Why Mandatory HIV Testing of Pregnant Women and Newborns Must Fail: A Legal, Historical, and Public Policy Analysis Special Issue: Mandatory HIV Testing of Newborns and Their Mothers

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WHY MANDATORY HIV TESTING OF PREGNANT WOMEN AND NEWBORNS MUST FAIL: A LEGAL, HISTORICAL, AND PUBLIC POLICY ANALYSIS*

ELIZABETH B. COOPER**

INTRODUCTION

The debate surrounding mandatory HIV testing of newborns and pregnant women requires an understanding of the historical context of women in the epidemic. Although the epidemic first was recognized in gay men in 1981,1 anecdotal reports reveal that women already were dying from what seems to have been HIV-related symptomatology. Indeed, in Gena Corea’s book, The Invisible Epidemic,2 we learn that, as early as 1981, not insignificant numbers of drug-using and former drug-using women were falling ill and not recovering from conditions that normally are not fatal, including bacterial pneumonia.3 Yet, because we did not necessarily expect these populations to be healthy4 or perhaps because our health care system is not structured to recognize such changes,5 or perhaps because, as Corea suggests, they were happening to

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3 Bacterial pneumonia was incorporated into the CDC’s revised surveillance definition of AIDS announced December 18, 1992. See id. at 1-3, 6, 12-15; CENTERS FOR DISEASE CONTROL, U.S. DEP’T OF HEALTH AND HUM. SERV., IMMUNODEFICIENCY AMONG FEMALE PARTNERS OF MALES WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS), 31 MORBIDITY & MORTALITY Wkly. REP. 697, 697-98 (1983) [hereinafter CDC, IMMUNODEFICIENCY].

4 It appears that the stark contrast of severe morbidity and extraordinary mortality among gay, mostly white, men, who otherwise would have been healthy, stood out in a way that the increased morbidity and mortality among drug using women did not.

5 Some may be tempted to say that the increase in severity and occurrence of morbidity and mortality went unnoticed because health care providers just did care enough. It would be far more appropriate, however, to take to task a health care system that neither universally nor adequately provides health care services to those in need. Sheldon H. Landesman & Susan Holman, Epidemiology and Natural History of HIV Infection, in PRIMARY CARE OF WOMEN AND CHILDREN WITH HIV INFECTION 19, 27 (Patricia Kelly et al. eds., 1995); R.P. Brettie & C.L. Leen, The Natural History of HIV and AIDS in Women, 5 AIDS 1283, 1289-92 (1991).
"others," these deaths passed virtually unnoticed. We failed early on to recognize that AIDS, as we later came to know the disease, could and would manifest in women. Consequently, we lost critical time in recognizing some of the symptoms that may accompany HIV disease in women and in developing research and prevention programs geared to the needs of women.

Remarkably, the first natural history study of HIV disease in women was not commenced until 1992. Moreover, it was not until 1993 — after six years of research and advocacy, and ten years since AIDS first was reported in women — that the Centers for Disease Control and Prevention ("CDC") recognized that HIV-related symptoms specific to women existed. Because the CDC did not consider certain women-specific conditions to be HIV-related, a number of things were happening: (a) the CDC was not getting an accurate picture of the epidemic; (b) women were not being properly diagnosed and, as a result, were getting HIV-related care late in their illness, if at all, and were dying far more quickly than other populations with HIV/AIDS; (c) health care providers and institutions did not integrate their gynecologic care into their HIV

