

TESTING PREGNANT WOMEN AND NEWBORNS FOR HIV:

LEGAL AND ETHICAL RESPONSES TO PUBLIC HEALTH EFFORTS TO PREVENT PEDIATRIC AIDS

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INTRODUCTION

Pediatric AIDS¹ occupies a charged landscape where a public health crisis attracting considerable social, political and scientific attention² collides with public distrust of the reproductive decisions of poor women of color and increasing scrutiny of the behavior of all pregnant women. The discovery of medical therapies that reduce significantly the likelihood that an HIV-infected woman will give birth to an HIV-infected child, as well as advances in the successful treatment of infected children, have produced a number of state laws and policy proposals calling for universal HIV testing of pregnant women and newborns so that all infected individuals can be identified for treatment.³ The continuing debate among policymakers in this area is whether pregnant women and new mothers should have the right to choose for themselves whether they and their children should be tested for HIV, or whether prenatal and newborn HIV testing should be mandatory or subject only to some truncated version of informed consent.

HIV-infected women may be particularly vulnerable to state intervention aimed at controlling their behavior during pregnancy and motherhood. They are

1. Acquired Immune Deficiency Syndrome (AIDS) is the final stage in the clinical progression of HIV disease, or infection with the Human Immunodeficiency Virus. Helena Brett-Smith & Gerald H. Friedland, *Transmission and Treatment*, in *AIDS LAW TODAY: A NEW GUIDE FOR THE PUBLIC* 18, 35 (Scott Burris et al. eds., 1993). HIV infection impairs immune function and makes the infected individual vulnerable to serious opportunistic infections. *Id.* at 33–34. HIV infection is recognized as AIDS when certain specific, severe complications develop. *Id.* at 30. Pediatric AIDS is AIDS occurring in children under thirteen years of age. Centers for Disease Control, *AIDS Among Children—United States, 1996*, 45 *MORBIDITY & MORTALITY WKLY. REP.* 1005, 1005 (1996).

2. One indication of the multidisciplinary controversy surrounding AIDS is the amount of litigation it has generated. "Sharp differences in perception of public health, ethics, and civil liberties have created the largest body of legal cases attributable to a single disease in the history of American jurisprudence." Lawrence O. Gostin, *The AIDS Litigation Project: A National Review of Court and Human Rights Commission Decisions, Part I: The Social Impact of AIDS*, 263 *JAMA* 1961, 1961 (1990).

3. Current proposals and their historical origins are discussed in detail in Part III *infra*.

overwhelmingly poor women of color,⁴ and their infection is seen by many as an unfortunate but not unblameworthy consequence of illegal drug use and irresponsible sex.⁵ Like pregnant drug users who have been frequent targets of public scorn and state coercion,⁶ HIV-infected women can be facily cast as bad mothers who must be stopped from harming their innocent children. At the same time, the “problem” of HIV-infected women giving birth to HIV-infected children can be “solved” largely with medical interventions that on a superficial level do not touch upon the issues of addiction and law enforcement that have made state efforts to prevent drug use during pregnancy so difficult and controversial.⁷ Proposals for coercive HIV-testing regimes do not raise the specter of women giving birth in chains⁸ that makes prenatal drug interventions so offensive to some, no matter how appropriate that image may be when the consequences of involuntary universal testing are explored.

In light of the risk that prenatal and newborn HIV-testing programs may be motivated in significant part by discrimination and moral judgment hidden beneath a veil of objective medical fact, proposals for widespread HIV testing of all pregnant women and newborns must be examined with some skepticism even if the potential health benefits of these programs are unquestionable. Part I of this paper discusses the epidemiology of HIV infection in women and children and the medical issues underlying public health proposals to test pregnant women and newborns for HIV. Part II places these proposals in a historical context that includes decades of state efforts to control childbearing by poor women of color and disabled women, and traces the increasing interest in monitoring the behavior of pregnant women in the name of fetal rights. Part III provides a timeline of various efforts to prevent perinatal⁹ transmission of HIV from mother to child and describes current proposals for universal HIV testing of pregnant women and newborns. Part IV analyzes current HIV-screening proposals within nonlegal frameworks provided by public health and ethics. Part V examines the constitutionality of prenatal and newborn HIV-testing regimes

4. In 1997, sixty percent of AIDS cases reported in women occurred in Black, non-Hispanic women, while Hispanic women account for another twenty percent of female AIDS patients. INSTITUTE OF MEDICINE, REDUCING THE ODDS: PREVENTING PERINATAL TRANSMISSION OF HIV IN THE UNITED STATES 38 (1999). Most women infected with HIV are poor. Lawrence Wilson et al., *Psychological Issues for Children Born to HIV-Infected Mothers*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES 78, 82 (Ruth R. Faden & Nancy E. Kass eds., 1996).

5. See, e.g., Melinda Madison, *Tragic Life or Tragic Death: Mandatory Testing of Newborns for HIV—Mothers' Rights Versus Children's Health*, 18 J. LEGAL MED. 361, 385 (1997) (“HIV infection often results from carelessness and promiscuity”). Injection drug use and exposure to semen during intercourse are two of the primary causes of HIV infection in women. See *infra* notes 12–13 and accompanying text.

6. Beginning in the 1980s, many states and municipalities began pursuing criminal sanctions and abuse and neglect charges against pregnant drug users. Katherine Acuff, *Perinatal Drug Use: State Interventions and the Implications for HIV-Infected Women*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, *supra* note 4, 214, 219–22.

7. See, e.g., *Ferguson v. City of Charleston*, 121 S. Ct. 1281, 1294 (U.S. March 21, 2001) (Kennedy, J., concurring) (emphasizing that constitutional objection to hospital's prenatal drug testing policy was founded on extensive coordination with law enforcement, not state intervention in medical care).

8. See *id.* at 1295.

9. Perinatal means “[o]ccurring during, or pertaining to, the periods before, during, or after the time of birth.” *STEDMAN'S MEDICAL DICTIONARY* 1329 (26th ed. 1995).

under the Due Process Clause and the Fourth Amendment. In conclusion, Part VI puts together the public health, ethical and legal frameworks of analysis, and offers a critique of current proposals to reduce the incidence of pediatric AIDS through universal HIV testing of pregnant women and newborns.

I. MEDICAL BACKGROUND

A. EPIDEMIOLOGY OF HIV/AIDS IN WOMEN AND CHILDREN

An estimated 125,000 American women have been diagnosed with AIDS,¹⁰ and approximately three-quarters of these women are of childbearing age.¹¹ Although, historically, most female AIDS cases have been attributed to injection drug use (IDU),¹² heterosexual contact is now the primary cause of AIDS in women.¹³

AIDS has a disproportionate impact on women of color. African-American, non-Hispanic women account for approximately sixty percent of AIDS cases reported in women, while Hispanic women constitute another twenty percent.¹⁴ Most women with AIDS are poor.¹⁵ While AIDS is the fourth leading cause of death among all women aged twenty-five to forty-four in the United States, it is the number one cause of death for African-American women in this age group.¹⁶

Approximately seven thousand babies are born to HIV-infected women each year.¹⁷ Anywhere from fourteen to thirty-three percent of these babies will be HIV-infected themselves.¹⁸ Children born to HIV-infected mothers account for

10. See DEPARTMENT OF HEALTH AND HUMAN SERVICES, HIV/AIDS SURVEILLANCE REPORT 12, 13 (2000).

11. *Id.* Less is known about the total number of HIV-infected women in the United States, as only 34 States report cases of non-AIDS HIV infection and even some of these states have only begun reporting cases as recently as 1999. *Id.* at 7. However, the information that is available indicates that an even greater proportion of HIV-infected women (eighty-six percent) are of childbearing age than the AIDS diagnosis figures indicate. *Id.* at 13.

12. INSTITUTE OF MEDICINE, HIV SCREENING OF PREGNANT WOMEN AND NEWBORNS 14 (Leslie M. Hardy ed., 1991).

13. For example, although forty-one percent of the female AIDS cases reported to the CDC cumulatively by June 2000 were attributed to IDU, only twenty-seven percent of the cases reported between July 1999 and June 2000 were so attributed. DEPARTMENT OF HEALTH AND HUMAN SERVICES, *supra* note 10, at 12. The number of AIDS cases attributed to heterosexual contact over these two time periods remained stable at forty percent and thirty-nine percent, respectively. *Id.* The proportion of cases in which a risk behavior was not identified was thirty-three percent among cases reported from July 1999 to June 2000, though this group represented only fifteen percent of cases reported cumulatively. *Id.* Most of the cases initially reported as risk not identified are later attributed to heterosexual contact. For example, of the cumulative total of female AIDS cases reported to the CDC as risk not identified by June 2000, sixty-eight percent were later attributed to heterosexual contact and twenty-seven percent to IDU. *Id.* at 25. Data available on HIV infection indicates that twenty percent of the cases reported by June 2000 were attributed to IDU and forty-one percent to heterosexual contact. Of the remaining cases of HIV infection, thirty-eight percent were reported as risk not identified. *Id.* at 13.

14. See *supra* note 4.

15. *Id.*

16. M.F. Rogers, *Epidemiology of HIV/AIDS in Women and Children in the USA*, 86 ACTA PAEDIATRICA 15, 15 (Supp. 421 1997).

17. Madison, *supra* note 5, at 362.

18. See Part I.B *infra*.

ninety-one percent of all pediatric AIDS cases.¹⁹ Due to the primary role perinatal transmission plays in causing pediatric AIDS, children with AIDS are overwhelmingly non-Hispanic Black and Hispanic,²⁰ just as their mothers are. Most HIV-infected mothers of children with perinatally-acquired AIDS report IDU (twenty-nine percent) and heterosexual contact (thirty-six percent) as their risk factors for HIV infection,²¹ mirroring the risk factors associated with HIV infection in women in general.²²

B. PERINATAL TRANSMISSION OF HIV

HIV transmission from mother to infant can occur during gestation, during labor and delivery, or postpartum as a result of breast feeding.²³ Although the exact timing of perinatal transmission is not perfectly understood, scientists believe that approximately twenty-five percent to thirty percent of instances of perinatal HIV transmission occur during gestation,²⁴ while up to seventy percent to seventy-five percent occur at the time of delivery.²⁵ The breast milk transmission rate is fourteen percent in the case of mothers who are seropositive, i.e. test positive for HIV antibodies, at the time of delivery, but a significantly higher transmission rate of twenty-nine percent is found in mothers experiencing primary HIV infection during the postpartum period.²⁶ Overall, in the absence of medical intervention, fourteen percent to thirty-three percent of children born to HIV-infected women become HIV-infected themselves.²⁷

The first major advance in the prevention of perinatal transmission of HIV occurred in 1994, when the results of AIDS Clinical Trials Group protocol 076 (ACTG 076) were announced to the public.²⁸ ACTG 076 was a double-blind, randomized clinical trial in which one group of HIV-infected women was given zidovudine (ZDV)²⁹ during their pregnancies, while another group of HIV-

19. DEPARTMENT OF HEALTH AND HUMAN SERVICES, *supra* note 10, at 12. Blood transfusions account for almost all remaining pediatric AIDS cases. As classified by the CDC, pediatric AIDS cases are those cases occurring in children less than thirteen years of age. *See supra* note 1.

20. As of September 30, 1996, fifty-eight percent of children under thirteen diagnosed with AIDS were non-Hispanic Black and twenty-three percent were Hispanic. Centers for Disease Control, *supra* note 1, at 1006. Together these two demographic groups make up only thirty percent of children under thirteen years of age in the United States. Rogers, *supra* note 16, at 15.

21. Rogers, *supra* note 16, at 15.

22. *See supra* note 13.

23. Katherine Luzuriaga & John L. Sullivan, *Prevention and Treatment of Pediatric HIV Infection*, 280 JAMA 17, 17 (1998).

24. INSTITUTE OF MEDICINE, *supra* note 4, at 45.

25. Luzuriaga & Sullivan, *supra* note 23, at 17. Possible mechanisms for neonatal acquisition of the HIV virus during labor and delivery include direct exposure to maternal blood and genital tract secretions, as well as transplacental microtransfusions. *Id.*

26. J. Kreiss, *Breastfeeding and Vertical Transmission of HIV-1*, 86 ACTA PAEDIATRICA 113, 113 (Supp. 421 1997).

27. INSTITUTE OF MEDICINE, *supra* note 4, at 39.

28. *See generally* Centers for Disease Control and Prevention, *Zidovudine for the Prevention of HIV Transmission from Mother to Infant*, 43 MORBIDITY & MORTALITY WKLY. REP. 285 (1994).

29. ZDV is a nucleoside analog reverse transcriptase inhibitor that has been shown to have moderate antiviral effects for the treatment of persons with HIV disease at all stages of the disease. Mary Culnane et al.,

infected women was given a placebo.³⁰ The HIV transmission rate in the placebo group was 25.5%, whereas only 8.3% of the children born to women in the ZDV group were infected with HIV. Compliance with the 076 regimen produced a 67.5% relative reduction in the transmission of the HIV virus from mother to infant.³¹

The United States Public Health Service quickly recommended that doctors offer the 076 regimen to their HIV-infected pregnant patients, and discuss the potential risks and benefits of the treatment with them.³² The substantial benefits of the regimen in terms of reducing the risk of perinatal transmission were clear; the risks of ZDV treatment during pregnancy were, and remain, less certain. For example, women taking ZDV have reported side effects including bone marrow suppression, muscle inflammation, headaches, nausea, vomiting and anemia.³³ Perhaps of more concern, it is unclear whether the use of ZDV during pregnancy solely to reduce the odds of perinatal transmission can cause the development of a ZDV-resistant virus strain in the mother that might lessen the drug's therapeutic effect when it is later needed to preserve her own health.³⁴

The Public Health Service also cautioned that the long-term effects of the 076 regimen on infants were not known. The only direct short-term effect experienced by infants in the 076 trial was mild and reversible anemia.³⁵ However, concerns about the long-term toxicity of perinatal exposure to ZDV include potential mutagenic and carcinogenic effects,³⁶ possible effects on heart or liver tissue,³⁷ and possible teratogenicity.³⁸ Despite these uncertainties, the

Lack of Long-Term Effects of In Utero Exposure to Zidovudine Among Uninfected Children Born to HIV-Infected Women, 281 JAMA 151, 151-52 (1999). ZDV was previously known as AZT. INSTITUTE OF MEDICINE, *supra* note 4, at 1.

30. The ACTG 076 treatment regimen is rather complex. Pregnant women enrolled in the trial took ZDV or a placebo orally five times daily for a median period of eleven weeks prior to the delivery. ZDV or the placebo was then given to the women intravenously during labor and delivery. Finally, the children born into the trial were given ZDV or a placebo orally every six hours for the first six weeks after birth. Edward M. Connor et al., *Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment*, 331 NEW ENG. J. MED 1173, 1173 (1994).

31. *Id.* at 1176.

32. Centers for Disease Control and Prevention, *Recommendations of the US Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus*, 43 MORBIDITY & MORTALITY WKLY. REP. 1, 6-7 (RR-11 1994).

33. THEODORE J. STEIN, *THE SOCIAL WELFARE OF WOMEN AND CHILDREN WITH HIV AND AIDS: LEGAL PROTECTIONS, POLICY AND PROGRAMS* 97 (1998).

34. K. McIntosh, *Antiretroviral Resistance and HIV Vertical Transmission*, 86 ACTA PAEDIATRICA 29, 31 (Supp. 421 1997); Centers for Disease Control, *supra* note 32, at 6.

35. Connor et al., *supra* note 30, at 1178.

36. At least two studies in mice have found that exposure to high doses of ZDV *in utero* increased risk for cancer in the exposed offspring. Inaam A. Nakchbandi et al., *A Decision Analysis of Mandatory Compared with Voluntary HIV Testing in Pregnant Women*, 128 ANNALS INTERNAL MED. 760, 766 (1998). *See also* Centers for Disease Control, *supra* note 32, at 5 (ZDV shown to be a carcinogen in rodents).

37. Centers for Disease Control, *supra* note 32, at 5.

38. The Food and Drug Administration places ZDV therapy during pregnancy in risk class C, indicating that the drug may have teratogenic or embryocidal effects but that available data are insufficient to make a firm conclusion on this issue. Craig J. Newschaffer et al., *Prenatal Zidovudine Use and Congenital Anomalies in a Medicaid Population*, 24 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 249, 249 (2000). One study analyzing all HIV-positive infants in the New York State Medicaid System, the vast majority of whom were presumably perinatally exposed to ZDV given the widespread adoption of the 076 regimen, found that the risk of a major

Public Health Service concluded that health care providers should recommend the full 076 regimen to all HIV-infected pregnant women who fit the criteria for admission to the clinical trial.³⁹

The 076 regimen has been very successful on the ground in reducing perinatal transmission of HIV. Studies conducted in the United States and Europe indicate widespread acceptance of the 076 regimen among HIV-infected pregnant women.⁴⁰ The number of perinatal AIDS cases peaked in 1992 and declined sixty-seven percent from 1992 to 1997.⁴¹ Although some of this decrease is associated with a reduction in the number of births to HIV-infected women,⁴² most of it reflects the effects of perinatal ZDV therapy.⁴³ Observed perinatal transmission rates in the developed world have fallen to between three percent and ten percent.⁴⁴

The continuing relevance of the 076 regimen and perinatal ZDV therapy is unclear. Ironically, dramatic breakthroughs in AIDS treatment involving the use of combination therapies may have seriously complicated efforts to reduce the perinatal transmission of HIV. The early initiation of aggressive combination

congenital anomaly was 2.79 times greater in the study cohort than in the general New York State population. *Id.* at 249–52; see also Centers for Disease Control, *supra* note 32, at 5 (acknowledging possible teratogenic effects of perinatal ZDV exposure). But see A. White et al., *Birth Outcomes Following Zidovudine Exposure in Pregnant Women: The Antiretroviral Pregnancy Registry*, 86 ACTA PAEDIATRICA 86, 86 (Supp. 421 1997) (finding no increase in the number of birth defects following perinatal ZDV exposure when compared to general population).

39. The ACTG 076 trial was open only to HIV-infected pregnant women who had CD4+ T-lymphocyte counts above two hundred cells per cubic millimeter and who had not received antiretroviral therapy during the current pregnancy prior to enrollment in the trial. Connor, *supra* note 30, at 1173. At the time the Public Health Service released its recommendations for ZDV treatment counseling of pregnant women in 1994, it was unclear whether the 076 results could be replicated in women with more advanced HIV disease or with prior antiretroviral treatment. *Id.* at 1178. As a result, the Public Health Service did not suggest that health care providers specifically recommend the 076 regimen to women who did not meet the trial's enrollment criteria. Rather, the Public Health Service merely indicated that HIV-infected pregnant women not meeting the 076 criteria be informed of the results and limitations of the 076 results, as well as the risks of treatment, and be allowed to make their own decisions about whether to undertake the treatment. Centers for Disease Control, *supra* note 32, at 6–7. Subsequent observational studies have shown that ZDV in fact is effective in reducing perinatal transmission in groups of women with more advanced disease and women with prior use of ZDV. Mary Lou Lindegren et al., *Trends in Prenatal Transmission of HIV/AIDS in the United States*, 282 JAMA 531, 531 (1999).

40. INSTITUTE OF MEDICINE, *supra* note 4, at 48; Susan Fiscus et al., *Perinatal HIV Infection and the Effect of Zidovudine Therapy on Transmission in Rural and Urban Counties*, 275 JAMA 1483, 1486 (1996). But see Andrew A. Wiznia et al., *Zidovudine Use to Reduce Perinatal HIV Type 1 Transmission in an Urban Medical Center*, 275 JAMA 1504, 1505 (1996) (finding that twenty-five percent of HIV-pregnant women refused ZDV treatment entirely and only sixty-seven percent of those women choosing to undertake the 076 regimen successfully completed all components thereof).

41. Lindegren et al., *supra* note 39, at 533.

42. Between 1992 and 1995, the CDC's Survey of Childbearing Women detected a seventeen percent decline in the number of births to HIV-infected women. INSTITUTE OF MEDICINE, *supra* note 4, at 40. The Survey of Childbearing Women was a blinded serosurveillance survey that operated from 1989 to 1995. Julie D. Levinson, *While Ignorance May Not Be Bliss, It Is a Mother's Right: Constitutional Implications of Testing Newborn Babies for HIV*, 3 CARDOZO WOMEN'S L.J. 71, 72 (1996). To conduct the survey, personal identifiers were removed from heelstick blood samples routinely taken from all newborns. The samples were then sent to labs where they were tested for HIV antibodies, thereby revealing the HIV status of the mother of the child from whom the blood was taken. The test did not reveal the HIV status of the child. INSTITUTE OF MEDICINE, *supra* note 4, at 33; see also *infra* notes 56–57 and accompanying text.

43. INSTITUTE OF MEDICINE, *supra* note 4, at 40; Centers for Disease Control, *supra* note 1, at 1008–09.

44. INSTITUTE OF MEDICINE, *supra* note 4, at 48.

therapy⁴⁵ is now the standard of care for the treatment of all HIV-infected individuals, including pregnant women, and ZDV monotherapy of the kind involved in the 076 regimen is no longer recommended.⁴⁶ In 1998, the Public Health Service issued guidelines stating that pregnancy is not a reason to defer standard HIV therapy, and urging health care providers to continue their HIV-infected patients on combination therapy during pregnancy.⁴⁷ However, there is little data on the efficacy of combination therapy to reduce perinatal transmission, or the tolerance and appropriate dosage when combination therapy is used in pregnant women.⁴⁸ Almost no information is available on the potential long-term toxic effects of antiretroviral drugs other than ZDV on infants exposed perinatally.⁴⁹ No studies document the acceptance of the experimental use of combination regimens during pregnancy by HIV-infected pregnant women.

Recently, elective cesarean section⁵⁰ also has been associated with reduced rates of perinatal HIV transmission. An analysis of fifteen perinatal transmission studies focusing on the mode of infant delivery documented a transmission rate of 10.4% in mothers receiving no antiretroviral therapy and delivering by elective cesarean section, and a transmission rate of only two percent in mothers receiving ZDV monotherapy and delivering by elective cesarean section.⁵¹ It is unclear whether the results of these delivery mode studies can be replicated in women receiving combination therapy rather than ZDV monotherapy.⁵²

45. Combination therapy generally consists of two nucleoside analog reverse transcriptase inhibitors and a protease inhibitor. Centers for Disease Control and Prevention, *Public Health Service Task Force Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the United States*, 47 MORBIDITY & MORTALITY WKLY. REP. 1, 2 (RR-2 1998).

46. Culnane et al., *supra* note 29, at 156.

47. Centers for Disease Control, *supra* note 45, at 1.

48. Luzuriaga & Sullivan, *supra* note 23, at 17.

49. Of eleven antiretrovirals other than ZDV commonly used in combination therapy, six are listed in FDA pregnancy category C. INSTITUTE OF MEDICINE, *supra* note 4, at 50; *see also supra* note 38 (describing significance of category C). Another, Efavirenz, has been associated with severe congenital anomalies in monkeys and is not recommended for use during pregnancy. INSTITUTE OF MEDICINE, *supra* note 4, at 49. A Phase 1 evaluation of perinatal use of antiretroviral combination regimens including protease inhibitors is underway through the AIDS Clinical Trials Group, as is a Phase 3 clinical trial of the nonnucleoside reverse transcriptase inhibitor nevirapine. Luzuriaga & Sullivan, *supra* note 23, at 17.

50. Elective cesarean sections are those performed before the onset of labor and rupture of membranes. International Perinatal HIV Group, *The Mode of Delivery and the Risk of Vertical Transmission of Human Immunodeficiency Virus Type 1: A Meta-Analysis of 15 Prospective Cohort Studies*, 340 NEW ENG. J. MED. 977, 977 (1999). Elective cesarean sections prevent perinatal transmission because they avoid both microtransfusions of maternal blood during labor and direct fetal contact with maternal blood and genital tract secretions during delivery. *Id.* at 984.

51. *Id.* at 983; *see also* The European Mode of Delivery Collaborative, *Elective Caesarean-Section Versus Vaginal Delivery in Prevention of Vertical HIV-1 Transmission: A Randomised Clinical Trial*, 353 LANCET 1035, 1037 (1999) (showing similar transmission rates with elective cesarean sections). The same analysis showed transmission rates of nineteen percent in women receiving no antiretroviral therapy and delivering by a method other than elective cesarean section, and 7.3% in women on ZDV monotherapy and delivering by a method other than elective cesarean section. International Perinatal HIV Group, *supra* note 50, at 983.

52. *Id.* at 985-86.

C. DIAGNOSIS OF HIV INFECTION IN WOMEN AND INFANTS

Pregnant women, like other adults, are screened for HIV infection using an enzyme-linked immunosorbent assay (ELISA) and a confirmatory Western blot test.⁵³ Both ELISA and the Western blot detect the presence of HIV antibodies, rather than the presence of the HIV virus itself.⁵⁴ Like other antibody tests, the ELISA and Western blot indicate the occurrence of past infection, and there may be a time lag between primary HIV infection and the production of detectable HIV antibodies.⁵⁵ All infants born to HIV-infected women are born with their mothers' antibodies and so test positive when given ELISA and Western blot tests at birth.⁵⁶ Infants lose their maternal antibodies at fifteen to eighteen months of age, and it is only at that time that the antibody tests used to detect HIV infection in adults will reveal the true HIV status of the tested child; prior to that time, antibody tests will only reveal the HIV status of the child's mother.⁵⁷ Nonetheless, most newborn HIV-screening programs rely initially on antibody tests to identify infants who have been born to HIV-infected mothers, with only the infants so identified receiving more specific virologic testing.⁵⁸ Once it is determined that an infant has been born to an HIV-infected mother,⁵⁹ the infant will receive tests that detect the presence of the HIV virus itself and thereby indicate whether the infant is truly infected with HIV. The American Academy of Pediatrics (AAP) recommends that all HIV-exposed infants be tested using polymerase chain reaction (PCR) at birth, at one to two months of age, and regularly thereafter until negative HIV status is confirmed.⁶⁰ HIV-exposed infants whose PCR results remain negative up to six months of age are considered HIV-negative.⁶¹

53. INSTITUTE OF MEDICINE, *supra* note 4, at 51. A diagnosis of HIV infection in adults requires two reactive ELISAs, confirmed by Western blot or immunofluorescence assay. *Id.*

54. John Modlin & Alfred Saah, *Public Health and Clinical Aspects of HIV Infection and Disease in Women and Children in the United States*, in AIDS, WOMEN AND THE NEXT GENERATION: TOWARDS A MORALLY ACCEPTABLE PUBLIC POLICY FOR HIV TESTING OF PREGNANT WOMEN AND NEWBORNS 29, 32-35 (Ruth R. Faden et al. eds., 1991).

