marriage,[220] procreation,[221] contraception,[222] family life,[223] and child rearing and education.[224] State action which infringes on self-determination within these zones traditionally triggers the highest level of constitutional review: *strict scrutiny*. Under strict scrutiny, the legislation in question must use narrowly tailored means to achieve a compelling state interest.[225]

1. *Autonomy after* Planned Parenthood v. Casey*: A New Standard?*

In reviewing the constitutionality of state imposed restrictions on access to abortion,[226] *Planned Parenthood v. Casey*[227] altered the interplay between strict scrutiny and autonomy. Like *Roe v. Wade*,[228] the seminal abortion case which *Casey* revisited and left substantially intact,[229] *Casey* lies squarely within the reproductive rights zone of privacy. Unlike *Roe*, however, *Casey* did not apply strict scrutiny review.[230] The Court instead offered an updated formulation of an "undue burden" test that had surfaced fleetingly, and without majority support, in earlier decisions.[231] The "undue

219. *Roe*, 410 U.S. at 152.

220. Loving v. Virginia, 388 U.S. 1, 12 (1967); Zablocki v. Redhail, 434 U.S. 374 (1978).

221. Skinner v. Oklahoma, 316 U.S. 535, 541-42 (1942).

222. Eisenstadt v. Baird, 405 U.S. 438, 453-54 (1971) (White, J., concurring in result).

223. Prince v. Massachusetts, 321 U.S. 158, 166 (1944); Moore v. City of East Cleveland, 431 U.S. 494 (1977).

224. Meyer v. Nebraska, 262 U.S. 390 (1923); Pierce v. Society of Sisters, 268 U.S. 510, 532 (1925). For a reiteration of these protected zones, see, e.g., Paul v. Davis, 424 U.S. 693, 713 (1976).

225. *See, e.g.*, *Roe*, 410 U.S. at 155.

226. In *Casey*, the Court examined a Pennsylvania statute restricting access to abortion through five preconditions; the informed consent, a 24-hour waiting period and parental notice requirements were all upheld while the spousal consent and the record-keeping requirement of spousal notice were struck as constituting an "undue burden" on a woman's right to seek an abortion.

227. 112 S. Ct. 2791 (1992).

228. 410 U.S. 113 (1973).

229. *See Casey*, 112 S. Ct. at 2821 ("Our adoption of the undue burden test does not disturb the central holding of Roe v. Wade, and we reaffirm that holding.").

230. The essence of *Casey* is contained in a plurality opinion signed by Justices Souter, Kennedy and O'Connor and written by Justice O'Connor. The plurality reflects a compromise position between that faction of the Court that wished to keep strict scrutiny as the level of review (Justices Blackmun and Stevens) and that faction which wished to overturn *Roe* and reduce the level of scrutiny to that of rational relationship (Chief Justice Rehnquist and Justices White, Scalia, and Thomas).

231. *Casey*, 112 S. Ct. at 2820 ("In our view the undue burden standard is the appropriate means of reconciling the state's interest with the woman's constitutionally

burden" test is a form of balancing that accommodates both personal liberty and important state interest by weighing one against the other.[232] As its factual touchstone, undue burden analysis asks whether the government has placed a "substantial obstacle in the path of a women seeking an abortion" of a pre-viable fetus.[233]

The extent of the change wrought by *Casey* has yet to be determined. The "undue burden" test may in practice apply *only* to instances of state interference with the decision to terminate a pregnancy, thus leaving strict scrutiny intact for all other fundamental rights review.[234] On the other hand, "undue burden" may emerge as the new, more flexible standard by which *any* interference with individual autonomy is measured.[235] Although commentators have generally assumed that *Casey* is apropos only to abortion-restrictive legislation,[236] and although the lower courts have yet to apply the undue burden analysis outside the issue of

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protected liberty."); *see also* City of Akron v. Akron Center for Reproductive Health, 462 U.S. 416, 453 (1983) (O'Connor, J., dissenting); Maher v. Roe, 432 U.S. 464, 473-74 (1977) (*Roe* protects the woman from "unduly burdensome" interference with her freedom to decide); Bellotti v. Baird, 428 U.S. 132, 147 (1976) (state may not impose "undue burdens" upon a minor capable of informed consent); Doe. v. Bolton, 410 U.S. 179, 198 (1973) (striking an abortion regulation that was "unduly burdensome").

232. *Casey*, 410 U.S. at 2821 ("An undue burden exists, and therefore a provision of law is invalid, if its purpose or effect is to place a substantial obstacle in the path of a woman seeking an abortion before the fetus attains viability.")

233. *Id.*

234. A restriction of "undue burden" to abortion cases is indicated by several factors, including: (1) the immediate concern of the *Casey* Court, and the sole issue before it, was access to abortion services; (2) the plurality stresses in its opinion that abortion is "unique to the human condition and so unique to the law", *Casey*, 112 S. Ct. at 2807, not a representational one; (3) the plurality prefaces its argument, and carefully circumscribes it, by noting "we find it imperative to review once more the principles that define the rights of the woman and the legitimate authority of the State respecting the termination of pregnancies by abortion procedures." *Id.* at 2804; and (4) the joint opinion stresses the special nature of the governmental interest in promoting abortion.

235. Strong evidence supporting this position includes: (1) the plurality anchors its opinion in a broad prefatory description of the evolution of liberty as a fundamental right, *id.* at 2805, thus placing the decision to terminate a pregnancy squarely within the substantive due process doctrine and alongside other protected areas of marriage, procreation, contraception, and child birth; *id.* at 2804, (2) the plurality stresses the "rational process" by which all fundamental rights are derived and the "reasoned judgment" by which they are *balanced* against the State interest; *id.* at 2805; (3)"undue burden" is interpreted to be consistent with the Court's earlier jurisprudence of liberty, *id.* 2818, and freedom of reproductive choice is linked to not only women's autonomy but to gender equality as well; and (4) *Roe*, under review, is seen "not only as the exemplar of *Griswold* liberty [freedom from unwarranted government intrusion] but of the rule . . . of personal autonomy and bodily integrity." *Id.*

236. *See, e.g.*, David L. Faigman, *Madisonian Balancing: A Theory of Constitutional Adjudication*, 88 Nw. U. L. Rev. 641 (1994); Kathryn Kolbert & David H.

abortion,[237] there have been no decisions which explicitly circumscribe *Casey's* undue burden balancing within the abortion context. Under either test, Bill no, 6747-B cannot survive constitutional review.

2. *Strict Scrutiny is Fatal to Bill No. 6747-B*

Under the strict scrutiny test, which requires that a compelling state interest be achieved through narrowly tailored means,[238] at least three protected zones of privacy would be unconstitutionally invaded by mandatory testing and disclosure of parturient women: procreation, family life, and child rearing.[239]

Strict scrutiny is fatal to Bill No. 6747-B because an alternative means exists which is more narrowly tailored to the State purpose. Voluntary testing tied to peer counseling avoids both the substantial privacy invasion of mandatory screening and the built-in obstacles (such as care avoidance, lack of follow-up care, alienation of the mother) to improved care associated with it.[240] The approach proposed by Bill No. 6747-B can hardly be found "narrowly tailored" when it applies a traditional public health solution to an issue that does not raise traditional public health problems.[241] As discussed below, the mandatory screening is also grossly overinclusive.[242] Furthermore, the purpose of the bill, improved care, is not "compelling," insofar as current medical treatment, even if available to and accessed by tested mothers, cannot offer a cure for pediatric AIDS or HIV infection.[243]

Gans, *Responding to Planned Parenthood v. Casey: Establishing Neutrality Principles in State Constitutional Law*, 66 TEMP. L. REV. 1151 (1993).

237. The typical district court case relying on *Casey* applies undue burden reasoning to evaluate, as did the *Casey* Court, the restrictive provisions of a given state's abortion statute to see if it placed a "substantial obstacle" in the path of women seeking abortions in that state. *See, e.g.*, Barnes v. Mississippi, 992 F.2d 1335, 1339 (5th Cir. 1993) (using *Casey* to uphold a Mississippi statute requiring two-parent consent to an abortion by a minor but providing a judicial by-pass); Sojourner v. Edwards, 974 F.2d 27, 30 (5th Cir. 1992) (using *Casey* to invalidate a Louisiana statute prohibiting abortions except under extreme circumstance).

238. *See, e.g.*, Carey v. Population Servs. Int'l, 431 U.S. 678, 686 (1977); *Zablocki*, 434 U.S. at 388; *Roe*, 410 U.S. at 155 ("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 interests at stake.") (citations omitted).

239. The nature of the intrusion into each of these zones is discussed *infra* part IV.B.3.

240. *See supra* part IV.A.2.f.

241. *See supra* part IV.A.2.e.

242. *See infra*, notes 339-49 and accompanying text.

243. *See supra* part IV.A.2.d.