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6 Corea, supra note 2, at 4-5.
7 The CDC HERS (HIV Epidemiology Research Study) began in 1992. Communication with Sally Zierler, Dr. P. H., Associate Professor of Medical Science, Department of Community Health, Brown University, Providence, R.I. (April 1995). See Landesman & Holman, supra note 5.
8 In January 1993, the CDC had reports of 43 cases, since June 1981, of previously healthy women who had developed opportunistic infections typical of AIDS. See CDC, Immunodeficiency, supra, note 3.
9 Effective January 1, 1993, the CDC modified its surveillance definition of AIDS by adding invasive cervical cancer to the list of AIDS-diagnosing conditions; the agency also added recurrent pneumonia, pulmonary tuberculosis, and confirmed HIV-antibody tests with T-cells (CD4+ cells) under 200 to the definition, and invasive cervical dysplasia to the HIV classification system. Centers for Disease Control, U.S. Dep't of Health & Human Serv., 1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults, 41 Morbidity & Mortality Wkly. Rep. 1, 1-10 (1992). Accuracy of the surveillance definition, in terms of specificity and sensitivity, is important for maintaining accurate surveillance records. Surveillance is used to predict trends in the epidemic, and implicitly, to direct funds as needed. Also, clinical trials largely are established to examine those conditions recognized by the CDC as being one of the now-93 AIDS-diagnosing events, and secondarily, by the host of non-AIDS-diagnosing but HIV-related conditions. See Risa Denenberg, Unique Aspects of HIV Infection in Women, in WOMEN, AIDS AND ACTIVISM 92 (The ACT UP/New York Women and AIDS Book Group, 1990); Landesman & Holman, supra note 5, at 19, 29-30. Therefore, a diagnosis of AIDS can effect one's ability to access clinical drug trials.
10 Following implementation of the revised definition, there was a 182% rise in the number of women diagnosed with AIDS and a 142% rise in diagnoses among men. Landesman & Holman, supra note 5, at 29-30.
11 Early studies of survival after AIDS diagnosis showed a shorter survival rate among women than among men, related to poor access to care and later presentation with more advanced symptoms. Although current studies of CD4 decline per year of HIV infection among men show a fairly predictable rate, few comparable studies have been conducted on women. Landesman & Holman, supra note 5, at 26. See also Brettle & Leen, supra note 5; Denenberg, supra note 9, at 92.
clinics and did not integrate HIV-related care into their gynecologic care provision and, as a result, women got “underinclusive” health care, and further, the CDC got an even more skewed look at the epidemic;\(^\text{12}\) (d) the development of and access to clinical trials did not reflect the medical needs of women in the epidemic, because trial development implicitly depended on the CDC’s sanctioning of certain conditions as being HIV-related or AIDS-diagnosing;\(^\text{13}\) and (e) in our world of limited resources, access to many services and benefits were highly dependent on receiving an AIDS diagnosis; because it was largely women and low-income people who had not yet been recognized in the surveillance definition, these were the populations that also were disproportionately not receiving benefits critical to their survival.\(^\text{14}\)

Furthermore, by failing to recognize the depth and breadth of the manifestation of HIV/AIDS in women, we also failed to understand the degree to which the epidemic would become a family disease. Even if only one person in a family unit were HIV-infected, the impact would be felt throughout. This is particularly true in single-parent households in which the mother is HIV-infected; demographically, this is not an unusual occurrence.\(^\text{15}\) Moreover, as approximately twenty-five percent of the offspring of HIV-infected women also will be HIV-infected,\(^\text{16}\) concerns are raised regarding school attendance, disclosure of serostatus, access to appropriate caregivers in case of parental disability or death, and a plethora of housing and government benefits issues.\(^\text{17}\)

**PART I - AN OVERVIEW OF THE POLICY ISSUES FACED BY WOMEN LIVING WITH HIV/AIDS: FAILURE OF THE ORIGINAL AIDS MODEL OF HEALTH CARE DELIVERY**

Although health care delivery systems are better established now than in 1993 to provide gynecologic services for women with

\(^\text{12}\) Landesman & Holman, *supra* note 5, at 27; Denenberg, *supra* note 9, at 32-35.


\(^\text{14}\) For a while, being AIDS-diagnosed was a prerequisite for receiving services from the Division of AIDS Services (DAS) in New York City. *See also* S.P. v. Sullivan, No. 90 Civ. 6294 (S.D.N.Y. 1990) (Cedarbaum, J.) (analyzing a legal challenge to the Social Security Administration’s failure to award benefits equitably).