55. *Id.* at 32.

56. Nancy Hutton, *Health Prospects for Children Born to HIV-Infected Women*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, 63, at 64 (Ruth R. Faden & Nancy E. Kass, eds., 1996) Throughout this paper, the group of all infants born to HIV-infected women, including both those infants that are HIV-infected themselves and those who are not, will be referred to HIV-exposed.

57. *Id.*

58. See, e.g., David F. McNeely, *Newborn Screening for Human Immunodeficiency Virus Infection in the Bronx, NY, and Evolving Public Health Policy*, 16 AM. J. PERINATOLOGY 503, 504 (1999).

59. This occurs either when the health care provider knows that the mother is HIV-infected prior to delivery, or when an antibody test performed on the newborn reveals the presence of maternal HIV antibodies. *Id.*

60. American Academy of Pediatrics, Committee on Pediatric AIDS, *Evaluation and Medical Treatment of the HIV-Exposed Infant*, 99 PEDIATRICS 909, 911 (1997).

61. Luzuriaga & Sullivan, *supra* note 23, at 18.

D. DISEASE PROGRESSION AND RECOMMENDED MEDICAL TREATMENT FOR CHILDREN WITH PERINATALLY ACQUIRED HIV INFECTION

HIV infection in children who acquire the virus perinatally follows one of two patterns. Rapid disease progression (RPD) occurs in ten percent to thirty percent of HIV-infected infants.⁶² When it occurs, RPD results in immunologic depletion and the occurrence of an AIDS-defining event in the first few months of life.⁶³ Infants exposed perinatally to ZDV are significantly more likely to exhibit RPD than infants not exposed to ZDV.⁶⁴

Seventy percent to ninety percent of HIV-infected infants exhibit non-rapid disease progression (NRPD). NRPD is characterized by the gradual impairment of immunologic function over a number of years, and generally follows a pattern of disease progression similar to that found in infected adults.⁶⁵ Accordingly, even before the widespread use of combination therapy for treatment of HIV infection, pediatric HIV disease usually presented as a chronic childhood condition rather than an immediate death sentence. For example, by the end of 1993, only fifty percent of children with perinatally-acquired HIV infection developed severe signs or symptoms by five years of age,⁶⁶ and the median survival time from birth to death of all children in this group was 9.4 years.⁶⁷ Most HIV-infected children had no symptoms or were only moderately symptomatic for more than half of their expected life.⁶⁸

The increased use first of *Pneumocystis carinii* pneumonia (PCP) prophylaxis,⁶⁹ and later of combination therapy, significantly improved the outlook for HIV-infected infants, and has spurred health care providers to strongly recommend the earliest possible identification of all infants exposed to

62. L.M. Mofenson, *Interaction Between Timing of Perinatal Human Immunodeficiency Virus Infection and the Design of Preventive and Therapeutic Interventions*, 86 ACTA PAEDIATRICA 1, 3 (Supp. 421 1997).

63. Ricardo S. de Souza et al., *Effect of Prenatal Zidovudine on Disease Progression in Perinatally HIV-1-Infected Infants*, 24 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 154, 154 (2000). An example of an AIDS-defining event is the onset of an opportunistic infection characteristic of HIV infection such as *Pneumocystis carinii* pneumonia. See generally, STEDMAN'S MEDICAL DICTIONARY, *supra* note 9, at 39.

64. In a recent study, 70.6% of infants exposed perinatally to ZDV exhibited RPD, while only 29.4% of infants with no ZDV exposure exhibited RPD. de Souza, *supra* note 63, at 157. If they do not receive early treatment with combination therapy after birth, HIV-infected infants exposed perinatally to ZDV are 1.8 times more likely to die of AIDS than infected infants with no ZDV exposure. Louise Kuhn et al., *Disease Progression and Early Viral Dynamics in Human Immunodeficiency Virus-Infected Children Exposed to Zidovudine During Prenatal and Perinatal Periods*, 182 J. INFECTIOUS DISEASES 104, 105 (2000). One author concludes that, with respect to AIDS death in the first year of life, the effects of the 076 regimen are a wash in light of the increased incidence of RPD associated with perinatal exposure to ZDV—approximately four percent of infants born to HIV-infected women will die in the first year of life, irrespective of whether the women receive the 076 therapy or not. *Id.* at 109. Combination therapy after birth mitigates the disproportionate incidence of RPD among ZDV-exposed children, however. *Id.* at 106.

65. de Souza, *supra* note 63, at 154.

66. Huiman X. Barnhart, *Natural History of Human Immunodeficiency Virus Disease in Perinatally Infected Children: An Analysis from the Pediatric Spectrum of Disease Project*, 97 PEDIATRICS 710, 713 (1996).

67. *Id.*

68. *Id.*

69. See *infra* notes 72–78 and accompanying text.

HIV.⁷⁰ The AAP counsels that all HIV-exposed infants should receive the postpartum portion of the 076 regimen for the first six weeks of life.⁷¹ Following that treatment, the most emphasized component of care for HIV-exposed infants is PCP prophylaxis.⁷² HIV-infected infants face a seven percent to twenty percent risk of developing PCP in their first year of life⁷³ and have a poor prognosis after onset of the disease, with a median survival time of nineteen months after PCP diagnosis.⁷⁴ PCP usually occurs between three and six months of age,⁷⁵ often at a time when PCR results will fail to identify many HIV-infected children,⁷⁶ so both the CDC and the AAP recommend that health care providers give all HIV-exposed infants PCP prophylaxis beginning at no later than six weeks of age.⁷⁷ Prophylaxis may reduce the incidence of PCP in HIV-infected infants to four percent, compared with an overall incidence of 11.8% to twenty-nine percent occurring in the absence of preventive care.⁷⁸

The CDC also recommends that combination antiretroviral therapy be initiated in HIV-infected infants as soon as their infection status is confirmed.⁷⁹ As the appropriate combination of antiretroviral drugs for treatment of HIV-infected infants is still somewhat controversial⁸⁰ and may vary with a particular infant's immunologic function and clinical condition, the AAP does not recommend a particular regimen but rather suggests case-by-case consultation with a pediatric HIV expert.⁸¹

70. See, e.g., American Academy of Pediatrics, *supra* note 60, at 916 (American Academy of Pediatrics pediatric AIDS treatment guidelines calling for treatment of all HIV-exposed infants beginning as soon as exposure has been identified); Centers for Disease Control and Prevention, *1995 Revised Guidelines for Prophylaxis Against Pneumocystis carinii Pneumonia for Children Infected with or Perinatally Exposed to Human Immunodeficiency Virus*, 44 MORBIDITY & MORTALITY WKLY. REP. 1, 2 (RR-4 1995) (CDC PCP prophylaxis guidelines calling for identification of all HIV-exposed infants either before or immediately following birth).

71. American Academy of Pediatrics, *supra* note 60, at 910.

72. PCP is the most commonly reported opportunistic infection in children with AIDS, representing thirty-four percent of all pediatric AIDS cases and 57.3% of pediatric AIDS cases diagnosed in children under one year of age. Rogers, *supra* note 16, at 16.

73. R.J. Simonds et al., *Pneumocystis carinii Pneumonia Among US Children with Perinatally Acquired HIV Infection*, 270 JAMA 470, 472 (1993).

74. *Id.* at 473.

75. Centers for Disease Control, *supra* note 70, at 2.

76. See *supra* note 61 and accompanying text.

77. American Academy of Pediatrics, *supra* note 60, at 910; Centers for Disease Control, *supra* note 70, at 5.

78. Donald M. Thea et al., *Benefit of Primary Prophylaxis Before 18 Months of Age in Reducing the Incidence of Pneumocystis carinii Pneumonia and Early Death in a Cohort of 112 Human Immunodeficiency Virus-Infected Infants*, 97 PEDIATRICS 59, 61 (1996).

79. Luzuriaga & Sullivan, *supra* note 23, at 18.

80. A number of studies are in progress examining the safety and antiretroviral activity of various combination therapies for use in infected infants. The appropriate dosage for infant use of a number of antiretroviral drugs is not well established. *Id.* at 18.

81. American Academy of Pediatrics, *supra* note 60, at 913-14. In addition to PCP prophylaxis and early initiation of combination therapy, the AAP also recommends a slightly altered vaccination schedule and diet, as well as regular monitoring of the immune system, for all HIV-exposed infants to continue if and until negative serostatus is confirmed. *Id.*

II. THE HISTORICAL CONTEXT OF CONTROLLING WOMEN'S CHILDBEARING

A. STATE REPRODUCTIVE POLICIES TARGETING POOR WOMEN OF COLOR AND DISABLED WOMEN

Given the demographic characteristics of HIV-infected women in the United States,⁸² any state policy aimed at reducing the rate of perinatal HIV transmission and/or improving health outcomes for HIV-infected newborns will have a disproportionate impact on poor women of color and their children. State intervention in the childbearing and childrearing decisions of these women should be analyzed not only in the context of a modern public health crisis, but also must be viewed with an eye toward the extensive history of state efforts to control childbearing by women who are poor, disabled,⁸³ or of color.

The state has played a coercive role in African-American women's reproduction since the time of slavery,⁸⁴ and has frequently engaged in direct efforts to control childbearing by women of color and/or low socioeconomic status. For example, in the early twentieth century, eugenicist ideology in the United States gave rise to public policies that embraced the belief that social problems such as poverty and disease could be solved by preventing targeted groups from reproducing.⁸⁵ Many states passed laws mandating sterilization of the disabled, individuals with syphilis, and prostitutes.⁸⁶ The Supreme Court upheld one such law in *Buck v. Bell*,⁸⁷ and affirmed a lower court's order directing the sterilization of a "feeble minded" woman. The Court, relying on a finding that Carrie Buck was "the probable potential parent of socially inadequate offspring," stated that "[i]t is better for all the world, if . . . society can prevent those who are manifestly unfit from continuing their kind."⁸⁸

82. See *supra* note 4.

83. Although HIV-infected individuals generally experience a long period averaging seven to eleven years during which their infection is asymptomatic, it is appropriate to consider all HIV-infected women as disabled at least in the context of policies targeting perinatal transmission. An asymptomatic HIV-infected woman may transmit the HIV virus to her fetus during gestation, labor or delivery, or through breastfeeding. See *supra* note 23 and accompanying text. It is this ability to transmit the disease from mother to infant that makes disabled women the target of state reproductive controls. Cf. *Buck v. Bell*, 274 U.S. 200, 205–06 (1927) (upholding constitutionality of Virginia law authorizing the sterilization of individuals with hereditary forms of insanity or imbecility). The Supreme Court has determined that asymptomatic HIV infection is a disability under the ADA because it is a physical condition affecting reproduction and childbearing. See *Bragdon v. Abbott*, 524 U.S. 624, 637–38 (1998).

84. See generally DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION AND THE MEANING OF LIBERTY* 22–55 (1997).

85. See *id.* at 56; Suzanne Sangree, *Control of Childbearing by HIV-Positive Women: Some Responses to Emerging Legal Policies*, 41 *BUFF. L. REV.* 309, 320 (1993).

86. Sangree, *supra* note 85, at 320–21.

87. 274 U.S. 200 (1927). Although *Buck v. Bell* has never been expressly overruled, its continued vitality is highly questionable in light of *Skinner v. Oklahoma*, 316 U.S. 535 (1942). In *Skinner*, the Court recognized a right to procreate and found that the forced sterilization of habitual criminals violated the equal protection clause. *Id.* at 541–42.

88. *Buck*, 274 U.S. at 207.

Between 1907 and 1945, 45,000 people were involuntarily sterilized in the United States, most of them poor women.⁸⁹

After World War II, eugenic sterilization laws fell into disuse, were judicially invalidated, or were repealed.⁹⁰ Sterilization abuse continued, however, generally characterized by economic coercion directed at poor women of color.⁹¹ In 1974, a federal district court judge noted

that an estimated 100,000 to 150,000 low-income persons had been sterilized annually under federally-funded programs.⁹² The court stated, “[A]n indefinite number of poor people have been improperly coerced into accepting a sterilization operation under the threat that various federally supported welfare benefits would be withdrawn unless they submitted to irreversible sterilization. Patients receiving Medicaid assistance at childbirth are...the most frequent targets of this pressure”⁹³ Doctors in public hospitals have refused to provide care to poor pregnant women unless they consent to sterilization,⁹⁴ or have obtained “consent” from women while they were in labor.⁹⁵ In other documented cases, medical residents have forced women of color to undergo tubal ligations and hysterectomies so they could practice performing those procedures.⁹⁶

In light of this history of reproductive coercion directed at disabled women and poor women of color, which continued uninterrupted in the United States up to the onset of the AIDS epidemic,⁹⁷ there is reason to be suspicious of state efforts to limit or otherwise control the reproductive rights of HIV-infected pregnant women.⁹⁸ Purported scientific bases for these controls cannot be accepted at face value, but rather must be examined critically to determine whether public health concerns can truly justify the public policies claimed to

89. Sangree, *supra* note 85, at 322–23.

90. *Id.* at 323.

91. Joelle S. Weiss, Comment, *Controlling HIV-Positive Women's Reproductive Destiny: A Critical Equal Protection Analysis*, 2 SETON HALL CONST. L.J. 643, 662–64 (1992).

92. *Relf v. Wienberger*, 372 F. Supp. 1196, 1199 (D.D.C. 1974), *vacated as moot* by 565 F.2d 722 (D.C. Cir. 1977).

93. *Id.*

94. *E.g., id.* (citing case of one plaintiff whose Medicaid doctor conditioned care on consent to sterilization). See also Sangree, *supra* note 85, at 324.

95. Sangree, *supra* note 85, at 325.

96. Taunya Lovell Banks, *Women and AIDS—Racism, Sexism and Classism*, 17 N.Y.U. REV. L. & SOC. CHANGE 351, 361 (1989/1990).

97. In response to documented instances of sterilization abuse such as those discussed in text accompanying notes 92–96 *supra*, regulations were adopted requiring written informed consent and a waiting period when federal funds were used to pay for sterilization. Even after these regulations were issued, however, a study conducted in 1981 indicated that thousands of poor women of color continued to be sterilized without their informed consent. Banks, *supra* note 96, at 362. With the development of long-acting contraceptives such as Norplant, state policymakers may have found a way to avoid controversial sterilization practices while still exerting control over women's childbearing. Many state legislators have proposed bills providing financial bonuses to encourage welfare recipients to use Norplant or conditioning benefits on implantation. ROBERTS, *supra* note 84, at 108–112. Welfare recipients are disproportionately women of color. *Id.*

98. Sangree, *supra* note 85, at 332; Banks, *supra* note 96, at 363. See Weiss, *supra* note 91, at 666–67 (noting that prior reproductive coercion by state sets precedent for future implementation of coercive policies targeting HIV-infected women).

follow from them.⁹⁹ As the eugenics movement demonstrates, a vocal body of medical experts can develop a public consensus around the idea of combating social problems not at their roots, but at the microlevel of women's wombs.¹⁰⁰ Particularly if the women at issue are poor, of color and disabled, society has been only too ready to identify them as the source of larger problems and therefore appropriate objects of state reproductive coercion.¹⁰¹

B. THE LATE TWENTIETH CENTURY RISE OF FETAL RIGHTS

Beginning soon after the Supreme Court's 1973 decision *Roe v. Wade*,¹⁰² a number of legal scholars began to develop theories of fetal rights that provided doctrinal underpinnings to support the state's historical suspicion of women's childbearing decisions, and that attempted to recast this suspicion as an exercise in justice and morality.¹⁰³ Fetal rights theorists advocate extensive control of women's behavior during pregnancy, including forced diagnosis and treatment of conditions potentially harmful to the fetus.¹⁰⁴ They also urge the recognition of a cause of action against the mother for prenatal injuries,¹⁰⁵ and do not shy away from the criminalization of certain maternal behavior harmful to the fetus.¹⁰⁶

The policies advocated by fetal rights proponents represent a significant move away from existing legal doctrine. While the common law has recognized fetuses as beings with certain legal rights and protections in very narrowly defined circumstances for quite some time,¹⁰⁷ the fetus has never been treated as

99. Sangree, *supra* note 85, at 332.

100. *Id.*

101. See ROBERTS, *supra* note 84, at 3; Jennifer Sinton, *Rights Discourse and Mandatory HIV Testing of Pregnant Women and Newborns*, 6 J.L. & POL'Y 187, 237-38 (1997).

102. 410 U.S. 113 (1973).

103. E.g., Margery W. Shaw, *Conditional Prospective Rights of the Fetus*, 5 J. LEG. MED. 63 (1984); Jeffrey A. Parness, *The Duty to Prevent Handicaps: Laws Promoting the Prevention of Handicaps to Newborns*, 5 W. NEW ENG. L. REV. 431 (1983); Jeffrey A. Parness & Susan K. Pritchard, *To Be or Not To Be: Protecting the Unborn's Potentiality of Life*, 51 U. CIN. L. REV. 257 (1982); Carol Ann Simon, *Parental Liability for Prenatal Injury*, 14 COLUM. J.L. & SOC. PROBS. 47 (1978); Beverly I. Chernaik, *Recovery for Prenatal Injuries: The Right of the Child Against Its Mother*, 10 SUFFOLK U. L. REV. 582 (1976).

104. E.g., John A. Robertson, *Procreative Liberty and the Control of Conception, Pregnancy and Childbirth*, 69 VA. L. REV. 405, 443-50 (1983).

105. E.g., Shaw, *supra* note 103 (arguing that parents should face tort liability and wrongful life claims for breach of legal duty to care for the fetus); Simon, *supra* note 103 (advocating tort liability of parent to child for prenatal injuries); Chernaik, *supra* note 103 (recommending that mothers be held liable for gross negligence toward fetus *in utero*).

106. E.g., Andre A. Panossian et al., *Criminalization of Perinatal HIV Transmission*, 19 J. LEG. MED. 223, 255 (1998) (advocating prosecution of perinatal transmission of HIV as assault under existing criminal statutes); Shaw, *supra* note 103 (urging prosecution of fetal abuse under child abuse laws).

107. For example, under the common law, a fetus could be named an heir in a will. However, the property rights so specified did not vest until live birth. Lawrence J. Nelson et al., *Forced Medical Treatment of Pregnant Women: "Compelling Each to Live as Seems Good to the Rest,"* 37 HASTINGS L.J. 703, 730 (1986). Beginning in 1946, courts began to allow recovery for tortious injury to a fetus subsequently born alive. See *Bonbrest v. Kotz*, 65 F. Supp. 138 (D.D.C. 1946). Prior to the *Bonbrest* decision, courts uniformly denied recovery for fetal injuries and conditioned recovery in a wrongful death action on the live birth of the fetus. Nelson at 733. Similarly, the criminal law historically did not recognize the killing of an unborn fetus as a homicide, and only recently has this begun to change. The most famous example of this shift in the criminal

a person under common law.¹⁰⁸ Similarly, the Supreme Court has held that fetuses are not constitutional persons under the Fourteenth Amendment.¹⁰⁹ Fetal rights, when recognized by the law, generally have been contingent upon live birth and only enforceable against third parties.¹¹⁰ Furthermore, even when courts began to recognize fetal rights in the absence of live birth, for example, allowing parental recovery in wrongful death actions for the loss of an expected child or criminal prosecutions for feticide, the purpose was to compensate and protect expectant parents.¹¹¹ The law traditionally has not viewed the fetus as an entity separate from the pregnant woman, but rather has sought to protect born persons, including the parents and the child born subsequently. Under this approach, the interests of parents and child are seen as unified.¹¹²

Although generally read as a decision promoting women's rights, *Roe v. Wade* also provided the doctrinal launching pad for the law's shift toward a broader vision of fetal rights that creates an adversarial relationship between the pregnant woman and her fetus. In setting limits on the power of the state to prohibit abortion, the *Roe* Court afforded legal status to the state's "important and legitimate interest in protecting the potentiality of human life,"¹¹³ separate and distinct from the state's established interest in preserving and protecting the pregnant woman.¹¹⁴ This state interest in the potentiality of life provides the legal basis for state interference in women's childbearing decisions,¹¹⁵ and animates fetal rights advocates' proposals for extensive state regulation of pregnant women's behavior and health care decisions.¹¹⁶ Theorists¹¹⁷ and courts¹¹⁸ relying on the state's interest in potential life to justify state interventions as drastic as compelled surgery on pregnant women for the benefit of the fetus typically have not felt constrained by the critical limit *Roe* places on the state's interest in the fetus, namely an overriding emphasis on the mother's

law is the California legislature's reaction to the California Supreme Court's decision in *Keeler v. Superior Court*, 470 P.2d 617 (Cal. 1970), in which the court held that a fetus was not a "human being" for purposes of the state murder statute. The legislature responded by adding "a fetus" to the list of possible murder victims specified in the statute. Nelson at 731.

108. Nelson, *supra* note 107, at 738. As the Supreme Court stated in *Roe*, "the unborn have never been recognized in the law as persons in the whole sense." *Roe*, 410 U.S. at 162.

109. *Roe*, 410 U.S. at 158.

110. Dawn E. Johnson, Note, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy and Equal Protection*, 95 YALE L.J. 599, 600-01 (1986).

111. *Id.* at 603.

112. *Id.* at 602.

113. *Roe*, 410 U.S. at 162.

114. Nelson, *supra* note 107, at 740.

115. *Id.* at 740-41.

116. Janet Gallagher, *Prenatal Invasions & Interventions: What's Wrong with Fetal Rights*, 10 HARV. WOMEN'S L.J. 9, 17 (1987); Nelson, *supra* note 107, at 741.

117. See, e.g., Robertson, *supra* note 104, at 437-450 (advocating extensive state management of women's pregnancies, including prohibitions of behavior dangerous to the fetus and mandatory prenatal diagnosis and *in utero* fetal therapy).

118. See, e.g., *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 S.E.2d 457 (Ga. 1981) (*per curiam*) (compelling a pregnant woman to undergo cesarean section, despite religious objections, to protect the health of her fetus).

life and health.¹¹⁹ Rather, fetal rights advocates often assert that pregnant women lose their right to bodily integrity once they decide to carry their pregnancies to term and waive the abortion right recognized in *Roe*.¹²⁰

Fetal rights rhetoric has a number of implications for state regulation of HIV-infected pregnant women's childbearing decisions. Most obviously, if accepted, fetal rights arguments would gut any possible objection to current proposals for mandatory HIV testing of all pregnant women without consent.¹²¹ What receives less attention are the possible implications of a positive HIV test result under a fetal rights rubric. HIV testing only provides information about a pregnant woman's serostatus, and standing alone does nothing to improve the woman's health or prevent perinatal transmission to her fetus.¹²² A positive test result only benefits the fetus if the mother chooses to undergo medical therapy recommended to prevent perinatal HIV transmission, or if the state compels her to do so.¹²³ Fetal rights advocates would have no qualms about compelling all HIV-infected pregnant women to undergo such therapy.¹²⁴

Furthermore, although modern fetal rights rhetoric argues for increased state intervention in the lives of pregnant women without any explicit reference to race or class, there is little reason to believe that beneath the surface the fetal rights movement is a different animal than other campaigns for state intervention in the childbearing decisions of poor women of color that have occurred repeatedly in one form or another throughout American history. A study conducted in the mid-1980s looked at compelled medical treatment of pregnant women that had been ordered by courts in the name of fetal rights.¹²⁵ In the vast majority of cases, the women forced by the state to undergo medical treatment for the benefit of their fetuses were women of color.¹²⁶ Similarly, current data suggests that although African-American women and white women are equally likely to use drugs during pregnancy, African-American women are much more likely to be reported for their drug use, and a significant majority of the defendants in recent fetal rights-inspired prosecutions of pregnant drug users

119. Gallagher, *supra* note 116, at 18; Nelson, *supra* note 107, at 742.

120. Robertson, *supra* note 104, at 437.

121. See *infra* Parts IV and V.

122. Susan J. Levy, *The Constitutional Implications of Mandatory Testing for Acquired Immune Deficiency Syndrome—AIDS*, 37 EMORY L.J. 217, 247 (1988).

123. Howard Minkoff & Anne Willoughby, *Pediatric HIV Disease, Zidovudine in Pregnancy, and Unblinding Heelstick Surveys: Reframing the Debate on Prenatal HIV Testing*, 274 JAMA 1165, 1167 (1995). The authors conclude that if the purpose justifying mandatory prenatal testing is universal perinatal therapy to reduce the risk of HIV transmission to the infant, then therapy would also have to be mandatory in order for the state purpose to be realized. *Id.*

124. See *supra* note 117.

125. Veronika E.B. Kolder et al., *Court-Ordered Obstetrical Interventions*, 316 NEW ENG. J. MED. 1192 (1987).

126. Responding hospitals reported all attempts to obtain court orders for the medical treatment of pregnant women, eighty-one percent of which were directed against African-American, Asian and Hispanic women, and twenty-four percent of which involved women who did not speak English as their primary language. Forty-four percent of the women involved in these attempts were unmarried. Court orders were granted in eighty-six percent of the reported attempts, usually less than six hours after legal efforts were initiated. A full nineteen percent of court orders were obtained in less than one hour, often by telephone. *Id.* at 1193.

have been African-American.¹²⁷ Although fetal rights is an equal opportunity theory in the abstract, in practice it operates primarily as a control on the childbearing decisions of poor women and women of color, the women most frequently infected with HIV.