3. Bill No. 6747-B Fails a Rigorous "Undue Burden" Analysis

In an expansive reading of *Casey*, State regulation of any constitutionally protected zone of privacy would be subject to undue burden review. A statute regulating one of these zones would be unconstitutional only if it created an undue burden in the form of a "substantial obstacle" placed between an individual and the constitutionally protected zone of privacy in which she chooses to act.[244] Undue burden analysis is essentially a balancing test which compares the free exercise of a fundamental right or liberty interest against the statutory effect of making the exercise of that fundamental right more difficult. As demonstrated in *Casey*, judging whether a statute has the purpose or effect of creating a substantial obstacle that makes it too difficult for an individual to act independently is an empirically based, fact-intensive exercise. In judging the multiple restrictions contained in the Pennsylvania statute,[245] the *Casey* Court essentially inquired whether each restriction on its own made it too difficult for a woman to choose abortion over childbirth.[246] As shown through a brief comparison of the Court's analysis of two of the Pennsylvania restrictions, a twenty-four hour waiting period and spousal consent, this empirical analysis requires fine line-drawing.

The Court stressed the benefit and de-emphasized the burdens of the twenty-four hour waiting period in finding that it did not constitute a substantial obstacle. According to findings of fact from the district court, the wait entailed increased costs and potential delays substantially longer than one day, as well as increased opportunity for exposure to harassment from anti-abortion demonstrators.[247] These hardships were expected to fall most heavily on those women with the least money, the farthest to travel, and the most difficulty in explaining absences to husbands, employers, and

244. *Casey*, 112 S. Ct. at 2820.

245. The statute at issue in *Casey*, the Pennsylvania Abortion Control Act of 1982, 18 PA. CONS. STAT. §§ 3203-3220 (1990), stipulated five prerequisites for access to abortions: (1) informed consent, (2) a twenty-four hour waiting period, (3) parental consent for minors (with a judicial by-pass option), (4) spousal notice, and (5) reporting of abortion related information to the State by the facilities providing the service. The statute allowed for exemption from these requirements in "medical emergencies." *Casey*, 112 S. Ct. at 2803.

246. *See Casey*, 112 S. Ct. at 2791. However, "[t]he *Casey* joint opinion manifests distinct confusion over which party bears the burden to demonstrate or refute the fact that the regulation poses a substantial obstacle to the exercise of the right." Faigman, *supra* note 236, at 688.

247. *Casey*, 112 S. Ct. at 2825.

others.[248] The primary benefit of the wait, pinned by the Court to the coattails of the statute's informed consent requirement, was that it allowed for the time to make an informed and deliberate choice. In light of the medical emergency exemption, the wait was not considered to create a health risk.[249] The Court also held that earlier decisions justified State regulations which favored child birth over abortion.[250] In sum, the Court, having reasoned that the wait did not make the right to choose too difficult to exercise, announced that "a particular burden is not of necessity a substantial obstacle."[251]

In contrast, the Court minimized the benefits and stressed the burdens imposed by the spousal notice requirement in finding that it represented a substantial, and therefore unconstitutional, obstacle to a woman's right to choose. The Court cited eighteen findings of fact from the district court regarding the effect of the notice provision, all emanating from issues of marital abuse, wife battering, and domestic violence.[252] The Court even went beyond the factual record to introduce studies in support of the lower court's conclusion that fear of physical and psychological abuse would justifiably deter abused women from notifying their husbands. Because there was no exemption from the notice requirement for such women, and because of the "millions of women in this country who are the victims of regular physical and psychological abuse at the hands of their husbands,"[253] the provision was "likely to prevent a significant number of women from obtaining an abortion."[254] The Court held that spousal notice "does not merely make abortions a little more difficult or expensive to obtain; for many women, it will impose a substantial obstacle."[255]

The outcome of an undue burden analysis of Bill No. 6747-B would depend on how *Casey* is interpreted and applied by a lower court, and on how it identifies and weighs the salient facts involved. If the court follows *Casey's* more lenient language and analysis, as was used for the twenty-four hour waiting period, the bill is likely to be upheld. This approach would require focusing on the bill's benefits—namely improved care for HIV-positive newborns—and

248. *Id.*
249. *Id.*
250. *Id.*
251. *Id.*
252. *Id.* at 2826-27.
253. *Id.* at 2828.
254. *Id.* at 2829.
255. *Id.*

discounting its burdens. In its most lenient language, the Court noted in upholding the record-keeping provision of the Pennsylvania statute that "it cannot be said that the requirements serve no purpose other than to make abortions more difficult."[256] If applied in so obliging a fashion, undue burden analysis cannot invalidate mandatory testing and disclosure to parturient mothers.

However, if *Casey* is applied more rigorously, a good argument can be made that Bill No. 6747-B would not survive an undue burden analysis. Several factors favor a more rigorous application: (1) the difficulties that would be experienced by mothers under the bill are not concerned merely with increased costs or inconvenience; (2) the State interest at stake is not the unique interest in promoting child birth, but the less compelling interest of improving health care to children, three-fourths of whom are not in fact HIV-infected; (3) the benefits promised by the bill are far more compromised and far less concrete than the relative benefit to the State of favoring child birth over abortion; and (4) the burdens implicit in mandatory AIDS testing and disclosure—fear of physical suffering and social discrimination— are similar to those "unfortunate yet persisting conditions"[257]—physical and psychological abuse—which the *Casey* Court found so disturbing in striking down the spousal notice requirement.

In discussing the bill's intrusion into the three zones of privacy discussed below, this Note argues that the difficulties impressed on women who are forced by the State to confront their HIV infection and the possible infection of their newborns constitutes a "substantial obstacle," and therefore an undue burden in their exercise of autonomy in those constitutionally protected areas.

a. Burden on Reproductive Rights.

Under Bill No. 6747-B, every woman giving birth in a hospital will be tested for HIV. Every woman giving birth in a hospital will therefore be forced to add to her basic childbearing decision-making process the separate issue of when and how to confront her HIV status. Considering the physical implications heralded by a positive test result (such as extreme weight loss, skin lesions, prolonged suffering, and death), and the profound discrimination which follows AIDS, this new factor is undoubtedly a significant burden on her decision-making. It would not be unreasonable for

256. *Id.* at 2833.
257. *Id.* at 2830.

a woman to choose not to know her status, and the State's denial of this choice would create a substantial obstacle in deciding when and how to have a child.

For women in high-risk areas, mandatory newborn screening represents a particularly burdensome intrusion.[258] Childbearing in these urban areas is frequently the culmination of strongly held personal, family, social, religious, and ethical values which help define the individual and establish vital bonds to something beyond the immediate landscape of poverty and despair.[259] Imposing compulsory HIV testing and disclosure on this self-defining moment seriously complicates the would-be mother's decision-making.

Mandatory testing may present so substantial an obstacle to a woman exercising her procreative rights that she avoids prenatal and intrapartal care altogether rather than risk being exposed, a pattern of care avoidance with serious health risks for both the mother and child.[260]

b. Burden on Childrearing and Family Life

It is well-settled that the Constitution restricts the "State's right to interfere with a person's most basic decisions about family and parenthood."[261] Within either zone, an individual is free to act autonomously, without unjustified governmental interference. If enacted, Bill No. 6747-B would represent a serious incursion into these two fundamental zones of privacy.

The vertical transmission of HIV from mother to child is first and foremost a family health matter. The genealogy of the infection encompasses the entire nuclear family, and can be traced back from the infant to its mother, and perhaps to its father as well. Transmission, after all, occurs during the *in utero* development of a new son or daughter and comes to light at the defining moment of life and family: birth. After imposed disclosure, the infection of the mother and possible infection of the newborn will cast the family under the shadow of AIDS and its medical, economic, and social complications. A positive diagnosis would place unexpected, substantial stresses on all facets of the family life. Among the se-

258. For many high-risk women, having children is an especially important passage. *See* Weiss, *supra* note 29, at 670 (discussing in depth the cultural, social, religious, economic, and personal realities of reproductive decision-making in this population).

259. *See id.* at 670-75. "[R]eproduction, babies, and motherhood serve as the only means by which some women, especially poor, minority women, can achieve a sense of self-identity, self-expression, and self-esteem." *Id.* at 673.

260. *See supra* notes 140-44 and accompanying text.

261. *See Casey*, 112 S. Ct. at 2806.

vere immediate implications for the family are: partners made aware of the infection may abandon or abuse the mother and child; new economic, psychological, and social pressures will have to be shouldered by often disadvantaged parents on top of already substantial problems; other children in the family may also be infected with the AIDS virus; all members of the family may reasonably be required to undertake voluntary behavioral change to minimize the risk of transmission or exacerbation of existing infections; acute care and supervision may be necessitated; and, perhaps most importantly, the family is faced with the dilemma that their primary care-giver, the mother, may soon be too sick to provide for the family's needs and will eventually die.

The physical and social suffering are not conditions *created* by the State, but that is not the focus of an undue burden analysis. The focus is rather on the woman's ability to choose when and how to have a child without that choice being made too difficult by governmental intrusion. It may be that the factors foreshadowed by a positive HIV test are exactly what a new mother or family would want to know as early as possible.[262] But it is equally reasonable, given the unavailability of a cure for AIDS' attendant social and physical ills, that the mother and family would prefer not to know, or would at least prefer to become informed on their own terms. In either case, the choice should be the mother's and the State creates an undue, and unconstitutional, burden when it removes that choice.