\(^\text{17}\) Cooper, *supra* note 15.
HIV, the availability or provision of such services still is not uniform. At the 1995 HIV Infection in Women Conference, one keynote speaker, a woman living with HIV, stated that in her numerous years of participating in a CDC-sponsored study, she had not once been given a pelvic exam. Inversely, women still experience chronic yeast or other HIV-related gynecologic conditions without being informed about the possible correlation with HIV, let alone being provided with HIV-related education, counseling, or the option of testing.

Second, women still have difficulty getting access to clinical drug trials. The Food and Drug Administration ("FDA") has been terribly lax in failing to eliminate extant barriers to HIV-positive women's participation in phase I and early phase II clinical trials. Even when formal barriers have been lifted, often implicit barriers remain: there are instances in which women have been told they must be sterilized or use Norplant in order to participate in trials. Additional obstacles continue to exist. For example, there are few clinical trials that are geared toward learning about HIV in women, rather than as vectors of HIV to their offspring. Also, and not infrequently, referrals to clinical trials continue to occur

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18 Address at the HIV Infection in Women Conference: Setting a New Agenda, Feb. 22-24, 1995 [hereinafter HIV Infection in Women Conference]. The conference was coordinated by the Philadelphia Sciences Group, and co-sponsored by the following government agencies: National Institute of Health; Centers For Disease Control and Prevention; Food and Drug Administration; Health Resources and Services Administration; Agency for Health Care Policy and Research; Public Health Service Office on Women's Health.

19 In July 1993, the FDA issued new proposed guidelines permitting women living with HIV, under certain circumstances, to participate in phase I and early phase II clinical trials. There remains concern, however, that this change in policy, even when implemented, will not be aggressively enforced. In January 1995, the National Task Force on AIDS Drug Development recommended that the FDA change pertinent regulations to ensure that women are not excluded from clinical drug trials. The FDA indicated its willingness to make such changes, but proposed regulations have not yet been put forward. Telephone Interview with Theresa McGovern, Director of the HIV Law Project, in New York, N.Y. (Apr., 1995) [hereinafter McGovern Interview].

20 The ACLU stood ready to challenge the failure of a New Jersey medical institution to permit women to participate in phase I of a clinical drug trial. Specifically, a woman who had had a hysterectomy sought to gain entrance to the trial. She was told that women were not allowed to participate. By the time the ACLU learned of this incident, the clinical trial had been discontinued because the drug was determined to be ineffective. Similar exclusions have been reported anecdotally. Telephone Interview with Theresa McGovern, Director of the HIV Law Project, in New York, N.Y. (Summer, 1992); Interview with Marion Banzhaf, Director of the New Jersey Women and AIDS Network, New Brunswick, N.J. (Summer, 1992). It is expected that the most egregious exclusions will be minimized with a change in FDA regulations. See McGovern Interview, supra note 20.

21 The first clinical trial that ostensibly focused on women, ACTG 076, actually was designed to look at whether administration of AZT during pregnancy and labor and to the child immediately after birth, could reduce maternal-child transmission rates. See Edward M. Connor, M.D. et al., Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type-I with Zidovudine Treatment, 331 New Eng. J. Med. 1173 (1994). For further discussion of this clinical trial, see infra notes 38-38 and accompanying text.
through an "old boys' network." This network generally is not available to many women and adolescent girls living with HIV. Demographically, women with HIV usually live on little money or in poverty, and therefore depend on a public health care system that is overburdened and not necessarily focused on broadening access to clinical trials.\(^\text{22}\) In addition, related to conditions of poverty, women frequently need assistance with transportation, and more importantly, child care, to participate in clinical trials.\(^\text{23}\)

Third, women still have a very difficult time obtaining access to drug treatment programs.\(^\text{24}\) Chavkin\(^\text{25}\) notes the nationwide lack of drug treatment in general and in particular for women who are pregnant or mothers of small children:

Out of the 24 states that have had criminal prosecutions of women for drug use during pregnancy, only one of them have [sic] any treatment available at all, and only two of them give pregnant women priority access to drug treatment.