III. PUBLIC HEALTH POLICIES TARGETING HIV INFECTION IN WOMEN AND NEWBORNS

A. EARLY PROGRAMS ADDRESSING THE REPRODUCTIVE DECISIONS OF HIV-INFECTED WOMEN AND THE FIRST PROPOSALS FOR SCREENING PREGNANT WOMEN AND NEWBORNS

1. Counseling HIV-infected women to not have children

Possibly more than any other group affected by HIV, HIV-infected women are particularly vulnerable to coercive state policies aimed at preventing transmission of the AIDS virus. HIV-infected women are not merely capable of infecting others who engage in high-risk behaviors with them; their pregnancies also are the primary means of transmission to HIV-infected infants,¹²⁸ who often are seen as the most innocent victims of AIDS.¹²⁹ In fact, much more than men, HIV-infected women often have been perceived *only* as vectors of perinatal transmission, rather than as sick persons with their own health care needs. For example, women who are not pregnant are frequently excluded from clinical trials of new HIV medications on grounds that they may become pregnant and the potential effects of the trial drugs on a fetus are not known.¹³⁰ At the same time, researchers have been highly interested in studying drug therapies that might prevent perinatal transmission, with the result that almost all women able to access experimental drug therapies are pregnant.¹³¹

127. African-American women are ten times more likely to be reported for drug use during pregnancy than white women, despite similar rates of drug use, and seventy percent of state prosecutions for drug use during pregnancy involve African-American defendants. ROBERTS, *supra* note 84, at 172-75.

128. See *supra* note 19 and accompanying text.

129. E.g., Madison, *supra* note 5, at 385-86 ("HIV infection often results from carelessness and promiscuity. While adults may take precautions against this disease by using condoms and not sharing drug needles, many choose not to do so. Newborns, on the other hand, cannot make this choice, and they end up paying the price for their mothers' illicit behavior.").

130. Sinton, *supra* note 101, at 233. In other instances, women have been told they must be sterilized or use Norplant in order to participate in clinical trials. Elizabeth B. Cooper, *Why Mandatory HIV Testing of Pregnant Women and Newborns Must Fail: A Legal, Historical, and Public Policy Analysis*, 3 CARDOZO WOMEN'S L.J. 13, 16 (1996). Women historically have been underrepresented in HIV clinical trials, most likely as a result of this policy of excluding childbearing women. For example, by the end of 1990, only 6.7% of ACTG participants were women, whereas women represented 9.8% of AIDS cases diagnosed in the United States. Liza Solomon & Sylvia Cohn, *Access to, and Utilization of, Health Services for HIV-Infected Women, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES*, *supra* note 4, at 96, 102.

131. In 1991, only 8.3% of women enrolled in ACTG trials were not pregnant. Solomon & Cohn, *supra* note 130, at 102. HIV-infected women's inability to access HIV drugs is not limited to the clinical trial setting, either. Prior to the publication of the ACTG 076 results, symptomatic HIV-infected men were three times more likely than symptomatic HIV-infected women to be offered ZDV treatment, and consequently survived significantly longer after an AIDS diagnosis than did their female counterparts. *Id.* at 97-98; see also Lois

Given this focus on women as potential producers of HIV-infected infants, it is not surprising that public health officials focused on the transmission risk HIV-infected women posed to their children long before addressing other issues affecting HIV-infected women and their families.¹³² In 1985, when there were no known therapies for reducing the risk of perinatal HIV transmission, the CDC published guidelines recommending that HIV-infected women be advised to “delay” pregnancy.¹³³ The health departments of forty-nine states similarly advised that HIV-infected women should be counseled to avoid pregnancy.¹³⁴ Although these public recommendations only addressed directly those reproductive decisions women made prior to pregnancy, they clearly signaled that HIV-infected women who became pregnant should choose abortion over childbirth.¹³⁵ Health care providers picked up on this signal, as indicated by striking anecdotal evidence that pregnant HIV-infected women frequently were pressured by doctors to terminate their pregnancies.¹³⁶

Eldred & Richard Chaisson, *The Clinical Course of HIV Infection in Women*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, *supra* note 4, at 15, 19 (reporting that median survival time in persons receiving ZDV was 770 days after AIDS diagnosis compared to 190 days in persons not receiving ZDV); Jeffrey T. Berger et al., *The Ethics of Mandatory HIV Testing in Newborns*, 7 J. CLINICAL ETHICS 77, 80 (1996) (noting HIV-infected women less likely to be offered ZDV than HIV-infected men); Thomas C. Quinn, *Screening for HIV Infection—Benefits and Costs*, 327 NEW ENG. J. MED. 486, 486 (1992) (attributing women’s shorter survival time after AIDS diagnosis to their differential use of ZDV).

132. For example, the CDC published the first of a series of guidelines regarding HIV infection and pregnancy in 1985. Taunya Lovell Banks, *Legal Challenges: State Intervention, Reproduction, and HIV-Infected Women*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, *supra* note 4, at 143. In contrast, it was not until 1993, and then only in response to a class action lawsuit, that the CDC’s AIDS definition was changed to include opportunistic infections and other diseases commonly found in women with AIDS. Sinton, *supra* note 101, at 232. Access to health care and social services for the families of HIV-infected women in many cases was limited by their inability to receive an AIDS diagnosis under the earlier guidelines, which emphasized diseases frequently affecting HIV-infected men. Cooper, *supra* note 130, at 15; *see also* Karen K. Rothenberg, *Reproductive Choice and Reality: An Assessment of Tort Liability for Health Care Providers and Women with HIV/AIDS*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, *supra* note 4, at 178 (discussing public focus on limiting childbearing by HIV-infected women to prevent pediatric AIDS rather than on health and well-being of infected women).

133. Centers for Disease Control and Prevention, *Current Trends and Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immune Deficiency Syndrome*, 34 MORBIDITY & MORTALITY WKLY. REP. 721 (1985). The American College of Obstetrics & Gynecology (ACOG) seconded this recommendation in 1987, stating that HIV-infected women “should be strongly encouraged not to become pregnant.” Rothenberg, *supra* note 132, at 186 (quoting American College of Obstetrics and Gynecology, *Prevention of Human Immunodeficiency Virus Infection and Acquired Immune Deficiency Syndrome*, ACOG COMMITTEE STATEMENT NO. 53 (1987)). The editor of the Journal of the American Medical Association (JAMA) also counseled that “persons carrying the AIDS virus should not become pregnant.” George Lundberg, *The Age of AIDS: A Great Time for Defensive Living*, 253 JAMA 3440, 3440 (1985).

134. M. Gregg Bloche, *Clinical Counseling and the Problem of Autonomy-Negating Influence*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, *supra* note 4, at 257, 297 n.7.

135. *Id.* at 258.

136. Sangree, *supra* note 85, at 342–43. For example, two doctors in a prenatal clinic in Minnesota aggressively counseled an HIV-infected Native American woman to have an abortion. One doctor falsely told her that her baby would certainly develop AIDS and die within the first year. The second doctor asked her, “Who do you think you are to bring a baby into this world only to watch it suffer and die?” *Id.* Similarly, a complaint filed in New York state court alleged that doctors at Jamaica Hospital refused to provide prenatal care to an HIV-infected woman who wanted to continue her pregnancy after being counseled “that she would be wrong not to give up the baby to abortion, and that she would be adding another burden to society to have this child.” Rothenberg, *supra* note 132, at 186–87 (discussing allegations of complaint filed in *Doe v. Jamaica Hospital*).

Despite the widespread adoption of the CDC's 1985 guidelines, the incidence of perinatally-acquired AIDS continued to increase,¹³⁷ most likely as a consequence of two independent factors. First, many HIV-infected women ignored physicians' pressure to abort and instead chose to continue their pregnancies at rates similar to those found in groups of uninfected women.¹³⁸ Doctors' admonitions regarding the risk of giving birth to an "AIDS baby" did not resonate as anticipated among HIV-infected women facing intimate decisions about whether to have a child.¹³⁹

Second, efforts to reduce the perinatal transmission of HIV also were undermined by the health care system's failure to identify significant numbers of HIV-infected pregnant women, thereby missing many of the intended targets of its anti-childbearing message. The prevailing policies for HIV testing of pregnant women were the same as those followed for other adults, and relied on an individual's willingness to acknowledge high-risk behaviors and come forward for testing.¹⁴⁰ Beginning in 1988, the CDC conducted an anonymous serosurveillance survey to monitor the incidence of HIV infection in childbearing women,¹⁴¹ and for the first time data became available that did not

Ironically, those HIV-infected women who elect to have an abortion also face significant obstacles to effecting their reproductive decisions, due to the fact that many abortion providers refuse to treat HIV-infected women. A survey of New York City abortion clinics revealed that sixty-four percent refused to schedule an appointment for an HIV-infected woman to get an abortion. Carol Beth Barnett, *The Forgotten and Neglected: Pregnant Women and Women of Childbearing Age in the Context of the AIDS Epidemic*, 23 GOLDEN GATE U.L. REV. 863, 893 (1993). Even when an HIV-infected woman freely chooses to terminate her pregnancy and locates an abortion provider willing to treat her, she is not necessarily ensured of avoiding reproductive coercion. In one example, an abortion provider in South Carolina conditioned treatment on obtaining the "consent" of two HIV-infected women to permanent sterilization to prevent future pregnancies. Sangree, *supra* note 85, at 342.

137. The incidence of perinatally-acquired HIV infection continued to increase until 1992. See *supra* note 41 and accompanying text.

138. Jean Anderson, *Gynecological and Obstetrical Issues for HIV-Infected Women*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, *supra* note 4, at 31, 42. In a recent study of pregnant IDUs, fifty percent of those who were HIV-infected chose to have an abortion, compared to forty-four percent of those who were not infected with HIV. Peter A. Selwyn et al., *Knowledge of HIV Antibody Status and Decision to Continue or Terminate Pregnancy Among Intravenous Drug Users*, 261 JAMA 3567, 3568 (1989).

139. Commentators on this subject believe that the childbearing decisions of HIV-infected women often turn not on knowledge of their HIV status but on cultural, social, religious and personal norms that place an extremely high value on motherhood. "[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." Weiss, *supra* note 91, at 673; see also Carol Levine & Nancy Neveloff Dubler, *Uncertain Risks and Bitter Realities: The Reproductive Choices of HIV-Infected Women*, 68 MILBANK Q. 321, 332-337 (1990) (citing the significance of pronatalist ideologies and cultural value of reproduction in poor minority communities affected by HIV). HIV-infected intravenous drug users also may choose to continue their pregnancies as an expression of rehabilitation and lifestyle change. Selwyn, *supra* note 138, at 3570.

140. Sheldon A. Landesman et al., *Serosurvey of Human Immunodeficiency Virus Testing Infection in Parturients*, 258 JAMA 2701, 2701 (1987).

141. Under this program, dried blood samples collected from all newborns in forty-four states, the District of Columbia and Puerto Rico were tested for HIV after the removal of personal identifiers. Demographic data such as the mother's race and geographic region of residence were retained. The survey relied on antibody testing, so the results indicated HIV infection in the mother, not the infant. The information provided by the survey was considered to be particularly valuable because it provided a snapshot of the level of HIV infection that cut across geographical, socioeconomic, ethnic and age lines. John M. Naber & David R. Johnson, *Mandatory HIV Testing in State Newborn Screening Programs*, 7 J.L. & HEALTH 55, 58-59 (1992-1993). The survey was terminated in 1995. See generally *supra* note 42.

rely on targeted testing. Researchers were able to compare the number of HIV-infected pregnant women identified prior to childbirth by targeted testing with the number of HIV-infected women the serosurveillance results indicated actually gave birth. They found that existing risk factor-based testing policies were not capturing a significant number of HIV-infected women.¹⁴²

2. *Shifting the emphasis to prenatal and newborn screening*

Faced with growing numbers of HIV-infected women of childbearing age and HIV-infected children,¹⁴³ many public health officials soon came to the conclusion that the CDC's recommendations for "guiding" the reproductive decisions of HIV-infected women, when implemented in conjunction with targeted testing policies, did not go far enough to prevent perinatal transmission.¹⁴⁴ Commentators produced a flurry of proposals for new testing policies designed to overcome the limitations of targeted testing. The proposals differed as to the details, but generally called for testing pregnant women differently than other adults, in an attempt to identify as many HIV-infected pregnant women as possible prior to childbirth.¹⁴⁵ Some public health officials believed that all pregnant women should receive HIV counseling and be offered a test regardless of their stated risk factors;¹⁴⁶ others called for routine mandatory testing of all pregnant women without counseling or consent.¹⁴⁷ In light of the fact that there was no known therapy for preventing perinatal transmission at the time these prenatal testing policies were proposed, their implicit purpose was to identify additional HIV-infected women for directive reproductive counseling,¹⁴⁸

142. Landesman, *supra* note 140, at 2701. For example, a Brooklyn hospital analyzed 602 newborn blood samples and researchers found that twelve HIV-infected women were not identified prior to delivery. *Id.*

143. Throughout most of the 1990s, women were the fastest growing group of HIV-infected persons in the United States. See Eldred & Chaisson, *supra* note 131, at 24. The incidence of pediatric AIDS did not peak until 1992. See *supra* note 41 and accompanying text.

144. See, e.g., Howard L. Minkoff & Sheldon H. Landesman, *The Case for Routinely Offering Prenatal Testing for Human Immunodeficiency Virus*, 159 AM. J. OBSTETRICS & GYNECOLOGY 793, 794-95 (1988) (recommending routine prenatal testing given the failure of targeted counseling and testing); Marcia Angell, *A Dual Approach to the AIDS Epidemic*, 324 NEW ENG. J. MED. 1498, 1499 (1991) (proposing routine, if not mandatory, testing of all pregnant women and newborns); INSTITUTE OF MEDICINE, *supra* note 12, at 39-40 (rejecting risk-factor based testing and recommending voluntary HIV screening for all women in geographic areas with high levels of HIV infection).

145. *Id.*

146. Minkoff & Landesman, *supra* note 144, at 795.

147. See Angell, *supra* note 144. Also, evidence indicated that some hospitals were covertly screening pregnant patients for HIV. Martha A. Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402, 408 (1993).

148. Directive counseling occurs whenever a patient is urged by her health care provider to exercise one reproductive option over another. Nancy E. Kass, *Reproductive Decision Making in the Context of HIV: The Case for Nondirective Counseling*, in AIDS, WOMEN AND THE NEXT GENERATION, *supra* note 54, at 308, 313-12. Few commentators explicitly advocated directive counseling for abortion as part of their testing policies, but with no treatment available the only way to prevent transmission was to terminate the pregnancy. Authors made oblique statements, for example, noting that knowledge of HIV status during a pregnancy "empowers" a woman to make informed choices about childbearing. Minkoff & Landesman, *supra* note 144, at 793-94. However, if a woman's informed choice was to carry her child to term, she faced the same risk of transmitting HIV infection to her child perinatally as she did prior to discovering her status. The knowledge only served to get her to pay more attention to the abortion option.

i.e., to encourage HIV-infected pregnant women to abort their fetuses. Proposals also appeared for mandatory HIV testing of all newborns¹⁴⁹ in order to identify candidates for early medical intervention that would hopefully prevent serious opportunistic infections and early death.¹⁵⁰

When first proposed, mandatory prenatal and newborn testing was opposed by many public health officials¹⁵¹ and legal writers.¹⁵² Prenatal testing was attacked as an impermissible interference with women's reproductive decisions, particularly as the only way to prevent perinatal transmission at the time was to avoid childbearing.¹⁵³ Directive counseling appeared to many both as racist, given the demographic makeup of women with HIV-infection,¹⁵⁴ and ethically questionable, given that most infants born to HIV-infected women would be free of infection themselves.¹⁵⁵ Newborn testing faced similar criticism. The tests clinically available in the late 1980s and early 1990s all tested for HIV antibodies rather than the presence of the HIV virus, and consequently revealed the HIV status of the mother rather than the tested infant.¹⁵⁶ Furthermore, although an HIV-infected infant could not be identified until fifteen to eighteen months of age,¹⁵⁷ PCP prophylaxis and other preventive treatment had to be started much earlier for maximum effectiveness.¹⁵⁸ As a result, even if treatment were available, the approximately seventy percent of HIV-exposed children who

149. For example, in May 1993 New York State Assemblywoman Nettie Mayersohn introduced a "Baby AIDS" bill calling for HIV testing of all newborns in New York State. David Abramson, *Passing the Test: New York's Newborn HIV Testing Policy, 1987-1997*, in INSTITUTE OF MEDICINE, *REDUCING THE ODDS*, *supra* note 4 at 313, 327. The bill generally was described as "unblinding" the blind serosurveillance survey, but as the identities of subjects in the serosurveillance survey were not known, the proposal actually involved a new program of mandatory non-anonymous newborn screening. *See generally supra* notes 42, 141.

150. INSTITUTE OF MEDICINE, *supra* note 12, at 25.

151. *See, e.g.*, INSTITUTE OF MEDICINE, *supra* note 4; Berger et al., *supra* note 131 at 77; Ana O. Dumois, *The Case Against Mandatory Newborn Screening for HIV Antibodies*, 20 J. COMMUNITY HEALTH 143 (1995); Quinn, *Screening for HIV Infection—Benefits and Costs*, 327 NEW ENG. J. MED. 486 (1992); INSTITUTE OF MEDICINE, *supra* note 12.

152. *See, e.g.*, Eileen McKenna, Note, *The Mandatory Testing of Newborns for HIV: Too Much, Too Little, Too Late*, 13 N.Y.L. SCH. J. HUM. RIGHTS 307 (1997); Suzanne M. Malloy, Comment, *Mandatory HIV Screening of Newborns: A Proposition Whose Time Has Not Yet Come*, 45 AM. U. L. REV. 1185 (1996); Cooper, *supra* note 130; Linda Farber Post, Note, *Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?*, 16 CARDOZO L. REV. 169 (1994); Jean R. Sternlight, *Mandatory Non-Anonymous Testing of Newborns for HIV: Should It Ever Be Allowed?*, 27 J. MARSHALL L. REV. 373 (1994). *But see, e.g.*, Juliet J. McKenna, *Where Ignorance Is Not Bliss: A Proposal for Mandatory HIV Testing of Pregnant Women*, 7 STAN. L. & POL'Y REV. 133 (1996); Leonardo Renna, *New York State's Proposal to Unblind HIV Testing for Newborns: A Necessary Step in Addressing a Critical Problem*, 60 BROOK. L. REV. 407 (1994).

153. *See, e.g.*, Barnett, *supra* note 136, at 893.

154. One author noted that many women with chronic diseases are admired for risking their own health to become pregnant and have a child, citing Julia Roberts' diabetic character in the movie *Steel Magnolias* as one well-known, if fictional, example. However, HIV-infected women are considered irresponsible and condemned for having children. The author concluded that "[s]urely class and ethnicity play a role in these different societal responses and judgments." Levine & Dubler, *supra* note 139, at 323. *See also* Banks, *supra* note 96, at 383-84 (highlighting racial and class biases in proposals disregarding marginalized women's interests in the pursuit of public health goals).

155. In the absence of preventive prenatal therapies, sixty-seven percent to eighty-four percent of children born to HIV-infected women do not contract HIV themselves. *See supra* note 27 and accompanying text.

156. *See supra* notes 56-57 and accompanying text.

157. *See id.*

158. *See supra* notes 75-77 and accompanying text.

were not HIV-infected would be exposed to unnecessary medical treatment with unknown long-term consequences for their health.¹⁵⁹

B. CURRENT POLICIES AND PROPOSALS FOR HIV SCREENING OF PREGNANT WOMEN AND NEWBORNS

1. The 1995 Public Health Service recommendations

The publication of the ACTG 076 results and more recent advances in the science of HIV prevention and treatment¹⁶⁰ have only sharpened the debate over appropriate public health policies for HIV screening of pregnant women and newborns. Discussion has shifted away from counseling HIV-infected women to avoid pregnancy and now centers on how best to identify HIV-infected women and children for treatment purposes.¹⁶¹ The situation for HIV-infected women and their children appears to be win-win in many respects, as pregnant women identified through the proposed screening programs can be offered combination therapies that will both improve their own health and reduce the risk of perinatal transmission.¹⁶² However, there are a number of reasons HIV-infected pregnant women may refuse the therapies recommended to them,¹⁶³ so the threat of compelled treatment is always lurking, often unacknowledged, in the background of these proposals.¹⁶⁴ Furthermore, prenatal HIV-testing programs

159. “[PCP prophylaxis is] not without toxicity, and prescribing [it] for all seropositive infants means that uninfected children would be exposed to substantial toxicity without deriving any medical benefit. Moreover, the potential long-term toxicity of such exposure is still uncertain, particularly for infants.” INSTITUTE OF MEDICINE, *supra* note 12, at 27.

160. See *supra* notes 45–52 and accompanying text (discussing advances in combination therapy and use of elective cesarean section to reduce perinatal transmission rate to two percent).

161. For example, in 1995 the Public Health Service issued new recommendations on HIV counseling and testing for pregnant women. See *infra* notes 169–171 and accompanying text. The 1995 recommendations clearly emphasize preventive therapy. They include no mention of avoiding pregnancy, and can be seen as implicitly overruling the 1985 CDC guidelines recommending directive counseling. However, some unofficial moral pressure on HIV-infected women urging them not to reproduce most likely persists. See Rothenberg, *supra* note 132, at 178, 197.

162. See Centers for Disease Control, *supra* note 45, at 1 (noting that combination therapy is standard of care for all adults and should be continued during pregnancy). Although there is little information available comparing the effectiveness of combination therapies to the effectiveness of ZDV monotherapy in reducing perinatal HIV transmission, no increase in the incidence of perinatal transmission has been noted since combination therapy became the standard of care for HIV-infected women. See *supra* note 41 and accompanying text (number of perinatal AIDS cases has continually declined since 1992 despite increased use of combination therapy in interim.)

163. A woman could determine that the unknown fetal risks of perinatal exposure to antiretroviral drugs makes taking the drugs during pregnancy unacceptable to her. A woman could choose to undergo antiretroviral therapy or an elective cesarean section, but decide that the burdens or risks of electing both to achieve the lowest possible risk of perinatal transmission are too great. In a third example, a woman on Medicaid, who may have limited access to antiretroviral drugs after she gives birth, may determine that going on antiretrovirals only for the period of her pregnancy poses an unacceptable risk of developing a resistant virus strain that could compromise her own health. See R.J. Simonds & Martha Rogers, *Preventing Perinatal HIV Infection: How Far Have We Come?*, 275 JAMA 1514, 1514 (1996) (noting that the Health Care Financing Administration requires state Medicaid programs to cover the cost of ZDV to prevent perinatal transmission but is silent on funding for antiretrovirals for women who are not pregnant).

164. See *supra* notes 122–124.

do not guarantee access to the therapies most frequently recommended for HIV-infected pregnant women.¹⁶⁵ For their part, newborn testing policies enter the picture too late to prevent perinatal transmission, and shift resources away from prenatal interventions that may directly benefit both the mother and child.¹⁶⁶

Perhaps because of these issues, there is significant consensus in the medical community that HIV testing of pregnant women and newborns should be implemented on a voluntary basis.¹⁶⁷ In 1995, after the publication of the ACTG 076 results, the Public Health Service issued HIV guidelines recommending universal counseling and voluntary testing of all pregnant women “so that interventions to improve the woman’s health and the health of her infant can be offered in a timely and effective manner.”¹⁶⁸ The PHS proposed voluntary, as opposed to mandatory testing, because of the importance of a good relationship between a woman and her health care provider to the woman’s adherence to a complex drug therapy; concern that mandatory testing might deter women from seeking prenatal care; the possibility that in some cases the risks of testing positive, including discrimination and domestic violence, might outweigh the benefits; and evidence indicating high test acceptance rates in universal voluntary testing programs.¹⁶⁹ The PHS guidelines recognize that treatment decisions are complex and advise that discussions of treatment options should be noncoercive and allow the woman to come to her own decision.¹⁷⁰ PHS anticipated that most HIV-infected women would be identified prenatally, allowing for easy identification of HIV-exposed infants and avoiding any need for a specific proposal regarding newborn testing.¹⁷¹ The vast majority of states and health care professional organizations followed PHS’s lead and adopted voluntary testing policies.¹⁷²

165. INSTITUTE OF MEDICINE, *supra* note 4, at 67 (highlighting access to care as major barrier to further reduction in perinatal transmission rate).

166. *See id.* at 33–34.

167. *See generally, id.* at 69–73.

168. Centers for Disease Control and Prevention, *U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women*, 44 MORBIDITY & MORTALITY WKLY. REP. 1, 2 (RR-7 1995). In 1996 amendments to the Ryan White CARE Act, 42 U.S.C.A. §§ 300ff–300ff-111 (West 1991 & Supp. 2000), Congress seconded the PHS recommendations on prenatal testing, making findings that “routine HIV counseling and voluntary testing of pregnant women should become the standard of care.” Congress required all states “to effect regulations or measures to adopt the guidelines issued by the Centers for Disease Control and Prevention concerning recommendations for human immunodeficiency virus counseling and voluntary testing for pregnant women” in order to maintain eligibility for federal financial assistance for HIV counseling and testing for pregnant women. *Id.* § 300ff-33(a)-(b).