The implications for child rearing are equally imposing. The antibody-positive child will have her whole existence defined by her medical status. The possible burdens on her life include: a regular course of acute care both at home and at a hospital or treatment center; an overwhelmed mother may give her up for adoption or abandon her; schools, day care centers, neighbors, and family may regard her with fear and suspicion. Because the mother may have little control over most of these circumstance, her autonomy in raising an HIV-positive child will be substantially burdened. Under Bill No. 6747-B, the State co-opts a decision-making process—when and how to confront a child's illness—normally left in such circumstance to the parent(s).[263] In short, high-risk families

262. And in such cases, it might be assumed that these are the same women who, once counseled, will voluntarily cooperate with an HIV screening program.

263. In an enlightened discussion of mandatory prenatal testing in Martha Field, *Pregnancy and AIDS* 52 MD. L. REV. 402 (1993), Field traces a continuous line of liberty from *Griswold* through *Roe*, *Casey*, and *Cruzan*, arguing that these cases cre-

already faced with steep obstacles and unprepared for this new burden must confront an infection that is likely to become the focal point of their lives. Such drastic modification will affect all aspects of the family's daily life, including intra-family relationships and relations with neighbors, schools, employers, insurers and landlords. The potential impact on child rearing and family life is therefore tremendous.

The substantial obstacles to childrearing and family life created by mandatory testing and screening of parturient mothers is not justified by the State interests that would be advanced by Bill No. 6747-B. In *Casey*, the Pennsylvania statute involved "the State's profound interest in potential life."[264] New York's interest is not profound by *Casey* standards. The state is not saving life or potential life; rather it is merely trying to bring better care to the small percentage[265] of infants exposed to HIV/AIDS—an incurable condition. In addition, not only is improved care of positively tested newborns hampered by its own internal uncertainties,[266] but the bill creates its own external barriers by spurring care avoidance and failing to provide any linkage to follow-up care.[267]

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ate an autonomous shield for reproductive, family, and medical matters that involve, as the Court said in *Casey*, "intimate views with intimate variations [of] deep, personal character . . . . " *Casey*, 112 S. Ct. at 2808. Field then argues that:

> [a]s long as reasonable persons can differ as to the proper course of treatment, the state should not intrude on the decisions of parents . . . . It is only in extreme circumstances that government choice replaces parental choice. Pediatric AIDS is a serious problem and needs to be combatted, but this fact should not be used to make inroads upon our longstanding rules concerning parental authority. Today the medical benefits deriving from testing are not so compelling that a parental decision not to take the risks involved is an abusive decision, warranting forcible displacement of parental authority under prevailing principles of child abuse. Field, *supra*, at 431.

264. *Casey*, 112 S. Ct. at 2821.

265. The median seroprevalence rate in New York is 0.599, meaning that less than three-tenths of one percent of newborns are born HIV-positive. *Newborn Screening Subcommittee Report*, *supra* note 13, at 7-8. Of these only one-fourth are actually infected. *See supra* notes 57-60 and accompanying text.

266. *See supra* part IVA.2.d.

267. *See supra* parts IVA.2.a. & b. Furthermore, the undue burden of the bill is not minimized by the fact that the vast majority of New York women will not be seriously affected by it. As the *Casey* plurality noted in striking down Pennsylvania's spousal notice requirement, "analysis does not end with the one percent of women upon whom the statute operates; it begins there . . . . The proper focus of constitutional inquiry is the group for whom the law is a restriction, not the group for whom the law is irrelevant." *Casey*, 112 S. Ct. at 2829. In high-risk areas where mandatory testing and disclosure will be an issue, a significant number of women will find it a substantial obstacle to the autonomy that they are entitled to in matters of family, child rearing and procreation.

V. Equal Protection and Pregnancy Discrimination

Discrimination predicated on pregnancy for purposes of HIV testing also constitutes a violation of the Equal Protection Clause.[268] Although the Court has handed down several isolated and controversial opinions that appear to disassociate pregnancy and gender classifications, this slender line of cases has only a narrow application. Nothing in contemporary equal protection jurisprudence precludes finding that a statutory seizure of pregnancy as an occasion for compulsory HIV testing constitutes invidious gender discrimination, subject to a heightened standard of judicial scrutiny which it cannot survive.

A. The Supreme Court and Gender Discrimination

Departing from a restrictive common law tradition,[269] the Court in the 1970's formulated an "intermediate" level of scrutiny for state action that discriminates on the basis of sex.[270] Under intermediate scrutiny, any such state action must be substantially related to an important governmental objective.[271]

Although intermediate scrutiny and undue burden analysis both appear to fall between a rational relationship test and a strict scrutiny test, the two are conceptually, and in application, quite differ-

268. The Equal Protection Clause of the Fourteenth Amendment states that "[n]o state shall make or enforce any law which shall . . . deny to any person within its jurisdiction the equal protection of the laws." U.S. CONST. amend. XIV, § 1.

269. Justices regularly assented to the "archaic and overbroad generalizations" perpetuated by opinions such as Justice Bradley's concurrence in Bradwell v. Illinois, 83 U.S. (16 Wall) 130 (1872). Justifying the denial of woman's right to attend law school, Justice Bradley wrote that "[t]he natural and proper timidity and delicacy which belongs to the female sex evidently unfits it for many of the occupations of civil life," and that "man is, or should be, woman's protector and defender . . . . This is the law of the Creator." *Id.* at 141. In Thomas Jefferson's words, "[w]ere our state a pure democracy there would still be excluded from our deliberations women, who, to prevent deprivation of morals and ambiguity of issues, should not mix promiscuously in gatherings of men." Ruth Bader Ginsburg, *Gender in the Supreme Court: The 1973 and 1974 Terms*, 1974 SUP. CT. REV. 1 n.5 [hereinafter Ginsburg I] (quoting GRUBERG, WOMEN IN AMERICAN POLITICS (1968)); *see also* RUTH BADER GINSBURG, CONSTITUTIONAL ASPECTS OF SEX-BASED DISCRIMINATION (1974).

270. *See* Craig v. Boren, 429 U.S. 190 (1976); Frontiero v. Richardson, 411 U.S. 677 (1973); Reed v. Reed, 404 U.S. 71 (1971). *Craig* is discussed, *infra* notes 302-05; *Reed* and *Frontiero* are discussed, *infra* notes 317-18. For the most recent Court discussion of this line of cases, see J.E.B. v. Alabama, 62 U.S.L.W. 4219 (U.S. April 19, 1994) (No. 92-1239).

271. *See Craig*, 429 U.S. at 197 ("To withstand constitutional challenge, previous cases establish that classifications by gender must serve important governmental objectives and must be substantially related to the achievement of those objectives."); *see also* Mississippi Univ. for Women v. Hogan, 458 U.S. 718, 723 (1982); Wengler v. Druggists Mutual Ins. Co., 446 U.S. 142, 150 (1980).

ent. Undue burden analysis is derived from the Due Process Clause and concerns the right to privacy. It is triggered only when a fundamental right is infringed by a state or federal regulation. Intermediate scrutiny, on the other hand, is derived from the Equal Protection Clause and thus concerns equal protection under the law. It does not ordinarily implicate fundamental rights. In a balancing analysis dictated by an empirical weighing of the facts, the undue burden test focuses on the degree to which the implicated right has been made more difficult to exercise. If the difficulty encountered is great enough, it is considered a "substantial obstacle" and therefore an "undue burden" on the individual.

All undue burdens are also unconstitutional. All gender classifications are not unconstitutional. Intermediate scrutiny, rather than engaging in a balancing analysis, assumes that there has been a statutory discrimination based on gender (i.e., a statutory restriction applied only to women) and proceeds to assess whether that classification is justified. Those that are justified will be allowed to stand, those that are not will be invalidated. In order for a gender-based classification to comport with the Constitution, strict scrutiny requires that the State prove it to be "substantially related" to an "important governmental interest."

Bill No. 6747-B lies at the intersection of gender discrimination and pregnancy classifications, a hotly debated crossroads of contemporary constitutional law. The intersection defies easy analysis because, in part, although only women can become pregnant, not all women do so, and therefore a perfect correlation between pregnancy and gender is absent. Traditionally, debate at this crossroads is antithetical: discrimination in the context of pregnancy is either characterized as thinly veiled gender discrimination, and subject therefore to intermediate scrutiny, or as an entirely distinct and less objectionable classification subject merely to rational relationship scrutiny.[272] Pregnancy classifications, however, defy either pre-set formula.

An alternative, case-by-case framework would provide that in some cases such classification will constitute gender discrimination and in others it will not. Whether intermediate scrutiny is triggered

272. *See, e.g.*, Joanne Levine, *Pregnancy and Sex-Based Discrimination in Employment: A Post-Aeillo Analysis*, 44 U. CIN. L. REV. 57, 57-58 (1975) ("It is indisputable that only women can become pregnant. To some, this makes it obvious that an employer's discrimination against pregnant employees is unlawfully based on gender. To others, it is equally obvious that this makes job discrimination against pregnancy wholly permissable.").

will depend on the use of the pregnancy classification rather than its mere existence. When this case-by-case approach is applied to Bill No. 6747-B, it yields the conclusion that governmental isolation of pregnancy as an occasion for compulsory testing and disclosure is an invidious gender discrimination which fails intermediate judicial scrutiny.