Frequently, such drug treatment programs are geared to heroin addiction, rather than to crack, which has had particular impact on women. In addition, programs rarely accept pregnant women, are hesitant to accept women with HIV, and make no provisions for child care — even though one's children can provide significant motivation for breaking an addiction, and the fear of having one's children placed in foster care can serve as a significant deterrent from seeking drug treatment services.\(^\text{26}\)

Fourth, we still have not developed sufficient support for women living with HIV for whom HIV is a family-based concern. For example, in many states, inadequate means exist for a woman to arrange properly and comfortably for the care of her children for the time if and when she becomes less able to care for them.\(^\text{27}\)

\(^\text{22}\) Ironically, some physicians refer low-income patients to clinical trials as a means of obtaining either improved health care or access to drugs that otherwise would not be financially available. C.J. Rubin & M. Barry, Primary Care and Clinical Trials in HIV Disease: Should Primary Care Providers Recruit for AIDS Trials?, 6 AIDS CLINICAL CARE 36, 38-40 (1994).

\(^\text{23}\) Denenberg, supra note 9, at 73; Kim Christensen, How Do Women Live?, in WOMEN, AIDS AND ACTIVISM 5, 7 (The ACT UP/New York Women and AIDS Book Group, 1990).

\(^\text{24}\) See Connor et al., supra note 21 at 1173.


\(^\text{26}\) Id. at 8-9.

\(^\text{27}\) Cooper, supra note 15; Lauren Shapiro, Legal Concerns of Women with HIV Infection, in PRIMARY CARE OF WOMEN AND CHILDREN WITH HIV INFECTION 259 (Patricia Kelly et al. eds., 1995). Specifically, without statutory or regulatory authorization for the establishment of a "standby guardianship," women frequently must choose between giving up custody before they become ill or die without having settled matters, potentially leaving their children's future care at-risk.
Finally, to this laundry list, must be added issues of concerns of violence. As reflected in the program and submitted abstracts at the 1995 HIV Infection in Women Conference and elsewhere, only now are we beginning to understand the impact of women's fear of violence on their decision to be tested, to disclose their status to their partners, or to insist on engaging in risk reduction with their sex or drug-using partners.

Although a plethora of additional problems and obstacles face women living with HIV/AIDS, I will turn here to the issue of mandatory HIV testing of pregnant women and newborns.

PART II - MANDATORY TESTING OF PREGNANT WOMEN AND NEWBORNs: A PARADIGM FOR THE DEVELOPMENT OF DAMAGING PROGRAMS AND POLICIES

MEDICAL BACKGROUND

Increasing attention to maternal-infant HIV transmission, particularly in light of ACTG 076, a clinical trial indicating that adherence to an AZT regimen may reduce such transmission, means that there will be increasing calls for mandatory testing of newborns, delivering women, and pregnant women. Indeed, legislation has been introduced in New York, Illinois, Michigan, Pennsylvania, Florida, among other states, and the U.S. Congress, that would result in the mandatory testing of newborns or pregnant women. One must assume that the purpose of mandatory testing of pregnant women would be to "encourage" women to take AZT during pregnancy as a means of reducing transmission rates and that the purpose of mandatory testing of newborns would be to encourage use of PCP prophylaxis and other treatments. As will be addressed in greater detail infra, incidents involving coercive counseling, testing, and treatment already have arisen and raise concerns to be considered in the development of HIV counseling and testing policy.

The discussion must begin with an examination of relevant medical background. We know, for example, that the maternal-

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29 Connor et al., supra note 21. See also infra notes 33-36 and accompanying text.