169. Centers for Disease Control, *supra* note 168, at 4–6.

170. *Id.* at 4.

171. *See id.* at 5.

172. Four states (Michigan, Mississippi, Tennessee, and Texas) have routine “opt-out” procedures, under which a pregnant woman will be tested for HIV unless she specifically objects. Three states (Indiana, New Jersey, Rhode Island) have routine “opt-in” procedures requiring health care providers to offer an HIV test to all pregnant women seeking prenatal care. Testing is voluntary with informed consent in the remaining states. Under state policies and laws, prenatal HIV screening is required in 22 states, routine in 10 states, and recommended in 18 states. INSTITUTE OF MEDICINE, *supra* note 4, at 69–70.

Fewer states have laws or policies addressing newborn HIV testing. Most of these policies are mandatory, and are discussed below. *See infra* notes 183–184 and accompanying text. Texas has an “opt-out” newborn

2. Responses to the PHS guidelines: Voluntary programs are not enough

From certain perspectives, the widespread adoption of voluntary HIV-testing guidelines has been successful. The incidence of perinatal transmission has decreased significantly since its peak in 1992, largely due to the increased use of ZDV and other antiretroviral drugs by HIV-infected women during pregnancy.¹⁷³ Depending on the setting, seventy-seven percent to ninety-seven percent of pregnant women consent to HIV testing when it is offered to them,¹⁷⁴ and most HIV-infected pregnant women accept antiretroviral therapies recommended to reduce the risk of perinatal transmission.¹⁷⁵ However, to public health officials and politicians who see one avoidable case of pediatric AIDS as one too many, voluntary testing policies are not reducing the national perinatal transmission rate to the very low number that could be seen if all HIV-positive women were identified and all received optimal health care during pregnancy.¹⁷⁶ Studies indicate that the most significant obstacle to reaching the lowest possible perinatal transmission rate is health care providers' failure to implement universal counseling and voluntary testing guidelines.¹⁷⁷ However, critics of the

testing policy, requiring health care providers to test newborns unless the mother refuses. INSTITUTE OF MEDICINE, *supra* note 4, at 71.

Until recently, the American College of Obstetrics and Gynecology (ACOG) recommended routine HIV counseling of all pregnant women and voluntary testing with informed consent. *Id.* at 71. The American Academy of Pediatrics (AAP), the National Medical Association (NMA), the American Academy of Family Physicians (AAFP), the American College of Nurse Midwives (ACNM), and the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) all issued similar guidelines. *Id.* at 72–73. The American Medical Association (AMA) is the only professional organization that supports mandatory HIV testing of all pregnant women and newborns. *Id.* at 72.

173. See *supra* notes 41–44 and accompanying text.

174. Nakchbandi, *supra* note 36, at 762. For example, eighty-six percent of pregnant women in Texas are tested for HIV under that state's "opt-out" program described in note 173 *supra*. INSTITUTE OF MEDICINE, *supra* note 4, at 96.

175. INSTITUTE OF MEDICINE, *supra* note 4, at 97. A CDC review in four states showed that only five percent of HIV-infected pregnant women refused ZDV when it was offered. *Id.* However, success in providing ZDV treatment varies by state. For example, in New York State, sixty-seven percent of HIV-infected women received ZDV treatment during pregnancy, whereas ninety-three percent of HIV-infected women used ZDV prenatally in Michigan. *Id.* "Barriers to use of ZDV among HIV-infected pregnant women include not having information about maternal HIV status, late onset of prenatal care, insufficient time to administer ZDV (e.g., short labor), and discontinuity of care (e.g., delivery at hospital not associated with prenatal care providers)." *Id.*

176. For example, the Institute of Medicine assumed that the risk of transmission under optimal care is five percent given current medical knowledge. *Id.* at 104. The Institute of Medicine concluded that the reduction in perinatal transmission seen since 1992 "is far less than the ACTG 076 findings can offer." *Id.* at 1.

177. A CDC study evaluating physician compliance with the 1995 Public Health Service recommendations found that 63.4% to 86.7% of new mothers surveyed recalled discussing HIV testing with their prenatal health care provider, and fifty-eight percent to 80.7% recalled being tested for HIV during their pregnancy. Centers for Disease Control and Prevention, *Prenatal Discussion of HIV Testing and Maternal HIV Testing—14 States, 1996-1997*, 48 MORBIDITY & MORTALITY WKLY. REP. 401 (1999). The existence of state policies and laws requiring counseling and voluntary testing does not appear to have any impact on whether health care providers actually counsel or offer testing to their pregnant patients. INSTITUTE OF MEDICINE, *supra* note 4, at 71.

In its recent review of prenatal HIV testing practices, the Institute of Medicine found that many prenatal care providers were not following the PHS guidelines and concluded that "the most effective single intervention to reduce perinatal transmission is to increase providers' offering of HIV tests (reduces perinatal

PHS guidelines generally have focused on the small number of pregnant women who refuse the test, and conclude that voluntary testing policies are not enough.¹⁷⁸

Most political responses to the alleged failure of universal voluntary testing schemes such as that proposed by PHS have called for mandatory newborn testing. Congress' 1996 amendments to the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act¹⁷⁹ encouraged states to adopt mandatory newborn testing policies,¹⁸⁰ and recent 2000 amendments reward states who have mandatory newborn testing policies with preferential funding under the Act.¹⁸¹ Several states have adopted mandatory newborn testing laws, most notably New York, where a controversial "AIDS Baby" bill passed in June 1996,¹⁸² just a month after the 1996 Ryan White CARE Act amendments were enacted.¹⁸³ These mandatory newborn testing policies are somewhat bizarre from a public health standpoint, as newborn testing cannot play any role in preventing transmission and these testing programs do not respond at all to what are universally considered the most significant scientific breakthroughs in

HIV transmission by sixteen percent)." *Id.* at 105. If providers offered antiretroviral treatment to all identified HIV-infected pregnant women, the transmission rate could be reduced another five percent. *Id.*

In contrast, the IOM concluded that increasing test acceptance among pregnant women would reduce the perinatal transmission rate by twelve percent, and increasing HIV-infected women's acceptance of ZDV treatment would reduce the rate by another five percent. *Id.*

It should be noted that the IOM's figures may overstate the rate at which providers currently offer HIV testing to pregnant women, as well as pregnant women's refusal of HIV testing, thereby making the relative responsibility of health care providers appear smaller than it likely is in practice. The IOM's data showed that fifty percent to ninety-seven percent of health care providers routinely offered HIV testing to pregnant women. *Id.* at 75–84. In its model calculating possible reductions in the perinatal transmission rate, IOM assumed that seventy-five percent of health care providers routinely offered testing, roughly the midway point in the range it documented. *Id.* at 105. In contrast, pregnant women's test acceptance rates range from seventy-seven percent to ninety-seven percent, *see supra* note 174 and accompanying text, and the IOM incorporated a number from the low end of that range (eighty percent) into its model. *Id.*

178. *See, e.g.,* Madison, *supra* note 5, at 381–82 (calling for mandatory testing because many mothers may not consent to testing or treatment).

179. 42 U.S.C.A. §§ 300ff–300ff-111 (West 1991 & Supp. 2000). The Ryan White CARE Act supports medical care and other services for people with HIV or AIDS. Madison, *supra* note 5, at 382 n.198.

180. The 1996 amendments to the Act made Ryan White funding to the states after April 2000 contingent on demonstrating one of the following: (1) a fifty percent reduction (or a comparable measure for states with less than ten cases) in the rate of new AIDS cases resulting from perinatal transmission as compared to the rate of such cases in 1993; (2) at least ninety-five percent of women in the state who have received at least two prenatal visits prior to 34 weeks gestation have been tested for HIV; or (3) a program for mandatory testing of all newborns whose mothers have not undergone prenatal testing. 42 U.S.C.A. § 300ff–34(e)(2). *See also* INSTITUTE OF MEDICINE, *supra* note 4, at 16–17 (discussing 1996 amendments to the Ryan White CARE Act). Having a newborn testing policy was the clearest way for states to maintain funding eligibility, as it avoided statistical calculations and uncertainties.

181. The 2000 Amendments set aside funding for states that mandate testing of all newborns or, alternatively, all newborns whose mother's HIV status is not known to the delivering physician. 42 U.S.C. 300ff–33(c)(2)(B) (LEXIS 2001).

182. Abramson, *supra* note 149, at 335.

183. Connecticut also mandates newborn HIV testing, but waives the requirement in cases of religious objection. CONN. GEN. STAT. ANN. § 19a-55 (West 1997 & Supp. 2000). Texas requires newborn testing unless the mother refuses for any reason. INSTITUTE OF MEDICINE, *supra* note 4, at 71. At least six other states permit HIV testing of infant without parental consent, and in two states a health care provider may test a newborn for HIV if he or she determines it is medically necessary. *See id.*

reducing the toll of pediatric AIDS.¹⁸⁴ Mandatory newborn testing laws may be the result of a political compromise between forces intent on combating pediatric AIDS and forces attempting to minimize the intrusiveness of testing policies on the privacy of HIV-infected pregnant women. Other commentators suggest that these laws, which were in an embryonic stage as early as 1993, simply failed to adjust to intervening medical discoveries such as the ACTG 076 results enabling doctors and women to prevent the perinatal transmission of HIV.¹⁸⁵

The public health community generally has ignored politicians' calls for newborn testing, and recent proposals instead focus their attention on changing the understanding of what will constitute sufficiently informed consent in the prenatal HIV testing context. The Institute of Medicine's 1999 report to Congress on perinatal HIV transmission is the most prominent example of this approach. The IOM recommends a national policy of universal HIV testing, with patient notification, as a routine component of patient care.¹⁸⁶ As explained by the IOM, "[r]outine with notification' means that the test for HIV would be integrated into the standard battery of prenatal tests, and that women would be informed that the HIV test is being conducted and of their right to refuse it."¹⁸⁷ However, under the IOM plan, physicians would no longer provide pretest HIV counseling to their prenatal patients or even discuss the issue of perinatal HIV transmission and the potential benefits of knowing the woman's HIV status early in pregnancy.¹⁸⁸ The IOM developed its proposal largely in response to feedback that health care providers were failing to comply with the PHS guidelines because of the time and expense involved in providing standard HIV counseling to all of their pregnant patients and the administrative burdens of maintaining confidential HIV records.¹⁸⁹ Proponents of this "opt-out" approach also defend it as preserving (in some form) patient consent while shifting the psychological burden of prenatal HIV testing away from those who now must take affirmative action to accept the test and toward those who under the IOM proposal will have to take affirmative action to refuse it.¹⁹⁰ However, the IOM proposal goes a long way toward advocating effective mandatory prenatal testing, as under this plan pregnant women will not be provided with sufficient information about their HIV risk or perinatal transmission to make an informed decision about the appropriateness of prenatal testing for their situation, and health care providers will not be subject to any monitoring of whether they obtain even this minimal consent at all.¹⁹¹ The IOM proposal also fails to address the lurking issues of

184. INSTITUTE OF MEDICINE, *supra* note 4, at 33–34.

185. *Id.* at 34.

186. *Id.* at 110.

187. *Id.* ACOG and the AAP have now endorsed the IOM approach by updating clinical practice guidelines to facilitate universal and routine prenatal HIV testing with patient notification. Marie C. McCormick et al., *Preventing Perinatal Transmission of Human Immunodeficiency Virus in the United States*, 94 *OBSTETRICS & GYNECOLOGY* 795, 796 (1999).

188. INSTITUTE OF MEDICINE, *supra* note 4, at 110.

189. *Id.* at 85, 111–12.

190. Minkoff & Willoughby, *supra* note 123, at 1166.

191. See McCormick, *supra* note 187, at 797–98 (responding to critics of IOM recommendations).

access to treatment and compelled obstetrical interventions based on positive HIV test results.¹⁹²

IV. NON-LEGAL FRAMEWORKS FOR ANALYZING PROPOSED HIV-SCREENING PROGRAMS FOR PREGNANT WOMEN AND NEWBORNS

Proposals to screen pregnant women and newborns for HIV infection can be examined within ethical, public health, and legal frameworks of analysis. Each of these approaches involves interest balancing, either as a primary matter in applying the framework¹⁹³ or secondarily when comparing the relative merits of similar proposals.¹⁹⁴ As a result, analysis within each framework tends to devolve into a policy discussion that transcends the boundaries of any particular framework.¹⁹⁵ Nevertheless, each perspective highlights particular issues for consideration and thus contributes to a global analysis of the various proposals.

Applying the different frameworks only to the two proposals currently garnering the most attention—i.e., routine prenatal HIV testing with patient notification and mandatory newborn testing—ignores the history of these policies and the directions they will likely take in the future. For example, the political force behind mandatory newborn testing, coupled with a strong fetal rights movement and with growing public knowledge of the highly effective therapies available for reducing the risk of perinatal transmission, soon could lead to laws mandating prenatal testing,¹⁹⁶ a possibility that also will be discussed. Furthermore, no HIV-testing program will have any effect on health outcomes unless positive results lead to treatment. Accordingly, issues of access to care and the potential for compelled treatment of HIV-infected pregnant women and/or HIV-exposed newborns identified by screening programs also must be addressed in order to develop a complete picture of the implications of current testing proposals.

192. *See id.* at 798.

193. *See, e.g. infra* note 355 and accompanying text.

194. *See, e.g., infra* Part IV.A.4. The public health model is indeterminate when comparing mandatory prenatal screening to a policy of universal screening with consent. Choosing between these two public health policies therefore involves balancing the pros and cons of the policies against each other in a manner not explicitly set forth in the public health model itself.

195. *Cf. Sternlight, supra* note 152, at 380 (asserting that constitutional balancing analysis blurs into policy analysis of whether government can articulate a sufficiently strong interest to justify infringing individual liberties).

196. In fact, Connecticut recently passed a law requiring HIV testing of all pregnant women receiving prenatal care. *See* CONN. GEN. STAT. ANN. § 19a-90 (West 1997 & Supp. 2000). One of the primary concerns regarding the IOM's proposal for routine prenatal testing with patient notification is that it will quickly be translated by health care providers into a system of routine HIV testing without patient consent. *See supra* note 191 and accompanying text. These concerns are given weight by health care providers' previous reluctance to invest the time and expense necessary to incorporate HIV counseling into routine prenatal care. *See supra* note 177 and accompanying text. Compliance with requirements to document prenatal testing may not be accompanied by meaningful patient notification.

A. A PUBLIC HEALTH ANALYSIS OF PROPOSED SCREENING PROGRAMS

Prenatal and newborn HIV-screening programs would not be unprecedented in public health terms. All fifty states and the District of Columbia have statutes, regulations, or policies requiring prenatal or newborn screening for specified health risks.¹⁹⁷ For example, almost all states require prenatal screening for syphilis,¹⁹⁸ the test for which is generally performed on blood drawn from the woman for the purpose of conducting a number of prenatal screens, about many of which she may not be specifically informed.¹⁹⁹ Newborns also are subject to state-mandated screening programs, most commonly for phenylketonuria (PKU).²⁰⁰

1. The public health framework

At the most basic level, screening programs²⁰¹ are acceptable from a public health standpoint when there is significant potential for individual or public benefit, and where the harms of a program do not outweigh the benefits.²⁰² In addition, public health officials have identified a number of characteristics of successful and well-organized screening programs that provide a more sophisticated framework of analysis than a straightforward cost-benefit ratio. A screening program is advisable in public health terms if it meets the following criteria:

197. Katherine L. Acuff, *Prenatal and Newborn Screening: State Legislative Approaches and Current Practice Standards*, in AIDS, WOMEN AND THE NEXT GENERATION: TOWARDS A MORALLY ACCEPTABLE PUBLIC POLICY FOR HIV TESTING OF PREGNANT WOMEN AND NEWBORNS, *supra* note 54, at 121.

198. *Id.* at 122.

199. Consent for various tests involving blood analysis is presumed once a woman has consented to have blood drawn. Berger, *supra* note 151, at 78. The doctrine of presumed consent traditionally has not been applied in the HIV context, largely due to the socioeconomic implications of a positive test result, such as discrimination and the possible loss of employment, medical insurance, and housing. *Id.*

200. Acuff, *supra* note 197, at 123. PKU is a hereditary metabolic disorder that can produce brain damage resulting in severe mental retardation if left untreated. Retardation can be prevented by early restriction of dietary phenylalanine, preferably beginning before four weeks of age. Katherine L. Acuff & Ruth R. Faden, *A History of Prenatal and Newborn Screening Programs: Lessons for the Future*, in AIDS, WOMEN AND THE NEXT GENERATION: TOWARDS A MORALLY ACCEPTABLE PUBLIC POLICY FOR HIV TESTING OF PREGNANT WOMEN AND NEWBORNS, *supra* note 54, at 64. PKU screening is mandatory and occurs without parental consent in every state except Maryland, which has adopted a voluntary PKU screening scheme. Acuff, *supra* note 197, at 123; Neil A. Holtzman et al., *Effect of Informed Parental Consent on Mother's Knowledge of Newborn Screening*, 72 PEDIATRICS 807, 807 (1983).

201. In public health terms, "screening" refers to the application of a test to all individuals in a defined population. Screening stands in contrast to "testing," which is the application of a test or measurement to selected individuals for the purpose of identifying a disease or medical condition. INSTITUTE OF MEDICINE, *supra* note 4, at 22. All of the current proposals for prenatal and newborn diagnosis of HIV infection are screening programs because they call for testing all pregnant women and newborns, not just those who exhibit symptoms or have known risk factors for HIV infection.

202. Ruth R. Faden et al., *Warrants for Screening Programs: Public Health, Legal, and Ethical Frameworks*, in AIDS, WOMEN AND THE NEXT GENERATION: TOWARDS A MORALLY ACCEPTABLE PUBLIC POLICY FOR HIV TESTING OF PREGNANT WOMEN AND NEWBORNS, *supra* note 54, at 3, 7; Berger, *supra* note 151, at 78.

1. The goals of the public health program should be clearly specified and shown to be achievable.
2. The natural history of the condition should be adequately understood, and treatment or intervention for those found positive widely accepted by the scientific and medical community, with evidence that early intervention improves health outcomes.
3. The screening test should distinguish those individuals who are likely to have the condition from those who are unlikely to have it.
4. There should be adequate facilities for diagnosis and resources for treatment for all who are found to have the condition.
5. The test and possible interventions should be acceptable to the affected population.
6. The cost of case finding, diagnosis, and treatment or intervention should be economically balanced in relation to the medical cost savings that might result from the screening program.²⁰³

2. *Applying the framework to newborn screening*

Applying the six criteria to newborn screening for HIV infection, it is questionable whether newborn screening can be justified in public health terms. The goal of a newborn screening program presumably is to improve medical outcomes for HIV-infected infants.²⁰⁴ The natural history of pediatric HIV infection is well understood, and many interventions for HIV-infected newborns, such as PCP prophylaxis, are generally accepted in the medical community.²⁰⁵ Only the use of specific combinations and dosages of antiretroviral drugs appears to be a matter of continuing controversy,²⁰⁶ but even allowing for that debate, there appears to be consensus that some form of combination therapy is advisable for most infants.²⁰⁷

Significant questions arise over the matter of testing accuracy, however. Under most newborn testing programs, an ELISA test will be given shortly after

203. INSTITUTE OF MEDICINE, *supra* note 4, at 23; *see also* Naber & Johnson, *supra* note 141, at 57 (outlining simplified version of screening program criteria that does not include social acceptability of intervention).

204. Newborn screening comes too late to prevent infection of the newborn, *see supra* note 166 and accompanying text, and newborns pose no risk of infection to others, *see infra* note 263 and accompanying text.

An indirect effect of newborn screening is discovery of the mother's HIV status. *See supra* notes 57–58. It cannot credibly be argued, however, that improving medical outcomes for the HIV-infected mothers of tested newborns is in any meaningful sense one of the goals of newborn screening programs, which ignore the health of these women until they produce an at-risk child. *See also infra* note 220. Because of the role parents generally play in the effective medical treatment of their children, however, proponents of newborn screening programs must concern themselves with HIV-infected mothers as the “target audience” of any such program, whose cooperation must be enlisted in order to secure the program's maximum effectiveness. *See infra* note 218.

205. *See supra* notes 71–81 and accompanying text.

206. *See supra* notes 80–81 and accompanying text.

207. *See supra* notes 64, 79–81 and accompanying text.

birth to determine whether an infant is HIV-exposed.²⁰⁸ This test will not reveal the infant's HIV status, but rather will identify infants born to HIV-infected mothers as candidates for more specific testing. Assuming that the child is still available for testing when the ELISA test results are returned approximately a week after birth,²⁰⁹ an HIV-exposed infant will be tested with PCR, which is only twenty-five percent to thirty percent accurate at birth.²¹⁰ PCR testing will not identify all HIV-infected infants and exclude uninfected infants until six months of age, again assuming the child has remained available to the health care provider for follow-up testing. As a result of the limitations of newborn testing either, under an antibody testing regime, uninfected exposed infants will be subjected to unnecessary and possibly toxic treatment or, under a virologic testing regime, a number of HIV-infected infants will not be identified until after the best opportunity for early intervention has passed.

Access to care also is a potential stumbling block to the effectiveness of a newborn HIV-screening program. Sixty-six percent of children in the United States have private medical insurance, and approximately forty-nine percent of low-income children are covered under the Medicaid program.²¹¹ Since children with HIV infection are disproportionately poor, relatively few of them have private insurance, but a relatively larger proportion may be eligible for Medicaid than children found in the general population.²¹² Medicaid covers all HIV-related drugs, but many states have imposed limitations on this benefit by restricting the number of prescriptions a patient can purchase in a month, limiting the number of refills, and requiring a determination of "medical necessity."²¹³ Many private insurers, also, limit coverage for HIV care and have "medical necessity" requirements.²¹⁴ It is unclear whether prophylactic treatment for asymptomatic HIV infection will be deemed medically necessary by public and private insurers.²¹⁵

There also is some question as to whether the interventions anticipated by a newborn HIV-screening program will be acceptable to the "target audience," generally their HIV-infected mothers. Many families may object to treating their HIV-exposed infants with potentially toxic HIV therapies when it is uncertain whether the infants are infected with HIV or are getting any benefit from the treatment. Combination therapy is particularly uncertain for infants, as little is

208. See *supra* notes 57–58 and accompanying text.

209. "Reporting of conventional ELISA and Western blot test results generally takes one to two weeks." INSTITUTE OF MEDICINE, *supra* note 4, at 52.

210. Luzuriaga & Sullivan, *supra* note 23, at 18.

211. INSTITUTE OF MEDICINE, *supra* note 4, at 58–59.

212. For example, although seventy percent of women of childbearing age in the United States have private insurance, only fifteen percent of women in care for asymptomatic HIV have private insurance. *Id.* at 58–59. Sixty percent have public insurance (Medicaid) and twenty-five percent have no insurance. *Id.* Assuming that children with perinatally-acquired HIV infection are in the same socioeconomic position as their mothers, they will disproportionately either have no insurance or be dependent on Medicaid. In fact, Medicaid pays for the care of ninety percent of children with AIDS diagnoses. *Id.*

213. *Id.* at 59–60.

214. *Id.* at 58.

215. See *id.*

known about the appropriate dosage and tolerance in children of drugs that have been tested primarily in adults.²¹⁶ Finally, newborn HIV screening may be suspect and resented not only because treatment is controversial and risky, but also because of its disproportionate effect on poor communities of color. Public health authorities have engendered controversy and distrust with sickle cell screening programs in the past for similar reasons, and are wary of programs that may be ineffective due to public hostility.²¹⁷

Only a small proportion of HIV-infected infants will benefit significantly from early identification and treatment—those who develop a serious, life-threatening opportunistic infection as their first manifestation of HIV infection. As the majority of infected infants will exhibit NRDP, they generally will be diagnosed in the absence of newborn screening as a result of less serious symptoms and will not see dramatic returns from early treatment. Benefits from early diagnosis will be further limited if those HIV-infected infants prone to RPD who are identified through screening do not have access to prophylactic care. These limited benefits must be compared with potential costs that may be substantial, given problems of HIV diagnosis and treatment in infants and the screening program's disproportionate racial and class effects. Although a comprehensive medical cost-benefit analysis is beyond the scope of this Article, it is not at all clear that newborn HIV screening is justified in public health terms.²¹⁸

3. *Applying the framework to prenatal screening*

Although the preventive potential of prenatal HIV screening may make it a more compelling public health program than newborn screening, prenatal screening still does not neatly satisfy the accepted criteria for a public health screening program. In light of the fact that women are not screened until they become pregnant, it must be assumed that the primary goals of prenatal HIV screening are to identify HIV-infected women in time to reduce the risk of transmission to their children, and to identify HIV-exposed children as early as possible—before birth—for prophylactic treatment beginning soon after the time of delivery.²¹⁹

216. See *supra* notes 80–81 and accompanying text.

217. See INSTITUTE OF MEDICINE, *supra* note 4, at 23. “In practice, when screening is conducted in contexts of gender inequality, racial discrimination, sexual taboos, and poverty, these conditions shape the attitudes and beliefs of health system and public health decision makers as well as patients, including those who have lost confidence that the health care system will treat them fairly. Thus, if screening programs are poorly conceived, organized, or implemented, they may lead to interventions of questionable merit and enhance the vulnerability of groups and individuals.” *Id.* at 21; see also ROBERTS, *supra* note 84, at 256–58 (discussing perception in African-American community that sickle cell programs were genocidal, and programs’ related failure); Acuff & Faden, *supra* note 200, at 67–71 (same).

218. *But see* Madison, *supra* note 5, at 363–64 (claiming that newborn HIV screening arguably does meet public health screening program criteria).