B. Overcoming *Geduldig*: When Pregnancy Discrimination is not Gender Discrimination

1. The Peculiar Geduldig *Analysis*

The most commonly perceived obstacle to equating pregnancy and gender discrimination is *Geduldig v. Aiello*.[273] Decided twenty years ago, *Geduldig* involved a challenge to California's disability insurance program, which was designed to pay benefits to privately employed persons temporarily unable to work due to a disability not covered under workmen's compensation.[274] Participation in the program was mandatory unless the employee was enrolled in a private program approved by the state.[275] Coverage was funded by contributions of 1% of each participating employee's wages, deducted directly from his or her salary.[276] Benefits were administered by the state treasury from a special Unemployment Compensation Disability trust fund.[277]

Although the program provided coverage against disabilities arising from a broad spectrum of mental and physical illnesses or injuries, it expressly excluded coverage for any disability arising from normal pregnancy.[278] This exclusionary provision was challenged by four women who alleged that denial of coverage for their pregnancy-related medical care constituted invidious discrimination under the Equal Protection Clause.[279] The Court, in a 6-3 de-

273. 417 U.S. 484 (1974). This case represents the Court's first treatment of pregnancy discrimination under the Equal Protection Clause; in earlier cases, it had refused to consider equal protection arguments and instead relied on due process analysis. The Supreme Court has not faced an equal protection challenge to gender discrimination based on pregnancy since *Geduldig*.

274. *Id.* at 486.

275. *Id.* at 487 (citing CAL. ANN. UNEMP. INS. CODE §§ 3251-54 (West 1986)).

276. *See* CAL. ANN. UNEMP. INS. CODE §§ 984, 985, 2901 (West 1986 & Supp. 1994).

277. *Id.* § 3001.

278. "In no case shall the term 'disability' or 'disabled' include any injury or illness caused by or arising in connection with pregnancy up to the termination of such pregnancy and for a period of 28 days thereafter." *Id.* § 2626

279. The district court had ruled that "the exclusion of pregnancy-related disabilities is not based upon a classification having a rational and substantial relationship to a legitimate state purpose" and found that it was therefore unconstitutional under the

cision, rejected the plaintiff's equal protection arguments and declined to apply intermediate scrutiny.[280]

Justice Stewart wrote the two-part opinion. The first part stressed the success and efficiency of California's insurance program,[281] while the second argued that nothing in the Equal Protection Clause compelled the state to modify its program in order to provide for more coverage than it currently allotted.[282]

The Court approvingly noted that the 1% contribution rate was closely calibrated to the needs of the program, accounting for a payout of between 90% and 103% of the disability fund annually.[283] The program was thus efficiently structured "in terms of the level of benefits and the risks insured, to maintain solvency of the Disability Fund at a one-percent annual level of contribution."[284] The Court concluded that requiring California to pay benefits for disability incurred during normal pregnancy would impose a significant financial burden on the program.[285]

The Court next focused on whether the Equal Protection Clause compelled that "such policies be sacrificed or compromised in or-

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Equal Protection Clause. Aiello v. Hansen, 359 F. Supp. 792, 801 (N.D. Cal 1973), *rev'd sub nom.*, Geduldig v. Aiello, 417 U.S. 484 (1974). In what may have signaled a retreat from the position staked out in § 2626 of the CAL. UNEMP. INS. CODE, the California Court of Appeal, in a different action, found that § 2626 did not exclude from coverage disability resulting from abnormal pregnancies. Rentzer v. California Unemployment Ins. Appeals Bd., 32 Cal. App. 3d 604 (Ct. App. 1973). Section 2626 was subsequently amended to reflect this interpretation. CAL. ANN. UNEMP. INS. CODE § 2626.2 (West 1986 & Supp. 1994). Since three of the four women in the consolidated action where making claims for what the code classified as "abnormal" pregnancy complications (ectopic and tubal pregnancy, miscarriage), their claims were paid by the program, leaving the one woman who had experienced a normal pregnancy as the only plaintiff with a live controversy. *Geduldig*, 417 U.S. at 488.

280. Although intermediate scrutiny was not formally articulated until two years later in Craig v. Boren, 429 U.S. 190 (1976), heightened scrutiny had already been used by the Court in Reed v. Reed, 404 U.S. 71 (1971) and Frontiero v. Richardson, 411 U.S. 677 (1973). *See* Ginsburg I, *supra* note 269, at 3-4; Megan R. Golden, *When Pregnancy Discrimination is Gender Discrimination: The Constitutionality of Excluding Pregnant Women From Drug Treatment Programs*, 66 N.Y.U. L. REV. 1832, 1857 n.153 (1991).

281. *Geduldig*, 417 U.S. at 484-94.

282. *Id.* at 494-97.

283. *Id.* at 492.

284. *Id.* at 493 n.17. Governor Earl Warren's estimation of the program was influential on the Court: "It is not possible for employees to obtain from private insurance companies protection against loss of wages or salary during sickness as adequately or cheaply as that protection could be obtained by diverting their present 1% contribution for the support of a Disability Benefits Program." *Id.* at 493 n.16 (quoting CALIFORNIA SENATE JOURNAL, Jan. 23, 1946, at 229).

285. Estimates of the increased cost of including normal pregnancies as an insured risk ranged from $48.9 million to $131 million. *Geduldig*, 417 U.S. at 493 n.18.

der to finance the payment of benefits to those whose disability is attributable to normal pregnancy and delivery."[286] Answering in the negative—"California does not discriminate with respect to persons or groups which are eligible for disability insurance protection under the program,"[287]—the Court relied on its earlier decisions in *Williamson v. Lee Optical*[288] and *Dandridge v. Williams*.[289] These cases essentially established that a state, so long as its legislative line-drawing was "rationally supportable," could address only those aspects of a social welfare problem which it felt were most in need of attention.[290] The *Geduldig* Court found that California's decision to insure some risks and not insure others was rationally related to the legitimate purpose of "maintaining the self-supporting nature of its insurance program."[291]

2. *What* Geduldig *Means*

Geduldig's holding is constrained externally by its subsequent treatment from the Supreme Court, the lower courts, and Congress, and internally by its own highly qualified language. In addition, *Geduldig's* constrained reasoning further reduces its value as precedent; while carefully staking the narrow grounds on which a pregnancy classification *will not* trigger Equal Protection Clause protection, the Court indicates the wider field on which intermediate scrutiny *will* arise. It is into this wider field that Bill No. 6747-B falls. *Geduldig* may make it more difficult to argue that pregnancy discrimination constitutes gender discrimination, but it does not stand for the proposition that pregnancy discrimination can never constitute gender discrimination.

a. Geduldig's *Reception*

Geduldig's subsequent treatment from courts and commentators has not been affirmative. First, it was an immediate and longstanding target of vilification from legal scholars.[292] Second, the

286. *Id.* at 494.
287. *Id.*
288. 348 U.S. 483 (1955).
289. 397 U.S. 471 (1970).
290. *Geduldig*, 417 U.S. at 495 (discussing *Lee Optical* and *Dandridge*); *see Dandridge*, 397 U.S. at 486-87 ("[T]he Equal Protection Clause does not require that a State must choose between attacking every aspect of a problem or not attacking the problem at all.").
291. *Geduldig*, 471 U.S. at 494-95.
292. *See* Sylvia A. Law, *Rethinking Sex and the Constitution*, 132 U. PA. L. REV. 955, 983 ("Criticizing *Geduldig* has since [1974] become a cottage industry").

Supreme Court itself quickly squelched any expectation that *Geduldig* signalled a general disassociation of pregnancy and gender discrimination. In a 1975 per curiam opinion, Turner v. Department of Employment Security,[293] which addressed a Fourteenth Amendment challenge to a Utah statute that excluded pregnant women from unemployment compensation for an 18-week period commencing 12 weeks before delivery, the Court rejected the State's argument that it was simply applying the same rational cost-efficient decision-making as was used by the California program and rejected *Geduldig* as grounds to uphold the classification.[294] *Turner* refused to apply *Geduldig* because the Utah statute made "no mention of coverage limitations or insurance principles central to [*Geduldig v.*] *Aiello.*"[295]

Even in the rare cases where *Geduldig* has been favorably cited, as in *Bray v. Alexandria Women's Health Clinic*,[296] its spare use indicates a lack of vitality. In *Bray*, which held that antiabortion protestors did not invidiously discriminate against women for purposes of a Civil Rights Act provision concerning conspiracy to deprive a person or class of persons or equal protection,[297] *Geduldig* was cited only for the proposition that pregnancy distinctions are not *ipso facto* gender classifications.[298] This slim acknowledgement from Justice Scalia in a case that produced five separately written opinions did not extend *Geduldig's* narrow utility.