30 As of this writing, no State has adopted mandatory HIV testing of pregnant women or newborns. Rather, many States have begun to implement mandatory HIV counseling programs, with the option to test, thereby benefiting pregnant and delivering women and their newborns.
Infant HIV transmission rate is approximately twenty-five percent.\textsuperscript{31} Preliminary data from clinical trial ACTG 076, announced in February 1994, indicate the potential to reduce the vertical transmission rate by as much as sixty-seven percent.\textsuperscript{32} Preliminary investigation indicated similar low levels of birth defects and mortality in the newborns given AZT and those given a placebo. But, it is not yet possible to know the long term effects of AZT on children (e.g., with regard to growths, cancers, or other medical complications) or women (e.g., with regard to AZT resistance).\textsuperscript{33}

It is important to note that this trial began in the context of significant community concern that adequate protections for women were not put in place and that the trial was not sufficiently well-conceived to achieve its goals. For example, it was only after preliminary reports from the trial were announced, and after much community agitation, that researchers agreed to examine the long-term impact of AZT use during pregnancy among women trial participants; initially, follow-up studies were to focus solely on the newborns.

In addition, it is noteworthy that the significantly reduced transmission rates experienced in the trial are not expected to be fully replicated when women are faced with tangible concerns not present in the trial context, such as limited access to health care. Further, because the trial involved women in good health, with CD4 counts averaging above five hundred, it is not known whether the protocol will be effective for women with more advanced HIV

\begin{thebibliography}{9}
\bibitem{31} New York State AIDS Advisory Council, \textit{supra} note 16; McIntosh & Burchett, \textit{supra} note 16. Although virtually all newborns of HIV-infected women will test positive for HIV antibodies for the first 12-18 months of life, this actually reflects the transmission of the mother’s HIV antibodies to the child. New testing technology can determine whether a child actually is infected, or merely is carrying maternal antibodies, by the age of three to six months. In fact, only 20-25\% of children born to HIV-infected women (in the U.S.) actually are infected with HIV.

\bibitem{32} Approximately 477 women were enrolled in ACTG 076. Women were divided into two groups: those given AZT and those given a placebo. The drug/placebo was administered orally during the second and/or third trimester of pregnancy and intravenously during delivery; in addition, the newborn received the same substance as its mother for the first six weeks of life. In the placebo group, the transmission rate was 25.5\%; in the AZT group, the transmission rate was 8.3\%. Connor et al., \textit{supra} note 21, at 1173.

\bibitem{33} Connor et al., \textit{supra} note 21. ACTG 219, “Pediatric Late Outcomes Protocol,” will monitor pediatric participants’ use of ACTG 076 “for the possible development of unknown late effects of the study treatment” through age 20. Memorandum from Jack Moye, Jr., MD, Pediatric, Adolescent and Maternal Branch, Center for Research for Mothers and Children, National Institute of Child Health and Human Development, National Institutes of Health, to the members of the Northern Manhattan Pediatric AIDS Demonstration Project and the HIV Center for Clinical and Behavioral Studies 5 (Apr. 6, 1994). The memo was prepared for a meeting on Ethical, Legal and Policy Implications of Recent Findings on the Prospect of Reducing the Transmission of HIV from Pregnant Women to Their Babies, sponsored by the HIV Center for Clinical and Behavioral Studies, Columbia Univ. School of Pub. Health and AmFAR (the American Foundation for AIDS Research).
\end{thebibliography}
illness. To we also do not yet know the usefulness of the protocol for women with previous use of AZT or for women with AZT-resistant virus. Moreover, it is not known which part of the protocol, which involved the intake of AZT at three different points — gestation, delivery, and after birth — was effective in helping to reduce transmission. Finally, we must discover any effect on transmission of vitamin A — a relatively accessible and affordable substance — viral load, and other factors, and provide that information to HIV-positive women considering pregnancy and delivery options.

The Socio-Political Landscape

Because the women primarily affected by HIV are likely to be low-income women of color — women traditionally visited with undue coercion regarding reproductive choice and forced sterilization — the political landscape of how the "lessons" of ACTG 076 will be implemented must be subject to close scrutiny. For example, although the Public Health Service recently has issued guidelines on the counseling of HIV-positive women on the use of AZT in pregnancy, and now with regard to testing and counseling.