219. A secondary goal of prenatal screening may be to identify HIV-infected women so they can receive treatment benefiting their own health, but this concern for women’s health apparently only becomes compelling upon pregnancy. It should be noted that the public health model does not provide any basis for normatively

Perinatal transmission is relatively well understood by the medical community, but treatment to reduce the risk of transmission from mother to child has become somewhat controversial with advances in combination therapy. The ACTG 076 regimen is the only antiretroviral therapy which has been shown to reduce the risk of perinatal transmission effectively and safely.²²⁰ However, ZDV monotherapy is no longer the standard of care for pregnant women, prompting public health officials to recommend the use of combination therapy during pregnancy both to promote the health of the woman and to reduce the risk of perinatal transmission.²²¹ The 1998 PHS recommendations raise the concern that there is now no generally accepted antiretroviral intervention for reducing the risk of perinatal transmission, as little is known about the appropriate dosage or long-term effects of perinatal exposure to various combinations of antiretroviral drugs, nor has their efficacy in preventing perinatal transmission been demonstrated with any certainty.²²² Even assuming these developments indicate that there is no widely accepted antiretroviral intervention, however, the recent confirmation of the efficacy of elective cesarean section alone in significantly reducing the risk of perinatal transmission probably is enough to satisfy the second public health criterion in the case of prenatal screening.

The third criterion is easily met, as antibody testing is a highly reliable indicator of HIV infection in adults.²²³ In contrast, access to treatment upon the receipt of positive test results probably is the most significant hurdle that prenatal HIV screening must overcome in order to be justifiable. Well over half (61.5%) of women in care for HIV are insured by Medicaid, while another twenty-five percent of women in care for asymptomatic HIV infection have no insurance at all.²²⁴ While the federal government requires states to pay for drugs to prevent perinatal HIV transmission,²²⁵ there is no guaranteed access to the most current therapies, such as combination antiretrovirals, and no guarantee of continued treatment for the woman after delivery of her child.²²⁶ Furthermore, as discussed in the context of newborn screening, even women with public or private insurance may encounter barriers to adequate HIV care, such as insurer

evaluating what the goal(s) of a screening program *should* be. Instead, it analyzes whether a screening program can be justified in terms of what its goals actually are. In this regard, the public health model is agnostic on many of the thornier issues at the core of ethical and legal analyses of newborn and prenatal screening programs. See, e.g. *infra* Part IV.A.4.

220. And even under the ACTG 076 regimen, there are still some lingering questions about the long-term toxicity of ZDV monotherapy. See *supra* notes 35–38 and accompanying text.

221. See *supra* notes 45–47 and accompanying text.

222. See *supra* notes 48–49 and accompanying text.

223. See *generally supra* notes 53–55 and accompanying text.

224. INSTITUTE OF MEDICINE, *supra* note 4, at 59.

225. See *supra* note 163.

226. If a woman initiates antiretroviral therapy during pregnancy and then goes off antiretroviral drugs after delivery, it increases the likelihood that she will develop a drug resistant strain of HIV that will later compromise her own health and treatment. Cf. *supra* note 34 and accompanying text (discussing the problem of resistance in the context of ZDV monotherapy).

determinations that early antiretroviral therapy is not “medically necessary” for asymptomatic HIV infection.²²⁷

There also must be concern that available interventions for prenatally-diagnosed HIV will not be acceptable to HIV-infected women. Again, although ZDV monotherapy has been shown to reduce the risk of perinatal transmission and the majority of studies show no long-term effects from perinatal exposure to ZDV, this therapy is not optimal for the woman and jeopardizes her own health. Combination therapy, in contrast, is best for the woman but poses unknown risks to the fetus. Furthermore, outside the context of HIV, many women have objected to elective cesarean sections recommended for the sake of fetal health,²²⁸ and there is no reason to believe that the procedure will be any more acceptable to HIV-infected women faced with a similar risk to their child’s health. Finally, the mere existence of prenatal screening programs for HIV infection may alienate the target population, which may perceive an invidious purpose behind the disproportionate gender, racial and socioeconomic impacts of screening.²²⁹

The cost-benefit calculations underlying prenatal HIV screening are unclear, and in any event a precise monetary calculation of the value of lives saved is beyond the scope of this Article. Nevertheless, some general observations can be made. The potential benefits of prenatal HIV screening are dramatic—once a pregnant woman is identified as HIV-infected, treatment can significantly reduce the risk that her child also will be infected with HIV. Prevention represents a life of illness avoided, rather than merely a life of chronic illness possibly prolonged by early newborn identification.²³⁰ These benefits only are attainable, however, if the woman chooses treatment and has access to care.

4. *State coercion and the limits of the public health framework*

Public health screening programs can be completely mandatory, completely voluntary or, like “routine with notification,” lie somewhere between the two extremes.²³¹ Even assuming that either prenatal or newborn HIV testing clearly satisfied all six criteria for an ideal public health screening program, the criteria do not reveal whether the screening program should be mandatory or voluntary. For example, if we assume a prenatal HIV-testing regime in which access to

227. See *supra* notes 213–215 and accompanying text.

228. See generally Kolder, *supra* note 125.

229. See INSTITUTE OF MEDICINE, *supra* note 217, at 23 and accompanying text. Although the fact that all pregnant women will be screened is designed in part to mitigate the patient’s sense of being singled out as a likely victim of HIV infection, the women who will be forced through screening to identify themselves as HIV-infected and who will face state pressure to consent to treatment will be overwhelmingly poor women of color. See McCormick, *supra* note 187, at 795.

230. It should be noted that prenatal screening also achieves the objective of early newborn identification in the minority of cases where prenatal treatment fails to prevent perinatal transmission. A child born to a mother known to be HIV-infected will be monitored for HIV-exposure and possible infection from the moment of birth.

231. Faden, *supra* note 202, at 4.

prenatal and postpartum care for both mother and child were guaranteed, it is almost certain that prenatal screening could be justified within the public health framework. Tinkering with the consent scenario may produce subtle variations in criteria satisfaction, but generally will do so to inconclusive effect.²³² Even if such tinkering in a specific case clearly indicated that either voluntary or mandatory testing was preferable under the criteria, this answer would remain unsatisfying as the criteria only get at the issue of consent indirectly at best, and it is unclear what role it is intended to play in the public health paradigm. Accordingly, although the public health criteria provide a necessary medical starting point for an analysis of prenatal and newborn HIV-screening programs, the criteria alone cannot provide an answer to the question of whether state coercion in this area is justified.

B. AN ETHICAL ANALYSIS OF PROPOSED SCREENING PROGRAMS

Ethics fills in many of the gaps left by the public health model. While the public health framework of analysis provides important insight into the concrete medical benefits to be gained and implementation obstacles to be faced by any newborn or prenatal HIV-screening program, it leaves many of the hardest questions surrounding these programs unanswered. Ethical analysis, in contrast, with its emphasis on principles such as beneficence, respect for autonomy, and justice, allows for an examination of a number of controversial issues that the public health model avoids altogether. These issues include how to evaluate what the goals of a screening program should be,²³³ and how to balance autonomy concerns against medical outcomes when it is argued that allowing for consent will undermine a program's efficacy.

1. Beneficence

The ethical principle most closely associated with public health matters is beneficence, which is concerned with issues of human health and well-being.²³⁴ Beneficence encompasses a duty to confer benefits and to prevent and remove harms, as well as a duty to balance possible benefits against possible harms of an action.²³⁵ In the context of HIV-screening programs, both the state and pregnant women may have ethical duties under the beneficence principle.

Most public health programs are both motivated and justified by the state's duty to promote the welfare of the community, a duty which may be furthered by the prevention or treatment of disease.²³⁶ On the community level, prevention

232. For example, routine prenatal screening may identify with more accuracy *all* HIV-infected pregnant women because doctors will be more likely to perform the test than under a voluntary program, but the acceptability of the program may decline as it becomes more coercive.

233. *See supra* note 219.

234. Faden, *supra* note 202, at 13.

235. *Id.*

236. *Id.*

will decrease the incidence of HIV disease and will reduce the social costs of providing care for those who do become infected.²³⁷ The government may prevent perinatal transmission of HIV by reducing the number of births to HIV-infected women or by providing and/or compelling treatment that has been shown to reduce the risk of transmission. The product of testing—knowledge of one's HIV status—alone does nothing to accomplish the objective of prevention. The government must rely on the goodwill of HIV-infected women or take further coercive action against them in order to prevent perinatal transmission.²³⁸

The government arguably also has an ethical duty to reduce the severity of HIV-related illness for those affected. Improved treatment benefits not only affected citizens, but also society as a whole, to the extent that reduced medical expenses and increased social productivity exceed the cost of treatment.²³⁹ However, again, HIV test results do not lead inexorably to treatment. HIV-infected persons must consent to care and have access to it, or the state must compel treatment on the basis of test results.

For her part, an HIV-infected woman has an ethical duty not to harm her children, either by exposing them to toxic drugs during pregnancy, transmitting to them a chronic and eventually fatal disease, or by leaving them without family care when her own death and disability may prevent her from parenting.²⁴⁰ She also has a duty to provide her children with adequate medical treatment if they are ill. However, the principle of beneficence generally does not require her to compromise her own health or well-being for the sake of her children's.²⁴¹ Furthermore, to the extent that not giving birth at all is the only certain way to prevent perinatal transmission, the calculus of comparing possible benefits to possible harms becomes indeterminate. Most children infected with HIV live relatively normal childhoods, marked by an illness that is chronic but only mildly symptomatic for extended periods of time.²⁴² It is difficult to argue that

237. *Id.* at 23. HIV infection and AIDS present social costs related to their disproportionate burden on shared resources.

238. One may argue, of course, that the state also has an interest in determining the HIV status of pregnant women so as to reduce the risk of transmission to third parties other than the women's children. However, this more general prevention goal in no way justifies a testing program exclusively targeting pregnant women, who are no more likely than non-pregnant women or men to transmit HIV infection to adult third parties. Furthermore, just as with perinatal transmission, knowledge of HIV infection alone does nothing to prevent transmission to third-party adults. The state still would have to rely on the goodwill of the HIV-infected women identified through testing, or take further coercive action to prevent transmission to others.

239. *Cf.* INSTITUTE OF MEDICINE, *supra* note 4, at 112 (constructing cost-benefit model for prenatal HIV testing).

240. See Anita Allen, *Moral Multiculturalism, Childbearing, and AIDS*, in *HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES*, *supra* note 4, at 367, 373 (summarizing arguments of moralists). Seventy-four percent of HIV-infected women who have children live with at least one of their children. Mark A. Schuster, *HIV-Infected Parents and Their Children in the United States*, 90 AM. J. PUB. HEALTH 1074, 1076–1077 (2000). Forty-five percent of children born to HIV-infected mothers reside with a primary caregiver who is not their biological parent. American Academy of Pediatrics, *Identification and Care of HIV-Exposed and HIV-Infected Infants, Children and Adolescents in Foster Care*, 106 PEDIATRICS 149, 149 (2000).

241. Faden, *supra* note 202, at 14–15.

242. See *supra* notes 65–68 and accompanying text.

this is not a life worth living,²⁴³ and the argument that HIV-infected women should not reproduce becomes even more difficult when one considers that most children born to them will not be infected with HIV.²⁴⁴ Calculations regarding possible long-term effects of treatment regimens, fetal and infant toxicity, and relative reductions in the risk of adverse health outcomes are even less clear.

2. *Respect for autonomy*

The ethical principle of respect for autonomy emphasizes individual freedom and choice, consisting of freedom from controlling interference by others and from personal limitations that prevent meaningful choice.²⁴⁵ Prenatal HIV-screening programs impact autonomy concerns in two different ways. First, HIV screening will provide women with information that they may consider to be highly material and perhaps even essential to making informed choices about childbearing and medical treatment.²⁴⁶ For example, the mother of an HIV-infected newborn may be horrified to discover that she could have significantly reduced the chance of perinatal transmission to her child with antiretroviral treatment or elective cesarean section, if only she had known of her own HIV status prior to childbirth.²⁴⁷ Her “choice” not to take such precautions during pregnancy was not autonomous in the sense of being fully informed of the risks involved, and neither was her “choice” not to determine her HIV status prior to or during pregnancy, to the extent she was not aware of her possible risk of infection and available therapies to prevent perinatal transmission. HIV-screening programs that ensure that all pregnant women are provided risk and prevention information and have access to testing if they choose to learn their HIV status enhance women’s autonomy by providing them with information necessary to make the best possible choices for themselves and their children.²⁴⁸ HIV-related counseling may be particularly important to achieving true autonomy for women in light of the traditional HIV health care delivery system’s

243. See Madison Powers, *The Moral Right to Have Children*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, *supra* note 4, at 334 (finding no clear answer to inquiry measuring harm of being born HIV-infected against nonexistence); John D. Arras, *AIDS and Reproductive Decisions: Having Children in Fear and Trembling*, 68 MILBANK Q. 353, 367 (1990) (concluding that risk assumed by HIV-infected women on behalf of their children lies on the margin of social acceptability). “Taken as a whole, this is a group of children who, in the large majority, are physically healthy or who have a chronic but relatively stable illness that allows them to function in the community and in school.” Lawrence Wissow et al., *Psychosocial Issues for Children Born to HIV-Infected Mothers*, in HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES, *supra* note 4, at 78, 79.

244. See *supra* note 27 and accompanying text.

245. Faden, *supra* note 202, at 16–17.

246. See Juliet McKenna, *supra* note 152, at 134; see also Arras, *supra* note 243, at 374 (promoting implementation of nondirective reproductive counseling for HIV-infected women that expands their awareness of available options).

247. This troubling scenario is often emphasized by proponents of mandatory HIV testing programs. See Renna, *supra* note 152, at 407.

248. Of course, women’s autonomy would be maximized in this situation if they also had access to the care necessary to effect any of the full range of choices theoretically available to them given current medical knowledge.

failure to effectively identify HIV-infected women with its established risk factor approach to screening,²⁴⁹ and to offer effective HIV treatment to women on equal terms compared to men.²⁵⁰

On the other hand, mandatory prenatal and newborn testing policies undermine women's autonomy by forcing them to undergo medical testing without their consent, and by interfering with their customary authority to make medical decisions on behalf of their minor children.²⁵¹ HIV-screening policies also may compromise women's autonomy by requiring or offering testing without providing the related counseling that would enable them to understand the full significance of the tests being performed on them or their children and, under "voluntary" programs, make an informed decision about whether to agree to or refuse an HIV test.²⁵² Even completely voluntary newborn testing is dubious from an autonomy perspective because it focuses public attention and resources away from preventive prenatal interventions and provides women with HIV information too late for them to reduce the risk of perinatal transmission.

Finally, the specter of compelled treatment that lurks behind mandatory testing programs clearly constitutes autonomy-negating coercion. For example, in the absence of a pregnant woman's consent and cooperation, it would be impossible to assure adherence to the 076 regimen without detaining her for the second and third trimesters of her pregnancy and removing her infant from her care almost immediately after birth.²⁵³ There is no other way to guarantee that she would take five carefully timed doses of ZDV a day, and then administer ZDV to her infant six times a day after birth. This level of coercion will be almost impossible to justify on ethical grounds.

3. Justice

Justice here will be treated in its comparative sense, as a principle informing a discussion of the proper distribution of the benefits and burdens involved in prenatal and newborn HIV-screening programs.²⁵⁴ Any distributive justice inquiry into these proposals will focus on who should bear the various costs involved in reducing the incidence of perinatally-acquired HIV infection and

249. See *supra* notes 140–143 and accompanying text.

250. See *supra* note 131 and accompanying text.

251. Faden, *supra* note 202, at 17. Of course, newborn testing also directly impacts a mother's autonomy by revealing her own HIV status.

252. Of course, HIV counseling itself may threaten a woman's autonomy to the extent that the information provided so inaccurate and incomplete as to manipulate the woman's choice. *Id.* For example, if an HIV-infected pregnant woman is told that her child will almost certainly be infected by HIV, that misinformation negates her autonomy by implicitly encouraging her to choose abortion. See *supra* note 136. Also, a health care provider could undermine a pregnant patient's autonomy by informing her of the benefits of ZDV monotherapy without advising her that ZDV monotherapy, although arguably safer for the infant, is no longer the standard of care for the woman's own health. See *supra* notes 45–47 and accompanying text.

253. Ronald Bayer was the first commentator to recognize this new implication of prenatal HIV screening after publication of the ACTG 076 results. Ronald Bayer, *Ethical Challenges Posed by Zidovudine Treatment to Reduce Vertical Transmission of HIV*, 331 NEW ENG. J. MED. 1223, 1225 (1994).

254. See Faden, *supra* note 202, at 18.

AIDS. For example, one author has suggested that an HIV-infected woman should consider the extent to which she is able and willing to provide for a child.²⁵⁵ Under this view, perhaps only those women who can afford private insurance will be presumed to act ethically when they choose to have a child. However, to condition reproductive rights on wealth in this manner seems morally unacceptable,²⁵⁶ and privileges private wealth over an even distribution of resources among all children in society, which seems just as ethically plausible.²⁵⁷ A somewhat more defensible approach would be to condition publicly-subsidized care on acceptance of treatment to reduce the risk of perinatal transmission. In this scenario, a woman's decision to bear a child would not be questioned, but she would be pressured to bear some of the burdens of the state's program in order to reduce the social costs of perinatal transmission. Conditioning health care on medical treatment choices still raises autonomy concerns, however, as does denying treatment to an HIV-infected child because of his mother's medical choices.

Justice concerns also come into play in evaluating the more subtle burdens implicated in the counseling provisions of various HIV-testing proposals. For example, under the IOM's proposal for routine prenatal HIV testing with patient notification, it seems ethically questionable to deny women autonomy-enhancing information during counseling in order to reduce administrative burdens on prenatal care providers. Particularly when it was the providers' substantial failure to offer HIV testing to most pregnant women, and not women's failure to accept testing, that prompted the IOM to conclude that the PHS system was not working,²⁵⁸ placing some of the burdens of universal prenatal testing on the health care system seems more just than placing all of those burdens on pregnant women, as would occur under the IOM's truncated consent proposal.

4. *Balancing ethical principles*

As this discussion indicates, ethical principles are likely to conflict in any analysis of prenatal and newborn HIV-screening programs. Accordingly, the problem arises of how to weigh and balance ethical principles in order to arrive at a final evaluation of the various testing proposals from an ethics standpoint. Ethicists have developed the notion of *prima facie* duties to address this

255. Arras, *supra* note 243, at 363.

256. It also raises the specter of twentieth century eugenics programs, *see supra* notes 85–96 and accompanying text, which have been largely condemned as unjust policies whose lingering effects must be carefully guarded against. *See generally* ROBERTS, *supra* note 84.

257. “[C]hildren born of middle to upper class parents of first-world nations consume approximately 20–100 times the social resources either of children born to average-income parents in third-world nations or low-income parents in the United States.” Powers, *supra* note 243, at 339. Like the AIDS baby requiring disproportionately expensive medical care, these privileged children consume more than their share of social resources if we assume equal distribution as our ethical goal. Commentators complaining about the high cost of caring for HIV-infected children implicitly assume an unequal regime of private wealth as their baseline for justice.

258. *See supra* notes 177, 189 and accompanying text.

balancing difficulty.²⁵⁹ A prima facie duty is one “always to be acted upon unless it conflicts on a particular occasion with an equal or stronger duty.”²⁶⁰ A prima facie duty may be trumped when more compelling, opposing demands are presented by a competing moral principle.²⁶¹ Beneficence, respect for autonomy and justice each present a prima facie ethical duty, and this section attempts to analyze how their competing demands may be resolved in the prenatal and newborn HIV testing contexts.

Mandatory newborn testing appears to be morally unacceptable under ethical principles. By the time a child has been born, it is too late to reduce the risk that he²⁶² will be infected with HIV, and the child poses virtually no risk of infection to others.²⁶³ An early HIV test will indicate whether he has been exposed perinatally to HIV,²⁶⁴ and identify him as a candidate for early treatment that will reduce from approximately twenty percent to four percent his chance of developing a serious opportunistic infection in his first year of life.²⁶⁵ Although early identification may provide some benefit to the child, access to treatment is uneven,²⁶⁶ so the health benefits of prophylactic treatment may not be realized even assuming maternal consent to treatment.

At the same time, a mandatory newborn testing policy imposes significant costs on the mother’s autonomy, as her own HIV status is revealed without providing her with counseling or seeking her consent. Also significant are the huge potential costs of compelling treatment of the child over the mother’s objection, which generally would involve removing the child from her care.²⁶⁷ Compelled treatment would harm the child by interfering in his relationship with his parents²⁶⁸ and, secondarily, burden society by increasing the number of children in the foster care system. Taken together, these costs outweigh the limited benefits of early identification and treatment of HIV-exposed infants. Admittedly, the cost-benefit ratio would be more evenly balanced if we assume maternal consent to treatment once HIV exposure has been identified, but that assumption would make mandatory testing even less compelling. If a mother would consent to treatment, there is no reason to believe that she would not

259. See Faden, *supra* note 202, at 20.

260. *Id.*

261. *Id.*

262. Throughout this paper, children will be referred to with the male pronoun simply to make them more easily distinguishable from HIV-infected women, who will, of course, be referred to with the female pronoun.

263. The three primary routes of HIV transmission are sexual contact, needle sharing, and perinatal transmission from mother to child. Infants do not engage in high-risk behaviors or bear other children. HIV is not transmitted through casual contact, or even relatively intimate family contact such as diaper changing that involves exposure to urine and feces. See Brett-Smith & Friedland, *supra* note 1, at 23–29.

264. See *supra* notes 56–58 and accompanying text.

265. See *supra* notes 62–63, 73–78 and accompanying text.

266. See *supra* notes 211–215 and accompanying text.

267. See *supra* note 252 and accompanying text.

268. See Wissow, *supra* note 243, at 92 (noting benefit to child of parent’s participatory role in HIV-related medical care); see generally Ellen Wright Clayton, *Screening and Treatment of Newborns*, 29 HOUS. L. REV. 85 (1992) (discussing psychosocial harms to child of compelled treatment of newborns).

consent to testing (prenatal or newborn), and the benefits of early newborn identification then could be gained without any significant autonomy costs at all.

A mandatory prenatal testing program also does not appear to be ethically viable, for similar reasons. It is true that from the perspective of beneficence, it is much more compelling to determine a woman's HIV status when she is pregnant than to determine her child's status after she has given birth. Unlike newborn diagnosis, prenatal diagnosis, if it leads to treatment, allows an HIV-infected woman to increase significantly the odds that her child likely will be born uninfected with HIV. However, a mandatory prenatal testing program would impose substantial autonomy costs, particularly if it were linked to compelled treatment: the woman would be forced to submit to medical testing without her consent, learn that she has a fatal disease that also may have a serious impact on her child's health, and face detention so the state could ensure that she took potentially toxic medication five times daily during the last two trimesters of her pregnancy. These burdens cannot be justified, even if one assumed that a pregnant woman owes a greater moral duty of beneficence to her fetus than she would to a born child, for whose benefit it is established that she has no duty to undergo medical treatment.²⁶⁹ The autonomy costs of compelling treatment are far too high. Furthermore, if we assume the pregnant woman's cooperation with treatment, the lesser autonomy costs of merely mandating testing cannot be justified as there is no reason to assume the same woman will not cooperate with diagnosis.

A proposal such as the IOM's for routine prenatal HIV screening with patient notification involves a more complex balancing of ethical principles. Learning that a pregnant woman is HIV-infected may lead to a significantly improved medical outcome for her child. It also may lead to treatment for the sake of her own health which, given recent advances in AIDS medicine such as combination therapy, likely will directly benefit the woman to no small degree. However, under the IOM's proposal, health care providers would no longer be required to provide HIV counseling, regarding either the woman's own risk or perinatal transmission, before eliciting the woman's "consent" to testing. Her autonomy in medical decisionmaking would be compromised as a result. Although if an HIV test result proved positive much of the information omitted from pretest counseling could be provided in a post-test setting, shifting even this temporal burden to pregnant women seems unjust given that the primary reason fully voluntary prenatal testing policies are "failing" is doctors' reluctance to invest time in counseling their pregnant patients about a significant prenatal health risk²⁷⁰ that many women may know little about given women's historic invisibility in the AIDS epidemic.²⁷¹ Less certain autonomy costs of routine prenatal testing—such as encouraging women to learn their HIV status without guaranteeing access to the care required to effectuate informed medical

269. See *infra* note 395 and accompanying text.

270. See *supra* notes 177, 189 and accompanying text.

271. See *supra* notes 130–131, 140–142 and accompanying text.

decisions, the risk that routine testing will lead to a system of effective mandatory testing, and the threat of compelled care—only make this program more ethically suspect.

V. LEGAL FRAMEWORKS FOR ANALYZING PROPOSED HIV-SCREENING PROGRAMS FOR PREGNANT WOMEN AND NEWBORNS

Law provides the final framework for analyzing proposed prenatal and newborn HIV-screening programs. Legal frameworks for analyzing the permissibility of burdening individual liberties in order to advance the state's interest in promoting public health are attractive because they may be used to tie the medical perspective captured in the public health model together with ethical concerns for personal autonomy and the just distribution of public health programs' costs. However, although the law can provide insight into how some of the conflicts inherent in proposed HIV-screening programs may be most appropriately resolved, it does not contribute perfectly clear answers to the debate over these programs. Most fundamentally, the courts have not addressed for some time the constitutional limits of public health programs, and it is not apparent how they will balance the state's interest in promoting public health against individual rights. Only after this threshold issue is addressed, it is possible to analyze whether prenatal and newborn HIV-screening programs are consistent with constitutional protections found in the Due Process Clause and the Fourth Amendment.