The circuit courts have similarly circumscribed *Geduldig*, leaving it cordoned off from the mainstream of gender discrimination cases.[299] Perhaps most restrictive, although indirectly so, is the Congressional response to *Geduldig*-like reasoning. The first and only Supreme Court case to rely directly on *Geduldig* for its holding was *General Electric Co. v. Gilbert.*[300] In *Gilbert*, which was a Title VII[301] rather than a Constitutional case, Justice Rehnquist upheld the disability plan of a private employer that provided all em-

293. 423 U.S. 44 (1975).
294. *Id.* at 45.
295. *Id.*
296. 113 S. Ct. 753 (1993); *see also* Personnel Adm'r of Mass. v. Feeney, 442 U.S. 256 (1979) (upholding against equal protection challenge a gender-neutral statute which had an adverse affect on women because it was not overtly or covertly gender-based nor did its adverse effects reflect invidious intent to discriminate against women).
297. 42 U.S.C. § 1885(3).
298. *Id.* at 760.
299. *See infra* note 316.
300. 429 U.S. 125 (1976).
301. Civil Rights Act of 1964, 42 U.S.C. § 2000e.

ployees with non-occupational sickness and accident benefits but excluded pregnancy-related disabilities.[302] In response, Congress quickly passed the Pregnancy Discrimination Act of 1978 (PDA), part of Title VII of the Civil Rights Act of 1964.[303] The PDA prohibits pregnancy discrimination in the workplace, stating that it necessarily constitutes sex-based discrimination.[304] In passing the PDA, Congress directly refuted the reasoning used in *Gilbert*—reasoning derived from *Geduldig*—by expressing the view that "discrimination based on a woman's pregnancy is, on its face, discrimination because of her sex."[305] In the Court's own words, "[w]hen Congress amended Title VII in 1978, it unambiguously expressed its disapproval of both the holding and reasoning of the Court in the *Gilbert* decision."[306]

Although Bill No. 6747-B is not employment related and would not qualify for PDA analysis, the Court's own acknowledgement of Congress' unmistakable rejection of its initial handling of pregnancy classifications is not without weight.

b. Geduldig's *Language*

Much of the attention, and derision, focused on *Geduldig* is not directed at the text of the opinion, but at its controversial twentieth footnote,[307] in particular at the proposition therein that "[w]hile it

302. *Id.*

303. 92 Stat. 2076, amending Title VII, 42 U.S.C. § 2000e.

304. *Id.* § 2000e(k) ("women affected by pregnancy, childbirth, or related medical conditions shall be treated the same for all employment related services . . . as other persons not so affected but similar in their ability or inability to work . . .").

305. Newport News & Shipbuilding & Dry Dock v. EEOC, 462 U.S. 669, 684 (1983); *see also Bray*, 113 S. Ct. at 791 n.29 ("Congress directly repudiated the logic and result of *Gilbert*.").

306. *Newport News*, 462 U.S. at 678; *see also* H.R. REP. No. 95-948, 95th Cong., Sess., at 2 (1978); S. REP. No. 95-331, 95th Cong. Sess, at 2-3 (1977) (Congress intended to adopt the view of the *Gilbert* dissent that pregnancy classification constitutes gender discrimination).

307. The footnote reads as follows:

> [T]his case is thus a far cry from cases like *Reed* and *Frontiero*, involving discrimination based upon gender as such. The California insurance program does not exclude anyone from benefit eligibility because of gender but merely removes one physical condition—pregnancy—from the list of compensable disabilities. While it is true that only women can become pregnant it does not follow that every pregnancy is a sex-based classification like those considered in *Reed* and *Frontiero*. Normal pregnancy is an objectively identifiable physical condition with unique characteristics. Absent a showing that distinctions involving pregnancy are mere pretexts designed to effect an invidious discrimination against the members of one sex or the other, lawmakers are constitutionally free to include or exclude pregnancy from the coverage of legislation's such as this on any reasonable basis, just as with

is true that only women can become pregnant it does not follow that every pregnancy is a sex-based classification . . . ."[308] Although the curiously reasoned[309] footnote is perceived as more threatening than the text to an equal protection claim brought against a pregnancy discrimination, its import is undercut by two factors. First, it bears a tenuous logical relationship to the text of the decision, a circumstance which at least minimizes its precedential weight.[310] Second, it is repeatedly compromised by its highly qualified language. For example, in acknowledging that "[w]hile it is true that only women can become pregnant it does not follow that *every* legislative classification concerning pregnancy is a sex-based classification . . . ,"[311] the Court signals that some pregnancy classifications will trigger intermediate scrutiny. Similarly, by noting that "lawmakers are free to include or exclude pregnancy from the coverage of legislation *such as this* on any reasonable basis . . . ,"[312] the Court acknowledges that some legislation which classifies according to pregnancy—rather than on the basis of an efficient insurance program—will constitute sexually discriminatory legislation, and will thus be subject to intermediate scrutiny and not merely a rational relationship test. Finally, addressing "[t]he lack of identity between the excluded disability and gender *as such under this insurance program* . . . ,"[313] the Court concedes that its refusal to equate pregnancy-based and gender-based discrimina-

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respect to any other physical condition. The lack of identity between the excluded disability and gender as such under this insurance program becomes clear under the most cursory analysis. The program divides the potential recipient into two groups — pregnant women and nonpregnant persons. While the first group is exclusively female, the second group includes members of both sexes. The fiscal and actuarial benefits of the program thus accrue to members of both sexes.

Geduldig, 417 U.S. at 494-95 n.20 (citations omitted).

308. *Id.*

309. For example, against the proposition that pregnancy classifications inherently discriminate against women because only women can become pregnant, Justice Stewart frames the proposition that pregnancy classifications merely create two groups: "pregnant women and non-pregnant persons." *Id.* at 497 n.20.

310. The significance of footnote twenty has been seriously questioned by the Court itself. *See* Newport News & Shipbuilding & Dry Dock v. EEOC, 462 U.S. 669, 677 n.12 (1983) ("The principle emphasis in the test of the *Geduldig* opinion, *unlike the quoted footnote*, was on the reasonableness of the State's cost justifications for the classification in its insurance program.") (emphasis added). At least one commentator has suggested that the entire footnote could be considered dicta. *See* Levine, *supra* note 272, at 72.

311. *Geduldig*, 417 U.S. 490-94 & n.20 (emphasis added).

312. *Id.* (emphasis added).

313. *Id.* (emphasis added).

tion is predicated on its economic analysis, and that different circumstance will produce a different result. These different circumstance are provided by Bill No. 6747-B.

c. Geduldig's *Peculiar Reasoning Does not Fit Bill No. 6747-B*

With the exception of the narrow proposition for which it was cited in *Bray*,[314] *Geduldig* is closely tied to its facts. Its analysis of pregnancy classifications and the discriminatory California legislation are entirely dependent upon the insurance program/social welfare context in which it occurs.

The key to the *Geduldig* decision was the Court's ability to avoid applying any type of heightened scrutiny to the challenged legislation. The Court applied the more permissive rational relationship test to the California legislation because it was able to find that the legislation did not classify according to sex. Rather, the Court found, the legislation required only the more benign and more easily justifiable classification of what benefits the State would provide *to all persons alike*, regardless of their status as pregnant women or "non-pregnant persons." Under the California insurance program, in other words, no one group was entitled to any benefits to which any other group was not entitled. Men and nonpregnant women did not get insurance coverage that was any different from the insurance coverage that was provided to pregnant women; both groups were offered an identical package, and neither group was offered coverage for normal pregnancy costs. The discriminatory nature of the legislation applied not to persons but to the benefits supplied to them, an economic distinction that avoided the animus of group classification, by gender or otherwise. Having reasoned that far, the Court quickly dispensed with the plaintiff's equal protection claim by blankly stating that "California does not discriminate with respect to the persons or groups which are eligible for disability insurance protection under this program."[315] Sharp as it is, this is a short sword, its reach extending no further than the economic context which forged it.[316]

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314. *See supra* notes 296-98 and accompanying text.

315. *Geduldig*, 417 U.S. at 494.

316. See Justice Brennan's *Geduldig* dissent, in which he called the majority opinion essentially a "cost-saving" decision. *Geduldig*, 417 U.S. at 497 (Brennan, J., dissenting); *see also Bray*, 113 S. Ct. at 788 (Stevens, J., dissenting) ("*Geduldig*, of course, did not purport to establish that, as a matter of logic, a classification based on pregnancy is gender-neutral."). But *Geduldig's* limited application has been noted by the full Court as well. *See supra*, notes 293-95 and accompanying text (discussing *Turner*) and notes 305-06 (discussing *Newport News*). Federal Circuit Courts have also noted

Ironically, *Geduldig* opens the door to an equal protection claim arising, as Bill No. 6747-B would, in a different context. Justice Stewart begins footnote 20 by noting that *Geduldig* is "a far cry from cases like Reed v. Reed, and Frontiero v. Richardson,"[317] cases that involved gender discrimination and triggered intermediate scrutiny. So long as the Court was able to distinguish *Reed*[318] and *Frontiero*,[319] which did not arise in an insurance program context, it could avoid intermediate scrutiny. Bill No. 6747-B, however, unavoidably creates the same type of invidious gender discrimination struck down in those two cases.