34 Note, however, that women with lower CD4 cells may choose to take AZT because of their own declining CD4 count.
35 Connor et al., supra note 21.
36 A study in Blantyre, Malawi, in south central Africa, conducted by Richard Semba, MD, Johns Hopkins School of Medicine, and researchers from Malawi, suggest that vitamin A deficiency is associated with an increase of three to four times the risk of mother-to-child transmission of HIV and a higher infant mortality rate [hereinafter Semba study]. In the study, 93.3% of infants born to the mothers most deficient in vitamin A died in the first year of life. Only 14.2% of the children born to the mothers with the healthiest vitamin A levels died within a year. Vitamin A stores are depleted during birth and pregnancy, and a shortage of Vitamin A weakens an already compromised immune system. See Deficiency Linked with Increased HIV Transmission/Mortality, AIDS Weekly, Feb. 20, 1995, at 13; Tan Sheet, 3 F.D.C. REPORTS 38 (1995); Blue Sheet, 37 F.D.C. REPORTS 11, at 11-12 (1994). In a press briefing, Dr. Semba stated that, "This study raises the possibility that giving daily vitamin supplements to HIV-infected women during pregnancy may reduce the transmission of HIV from mother to child and may reduce mortality of both mother and infant. . . . It is now an urgent issue and unanswered question whether something as simple as vitamin A, which costs two cents per capsule, may be an appropriate therapy during HIV infection." See Blue Sheet, 38 F.D.C. REPORTS 14, 14-15 (1995).
38 Helen Rodriguez-Trias, Presidential Address at the 121st annual meeting, American Public Health Association (Oct. 25, 1993). See also Dorothy E. Roberts, The Future of Reproductive Choice for Poor Women and Women of Color, 14 WOMEN'S RTS. L. REP. 305 (Spring-Fall, 1992).
there remains concern that health care workers may attempt to coerce women into taking AZT, disregarding a perhaps well-considered decision whether to take the drug.\textsuperscript{41} Inversely, there is concern that women who wish to have access to the 076 AZT regimen during pregnancy will have limited access to treatment, much as they already may have limited access to care.\textsuperscript{42}

Although some are placing great emphasis on the importance of the increasing numbers of women who know their serostatus, and although it is important that women have the option of learning their serostatus, the manner in which this option is presented is even more important. First, many more women may already know their status than are perceived by health care providers; they may choose not to self-disclose because they fear discrimination, stigma, or breaches of confidentiality. Second, women, like men, may choose not to know their serostatus because of the many extant barriers to testing, including ongoing fears of breaches of confidentiality, insufficient access to care and services for those who test positive, and continuing discrimination against people (and families) with HIV.\textsuperscript{43}

As we have seen throughout the epidemic, mandatory testing programs frighten people away from services. For example, during the two years the state of Illinois required HIV-antibody testing of people seeking marriage licenses,\textsuperscript{44} approximately forty-thousand people left the state to get married elsewhere.\textsuperscript{45} When New York City required newborns to be screened for drug metabolites and started a policy of automatically initiating procedures to remove children testing positive from their mothers, there was a sig-

\textsuperscript{41} Institute for Family-Centered Care, Focus Group on ACTG, Preliminary Report (1994). There already have been reports of health care practitioners attempting to involve child welfare agencies when a mother has refused AZT for her newborn. Presentation of Theresa McGovern to the Ad Hoc Committee on AIDS of the Assoc. of the Bar of the City of New York. As will be discussed infra notes 54-73 and accompanying text, there is neither medical nor legal support for such actions. See also Editorial, Zidovudine [AZT] for Mother, Fetus, and Child: Hope or Poison?, 334 THE LANCET 207 (1994).

\textsuperscript{42} Landesman \& Holman, supra note 5, at 26.