A. *TRADITIONAL JUDICIAL DEFERENCE TO PUBLIC HEALTH PROGRAMS*

The states, by virtue of their police power, have the authority to enact and enforce laws and regulations designed to promote the public health and safety.²⁷² Under the broadest possible understanding of the police power, states may take "any steps necessary to ensure the public health and welfare, to foster prosperity, and to maintain public order."²⁷³ While courts generally have not construed the police power as authorizing *any* steps necessary to effect proper state goals, they have upheld various governmental restrictions on individual liberty when those restrictions are required to protect public health.²⁷⁴

272. Malloy, *supra* note 152, at 1195; Post, *supra* note 152, at 199. The police power is reserved to the states pursuant to the Tenth Amendment to the United States Constitution. Malloy, *supra* note 152, at 1193.

273. Malloy, *supra* note 152, at 1193.

274. Sangree, *supra* note 85, at 381.

1. *The early cases*

The leading case discussing the role of the courts in reviewing public health measures is *Jacobson v. Massachusetts*,²⁷⁵ decided by the Supreme Court in 1905. The petitioner in *Jacobson* challenged a local ordinance that ordered all residents of Cambridge to be vaccinated for smallpox.²⁷⁶ The Court recognized that police power legislation must yield to federal constitutional and statutory law, but also noted that the “possession and enjoyment of all rights are subject to such reasonable conditions as may be deemed by the governing authority of the country essential to the safety, health, peace, good order and morals of the community.”²⁷⁷ The Court refused to review the legislature’s determination, in the face of medical controversy, that vaccination prevented the spread of smallpox, and found that the ordinance was reasonably related to the state’s interest in reducing the incidence of communicable disease and therefore was constitutional.²⁷⁸

Courts reviewing constitutional challenges to public health regulations after *Jacobson* generally have upheld them, to the effect that, “[t]raditionally, the police power to legislate measures to control contagious disease epidemics was practically boundless in its ability to impose quarantine and mandatory treatment on persons with infectious diseases.”²⁷⁹ Judges usually have given great deference to the factual conclusions underlying exercises of the police power, and have subjected public health laws to minimal scrutiny, requiring only a reasonable relationship between the stated public health goal and restrictions imposed on individual liberties.²⁸⁰ Under this standard of review, personal intrusions ranging from the relatively inoffensive, such as municipal water fluoridation,²⁸¹ to the extreme, including indefinite confinement of individuals infected with or exposed to a communicable disease,²⁸² have been found constitutional. And although public health measures are only justified to the extent that the targeted behaviors injure other people,²⁸³ quarantines have been upheld even in situations where isolation was not necessarily required to protect the public, most typically in cases of venereal disease where behavior

275. 197 U.S. 11 (1905).

276. *Id.* at 12–14.

277. *Id.* at 26 (internal quotations omitted).

278. *Id.* at 30–31. “It is no part of the function of a court or a jury to determine which one of two modes [of public health response to the smallpox outbreak] was likely to be the most effective for the protection of the public against disease. That was for the legislative department to determine in light of all the information it had or could obtain.” *Id.* at 30.

279. Sangree, *supra* note 85, at 381–82.

280. Post, *supra* note 152, at 200.

281. See *Dowell v. City of Tulsa*, 273 P.2d 859 (Okla. 1954), *cert. denied*, 348 U.S. 912 (1955).

282. See, e.g., *Kirk v. Bd. of Health*, 65 S.E. 387, 390 (S.C. 1909) (approving permanent quarantine of woman with “slightly contagious” form of leprosy); *Crayton v. Larabee*, 116 N.E. 355, 358 (N.Y. 1917) (upholding two week quarantine of healthy woman living next door to house of smallpox patient); *People v. Barmore*, 134 N.E. 815 (Ill. 1922), *reh’g denied*, (unreported) (approving indefinite confinement of typhoid carrier); see generally Deborah Jones Merritt, *Communicable Disease and Constitutional Law: Controlling AIDS*, 61 N.Y.U. L. REV. 739, 776–77 (1986).

283. Sangree, *supra* note 85, at 381.

modifications such as avoiding unsafe sex practices could have been an effective means of preventing infections not spread by casual contact.²⁸⁴

2. *Applying the traditional public health law model to prenatal and newborn HIV screening*

If a court were to apply the *Jacobson* reasoning to prenatal and newborn HIV screening, the state would need to justify only minimally any resulting restrictions on the liberty of HIV-infected pregnant women and new mothers. It is very likely that mandatory prenatal HIV screening, even if coupled with compelled adherence to therapies shown to reduce the risk of perinatal transmission, would be deemed a valid exercise of the state's police powers under this standard of review. The state's interest in preventing the spread of communicable disease is unquestionably a proper purpose of police power legislation.²⁸⁵ The legislature's determination that ZDV monotherapy is preferable to antiretroviral combination therapy as a prevention method, or vice versa, would be granted deference by the court, as would the state's determination whether pregnant women should be compelled to undergo antiretroviral therapy, elective cesarean section, or both.²⁸⁶ The fact that this public health policy would sacrifice pregnant women's liberty to public health goals would not render the public policy unconstitutional, for such rights would be viewed as properly limited by the health needs of the community, and no less permissible than the confinement and compelled treatment of other carriers of communicable disease.²⁸⁷

A mandatory newborn HIV-screening program would be much more difficult for the state to justify under public health law doctrine. Newborn screening, even when accompanied by compelled treatment, does nothing to prevent the spread of HIV infection and resulting harm to third persons. As previously discussed, newborns themselves, once infected, pose virtually no risk

284. See *Varholy v. Sweat*, 15 So. 2d 267 (Fla. 1943) (affirming order confining woman with gonorrhea to venereal disease camp despite evidence that she did not engage in activities risking transmission); *In re McGee*, 184 P. 14 (Cal. 1919) (rejecting claim that state had to treat venereal disease patients at home rather than in quarantine camps). The practice of detaining individuals suffering from venereal disease was widespread. For example, during World War I, more than 30,000 prostitutes were incarcerated in federally-supported institutions with the aim of reducing the incidence of syphilis. Court challenges to this practice were rejected. Sangree, *supra* note 85, at 385.

285. See *Jacobson*, 197 U.S. at 27 (1905). The Supreme Court has held that "[u]pon the principle of self-defense, of paramount necessity, a community has a right to protect itself against an epidemic of disease which threatens the safety of its members." *Id.*

286. Cf. *supra* notes 278–283 and accompanying text (discussing traditional judicial deference to factual determinations by public health officials on matters of disease control).

287. Perversely, a policy of mandatory prenatal HIV screening may be more vulnerable to attack under traditional public health law doctrine if the state did not also require HIV-infected women identified by the program to undergo treatment in order to reduce the risk of perinatal transmission. Since testing alone does not reduce the risk to others of infection, a court could well find that mere testing is not reasonably related to protecting the public health. However, under precedents such as those allowing complete isolation of individuals infected with diseases communicable only through intimate contact, see *supra* note 284 and accompanying text, a court could apply the reasonable relationship test very loosely and find that mandating testing alone is a permissible exercise of the state's police powers.

of infection to others.²⁸⁸ The state's police powers generally do not extend to compelling treatment when failure to treat would harm only the patient.²⁸⁹ The only arguable public harm resulting from failure to intervene as early as possible in the medical treatment of HIV-exposed children is the economic cost of caring for children with rapid disease progression. However, the courts have never relied on economic harm as a rationale for public health regulation, and even if they did it is unclear whether prolonging the life of a chronically ill child is less expensive than his or her early death. Accordingly, even under the highly permissive public health law doctrine of the early twentieth century, newborn HIV testing is unlikely to be found a valid exercise of the state's police power.²⁹⁰

3. *Rethinking public health law*

Although the Supreme Court revisited the constitutional boundaries of state public health regulation set forth in *Jacobson*,²⁹¹ many scholars have pointed out that *Jacobson* has not aged well in the face of the Supreme Court's expansion of constitutionally protected individual rights and scientific advances permitting more focused disease control measures.²⁹² Recent lower court decisions evince decreasing judicial deference to the conclusions of public health regulators.²⁹³ Therefore, even assuming that mandatory prenatal HIV testing and, more questionably, mandatory newborn HIV testing would be found constitutional under traditional public health law doctrine, it is very likely that a modern court would apply a more stringent standard of review.

Even the more conservative critics of traditional public health doctrine agree that courts should not accept state public health determinations at face value, and should themselves evaluate the relevant medical evidence to determine whether it justifies challenged restraints on individual liberty.²⁹⁴ This shift in approach is motivated by two related considerations. The first—aimed at eliminating situations such as that presented here where mandatory prenatal testing does not clearly meet public health criteria yet easily passes constitutional muster despite its burdens on individual liberty—is the relatively uncontroversial premise that the law should only tolerate the burdens public health measures place on individual liberties when those measures are medically justifiable.²⁹⁵ Secondly, courts also have been concerned that the state may pass impermissibly motivated

288. See *supra* note 263.

289. See Sangree, *supra* note 85, at 381.

290. The state's *parens patriae* power to protect the child's health is discussed in notes 355–369 and accompanying text, *infra*.

291. The Supreme Court last addressed the constitutional validity of public health laws implemented under the police power in *Zucht v. King*, 260 U.S. 174 (1922), a case upholding an ordinance conditioning enrollment in school on compliance with vaccination requirements. See generally Scott Burris, *Fear Itself: AIDS, Herpes and Public Health Decisions*, 3 YALE L. & POL'Y REV. 479, 489–90 (1985).

292. See, e.g., Post, *supra* note 152, at 200; Sangree, *supra* note 85, at 394; Note, *The Constitutional Rights of AIDS Carriers*, 99 HARV. L. REV. 1274, 1276–79 (1986).

293. See, e.g., *New York Ass'n for Retarded Children v. Carey*, 612 F.2d 644 (2d Cir. 1979).

294. See Burris, *supra* note 291, at 493.

295. *Id.* at 481.

regulations and then evade constitutional review by hiding behind judicial deference to its exercise of the police power.²⁹⁶ Courts can only determine whether a regulation is medically necessary and justified by the legitimate state interest in protecting the public health if they look at the underlying medical evidence offered to support the regulation.²⁹⁷

Critics of the traditional deference afforded public health regulations generally also agree that intervening case law on constitutionally recognized individual liberties dictates that, where fundamental rights are compromised, the state must show both a compelling interest and that the regulation represents the least restrictive means of achieving that interest.²⁹⁸ Scholars differ in their understanding of how government and private interests should be balanced when public health is at stake, however. Some commentators assume that the law should remain particularly deferential to public health regulation, after assuring that the medical evidence supports the state's intervention. In practice, this view is represented in proposed legal frameworks that essentially allow public health concerns to trump individual liberties by construing "least intrusive means" to mean the least intrusive means for obtaining the best public health outcome.²⁹⁹ According to these authors, individual rights, no matter how compelling, must submit to restrictive public health measures even if another public health response would be less restrictive, less costly or less controversial, so long as the alternate response is even slightly less effective.³⁰⁰

Other scholars believe that the state's interest in promoting the public health should be treated no differently than other state interests, and should be weighed against, and not automatically trump, conflicting individual liberties.³⁰¹ This view is the most persuasive. In modern cases, the courts have frequently placed constitutional limits on state action under the police power, such as law enforcement action to protect the public safety, even when the alternatives available were less effective at achieving the state's admittedly compelling objective.³⁰² Although the early cases broadly interpreting the police power in the public health context have not been revisited or overruled by the Supreme

296. See *New York Ass'n for Retarded Children*, 612 F.2d at 648-49.

297. See *id.* (rejecting argument that court defer to school board's determination regarding risk of hepatitis B transmission in classroom). "To permit the factual determinations of these [government] agencies to go unchallenged may be to neglect [the court's task to ensure that constitutional and statutory standards are followed by these agencies], for the facts will often be dispositive, and the question of compliance with prevailing legal standards will often be determined by the manner in which the agency has found these facts." *Id.* at 648.

298. Sangree, *supra* note 85, at 394; Burris, *supra* note 291, at 481; see also Note, *supra* note 292, at 1292 (asserting modern medical knowledge makes it realistic for courts to require very close fit between public health means and ends). Courts have begun to demand a showing of least restrictive means, as well. *City of New York v. New St. Mark's Baths*, 497 N.Y.S.2d 979, 982 (N.Y. Sup. Ct. 1986), *aff'd*, 505 N.Y.S.2d 1015 (N.Y. App. Div. 1986) (closing gay bathhouses permissible restriction on freedom of association because least restrictive means to protect public health).

299. Burris, *supra* note 291, at 483.

300. *Id.*

301. See Note, *supra* note 292, at 1280-81.

302. See, e.g., *Weeks v. United States*, 232 U.S. 383 (1914) (creating exclusionary rule as remedy for unconstitutional search and seizure).

Court, there does not seem to be any justification for the assertion that the state's interest in public health is more compelling than its interest in public safety, or that the individual liberties of criminal suspects are entitled to more protection than those of the general citizenry. Under this view, modern cases limiting the weight given the police power when individual liberties are at stake indirectly overrule the early public health police power cases. Outdated precedent that has not been revisited since the Warren Court's expansion of constitutionally protected individual rights does not provide a convincing basis for treating the protection of public health differently than other state interests arising under the police power. Accordingly, the remainder of this paper will focus on applying modern constitutional frameworks to prenatal and newborn HIV-testing policies, without assuming that the public health rationales for these policies are entitled to any greater deference than other state interests.

B. MODERN SUBSTANTIVE DUE PROCESS RIGHTS

The Due Process Clause of the Fourteenth Amendment provides that no state shall "deprive any person of life, liberty, or property, without due process of law."³⁰³ The Due Process Clause affords certain substantive rights to individuals in addition to procedural rights and has been interpreted by the Supreme Court as "barring certain government actions regardless of the fairness of the procedures used to implement them."³⁰⁴ One of the liberty interests substantively protected by the Due Process Clause is a zone of privacy that arguably would be invaded under current proposals for prenatal and newborn HIV-screening programs. The Court has identified two distinct strands of this privacy interest—confidentiality and autonomy³⁰⁵—both of which are implicated by HIV-screening programs and each of which will be discussed in turn.

1. Informational privacy

The Court has characterized the confidentiality strand of privacy as encompassing the individual's interest in avoiding disclosure of personal matters.³⁰⁶ The leading case on the constitutional right to confidentiality is *Whalen v. Roe*.³⁰⁷ In *Whalen*, physicians and patients challenged a New York statute that required health care providers to report all prescriptions for certain highly abused drugs to the state department of health so that overuse by individual patients could be monitored and investigated. The State maintained the collected information in a vault and reviewed it on computers whose data

303. U.S. CONST. amend. XIV, § 1. Individuals have the same protection against the Federal Government pursuant to the Fifth Amendment, which contains similar language. U.S. CONST. amend. V.

304. *Daniels v. Williams*, 474 U.S. 327, 331 (1986).

305. *Whalen v. Roe*, 429 U.S. 589, 598–99 (1977).

306. *Id.* at 599.

307. *Id.*

could be retrieved only inside a designated reading room to which access was strictly limited. The patient plaintiffs alleged that being forced to disclose sensitive medical information to the State violated their right to confidentiality and exposed them to potential stigma as drug users should any of the collected information be leaked or improperly accessed. The Court recognized the patients' constitutional interest in nondisclosure but, after balancing the individuals' privacy concerns against the State's interest in detecting abuse of addictive prescription drugs, found the New York statute constitutional. In weighing the individual interests at stake as slight, the Court emphasized that the infringement of confidentiality rights under the statute was particularly limited due to the very small number of State regulators with access to the collected information, noting that broader disclosure was highly unlikely given the security measures employed by the State to protect the personal data.

Subsequent cases have further clarified how courts are to balance the competing interests at stake in confidentiality disputes. In general, the purpose of the challenged statute and the public interest it serves must be weighed against the scope and extent of its intrusion on individual privacy.³⁰⁸ Lower courts have interpreted this balancing test as imposing a burden on the State to justify an invasion of informational privacy; that burden increases as the sensitivity of the information disclosed and the severity of the intrusion likewise increase.³⁰⁹ The state regulation authorizing the invasion need not be perfectly tailored, however, as legislation that has some effect on individual liberty or privacy will not be held unconstitutional simply because a court finds it unnecessary, in whole or in part.³¹⁰

As no state intrusion to informational privacy occurs when a woman consents to HIV testing for herself or her child, only mandatory testing programs implicate constitutional confidentiality interests and will be discussed in this Section. A woman's interest in avoiding unwanted disclosure of her HIV status is implicated by both prenatal and newborn mandatory HIV-screening proposals.³¹¹ The intrusion at stake in these contexts is unusually severe because, unlike most confidentiality cases where the state is collecting and/or releasing information that has been independently produced or assembled, the state here is compelling the woman to generate very personal information that previously did not exist at all. In the woman's own hands, this state-created information will

308. *Nixon v. Adm'r of Gen. Serv.*, 433 U.S. 425, 458 (1977).

309. *See, e.g., Tavoulares v. Washington Post Co.*, 724 F.2d 1010, 1019 (D.C. Cir. 1984); *Thome v. City of El Segundo*, 726 F.2d 459, 469 (9th Cir. 1983), *cert. denied*, 469 U.S. 979 (1984).

310. *Whalen*, 429 U.S. at 597.

311. A woman's HIV status is revealed both by prenatal and, if she is infected, newborn HIV testing. *See supra* notes 53-58. For purposes of this discussion, the confidentiality interest at stake encompasses both the generation of medical records containing the woman's HIV status and the subsequent reporting of positive results to health care providers who receive and inform the woman of her test results, and to public health officials under HIV/AIDS case reporting laws. State reporting requirements are not the primary target of objections to prenatal and newborn HIV-screening programs and will not be discussed here in the context of voluntary HIV testing. State reporting requirements do increase the intrusiveness of mandatory HIV screening, however, as they generally are automatically triggered by a positive test result.

likely have a profound effect on her self-perception, transforming her expectations of how long she will live and what her quality of life will be, which in turn may affect her decisionmaking on such intimate matters as marriage, sexual relationships, and childbearing. In the hands of her health care providers, information that a woman is HIV-infected may lead to loss of control over her own medical decisions³¹² and loss of medical services for herself and her children.³¹³ If disclosed to her sexual partner,³¹⁴ either by virtue of state partner notification laws³¹⁵ or “voluntarily” after knowledge of the woman’s HIV status was forced upon her by the state, it may lead to domestic violence³¹⁶ and the dissolution of her family/sexual relationships.³¹⁷ Finally, in light of documented discrimination against individuals infected with HIV, information that a woman is HIV-infected, if disseminated more broadly, may jeopardize her housing and employment.³¹⁸

In the case of newborn HIV testing, a persuasive argument can be made that the newborn, as a separate individual, has a right to obtain all information relevant to providing him with the best health care possible, regardless of whether that information indirectly reveals information about either parent’s health status. Accordingly, although the mother’s HIV status is revealed when her newborn is tested for the virus, her confidentiality interest in that information

312. See Field, *supra* note 147, at 414–16 (discussing potential for pressure to abort or compelled preventive treatment if a pregnant woman tests positive for HIV). In this respect the confidentiality strand and the autonomy strand, discussed in Part V.B.2, of privacy are very closely related.

313. See generally Lawrence O. Gostin, *The AIDS Litigation Project: A National Review of Court and Human Rights Decisions, Part II: Discrimination*, 263 JAMA 2086 (1990) (discussing discrimination experienced by people with AIDS, including discrimination by health care workers). A 1989 survey of health care providers specializing in neonatal care indicated that providers are significantly less likely to recommend aggressive treatment for non-HIV-related medical problems if they know a child is HIV-exposed. Recommendations for treatment of children born to HIV-infected mothers were similar to recommendations made for children with Down’s Syndrome (a chromosomal abnormality causing mental retardation) and cystic fibrosis (a chronic, debilitating condition often causing death in adolescence). If a child was known to be HIV-infected and not just HIV-exposed, recommendations for treatment were similar to those made for children with Tay-Sachs disease, a severe neurological condition that causes death within the first two years of life. Betty Wolder Levin et al., *Treatment Choices for Infants in the Neonatal Intensive Care Unit at Risk for AIDS*, 265 JAMA 2976, 2979 (1991).

314. It is possible to argue that an infected woman’s sexual partner has an independent interest in obtaining knowledge of her HIV status, due to the risk that sexual activity with an infected partner poses to one’s own health. However, the state has not chosen to mandate HIV testing of all adults for the purpose of disclosing potential transmission risks to sexual partners and others at risk of infection. The state therefore should not be permitted to “load” its argument for prenatal testing by relying on infection risks posed to third-party adults. The reason pregnant women are singled out for testing is the risk they pose to their prospective children, and the state’s testing policy should be required to stand or fall on that basis.

315. The Ryan White CARE Act requires states to make good faith efforts to notify the spouse of an HIV-infected person that he or she may have been exposed to HIV and should be tested. 42 U.S.C.A. § 300ff–27a (West 1991 & Supp. 2000). Certain states mandate contact tracing and the notification of all partners the infected individual may have exposed to HIV. STEIN, *supra* note 33, at 94.

316. The National Association of People with AIDS has documented a strong link between domestic violence and HIV infection. In a national survey of HIV-infected women, seventeen percent of all women and twenty-five percent of Hispanic women reported violence in the home. Richard L. North & Karen H. Rothenberg, *Partner Notification and the Threat of Domestic Violence Against Women with HIV Infection*, 329 NEW ENG. J. MED. 1194, 1195 (1993).

317. Wissow et al., *supra* note 243, at 84–85.

318. See generally Gostin, *supra* note 313.

should be at least somewhat discounted in the context of newborn testing. Several hurdles remain, however, before the state will be able to justify even the newborn intrusion on informational privacy grounds.

First, it is inappropriate to ignore entirely the intrusion to the mother's confidentiality that results from newborn testing. Even though virologic HIV-testing technology has improved significantly since newborn testing was first proposed, newborn screening programs rely on antibody tests such as ELISA to initially identify those infants who are born to HIV-infected mothers and thus are candidates for more specific testing.³¹⁹ As a result, newborn screening programs in practice identify many more HIV-infected women than are necessary to identify all children who are HIV-infected.³²⁰ Furthermore, even accepting the abstract concept of a child's independent right to obtain all relevant medical information by waiving his confidentiality interest and submitting to testing, it is less than clear who can exercise that right on behalf of the child while he is a legally incompetent minor.³²¹ Traditionally, the child's parents have the recognized legal authority to make such decisions on behalf of the child³²² so, even allowing for the existence of an independent right in the child, the state still may not be free to disregard any objections the mother may have to newborn HIV testing.³²³

Irrespective of who is allowed to stand in the child's shoes for purposes of asserting his confidentiality interest in HIV-related medical information, the child has a number of interests that weigh against testing, many of which parallel his mother's interests in this regard. For example, mandatory newborn testing is highly intrusive, compelling not only the release of otherwise existing medical records generated in the course of routine newborn care, but also the creation of highly sensitive medical data. Discovery of that information may undermine the newborn's relationship with his primary caregiver, as identifying a child as ill in the newborn period has been shown to disrupt the developing parent-child relationship, often with significant long-term psychological consequences for the child.³²⁴ Bonds between parent and child may be further weakened if the state compels particular medical treatment for HIV-exposed children, displacing the

319. See *supra* note 58 and accompanying text.

320. To the extent medical experts recommend specific treatments for HIV-exposed infants that are most effective before an infant's own HIV status can be confirmed, however, knowledge of perinatal HIV exposure alone may be deemed relevant to the child's health care, conceived of in preventive terms. See *supra* notes 72-78 and accompanying text.

321. The confidentiality cases generally have not dealt with information concerning minors. The potential conflict between the parent's right to make decisions for her child and the state's interest in the child's well-being have been addressed most frequently in the medical decisionmaking context, discussed extensively in Part V.B.2.b. That analysis will not be repeated here, where it is sufficient to point out that the mother may well have the right to make the decision whether to waive confidentiality on behalf of her child.

322. See *infra* note 351 and accompanying text.

323. Since the parent's role as family decisionmaker is to promote the interests of the family and not merely the interest of any individual member, it is entirely appropriate for a parent to take the needs of other family members into consideration when making decisions on an individual child's behalf. See Ferdinand Schoeman, *Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making*, 10 J. MED. & PHIL. 45, 48-49 (1985).

324. Clayton, *supra* note 268, at 106.

parent from their primary caregiver role.³²⁵ The child also will be vulnerable to discrimination in medical treatment if he is shown to be HIV-exposed³²⁶ and, if his HIV status becomes known outside of the health care setting, that information will pose a risk both to his housing and the economic support he receives from his parents.

Although under mandatory testing regimes the state appears only to compel the creation of individual HIV status information and its disclosure to health care providers and public health officials, the state interest served by prenatal and newborn HIV testing cannot simply be HIV testing and disclosure.³²⁷ Forcing an individual to confront her own health information for no purpose other than the confrontation itself would not outweigh the individual's liberty interest in informational privacy. The larger state purposes motivating prenatal HIV-screening programs presumably are preventing perinatal transmission and enabling immediate, improved medical care for pregnant women and newborns.³²⁸ Likewise, the state interests asserted to justify newborn HIV screening include early medical intervention to improve health outcomes for HIV-infected infants.

As this Article has repeatedly emphasized, these state purposes cannot be fulfilled without assuring access to care and otherwise ensuring treatment for all HIV-infected pregnant women and HIV-exposed newborns identified by the mandatory testing programs, for example by compelling treatment.³²⁹ None of the current proposals for mandatory prenatal or newborn HIV-testing programs includes a guarantee of access to care or even addresses the issue of how or whether treatment is expected to result when a woman or newborn tests positive for HIV. The state interest at stake in the screening programs therefore must be significantly discounted as the purpose of these programs is unlikely to be achieved even if invasion of the woman's and/or child's privacy were allowed.