Unlike *Geduldig*, and like *Reed* and *Frontiero*, Bill No. 6747-B creates a gender-based classification by imposing HIV testing and disclosure on all parturient women. Its proposed testing scheme involves no insurance plan or State allocation of economic benefits with which to obscure this classification. In *Geduldig*, everyone received equal access to an insurance program in which certain benefits were offered and certain others were not; regardless of one's status, the same benefits were available. Bill No. 6747-B represents the converse situation. Under its compulsory testing scheme, the State does not distinguish between those benefits it offers and

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the limited nature of *Geduldig's* holding and reasoning. *See, e.g.*, Manufacturers Hanover Trust Co. v. United States, 775 F.2d 459, 466 (2d Cir. 1989) ("The *Geduldig* Court upheld the [California] statute . . . because 'the aggregate risk protection' provided by the statutory disability program did not disadvantage the class of women compared to the class of men.") (citation omitted); Cook v. Arentzen, 14 Fair Empl. Prac. Cas. (BNA) 1643, 1645 (4th Cir. 1977) ("[Geduldig] is an insurance case and simply allows the exclusion of pregnancy-related disabilities from an employer's disability benefits plan.") (citation omitted); Barnes v. Costle, 561 F.2d 983, 992 n.68 (D.C. Cir. 1977) ("As we read [*Geduldig* and *Gilbert*], they do not condone sex discrimination bottomed partly though not wholly on sex, or sex discrimination against some but not all women. By the Court's appraisal, men and women were treated equally in terms of protection conferred by the disability plans, and that led to the view that there was no discrimination at all.") (emphasis added).

317. *Geduldig*, 417 U.S. at 497 n.20 (citations omitted); *see supra* note 307, for full text of footnote 20.

318. 404 U.S. 71 (1971). *Reed* was the Supreme Court's first use of the Equal Protection Clause to invalidate a gender-based classification. The Court struck down an Idaho statute that preferred men over women in appointing administrators for the estates of persons who had died intestate.

319. 411 U.S. 677 (1973). *Frontiero* crystallized the Court's use of intermediate scrutiny for gender-based classifications. The plurality rejected an Oklahoma statute allowing male members of the armed forces automatically to claim their wives as dependents for purposes of collecting benefits, but requiring female members to prove spousal dependency before receiving additional benefits. *Id.* at 678. The plurality found that sex, like race, was based on a highly visible immutable characteristic that was rarely relevant to performance, and had a long history of discrimination. *Id.* at 684.

those it does not, but rather between those persons entitled to "benefits" and those persons who are not. The analogous situation under the California program would be if "nonpregnant persons" received coverage for broken legs and pregnant women did not. Both groups would not receive the same protection. That is the same type of discrimination that Bill No. 6747-B would impose, only the benefit denied to pregnant women would be the privacy protection provided by Article 27-F of the New York Public Health Laws. All persons in New York currently enjoy the confidentiality and autonomy afforded by Article 27-F, but under Bill No. 6747-B, the woman who becomes pregnant and decides to have her child is denied that privacy. The pregnant woman would not, therefore, have equal access to the same privileges enjoyed by nonpregnant persons.

Although California's legislation could, however awkwardly, be shoehorned into an insurance program context reviewable only under the rational relationship test, Bill No. 6747-B cannot. The result under the bill would be similar to that under a Tennessee statute struck down by the Court in *Nashville Gas Co. v. Satty*.[320] The Tennessee statute stripped seniority from women returning to work after pregnancy leave. The Court, in a Title VII analysis not unlike that used in Equal Protection Clause cases, stated that "petitioner has not merely refused to extend to women a benefit that men cannot and do not receive, but has imposed on women a substantial burden that men need not suffer. The distinction between benefits and burdens is more than one of semantics."[321]

The fact that not all women will be subject to the discriminatory effect of the bill does not save it from heightened scrutiny. *Geduldig* may stand for the proposition that the State is free to reasonably exclude pregnancy-related services from its insurance programs, but it does "not condone sex discrimination bottomed partly though not wholly on sex, or sex discrimination against some but not all women."[322] Unlike *Geduldig*, and like the discrimination in *Reed* and *Frontiero*, Bill No. 6747-B creates what Justice Brennan called in his dissent a "double standard"[323] in which "dissimilar treatment of men and women, on the basis of physical char-

320. 434 U.S. 136 (1977).
321. *Id.* at 142.
322. Barnes v. Costle, 561 F.2d 983, 992 n. 68 (D.C. Cir. 1977).
323. *Geduldig*, 417 U.S. at 501.

acteristics inextricably linked to one sex, inevitably constitutes sex discrimination."[324]

The peculiar reasoning of the *Geduldig* decision, narrowly tethered to its insurance program context, cannot be stretched to fit the far different circumstances proposed in Bill No. 6747-B. As a form of pregnancy classification which constitutes gender discrimination, Bill No. 6747-B will be subject to intermediate scrutiny.

3. *Light in the Tunnel: The* Johnson Controls *Decision*

The Supreme Court's more recent decision in *U.A.W. v. Johnson Controls*[325] supports the conclusion that Bill No. 6747-B involves a sex classification similar to those found unconstitutional in *Reed* and *Frontiero*. *Johnson Controls* is useful because, although decided under Title VII, it uses reasoning not unlike that employed by the Court when gender classifications are challenged under the Equal Protection Clause of the Fourteenth Amendment.[326]

Johnson Controls, which did not directly address *Geduldig*, considered whether an employer could exclude fertile women from certain jobs out of concern for the health of the fetus the woman might conceive.[327] The employer/respondent operated a battery manufacturing plant. The primary ingredient in the manufacturing process was lead, exposure to which involves substantial health risks, including risk of harm to any fetus carried by female workers.[328] The manufacturer had instituted a policy forbidding all fertile female employees from engaging in work at the plant that risked exposing them to excessive levels of lead.[329]

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324. *Id.* Feminist legal theorist Wendy Williams argues that it is not a double standard which prevents equal protection in such cases, but a single standard, and that standard is male. Wendy Williams, *The Equality Crisis: Some Reflections on Culture, Courts, and Feminism*, *in* MODERN CONSTITUTIONAL THEORY: A READER, at 140 (John H. Garvey & T. Alexander Aleinikoff eds., 2d ed. 1991).

325. UAW v. Johnson Controls, 499 U.S. 187 (1991).

326. "Even though the Pregnancy Discrimination Act has no bearing on the Court's interpretation of the Equal Protection Clause, it would be ludicrous for the Court to recognize pregnancy based discrimination as sex discrimination in the workplace, but not in other settings." Michelle Oberman, *Sex, Drugs, Pregnancy, and the Law: Rethinking the Problems of Pregnant Women Who Use Drugs*, 43 HASTINGS L. J. 505 (Mar. 1992) (arguing that, in light of subsequent legislative and judicial decisions and *Geduldig* notwithstanding, present policy behind statutes that restrict or criminalize the behavior of women who use drugs during pregnancy constitutes unlawful gender discrimination in violation of the Equal Protection Clause).

327. *Johnson Controls*, 499 U.S. at 190.

328. *Id.* at 187.

329. *Id.* at 191.

In addressing the class action that challenged the ban, the Court held that the exclusion of fertile women, but not fertile men, from lead-exposed jobs, created a facial classification based on gender that explicitly discriminates against women on the basis of sex.[330] The Court thus determined that a classification need not apply to *all* women to constitute a facially discriminatory act of sex discrimination.[331] Respondent's benevolent motives did not "convert a facially discriminatory policy into a neutral policy with a discriminatory effect."[332]

Writing for the majority, Justice Blackmun provided a useful device for disentangling the lawfulness of pregnancy-related classifications. "Johnson Control's policy is not neutral," Blackmun wrote, "because it does not apply to the *reproductive capacity* of the company's male employees in the same way as it applies to that of the females."[333] Because pregnancy is a uniquely female experience, its pertinence to governmental classification runs the risk of assuming *a priori* a difference between men and women that automatically justifies different treatment. Conceptualizing a classification as predicated on "reproductive capacity" rather than "pregnancy," however, may free courts and legislators from that trap.[334]

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330. *Id.* Respondent was unable to establish that sex in these circumstances was a "bona fide occupational qualification" under Title VII. *Id.* at 199; *cf.* Phillips v. Martin Marietta Corp., 400 U.S. 542 (1971) (holding that a hiring policy preferring men with school age children over women with school age children constituted sex discrimination under Title VII that could only be justified by BFOQ).

331. *Johnson Controls*, 499 U.S. at 199. This case implicitly rejects the reasoning used in *Geduldig* that relied on the existence of an excluded group of "nonpregnant persons" that included men and women. Just as the statutory discrimination in *Johnson Controls* was not saved because it applied not to all women but only to fertile women, thus excluding a group of "nonfertile persons" that included men and women, the classification of Bill No. 6747-B cannot be saved because it also excludes a group—"non-parturient persons"—consisting of men and women.

332. *Id.*

333. *Id.* (emphasis added).