Furthermore, as *Whalen* makes clear, the likelihood that the state program will result in the disclosure of confidential information to individuals other than the state regulators designated to receive it must be considered when weighing the interests at stake. As an initial matter, prenatal and newborn HIV-testing programs not only fail to protect against disclosure to all third parties but in operation *require* disclosure to health care providers who would not otherwise know the patient's HIV status. By operation of state and federal law, the

325. Cf. Dumois, *supra* note 151, at 155 (noting that mother is essential to successful treatment of child and noting potential harm to child if mother's cooperation not elicited).

326. See *supra* note 313.

327. Kevin J. Cumin, *Newborn HIV Screening and New York Assembly Bill No. 6747-B: Privacy and Equal Protection of Pregnant Women*, 21 *FORDHAM URB. L.J.* 857, 875 (1994) (discussing the state interests reflected in New York's AIDS Baby Bill).

328. The state also may assert an interest in obtaining the woman's HIV status in order to reduce the risk of infection to adult third parties. Several reasons why such an interest must be rejected as a justification for mandatory prenatal testing are discussed in *supra* notes 239 and 315.

329. As has been stated previously, it is inappropriate and illogical to assume consent to treatment in a public health regime that explicitly assumes that women will not consent to HIV testing for themselves and for their children. See Section IV.B.4.

information also may be disclosed to spouses and other sexual and needle sharing partners.³³⁰ Beyond these intended disclosures, unintended disclosure also is a substantial likelihood. Unlike the medical information at issue in *Whalen*, in a modern health care setting HIV-related patient information is not kept locked in a vault, but instead is in a patient's medical file that can be accessed by a significant number of hospital personnel both on paper and via computer.³³¹ Through the operation of public and private insurance, HIV-related information also may be revealed to Medicaid, private insurers and, through the latter, possibly private employers.³³²

In light of these significant problems with maintaining confidentiality for mandated HIV test results, the minimal state interests served by testing, and the severity of the intrusion imposed on an individual's informational privacy, mandatory prenatal and newborn HIV-testing programs cannot be justified and therefore violate the individual's constitutionally protected confidentiality right. Of course, the outcome of this balancing test could change significantly if the state were able to compel treatment for HIV-infected individuals identified through mandatory screening.³³³ In that situation, the weight of the state objectives achieved under testing programs would increase dramatically, whereas the intrusiveness to the individual would increase only incrementally.³³⁴ However, it is unclear whether the state has authority to compel treatment in this situation, and as a result to bolster its interest in obtaining HIV status information. That question touches on the autonomy strand of privacy rights protected under the Due Process Clause, and is discussed in the following Section.

2. *Privacy as autonomy*

The autonomy strand of the Due Process concept of privacy encompasses the individual's liberty interest in "independence in making certain kinds of important decisions."³³⁵ One kind of important decision included in the autonomy aspect of the Due Process Clause involves bodily integrity, or the

330. See *supra* note 315 and accompanying text.

331. Poor women who receive care in public health care settings, like most HIV-infected women and children do, particularly lack control over how their confidentiality is respected in health care institutions, and may have to exchange their medical privacy for public social services. Berger et al., *supra* note 131, at 79.

332. Madison Powers, *Legal Protections of Confidential Medical Information and the Need for Antidiscrimination Laws*, in AIDS, WOMEN AND THE NEXT GENERATION: TOWARDS A MORALLY ACCEPTABLE PUBLIC POLICY FOR HIV TESTING OF PREGNANT WOMEN AND NEWBORNS, *supra* note 54, at 221, 237-38.

333. In order to realize the state objectives justifying HIV-screening programs, it will be necessary to have a system in which access to care is guaranteed, and HIV-infected pregnant women and newborns are compelled to undergo treatment. See *supra* notes 326-29 and accompanying text. A model of compelled care assumes access to treatment.

334. The risk of increased medical coercion already exists under mandatory testing regimes as women and children found to be infected presumably would be subject to extremely strong pressure to accede to the treatment recommendations of their physicians. A policy or practice of compelling treatment in this situation would only increase the certainty of coercion.

335. *Whalen*, 429 U.S. 589, 599-60 (1977).

“right to determine what shall be done with [one’s] own body.”³³⁶ A competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment³³⁷ that is compromised under mandatory prenatal or newborn HIV-testing programs. The right to refuse medical treatment is not absolute, however, and “whether [an individual’s] constitutional rights have been violated must be determined by balancing his liberty interests against the relevant state interests.”³³⁸

a. **The nonpregnant adult’s right to refuse medical treatment**

Although this issue is not directly implicated by prenatal or newborn HIV-testing programs, the right of a competent adult who is not pregnant to refuse medical treatment is an important baseline from which to discuss possible limits on the state’s ability to compel treatment for pregnant women and newborns. The competent adult generally has the right to decline to have any medical treatment initiated or continued.³³⁹ This right is of constitutional dimension, and extends to the right to refuse lifesaving medical treatment³⁴⁰ and even to the right of prisoners to refuse the administration of unwanted antipsychotic drugs.³⁴¹ The right to refuse medical treatment and the related common law right of informed consent also extend to the right to refuse diagnostic testing.³⁴²

The individual’s right to refuse medical treatment is not unchecked, however. The state has four commonly recognized countervailing interests that may outweigh or otherwise limit the individual’s right to refuse medical treatment: preserving life, preventing suicide, safeguarding the integrity of the medical profession, and protecting innocent third parties.³⁴³ Only the first and fourth state interests are implicated to any significant degree in the HIV-screening context, and even those will not always justify compelling a nonpregnant adult to undergo medical treatment. For example, when death likely will result from an individual’s refusal to accept medical treatment, the Supreme Court has held that the state can impose heightened evidentiary requirements on third parties seeking to assert an incompetent’s right to refuse medical treatment.³⁴⁴ At the same time, however, the Court has reaffirmed the competent adult’s right to refuse life-preserving medical treatment,³⁴⁵ indicating that the state’s interest in preserving life does not trump individual autonomy so long as the individual’s wishes regarding treatment can be determined to a sufficient degree of certainty.

336. *Schloendorff v. Soc’y of New York Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) (J. Cardozo).

337. *Cruzan v. Dir., Missouri Dep’t of Health*, 497 U.S. 261, 278 (1990).

338. *Id.* at 279.

339. *Id.*; *In re Farrell*, 529 A.2d 404 (N.J. 1987).

340. *Cruzan*, 497 U.S. at 279.

341. *Washington v. Harper*, 494 U.S. 210, 221–22 (1990).

342. *Sternlight*, *supra* note 152, at 378. *But see supra* note 199 and accompanying text (discussing doctrine of presumed consent for certain blood tests).

343. *See, e.g., Farrell*, 529 A.2d at 348–49; *Fosmire v. Nicoleau*, 536 N.Y.S.2d 492 (N.Y. App. Div. 1989), *aff’d*, 551 N.E.2d 77 (1990).

344. *Cruzan*, 497 U.S. at 281.

345. *See id.* at 279.

When the state's interest in protecting innocent third parties has been at stake, however, a number of lower courts have found that the state can impose medical treatment on an unconsenting adult in order to maintain parental support for that adult's minor children.³⁴⁶ These cases generally have focused on the abandonment of minor children as a result of the death of the parent, and place the burden on the state to prove that a surviving parent or extended family member would not properly assume responsibility for the children.³⁴⁷ Given this emphasis, it is unlikely that a court would order a parent to accept unwanted medical treatment for a noncontagious condition that was not life-threatening, and where failure to receive treatment would not result in abandonment. An ultimately fatal condition such as HIV infection falls in an uncertain intermediate area, where unwanted medical treatment can prolong life and thus support for the minor child but cannot cure a condition that sooner or later will result in death. It is unclear how a court would treat this situation. The issue of how far the state can go to protect innocent third parties is further complicated in the case of a communicable disease such as HIV, because generally the state can order medical treatment to protect a class of third parties much broader than the infected person's dependent children—namely, society at large—even when the treatment is for a condition that is not immediately life-threatening, so long as treatment will prevent the transmission of disease.³⁴⁸

b. Newborn HIV testing and medical treatment of children over a parent's objection

Although children arguably have a right to refuse medical testing and treatment just as adults do, their legal incompetency makes that right largely hypothetical. As the law does not recognize a minor child's ability to make his own informed and voluntary decisions regarding medical treatment, and a newborn certainly does not have the ability to express any preference on the matter at all, a newborn's "right" to refuse medical treatment must be exercised for him, if at all, by a surrogate decisionmaker.³⁴⁹

Under the common law, the parents of a child are presumed to fill the role of surrogate decisionmaker and have the right to consent to or refuse medical

346. See, e.g., *Application of President and Directors of Georgetown College*, 331 F.2d 1000 (D.C. Cir.), cert. denied, 377 U.S. 978 (1964) (ordering blood transfusion to save life of Jehovah's Witness with seven month old child); *In re Estate of Brooks*, 205 N.E.2d 435 (Ill. 1965) (reversing lower court order compelling medical treatment while emphasizing fact that patient had no minor children); *In re Dubreuil*, 629 So. 2d 819 (Fla. 1993) (recognizing right to compel medical treatment to avoid abandonment of minor children).

347. See *Dubreuil*, 629 So. 2d 828 (reversing order compelling blood transfusion on grounds that state presented no evidence that noncustodial father or other relatives would not provide for children and citing similar cases). But see *President and Directors of Georgetown College*, 331 F.2d at 1010 (ordering blood transfusion to save life of mother of seven-month old infant though father was living and prepared to care for child).

348. See, e.g., *Jacobson v. Massachusetts*, 197 U.S. 11 (1905) (ordering smallpox vaccination to protect community from infection). Of course, there is no medical treatment to prevent transmission, with the exception of the preventive prenatal therapies discussed in Part I.B *supra*.

349. Cf. *Cruzan*, 479 U.S. at 280 (discussing similar limitations on an adult incompetent's ability to exercise her right to refuse medical treatment).

treatment on his behalf.³⁵⁰ Furthermore, parents in this situation are not only exercising their child's autonomy rights, but also possess an independent interest in parental autonomy that operates to shield family privacy from coercive state intervention.³⁵¹ Parents have a constitutionally protected liberty interest in establishing a home and rearing children,³⁵² and are presumed under the law to be acting in the best interests of their child when they make decisions on his behalf.³⁵³ The deference given to parental authority is justified not only by a parent's individual freedom to structure her home life and raise her child as she sees fit, but also by the child's biological and psychological need for unthreatened and unbroken continuity of care by his parents.³⁵⁴ The parent provides intimate, individualized care for the child and fills a valued socializing role in a manner that the state cannot replicate.³⁵⁵

However, the state, as *parens patriae*, also has an interest in the well-being of the child and may limit parental authority when necessary to protect a child's general welfare. The state's *parens patriae* power is in an important sense greater than the police power relied on to justify limitations on individual autonomy for the sake of public health and public safety, because under its *parens patriae* authority the state can act directly to protect the welfare of the child and its interventions are not limited to preventing harm to third parties.³⁵⁶

When parental autonomy and the state's interest in the child conflict, the constitutionality of the state's intervention in the family is measured using the same balancing test applied when other Due Process Clause liberty interests are at stake. In this context, a court specifically must weigh the parent's liberty interest in the care, custody and management of her child against the state's interests in protecting the best interests of the child when the parent fails to do so.³⁵⁷ As parental autonomy does not extend to exposing children to illness and death,³⁵⁸ courts often have allowed the state to compel medical treatment for a child over his parent's objection.³⁵⁹ When necessary to preserve the life of the child, courts almost without exception have ordered medical treatment for the child and disregarded parental objections even when grounded in the family's religious beliefs.³⁶⁰ In non-emergency health care situations, the courts have

350. Sternlight, *supra* note 152, at 379; Robert Bennett, *Allocation of Child Medical Care Decisionmaking Authority: A Suggested Interest Analysis*, 62 VA. L. REV. 285, 286–87 (1976).

351. Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L.J. 645, 648 (1977).

352. *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923); *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 534–35 (1925).

353. *Parham v. J.R.*, 442 U.S. 584, 602 (1979).

354. Goldstein, *supra* note 351, at 649.

355. *Cf. Meyer*, 262 U.S. at 402 (criticizing Platonic ideal of homogenized childrearing by the state).

356. *See* Madison, *supra* note 5, at 377. This is so because *parens patriae* encompasses "the right and duty of the state to exercise its power to protect those unable to protect themselves." Richard L. Manner, *Court-Ordered Surgery for the Protection of a Viable Fetus*, 5 W. NEW ENG. L. REV. 125, 128 (1982).

357. *Cf. supra* note 338 and accompanying text (outlining balancing test when adult's right to bodily integrity at stake).

358. *See Prince v. Massachusetts*, 321 U.S. 158, 166–67 (1944).

359. *See generally* 42 AM. JUR. 2d *Infants* § 25.

360. *See Manner, supra* note 356, at 133.

been more uneven in their resolution of the parent/state conflict, and generally have focused on the reasonableness of the parent's refusal to consent to medical treatment recommended for her child, evaluated in light of the nature of the proposed intervention and its efficacy in temporarily or permanently resolving the child's medical problem.³⁶¹

The state's ability to compel medical treatment in the context of newborn HIV-screening programs, therefore, will in the first instance turn on whether HIV screening and subsequent preventive treatment for HIV-exposed newborns is appropriately characterized as involving a life-or-death risk to the child. Clearly, a parent's refusal to consent to HIV screening for her child is not life-threatening in the manner that typically has triggered judicial rubber-stamping of a state's determination that medical treatment is in the best interest of the child. When HIV testing occurs shortly after birth, the child is not known to have a life-threatening illness and is not even suspected of having one. All children are tested indiscriminately, so the test cannot be justified by any diagnostic purposes it may serve when ordered in a particular case to identify or exclude a potential cause of physical symptoms that untreated may pose a risk to the child's life. Under a newborn testing regime, HIV testing is not indicated to preserve the health of any particular child, so no threat to a particular child's life can be shown to result from his parent's refusal to allow testing.

As there is no colorable claim that a child's life is at stake, in order to compel testing the state must show that parental refusal to allow testing is unreasonable. Given the incidence and typical progression of pediatric HIV infection, although some may question a parent's decision to refuse HIV testing for her child, it will be difficult for the state to show that this refusal is unreasonable. The vast majority of children born in the United States have no perinatal exposure to HIV.³⁶² Approximately seventy percent of children born to HIV-infected mothers will not be infected with the virus, even if their mothers receive no antiretroviral prenatal care to prevent perinatal transmission of HIV.³⁶³ Finally, even among HIV-infected newborns, only thirty percent will suffer from rapid disease progression and thus benefit to any significant degree from early identification through newborn testing.³⁶⁴ Overall, the risk to a child who is not tested for HIV is slight, whereas the parent may have particular knowledge about her situation that would make her decision to avoid such testing reasonable, even if the child were in fact infected. For example, she may know that she and her children are likely to face domestic violence should the child be diagnosed with HIV, that her family is particularly vulnerable to discrimination and loss of economic stability,

361. See Jay M. Zitter, Annotation, *Power of Court or Other Public Agency to Order Medical Treatment Over Parental Religious Objections for Child Whose Life Is Not Immediately Endangered*, 21 A.L.R. 5th 248 (2000); see also Manner, *supra* note 356, at 133-34 (discussing cases where courts upheld parent's refusal of medical treatment for child).

362. Seventeen per 10,000 women giving birth are infected with HIV. INSTITUTE OF MEDICINE, *supra* note 4, at 39.

363. See *supra* note 155.

364. See *supra* note 62 and accompanying text.

or that the family does not have the resources or insurance to pay for treatment even if it is indicated by test results. Whatever her reasons for refusing to allow HIV testing of her child, given the statistically slight benefit to her child's health that would result from being tested, there is no basis for a court to step in and find her refusal unreasonable.

Assuming the testing hurdle can be overcome despite this analysis, the state also may seek to compel treatment for a child after test results have indicated he is HIV-exposed.³⁶⁵ In this circumstance, a court may well find that preventive treatment for an HIV-exposed child presents a life-or-death situation, and accordingly order treatment over a parent's objection. Although it is still more likely than not that the child will not receive any significant benefit from early treatment and may even be harmed by unnecessary treatment, PCP prophylaxis will prevent death for a significant minority of HIV-exposed infants.³⁶⁶ Furthermore, there is unanimous agreement in the medical community that PCP prophylaxis is an appropriate and life-saving treatment for all HIV-exposed children.³⁶⁷ In light of these factors and judicial deference to the state in life-or-death situations involving child health care, a court will almost certainly order treatment to prevent PCP.³⁶⁸

State efforts to compel combination therapy for an HIV-infected child would present a more difficult issue. Combination therapy will not prevent an HIV-related death, but may significantly prolong the life of an infected child. There is little guidance on how the courts will approach parental medical decisions that are life-preserving only in the short- or middle-term, and implicate intimate family decisions regarding the quality of life of a terminally ill child. Treatment issues in this area are further complicated by a lack of information or medical consensus on the appropriate dosage and combination of antiretroviral medications to prescribe for a terminally ill child. A court may be tempted to find that if the child's quality of life can be preserved for a sufficiently long period of time then it is appropriate to do so, especially when HIV medicine is developing rapidly and a cure may be discovered while the child is still alive. Although this is a superficially appealing position, it lacks precedential support and conflicts with traditional constitutional concern for family privacy. When decisions involving medical treatment of a child are medically controversial and touch on the highly private issue of quality of life, they cannot be made in reliance on legal or medical values alone, but rather involve calling on ethical and other personal values that are at the core of constitutional protection of

365. This situation may arise when the parent consents to HIV testing but refuses to allow all or part of the recommended treatment for pediatric HIV infection. It also may occur under an involuntary testing regime.

366. See *supra* notes 72–78 and accompanying text.

367. See *supra* note 77 and accompanying text.

368. It should be noted that to ensure compliance with the PCP prophylaxis regimen, the state will need to remove the child from the parent's care from age six weeks until either (1) the child is confirmed to be uninfected with HIV at age six months, or (2) the child is over one year of age and no longer as susceptible to PCP.

family autonomy.³⁶⁹ In this situation, which arises with the decision whether to put a child on combination therapy, the state should not intervene in family decisionmaking and undermine parental autonomy.³⁷⁰

c. **Prenatal HIV testing and compelled medical treatment of pregnant women**

The pregnant woman is in a unique position under the law protecting bodily integrity, as she is a competent adult who generally may refuse unwanted medical treatment, but she also is carrying a fetus in whose life the state has an interest from the moment of conception.³⁷¹ It is unclear in the case law whether the state should be as severely limited in its ability to compel medical treatment over her objection as it is in the case of a non-pregnant competent adult, or whether some modified form of the state's power to compel treatment to benefit a minor child should apply.³⁷² In practice, a number of courts have determined that it does not unconstitutionally violate a pregnant woman's liberty to force her to receive medical care for the benefit of her fetus, and so have ordered pregnant women to submit to treatment over their objections.³⁷³ These courts generally have reached this result by balancing the mother's interest in refusing unwanted medical care against the state's interest in preserving a threatened fetal life, and finding that the state's interest outweighed the woman's interest to such an extent that the intrusion into her body was constitutional.³⁷⁴

Other courts have refused to balance the state's interest in the fetus against the woman's interest in bodily integrity, and have afforded pregnant women the same right as competent adults to refuse unwanted medical treatment.³⁷⁵ Under this view, the state's interest in fetal life is insufficient to outweigh the pregnant woman's right of privacy and bodily integrity.³⁷⁶ Even if the child were alive and an appropriate object of the state's full *parens patriae* powers, the state could not force the child's mother to submit to medical treatment in order to save the child's life.³⁷⁷ The state's interest in the fetus cannot be greater than its interest in

369. See Goldstein, *supra* note 351, at 664 ("[T]he law must recognize that it cannot find in medicine or for that matter in any science the ethical, political, or social values for evaluating health care choices.") (internal parentheses omitted).

370. Some commentators assert that the state should never intervene to compel medical treatment of child when the procedure at issue is medically or personally controversial. See Bennett, *supra* note 350, at 324.

371. Planned Parenthood of Southeastern Pa. v. Casey, 505 U.S. 833, 869 (1992).

372. See, e.g., Peta Lewis Hallisey, *The Fetal Patient and the Unwilling Mother: A Standard for Judicial Intervention*, 14 PAC. L.J. 1065, 1092 (1983) (proposing a rule where a state could intervene when the recommended treatment would prevent serious irreversible harm to the fetus without posing a serious risk to the mother's life).

373. See *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 S.E.2d 457 (Ga. 1981); *Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 201 A.2d 537 (N.J.); *In re Jamaica Hosp.*, 491 N.Y.S.2d 898 (N.Y. Sup. Ct. 1985).

374. E.g., *Jefferson*, 274 S.E.2d at 460.

375. See *In re Baby Boy Doe*, 632 N.E.2d 326 (Ill. App. Ct. 1994); *In re A.C.*, 573 A.2d 1235 (D.C. 1990).

376. Nelson, *supra* note 107, at 757.

377. See *A.C.*, 573 A.2d at 1243-44. Courts cannot compel one person to submit to a bodily intrusion for the benefit of another person's health. *Id.*

a born child.³⁷⁸ The abortion cases also make this point clear, by expressly subordinating the state's interest in fetal life to the woman's health.³⁷⁹

The cases affording pregnant women the same right as non-pregnant adults to refuse unwanted medical treatment clearly involve a more defensible interpretation of the extent of the state's interest in the fetus under existing law. However, even in jurisdictions where courts have aggressively intervened in pregnant women's medical care, there remain arguments that mandatory HIV testing and compelled treatment to reduce the risk of perinatal HIV transmission unconstitutionally invade a pregnant woman's right to bodily integrity. First of all, as in the case of newborn screening, prior to HIV testing the state has no basis to assert that any particular woman is HIV-infected and poses a risk of transmission to her fetus. Accordingly, there is no threat to a specific fetus's health upon which the state could seek to justify testing its mother for HIV against her will.

Furthermore, even if a court were to allow prenatal testing under the doctrine of presumed consent,³⁸⁰ the case law compelling medical treatment of pregnant women does not clearly justify ordering preventive treatment of an HIV-infected pregnant woman. All of the compelled treatment cases involve fetuses who would have died prior to or upon delivery if the mother did not undergo the recommended treatment, and as a result the state's interest in fetal life was clearly implicated in the mother's medical decision-making. No court has ordered a pregnant woman to undergo medical treatment merely to improve the health of a fetus whose live delivery was not threatened,³⁸¹ and it is far from clear that the state has any interest in fetal health *per se*.³⁸² *Roe* and *Casey* recognize the state's interest in fetal life,³⁸³ but not in fetal health in any broader sense. A pregnant woman's HIV-infection does not jeopardize the live birth of her fetus,³⁸⁴ so it is unlikely that any state interest in the fetus is triggered. Although the Supreme Court has not addressed the ultimate extent of the state's interest in the fetus, any doubt over this issue should be resolved in favor of the pregnant woman, given her established liberty interest in avoiding unwanted

378. *Id.* at 1244.

379. *See supra* note 119 and accompanying text.

380. *See supra* note 199 and accompanying text.

381. Even the lower courts that have compelled treatment of pregnant women have done so in reliance on the state's interest in fetal life, not in any purported state interest in fetal health when the fetus's survival was not at stake. *See supra* notes 373–374 and accompanying text.

382. Tort cases allowing children to collect damages for prenatal injuries also fail to recognize a state interest in fetal health, and instead are founded on the born child's personal interest in being made whole for prenatal damage to his health. *See generally* Johnson, *supra* note 110.

383. *Planned Parenthood of Southeastern Pa. v. Casey*, 505 U.S. 833, 869 (1992) (noting a state's interest in the life of the unborn throughout pregnancy); *Roe v. Wade*, 410 U.S. 113, 162 (1973) (holding that a state has an interest in potentiality of life).

384. In fact, there is a greater than seventy percent chance that the child will not suffer from any HIV-related illness at all. *See supra* note 155 and accompanying text.

medical treatment and the weak legal basis for asserting the full extent of the state's *parens patriae* interest in this context.³⁸⁵

C. MANDATORY HIV TESTING AS A FOURTH AMENDMENT SEARCH

Prenatal and newborn HIV-testing programs also raise Fourth Amendment concerns. The Fourth Amendment provides that "the right of people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated . . ."³⁸⁶ Under Supreme Court precedent, drawing blood and subsequently analyzing a blood sample to obtain physiological data each constitutes a separate and distinct search under the Fourth Amendment.³⁸⁷ A private actor, such as a health care provider, that draws and tests blood in order to comply with state regulations is subject to the Fourth Amendment's restrictions on state action,³⁸⁸ as are all employees of public hospitals.³⁸⁹ Accordingly, the health care providers who implement any federal or state mandatory prenatal or newborn HIV-screening program must do so, if at all, in a manner consistent with the Fourth Amendment.³⁹⁰

The Fourth Amendment does not proscribe all searches and seizures, but only those that are unreasonable.³⁹¹ In the HIV context, reasonableness will be judged by balancing the intrusion the HIV test imposes on an individual's Fourth Amendment privacy against the test's promotion of legitimate governmental interests.³⁹² In criminal cases, a search generally is deemed unreasonable unless it is accomplished pursuant to a warrant issued upon probable cause.³⁹³ Searches

385. As previously discussed, there is no basis for inferring any state interest in fetal health that is broader than the state's interest in a born child's health (and, as the fetus is not a person, there is a strong argument that any state interest in its health should in fact be narrower than the state's interest in a born child's health). *Supra* note 378 and accompanying text. The state's interest in a born child's health does not justify compelling either of the child's parents to undergo medical treatment on the child's behalf, even if the child's life is at stake. *See id.* The state interest in the fetus's potentiality of life relied on by the Court to limit a woman's right to seek abortion services from others, as in *Casey*, 505 U.S. at 869, should be read narrowly. Any reading that embraces a broader view of the state's interest as one encompassing fetal health, and not merely the fetus's life or death, is inconsistent with legal doctrine on the limit of the state's interest with respect to born children. A broad reading also would go much farther than *Casey* itself by justifying active state invasion of the woman's body for medical treatment purposes, and not merely passive restraint that forecloses otherwise available medical options.