334. Part of the trap of seeing classifications in terms of pregnancy rather than reproductive capacity is that the former is more easily associated with stereotypical generalizations and societal expectations about childbearing, childrearing, family, and parenting. Because only women become pregnant and give birth, and therefore they share a physical and emotional bond with the baby that a male cannot, there is a different set of social norms pertaining to mothers' responsibilities to the baby. *See Martin Marietta*, 400 U.S. at 545 ("ancient canards about the proper role of women" and "characterizations about the proper domestic roles of the sexes" do not justify discriminatory employment practices) (Marshall, J., concurring). The Supreme Court has made it clear that moral and ethical concerns predicated on biological differences are not an adequate basis for legal discriminations between men and women. "*Johnson Controls*' professed moral and ethical concerns about the welfare of the next generation do not suffice to establish a BFOQ (bona fide occupational qualification) of female sterility. Decisions about the welfare of future children must be left to the

Under a "reproductive capacity" framework, Bill No. 6747-B constitutes a facially invidious discrimination based on sex because it requires only women to avoid the full consequences of their reproductive capacity if they wish to preserve their confidentiality and autonomy against State intrusion. This proposal is a far cry from *Geduldig*, in that women entering hospitals to give birth would not seek legal protections beyond what is offered to "non-pregnant persons," they would seek only to retain the rights they walked into the hospital with, and that others capable of reproduction retain; in other words, they would seek only equal treatment under the law.[335]

4. *Applying Intermediate Scrutiny to the New York Proposal*

Under intermediate scrutiny, a party seeking to uphold a statute that classifies on the basis of gender can do so "only by showing at least that the classification serves important governmental objectives and that the discriminatory means employed are substantially related to the achievement of those objectives."[336] The Court has also interpreted this standard of review to place on the party seeking to justify the statute the burden of showing an "exceedingly persuasive justification" for the classification.[337]

The importance of the state's given purpose—improved management of HIV-infected or possibly HIV-infected newborns—is not

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parents who conceive, bear, support, and raise them rather than to the employers who hire those parents." *Johnson Controls*, 499 U.S. at 206.

335. The type of approach suggested by *Johnson Controls* and endorsed by this Note has been called "substantive equality analysis" by one commentator. *See* Donna M. Eansor, *To Bespeak the Obvious: A Substantive Equality Analysis of Reproduction and Equal Employment*, 6 NOTRE DAME J.L. ETHICS & PUB. POL'Y 417 (1992). Eansor argues that because this more liberal approach is better suited to freeing legal analysis from the distorting effect of stereotyping, biological determinism, nature theory, and biased assumptions that has plagued "formal equality analysis" it has produced "results that are more equitable in nature." *Id.* at 421. Eansor sees an emerging trend in cases like *Johnson Controls* to reject formal equality analysis because it is entrenched in biological determinism and perpetuates stereotyping of women. *Id.* at 422.

336. *Hogan*, 458 U.S. at 723 (quoting *Wengler*, 446 U.S. at 150) (citations omitted).

337. Harris v. Forklift Systems, Inc., 114 S.Ct. 367, 373 (1993); *Hogan*, 458 U.S. at 724; Kirchberg v. Feenstra, 450 U.S. 455, 461 (1981); Personnel Adm'r of Mass. v. Feeney, 442 U.S. 256, 273 (1979). It should also be noted here that at least a faction of the Court believes that "it remains an open question whether classifications on the basis of gender are inherently suspect." *Harris*, 114 S.Ct. at 373 (Ginsburg, J., concurring) (citations omitted); *Hogan*, 458 U.S. at 724 (O'Connor, J.); Stanton v. Stanton, 421 U.S. 7, 13 (1975) (Blackmun, J.) ("We find it unnecessary in this case to decide whether a classification based on sex is inherently suspect."). If gender classifications were to be found inherently suspect, then presumably, like other suspect classifications (race, national origin, alienage), would be subject to strict scrutiny review.

disputed here: stopping the spread of pediatric AIDS surely qualifies as an important objective. Yet courts must not allow the obvious and urgent importance of this end to somehow compensate for deficiencies in the chosen means.[338] It is the means which must receive the most careful attention.[339]

The most glaring failure of Bill No. 6747-B's means is its gross overinclusiveness. Statistical analysis can be a critical tool for means assessment,[340] and a persuasive argument can be made that New York's numbers simply do not justify statewide testing of pregnant women. There are approximately 1800 HIV-positive births in New York each year (a rate which has remained flat for several years), and yet Bill No. 6747-B requires statewide testing of all of the more than 270,000 women who give birth in the state annually.[341] Such statistical imbalance—nearly 100%[342] of the New York women who give birth will suffer a substantial intrusion of their autonomy and confidentiality in an effort to guard against a risk found in less than three-fifths of one percent of that population[343]—would not survive the heightened scrutiny applied to gender classifications.

In *Craig v. Boren*,[344] the Court relied heavily on a gross statistical imbalance to find that an Oklahoma drinking statute which allowed the sale of "near beer" to women once they turned 18 but not to men until they were 21 failed intermediate scrutiny.[345] The

338. Nor will an ostensibly benign purpose excuse a sex-based discrimination. *Johnson Controls*, 499 U.S. at 198.

339. In Korematsu v. United States, 323 U.S. 214, 246 (1944), a dissenting Justice Jackson chastised the majority in that infamous opinion for allowing the compelling end of national security to overshadow doubts about the dubious means of achieving that goal and thereby creating a "principle that lies about like a loaded weapon ready for the hand of any authority that can bring forward a claim of urgent need."

340. *See* Craig v. Boren, 429 U.S. 190, 200-02 (using statistical analysis to strike down a gender specific classification); *see also* Manufacturer Hanover Trust Co. v. United States, 775 F.2d 459, 467 (2d Cir. 1985) ("Satisfying the substantial relationship test will prove difficult to the extent that the gender classification is based on statistical generalizations that are unreliable, that show only weak correlations, or that are flawed in other ways."). If the numbers in New York do not justify statewide testing, it is unlikely that any other state's will, since New York has the highest proportion of HIV/AIDS cases in the nation.

341. *See, NY Seroprevalence Project, supra* note 12.

342. In 1988, the Seroprevalence Program reached 96.3% of all New York newborns. *Id.* at 24.

343. Only .59% of the children born in New York test positive for HIV, meaning that .59% of parturient mothers are HIV-infected. *See supra* note 69.

344. 429 U.S. 190 (1976).

345. *Id.* at 457.

Craig majority, citing earlier cases,[346] held that "if maleness is to serve as a proxy for drinking and driving, a correlation of 2% must be considered an unduly tenuous fit."[347] In concurrence, Justice Stevens noted that the statute failed intermediate scrutiny because

> [t]he legislation imposes a restraint on 100% of the males in the class allegedly because about 2% of them have probably violated one or more laws relating the consumption of alcoholic beverages . . . [even assuming that the legislation will achieve its slight benefit], it does not seem to me that an insult to all of the young men of the State can be justified by visiting the sins of the 2% on the 98%.[348]

The numbers in New York are even more extremely disproportionate than those in *Craig*. And they are further imbalanced outside of New York City, in rural and upstate areas that report far fewer HIV-positive births.[349]

The efficacy of the very program it seeks to replace further undermines the fair and substantial relationship between newborn screening and its purpose. The results of the current New York State HIV Seroprevalence Project contraindicate a sweeping, statewide approach to controlling pediatric AIDS. There is no mystery as to where pediatric AIDS is most likely to proliferate or where infected neonates are going to be born. After six years of anonymous but demographically linked testing, the state knows exactly who is at risk and where.[350] Statewide testing is vastly overinclusive, to the detriment of a group that has been historically disadvantaged by sweeping, paternalistic generalizations based on gender.

There are numerous medical and policy reasons why compulsory testing of parturient women is not substantially related to the goal of improved care of antibody-positive babies. The first is that there

346. *Id.* at 459 n.13. Conjecturing from the facts in *Reed*, the *Craig* Court suggested that premise that women lacked formal business experience would have to be proved accurate in "substantially more than 2% of all cases." *Id.* In both *Frontiero* and Weinberger v. Weisenfeld, 420 U.S. 636 (1975), mandatory dependency tests for men but not women were rejected even though the Court recognized that there was less likelihood that husbands would be dependent on their wives than vice versa. *Craig*, 429 U.S. at 459.

347. *Id.*

348. *Id.* at 685; *see also Johnson Controls*, 499 U.S. at 196, wherein the Court favorably cited the Seventh Circuit's admonition that "[c]oncerns about a tiny minority of women cannot set the standard by which all are judged." 886 F.2d 871 (1989).

349. The seroprevalence rate in New York exclusive of the City is .17; in rural upstate New York the rate in .07. *NY Seroprevalence Project*, *supra* note 12, at 16.

350. *See supra* part III.A.

is absolutely no provision in Bill No. 6747-B for linkage to services,[351] without which improved care is an illusory goal. The second is that a compulsory, intrusive, and traumatic disclosure system is prone to other mechanical deficiencies. These primarily include an absence of pre-test counseling and a deficiency of post-disclosure support services. Even if sufficient neonatal treatment facilities were available in the areas that most need them, these breakdowns are magnified by the profound personal and social stigma which attach to an HIV-infection and diminish the likelihood of cooperation with such a program.[352] Third, there appears to be a broad consensus among health care providers, obstetricians, midwives, social workers, hospital administrators, community services providers, nurses and others that the superior method for optimizing care for HIV-infected newborns is voluntary testing.[353] The argument for voluntary testing posits that when such a program is given a legitimate chance, in terms of staffing, training and funding, it will produce high compliance rates, not only for testing but for the follow-up care and behavioral change without which disclosure is no more than one more piece of bad news in lives that are too often physically and emotionally impoverished from want of good news.

V. An Alternative to Bill No. 6747-B

The constitutional, medical, and policy deficiencies of Bill No. 6747-B do not leave New York without a viable option to fight the spread of pediatric AIDS. Two steps are necessary to reach this goal: (1) maximizing the number of mothers tested and informed of their results, and (2) maximizing the number of infected mothers and infants who then receive improved care, including both medical treatment and supportive social services. These integral goals are best served by a two-tiered approach in which HIV counseling is made mandatory and voluntary testing is strongly encouraged.

Mandatory counseling should become part of the standard operating procedure of *all* health care providers in contact with pregnant women at *any* stage of their pregnancy, including post-partum if testing has not yet occurred. Counseling should be engrained and encouraged at all levels, from hospital and care center administrators to primary caregivers to paraprofessionals to community leaders. Educators should also join the effort, both school teachers

351. *See supra* part IV.A.2.a.
352. *See supra* part IV.A.3., IV.B.3.a. & b.
353. *See supra* part IV.A.2.f.

of pregnant adolescents and graduate teachers of tomorrow's care providers. The presence of a counseling apparatus alone is not enough. Counseling should be culturally and linguistically appropriate, non-threatening, focused on family needs, accessible; counselors should be well-trained and fully informed about current and community issues.

Counseling becomes even more important with the recent announcement that AZT can prevent the vertical transmission of HIV from mother to child.[354] Surely, this is the most welcome news of all since blocking vertical transmission will virtually eliminate new cases of pediatric AIDS. If this breakthrough study proves as successful as its early results indicate[355] (and this success as yet falls far short of blocking all vertical transmission[356]), the debate about the efficacy of various prophylactic and therapeutic treatments, and when and how to initiate them, will be mooted. As early as possible in their pregnancy, mothers should be counseled on the risks of transmission and the availablity and effectiveness of AZT. Although the primary means of treatment, or rather prevention, will have been clarified, a new debate will arise that focuses on prenatal rather than post-natal testing. If AZT blocks vertical transmission, and if at-risk babies can therefore be definitively spared infection, should prenatal testing be made mandatory? And, if maternal testing is made mandatory, and positive results are returned, should taking AZT also be mandatory? With a proven solution to in utero transmission, the state will have a more compelling argument to override the mother's rights than it does now, but whether that will be sufficient to overcome countervailing confidentiality, autonomy, and equal protection arguments is unclear.

Even in the absence of a proven in utero solution, the AZT announcement has already spurred legislative action. As of the time this Note was completed, New York State Senator Michael J. Tully,

354. Lawrence K. Altman, *In Major Finding, Drug Curbs H.I.V. Infection in Newborns*, N.Y. TIMES, Feb. 21, 1994, at A1.

355. In the study, conducted jointly in the United States and France, 26% of newborns whose HIV-infected mothers received placebos during their pregnancies were themselves infected; among newborns whose mothers received AZT, only 8% were infected. *Id.* at A13.

356. For example, the women in the test group all had a minimum number of CD4 cells and none of them had taken AZT previously. In addition, AZT was first given to these women during pregnancy, second through an infusion at delivery, and third to the newborn at delivery. Nevertheless, transmission was not blocked in all cases. In addition, it is not clear just which aspect of the test, or which combination, prevented transmission.

Jr., had recently proposed an alternative to Bill No. 6747-B.[357] Senate Bill No. 6775,[358] focusing on voluntary cooperation with prenatal detection and prevention, has the dual purpose of facilitating early treatment of HIV-infection in pregnant women and reducing the rate of vertical transmission.[359] To do so, the bill would mandate that all expectant mothers be counseled about the risks of HIV transmission and the availability and benefits of HIV testing as part of their standard prenatal care. For most mothers, counseling would occur at their first prenatal visit; for those who do not seek prenatal care, it would occur after delivery and prior to discharge. A second element of the Tully proposal[360] would require the State to develop "an educational booklet that prenatal care providers will use in providing information about the health benefits of early HIV testing to their patients."[361] Such booklets would include an explanation of the confidentiality provisions of Article 27-F. In coupling a voluntary approach with routine counseling about the benefits of early testing and disclosure, the Tully proposal resembles the recommendations made by this Note and the Newborn Screening Committee Report.[362]

In the effort to save the infant, under any scenario, the mother and the family should not be forgotten. The fundamental link between child and mother must not be severed, because regardless of how the unfortunate transfer of HIV from mother to child occurred, and regardless of the ease with which we can isolate and blame the mother, an intervention which severs the family unit severs its own chance of success. Under no circumstances should pregnancy become an opportunity for the state to manipulate a woman's procreative choices. On the contrary, any initiative which isolates, blames, or otherwise unnecessarily burdens the mother should be avoided. The mother must be respected and encouraged as the key to her infant's health.

Expansion of counseling and testing will necessitate increased funding. This funding should be allocated to both improved treatment (diagnostic procedures which shorten the testing process and

357. *See* Sack, *supra* note 18, at B5.

358. New York Senate Bill proposal No. 6775 was presented to the Senate on February 24, 1994.

359. *See New York State Introducer's Memorandum in Support of Senate Bill No. 6775* [hereinafter *Introducer's Memo*].

360. The bill is co-sponsored by Assemblyman Richard N. Gottfried. *Id.*

361. *See id.*

362. *See Newborn Screening Subcommittee Report, supra* note 13, at 39-43. On April 14, 1994, the Tully bill passed the Senate in a 50-1 vote.

increase its accuracy and medical procedures which improve prophylaxis and therapeutic techniques) and to improved social support services (continuing counselor training attuned to the complexities of living with HIV/AIDS is the inner city). When mandatory counseling and strongly encouraged testing are put in place, they must not be regarded as a solution in an of themselves. Testing results must be returned as soon as possible to maximize their usefulness, an efficient and humane disclosure procedure must be exercised, and direct linkage to care—especially through "co-location"[363]—must be facilitated. Co-location, which clusters the multiple medical and social services required by a family infected with HIV, is a realistic, thoughtful response to pediatric AIDS that looks beyond the expediency of identification to the urgency of treatment.[364]

Finally, in conjunction with any alternative solution to pediatric AIDS, the current seroprevalence testing program should be reevaluated to determine whether it has fulfilled its purpose and outlived its usefulness, whether it is still an effective tool for epidemiological research, or whether it can be modified to serve the integral goals discussed here.[365]

VI. Conclusion

Pediatric AIDS is a fitting and tragic emblem for the HIV/AIDS crisis from which it sprang. The concentration in an infant of the physical and social suffering which accompany HIV infection not only demonstrates dramatically the changing demographic profile of the AIDS epidemic, it also provides an opportunity to test our social resolve and fairness—as well as our medical ingenuity—in dealing with this deadly disease. Bill No. 6747-B reflects the folly

363. *See id.* at 21.

364. *Id.*

365. Bill No. 6747-B would use New York's current seroprevalence testing program as a springboard for mandatory testing. Families would be better served if, instead, a mechanism were put in place that gives mothers who have just delivered a final option of learning the results acquired by current unlinked testing. This would require that the program be altered so as to allow for results to be linked, such as by adding a new function to the computerized process by which identifying data is stripped from blood samples (perhaps the randomly-generated number that is currently assigned to both the test results and the demographic identifiers could be reassigned to personal identifiers as well). The integrity of the current program could thus be maintained while allowing care providers present at the birth or immediately thereafter to inform the mother that this test is being done and ask if she would like to receive the results for the benefit of her child. The timing of this option, which should not be made coercive, after the mother has completed her delivery and begun her role as caregiver may well elicit a high rate of cooperation.

of attempting an expedient, one-dimensional legal solution to this complex problem. The bill's failure to withstand constitutional scrutiny is hastened by its inattentiveness to the medical and social realities of AIDS.

A vote against Bill No. 6747-B is not a vote against improved care for HIV-positive newborns. Rather, a fully-informed vote against the bill should send two important messages. The first is that the New York Assembly will not unnecessarily compromise fundamental constitutional principles—such as privacy and equal protection of the law—in order to give the appearance of doing something about AIDS.

Second, a vote against the bill should be translated into a vote for an alternative solution. The energy, publicity, and concern sparked by the bill should not be wasted. In the debate that surrounded its proposal, many good ideas came forward. These ideas should be developed into an alternative proposal that avoids a mandatory testing scheme and its inherent invasion of the mother's right to confidentiality, autonomy, and equal protection. Whereas these invasions under Bill No. 6747-B could not be justified in the absence of a significant benefit to the infected infant, a voluntary, peer-counseled approach closely linked to follow up care will offer greater hope to the children of HIV-positive women. All future legislative action should be attuned to the recently discovered ability of AZT to block vertical transmission altogether, thus recharacterizing, but not resolving, the legal and social complexities of treating pediatric AIDS.

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