386. U.S. CONST. amend. IV.

387. *Skinner v. Ry. Labor Executives' Ass'n*, 489 U.S. 602, 616 (1989).

388. *Id.* at 614.

389. *Ferguson v. City of Charleston*, 121 S. Ct. 1281, 1287 (2001).

390. Consensual searches generally do not violate the Fourth Amendment if consent is given voluntarily. *Schneckloth v. Bustamonte*, 412 U.S. 218, 222 (1973). "[T]he question of whether a consent to a search was in fact 'voluntary' or was the product of duress or coercion, express or implied, is a question of fact to be determined from the totality of the circumstances." *Id.* at 227. "Routine with notification" HIV testing will not implicate the Fourth Amendment if it is administered in such a way that consent is voluntarily given. If "routine with notification" HIV testing were to become coercive in practice, however, it would be subject to the same Fourth Amendment restrictions as mandatory HIV testing, and the analysis at *infra* notes 396-414 and accompanying text would apply.

391. *Skinner*, 489 U.S. at 619.

392. *See id.*

393. *Id.* Under certain circumstances not relevant here, law enforcement officers may effect a reasonable warrantless search when they have probable cause or a reasonable basis for suspecting criminal activity. *See,*

of a primarily civil nature or purpose rarely are subject to the warrant requirement, however, and have been found constitutional when they reasonably serve “special needs” that make the warrant and probable cause requirements impracticable.³⁹⁴ Current proposals for prenatal and newborn screening programs are best characterized as civil searches,³⁹⁵ and therefore the state is likely to attempt to justify these HIV tests as special needs searches.

1. *Mandatory prenatal HIV screening*

The first factor to be considered in a special needs reasonableness analysis of mandatory prenatal HIV screening is the nature of the privacy interest upon which the search intrudes.³⁹⁶ This factor focuses on the extent to which the searched individual’s expectations of privacy are reasonable.³⁹⁷ Pregnant women clearly have a legitimate expectation of privacy in the health care setting. They have a right to consent to or refuse unwanted medical treatment at their discretion,³⁹⁸ and a reasonable expectation that their confidential medical information will not be disclosed to third parties.³⁹⁹ Although they are subject to a certain amount of regulation as a consequence of the state’s interest in the life of their fetus, that regulation is limited in its scope⁴⁰⁰ and always subordinate to the life and health of the mother.⁴⁰¹ Pregnant women continue to have a reasonable expectation of privacy with respect to those issues beyond the scope of the state’s interest, such as the general health of their fetuses (as opposed to the fetuses’ life or death).⁴⁰²

Furthermore, pregnant women’s legitimate expectation of privacy in their own and their fetus’s health is not limited in any of the specific ways that the

e.g., *Scherber v. California*, 384 U.S. 757, 770 (1966) (upholding the reasonableness of warrantless alcohol blood tests when delay would have risked the destruction of evidence).

394. See, e.g., *Skinner*, 489 U.S. 602, at 619; *Vernonia Sch. Dist. 47J v. Acton*, 515 U.S. 646 (1995); *National Treasury Employees Union v. Von Raab*, 489 U.S. 656 (1989).

395. Current proposals for prenatal and newborn HIV testing rely on civil personnel and emphasize civil goals such as preventing HIV infection and protecting the health of HIV-exposed children. See *supra* note 161 and accompanying text. However, given the existence of criminal HIV transmission statutes and proposals to prosecute perinatal transmission under traditional criminal law doctrines, see *Panossian*, *supra* note 106, at 255, prenatal HIV-screening programs could foreseeably trigger criminal sanctions. If some future prenatal HIV-screening program heavily involved law enforcement and criminal prosecution in its public health efforts, the special needs doctrine would no longer apply and the state would have to justify the intrusion under the warrant/probable cause analysis employed in criminal cases. See *Ferguson v. City of Charleston*, 121 S. Ct. 1281, 1290 (2001). However, it is unclear what level of law enforcement involvement would need to be shown before a court would find the special needs doctrine inapplicable. See *id.* at 1290-1292 (noting excessive level of police involvement on the facts of the case and not addressing whether some lesser level of involvement would avoid constitutional violation).

396. *Vernonia Sch. Dist. 47J v. Acton*, 515 U.S. 646, 654 (1995).

397. *Id.*

398. See *supra* notes 337-346, 369-383 and accompanying text.

399. See *Ferguson*, 121 S. Ct. at 1289.

400. See *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833, 874 (1992) (holding that the state cannot constitutionally enact regulation that places undue burden on woman’s pre-viability abortion decision).

401. See *supra* note 119 and accompanying text.

402. See *supra* note 379-383 and accompanying text.

Supreme Court has relied upon to justify special needs searches in the past. The Court has upheld special needs searches both in heavily regulated industries⁴⁰³ and when submission to the search has been established as a condition for eligibility for a particular benefit.⁴⁰⁴ In those cases, the searched individuals were deemed to have a lesser expectation of privacy because they chose to work in the regulated industry or affirmatively sought the conditional benefit. Pregnancy, on the other hand, is not a heavily regulated industry, but instead falls squarely within the ambit of reproductive and childbearing decisions afforded particular privacy under the Constitution.⁴⁰⁵ Furthermore, reproduction is a right, and not a conditional benefit afforded by the state.⁴⁰⁶ Although it is possible to make the argument that the state is conditioning not pregnancy but prenatal care on submission to HIV testing, that construction does not justify inferring a lesser expectation of privacy in light of the pregnant woman's expectation of privacy in the doctor-patient relationship itself. Also, a pregnant woman may plausibly assert that the right to reproduce includes the right to a pregnancy free of state interference with her access to health care.⁴⁰⁷

The second factor to be considered in the Fourth Amendment analysis is the character of the state intrusion.⁴⁰⁸ The Court has determined that drawing blood itself imposes a minimal intrusion on the individual.⁴⁰⁹ Much more intrusive, however, is the nature of the physiological information obtained when the blood sample is chemically analyzed for HIV infection. The Court's special needs cases all have involved screening blood and urine samples for illegal drugs, and the Court has not recognized any troubling level of intrusiveness in obtaining

403. See *Skinner v. Ry. Labor Executives' Ass'n*, 489 U.S. 602 (1989) (approving drug testing for railroad workers involved in major rail accidents); cf. *Vernonia Sch. Dist. 47J v. Acton*, 515 U.S. 646 (1995) (upholding random drug testing of student athletes).

404. *Vernonia Sch. Dist.*, 515 U.S. 646 (upholding drug testing as condition for participation in school athletics); *National Treasury Employees' Union v. Von Raab*, 489 U.S. 656 (1989) (upholding drug test as condition for promotion to Customs post entailing direct drug interdiction or use of a firearm); see also *Local 1812, Am. Fed'n of Gov't Employees v. United States Dep't of State*, 662 F.Supp. 50 (D.D.C. 1987) (approving mandatory HIV testing of foreign service officers due to hazards of foreign postings); *Anonymous Fireman v. City of Willoughby*, 779 F. Supp. 402 (N.D. Ohio 1991) (approving mandatory HIV testing for firefighters due to hazards of job). But see *Chandler v. Miller*, 520 U.S. 305 (1997) (holding state could not require candidates for public office to submit to drug testing).

405. See generally *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Roe v. Wade*, 410 U.S. 113 (1973). To the extent that intervention in the pregnant woman's health is justified by characterizing the fetus as a prospective child with conditional rights, it should be noted that the woman also has a liberty interest in family privacy and autonomy that affords her childrearing decisions constitutional protection. See *supra* notes 349-353 and accompanying text.

406. See *Griswold*, 381 U.S. at 485; *Eisenstat v. Baird*, 405 U.S. 438, 454-455 (1972); *Roe*, 410 U.S. at 152.

407. A pregnant woman is a competent adult who has a recognized interest in making her own medical decisions. See *supra* notes 339-40 and accompanying text. The right to refuse treatment is in this sense simply a correlate of the right to exercise informed consent when medical decisions are at stake. State interference with a pregnant woman's access to health care actively prevents her from making individual decisions regarding health care, and is not permissible unless a recognized state interest justifies such a burden on individual liberties. See *supra* notes 341-345 and accompanying text. The state cannot justify this burden in the HIV-screening context. See Part V.B.2.C.

408. *Vernonia Sch. Dist. 47J v. Acton*, 515 U.S. 646, 658 (1995).

409. *Schmerber v. California*, 384 U.S. 757, 771 (1966).

that particular information.⁴¹⁰ Notably, these decisions have repeatedly emphasized that no personal health information was obtained from the relevant samples,⁴¹¹ and imply that the Court would recognize the increased intrusiveness of a screen for medical information that was not drug-related. Furthermore, the intrusiveness of obtaining medical information itself would be greater than average for HIV information, which is particularly sensitive given the social stigma and discrimination that often accompany an HIV diagnosis.

The final factor to be considered in the special needs balancing test is the nature and immediacy of the governmental concern prompting the intrusion.⁴¹² Under its police powers, the state clearly has an interest in preventing perinatal transmission of HIV.⁴¹³ That interest is immediate when a woman who may be infected with HIV becomes pregnant, as the risk of transmission can only be reduced by discovering the woman's HIV status prior to delivery. However, since the state cannot compel the woman to submit to preventive treatment,⁴¹⁴ the state's interest is not well-served by mandatory testing and cannot be justified on public health grounds.⁴¹⁵ The state also has a limited *parens patriae* interest in the life of the woman's fetus. Nevertheless, as live delivery of the fetus is not jeopardized by untreated HIV infection, the state cannot justify the search on this basis, either. The state has no special need that is actually served by discovering the HIV status of pregnant women. Mandatory prenatal HIV screening, therefore, should be found unconstitutional under the Fourth Amendment.

2. *Mandatory newborn HIV screening*

Mandatory newborn HIV screening involves both different expectations of privacy and enhanced state interests for Fourth Amendment purposes. Although a parent has a constitutionally protected interest in family autonomy, her interest in the care, custody and management of her child is always limited by the state's *parens patriae* interest in the child. The limited nature of parental authority is particularly clear in the medical context, where health care providers have a legal duty in most states to report suspected child abuse to state authorities⁴¹⁶ and

410. See *Von Raab*, 489 U.S. at 659; *Vernonia Sch. Dist.*, 515 U.S. at 646; *Chandler v. Miller*, 520 U.S. 305, 305 (1997).

411. See, e.g., *Vernonia Sch. Dist.*, 515 U.S. at 658 (“[I]t is significant that the tests at issue here look only for drugs, and not for whether the student is, for example, epileptic, pregnant, or diabetic”).

412. *Id.* at 660.

413. See *supra* note 278 and accompanying text.

414. See *supra* notes 378–383 and accompanying text.

415. *But see id.* *Ferguson v. City of Charleston*, 121 S. Ct. 1281, 1295 (2001) (Kennedy, J. concurring) (“There can be no doubt that a mother’s ingesting [cocaine] can cause tragic injury to a fetus and a child. There should be no doubt that South Carolina can impose punishment on an expectant mother who has so little regard for her own unborn that she risks causing him or her lifelong damage and suffering. The State, by taking special measures to give rehabilitation and training to expectant mothers with this tragic addiction or weakness, acts well within its powers and its civic obligations.”).

416. See, e.g., *id.*, at 1290 (noting health care providers’ obligation under state law to report suspected child abuse and neglect).

where compelled treatment of children over parent's objection is not uncommon.⁴¹⁷

At the same time, the state's *parens patriae* interest is fully implicated under newborn testing programs, as it is not in the prenatal context where testing occurs prior to the live birth of a child. In light of medical practice guidelines calling for very early treatment of HIV-exposed newborns in order to prevent the risk of serious illness, the state's interest also is immediate. Furthermore, given the strong possibility that the state will succeed in compelling at least PCP prophylaxis over any objection by the parent,⁴¹⁸ the state's interest can be achieved as a result of the search. Accordingly, even though newborn HIV screening is highly intrusive in terms of the sensitive medical information it reveals, a court is likely to find that newborn testing constitutes a special needs search justified by the state's traditional interest in the welfare of born children, which has been afforded particular deference in the health care context.⁴¹⁹

VI. PUTTING THE FRAMEWORKS TOGETHER: A CRITIQUE OF CURRENT PROPOSALS FOR HIV TESTING OF PREGNANT WOMEN AND NEWBORNS

A. MANDATORY NEWBORN HIV SCREENING

Mandatory newborn HIV-screening programs, such as the one currently in place in New York State, will almost certainly be found constitutional under existing law. The fact that the state can compel treatment for an HIV-exposed child⁴²⁰ will tip the constitutional balancing tests applied under the Due Process Clause and the Fourth Amendment decisively in the state's favor.⁴²¹

Despite its constitutionality, mandatory newborn testing is not justifiable in public health terms. Newborn testing will benefit only a negligible percentage of all infants tested, while creating a situation in which a significant majority of the

417. See *supra* notes 356–359 and accompanying text.

418. See *supra* notes 363–365 and accompanying text.

419. See Renna, *supra* note 152, at 445–46. *But see* Post, *supra* note 152, at 212–13 (asserting newborn testing not a constitutional special needs search because it violates the mother's right to privacy in her own HIV status and applying strict scrutiny review).

420. See *supra* notes 363–366 and accompanying text.

421. Mandatory newborn HIV testing is a constitutional special needs search under the Fourth Amendment, see *supra* notes 414–418 and accompanying text, and likely will be found to be a constitutional infringement of the newborn's confidentiality interest when linked to compelled care, see *supra* note 332 and accompanying text. Although it is less clear that newborn HIV testing, as opposed to treatment, constitutionally burdens the child's right to bodily integrity and the parent's right to autonomy in the care of her child, see *supra* notes 360–362 and accompanying text, this basis for challenge retains little vitality once the test has been deemed a constitutional search where the state need no longer rely on consent.

HIV-exposed infants identified through testing will be subject to unnecessary and potentially toxic treatment. Mandatory testing also could generate distrust among affected social groups whose cooperation is essential to reducing the transmission of HIV, and create situations in which families would be forced by the state to confront knowledge of their child's HIV status while not receiving access to the medical treatments necessary to preserve and improve his health. Mandatory newborn testing is questionable, as well, because it will divert attention and resources away from prenatal programs that can prevent new cases of pediatric HIV infection.

Mandatory newborn HIV testing, then, presents a striking disconnect between public health science and public health law. This disconnect may in part explain why politicians have focused on newborn testing as their preferred strategy for combating pediatric AIDS, while most public health commentators have rejected it in favor of prenatal interventions that can actually prevent perinatal transmission. In general terms, a disconnect such as this probably only is possible when children's health is at stake. The modern legal framework for analyzing the constitutionality of public health programs is attractive precisely because it precludes the state from placing restrictions on individual liberties in the name of public health when public health science fails to justify the restrictive policy. Furthermore, even under the traditional public health doctrine with its deference to state public health policies, courts would be unlikely to uphold mandatory newborn HIV testing as a constitutional exercise of the police power, as it is not medically justifiable and will not withstand factual scrutiny by the court. Accordingly, programs such as mandatory newborn testing that do not meet public health criteria will only survive review when they are supported by the state's *parens patriae* power, which is not subject to the "medical necessity" constraints that limit the state's police power to enact public health programs targeting adults.

B. MANDATORY PRENATAL HIV SCREENING

Mandatory prenatal testing presents almost the opposite analysis. Although prenatal HIV testing may well be justified in public health terms if it were linked to treatment,⁴²² it clearly is unconstitutional under the Due Process Clause⁴²³ and the Fourth Amendment.⁴²⁴ Mandatory prenatal testing also unethically sacrifices

422. See *supra* Parts IV.A.3–IV.A.4. Of course, none of the current proposals for prenatal HIV testing include any guarantee of access to treatment. See, e.g., McCormick, *supra* note 187, at 798 (noting that IOM's "routine with notification" proposal does not emphasize improving access to care). The federal government does require state Medicaid programs to fund antiretroviral treatment to reduce the risk of perinatal transmission, see *supra* note 163, but not all women have access to Medicaid. Even those women on Medicaid are not guaranteed antiretroviral treatment postpartum, and may have legitimate concerns about developing a virus-resistant strain of HIV if they take the government up on its limited offer to provide them with medical care only during pregnancy. See *supra* note 226. Current prenatal screening programs are ominously silent on the issue of compelled treatment, as well.

423. See *supra* notes 310–317, 326–332, 369–370 and accompanying text.

424. See *supra* notes 396–415 and accompanying text.

pregnant women's autonomy to a specific vision of fetal rights, assuming both that women are in a confrontational relationship with their fetuses,⁴²⁵ and that they have a duty to undergo treatment for their fetuses irrespective of consent or any harm such treatment may pose to the women's own health.⁴²⁶

Mandatory prenatal HIV-testing proposals provide a stark example of the policies that can emerge when distrust of the reproductive decisions of poor women of color converges with fetal rights rhetoric. Proponents of mandatory prenatal testing often present the issue as one involving a conflict between the mother's civil liberties and public health.⁴²⁷ They assume, contrary to reason, that the mother's interests and the fetus's interests conflict⁴²⁸ and that the fetus, backed by the force of the state, has some right to have his interests prevail.⁴²⁹ This idea that a pregnant woman is subordinate to her fetus is not unique to the HIV context,⁴³⁰ but gathers disproportionate strength when the pregnant women affected are poor women of color.⁴³¹

Under mandatory prenatal HIV-testing policies, HIV-infected women are treated more like pregnant drug users⁴³² than like potential carriers of other hereditary physical conditions, who generally are allowed to make their own decisions about whether to be tested for heritable conditions and how to respond to the results.⁴³³ Although purportedly motivated by concern for fetal health,⁴³⁴ mandatory HIV-testing policies in fact undermine fetal health care by

425. Cf. Post, *supra* note 152, at 195 (asserting that mandatory newborn policies assume that coercion is the only way to get HIV-infected mothers to do what is in the best interests of their children).

426. See *supra* note 268 and accompanying text.

427. See Field, *supra* note 147, at 422–23.

428. It is much more plausible that the mother's and fetus's interests are particularly likely to converge in the HIV context. A fetus is only at risk for HIV infection if its mother is already HIV-infected. The pregnant woman is facing HIV disease and making treatment decisions on her own behalf, and she and her fetus face similar treatment options. See *supra* notes 45–47, 79 and accompanying text. If the mother, facing similar and arguably even more compelling decision factors as the fetus, decides that treatment is not in her own best interest, it is unclear what basis the state, which is much less familiar with the context of a specific treatment decision, has for asserting that it is in the child's best interest. See Sternlight, *supra* note 152, at 388.

429. See *supra* notes 113–116 and accompanying text.

430. See generally *supra* Part II.B.

431. See *supra* notes 125–127 and accompanying text.

432. See *supra* note 6 and accompanying text; *Ferguson v. City of Charleston*, 121 S. Ct. 1281, 1286 (2001) (describing hospital policy of conducting unconsented drug screens of pregnant women and efforts to coerce drug treatment with criminal charges).

433. For example, genetic counseling is based on the concept of nondirective counseling. Nondirective counseling involves advising couples who seek genetic counseling of their reproductive risks and their options for dealing with those risks, and helping each couple choose the course of action most appropriate to them in terms of their own values. See Kass, *supra* note 148, at 312.

434. Of course, these “[p]rofessions of concern for the offspring of HIV-infected women would ring truer if those advocating more reproductive responsibility also called for some long overdue *social* responsibility towards the needs of poor women of color.” See Arras, *supra* note 243, at 358 (emphasis in original).

constructing an adversarial relationship between the fetus's primary caregiver⁴³⁵ and the health care system.⁴³⁶

C. UNIVERSAL "ROUTINE WITH NOTIFICATION" PRENATAL HIV SCREENING

The implementation of the IOM's "routine with notification" prenatal testing problem will encounter few legal obstacles. To the extent that health care providers actually seek, and pregnant women voluntarily give, consent to testing, there is no basis upon which to assert that the state is forcing pregnant women to do anything they have a right not to do or not to allow under the Constitution.⁴³⁷ Prenatal testing arguably also can be justified on public health grounds,⁴³⁸ making the IOM's proposal appear to be an attractive formula for identifying a greater number of HIV-infected pregnant women for preventive treatment while at the same time preserving the women's autonomy.

The most compelling objections to the IOM's proposal rest on ethical grounds. The IOM's proposal undermines women's autonomy in two significant ways. First, although consent is formally retained under a "routine with notification" scheme, the deemphasis on counseling and informed consent unquestionably opens the door to a *de facto* mandatory testing regime in which health care providers quietly slip an HIV test into the standard prenatal panel.⁴³⁹ Given the lack of any evidence that pregnant women are likely to refuse testing when they receive counseling and have an opportunity for fully informed consent, it seems unjust to place the risk of involuntary testing on pregnant women in this manner. Furthermore, even if the IOM's guidelines for eliciting consent are followed in their entirety, pregnant women will not receive all of the information required for them to give *informed* consent to HIV testing, or make a truly autonomous decision in this regard. Imposing this burden on pregnant women is entirely unacceptable from a justice standpoint, as women's health arguably has already suffered due to the health care system's failure to address their HIV-related risks and health care needs, and most of the purported "failures" of current voluntary testing policies result from health care providers'

435. It is undisputed that the mother plays an essential role in facilitating her child's medical care, both before and after birth, and that her cooperation with health care providers results in better care for the child. See Post, *supra* note 152, at 181; Dumois, *supra* note 151, at 155.

436. "HIV testing 'is likely to be most successful if it begins with an informed patient and a trusted advisor. Voluntary testing accomplishes this; mandatory testing . . . may actually reduce the chance that a woman and her baby will receive needed therapies if they are alienated from the health care system.'" Nina Loewenstein, *Mandatory Screening of Newborns for HIV: An Idea Whose Time Has Not Yet Come*, 3 CARDOZO WOMEN'S L.J. 43, 50 (1996) (quoting Dr. Helen Gayle of the CDC).

437. No state intrusion to informational privacy occurs when a woman consents to testing, see *supra* note 310 and accompanying text, and consent to treatment facially negates a woman's claim that her right to refuse treatment was violated. Consensual searches do not violate the Fourth Amendment. See *supra* note 390.

438. See *supra* notes 230-232 and accompanying text.

439. See McCormick et al., *supra* note 187, at 797-98 (acknowledging danger that providers will not seek effective consent but suggesting a sufficient response is to rely on providers' responsibility to their pregnant patients).

failure to offer HIV testing and treatment to pregnant women, not women's refusal to consent to testing. Finally, limiting the amount of HIV-related information provided to pregnant women may in fact actually lead to worse health outcomes for their children, as the primary reason patients in general refuse recommended treatment is poor communication with health care providers who do not adequately explain the need for treatment.⁴⁴⁰

Pediatric AIDS, and HIV infection in women, are highly concentrated in minority communities and correlate with social problems of poverty and drug use.⁴⁴¹ It is easy to blame HIV-infected pregnant women and new mothers for perinatal HIV infection,⁴⁴² and mandatory prenatal and newborn HIV-testing policies clearly do so, assuming that these pregnant women and mothers will not do what is "right" for their fetuses and children. Shortly after the announcement of the ACTG 076 results, James W. Curran, then associate director for HIV/AIDS at the CDC, stated:

How successful we are in implementing this prevention breakthrough will be a test for all of us—in particular, a test of the community affected by HIV in accepting the science and weighing the risks and benefits, a test of the public health community in building trust and developing consensus, and a test of society and the health care system in providing the resources needed to implement it.⁴⁴³

Seven years later, the public health community, the health care system and society are failing that test, and seem intent on shifting the blame to HIV-infected women. The move away from universal counseling of pregnant women, and HIV testing only upon informed consent, may appear to be reasonable on many levels, but its proponents seem to ignore the social context of HIV infection in women, as well as the primary role the medical profession has played in undermining the effectiveness of current voluntary screening programs. Although the IOM's proposal for routine with notification prenatal testing seems to afford a certain amount of respect to these women by allowing them a limited form of consent, this proposal, no less than mandatory testing schemes, places almost the entire burden of preventing pediatric HIV infection on HIV-infected women. This narrow vision of consent may satisfy legal objections, but it should not be allowed to hide the fact that routine with notification prenatal HIV testing, and the burdens on HIV-infected women associated therewith, are neither ethically justifiable nor necessary from a public health standpoint⁴⁴⁴ to efforts aimed at preventing perinatal HIV infection. The

440. A study of hospital patients showed that the primary reason patients refused treatment was the perceived failure of doctors to inform them of the fact and purpose of ordered treatments or procedures. Paul S. Appelbaum & Loren H. Roth, *Patients Who Refuse Treatment in Medical Hospitals*, 250 JAMA 1296, 1299 (1983). "Clearly, some patients desire to know more than they are ordinarily told about the purposes and risks of treatment and diagnostic procedures, even when the physician considers them 'routine.'" *Id.* at 1301.

441. See Sinton, *supra* note 101, at 231–232.

442. See *supra* note 129 and accompanying text.

443. Simonds & Rogers, *supra* note 163, at 1515.

444. Although routine with notification testing can be justified on public health grounds, the public health model does not prefer a truncated consent screening program to a fully voluntary screening program.

IOM's proposal is flawed because it unjustly places doctors' convenience ahead of poor women of color, and their access to information regarding one of the most significant health problems facing themselves and their children.

Rather, the public health model simply does not directly address whether state coercion is justifiable as a component of a screening program and, specifically in the context of prenatal HIV screening, is indeterminate on the issue of consent. See Part IV.A.4 *supra*. Truncated consent therefore is not necessary, in public health terms, to a prenatal screening program.