\textsuperscript{43} In a 1990 report, the ACLU concluded that "HIV-related discrimination occurs all over America, cutting across lines of race, gender, ethnicity and sexual orientation; it affects a wide spectrum of people ranging from those with full-blown AIDS to those helping to take care of them; and it is on the rise." ACLU AIDS Project, Epidemic of Fear: A Survey of AIDS Discrimination in the 1980s and Policy Recommendations for the 1990s 1 (1990). The ACLU's nationwide survey also indicated that such discrimination often is experienced in areas crucial to survival, including insurance, housing, and access to care and government benefits.

\textsuperscript{44} Ill. Rev. Stat. § 5-204, as amended by Ill. Pub. Act 86-884 (Sept. 11, 1989).

nificant increase in the number of babies not taken home from the hospital; women feared prosecution or assumed that their children would be taken from them regardless.\textsuperscript{46} Finally, it is worth noting that disproportionately high testing rates occur at anonymous HIV-antibody sites located across the border from states that require testing sites to report the names of all people testing HIV-positive.\textsuperscript{47}

By strong contrast, when HIV-related counseling is offered universally in pre-natal and delivery settings, and testing is voluntary, confidential, and linked to available care and services, pregnant and parturient women overwhelmingly consent to testing. For example, at Harlem Hospital in New York City, more than ninety percent of counseled women consent to testing;\textsuperscript{48} similar proportions are found in Cook County Hospital in Chicago,\textsuperscript{49} Johns Hopkins in Baltimore,\textsuperscript{50} Grady Hospital in Atlanta,\textsuperscript{51} and at numerous other sites.\textsuperscript{52} Notably, the patient population at each of these hospitals is overwhelmingly poor and African-American, women who stereotypically — and falsely — are perceived as being "non-compliant" or "difficult" patients. Yet, consent-to-testing rates and rates of bringing HIV-positive children and their mothers into care are consistently high. In other words, these programs work.

**LEGAL ANALYSIS**

Finally, it is important to assess the legal prospects of a mandatory testing program. Many legal experts believe that such

\textsuperscript{47} AIDS ACTION FOUNDATION, SHOULD HIV TEST REPORTS BE REPORTABLE?: A DISCUSSION OF KEY POLICY QUESTIONS (1993).  
\textsuperscript{48} NEW YORK STATE AIDS ADVISORY COUNCIL, supra note 16.  
\textsuperscript{49} Interview with Mardge Cohen, MD, Director, Women and Children's HIV Program, Cook County Hospital, in Chicago, Ill. (July 1994) [hereinafter Cohen Interview].  
\textsuperscript{50} According to Dr. Jean Anderson at Johns Hopkins Hospital, Baltimore, "if it's [testing] presented in a reasonable way, people are going to accept screening; to force them into it is only going to drive them away and alienate them." More than 90\% of women who receive obstetric care at the clinic at Johns Hopkins voluntarily agree to be tested. Christine Gorman, *Moms, Kids, and AIDS*, Time, at 60 (July 4, 1994).  
\textsuperscript{52} At the HIV Infection in Women Conference, Dr. Judith Cohen and Dr. Carmen Zorilla each identified a number of sites, particularly in California and in Puerto Rico, at which similarly high consent-to-testing rates were observed. *See* HIV Infection in Women Conference, supra note 18.
programs likely would be found to violate many of a woman’s constitutional and statutory rights. These rights include:

**The Right to Privacy.** A woman’s right to privacy includes the right to bodily integrity,

53 including the right to make personal decisions regarding medical tests and treatment.54 The state cannot intrude on a person’s right to privacy in the absence of a compelling state interest; moreover, any intrusion must be “narrowly tailored” to meet that interest.55 The right to privacy also includes one’s interest in avoiding disclosure of personal matters, including HIV status.56 A number of states, including New York, have enacted statutes creating a level of HIV-related confidentiality that surpasses general medical confidentiality.57 The protections regarding bodily integrity and personal decision-making are most philosophically appropriate and availing.

**The Right to Informed Consent.** Although this right specifically is found in many state HIV-specific statutes regarding consent to testing and confidentiality, its underpinnings can be found in the broader constitutional principles of privacy and due process which provide that individuals are imbued with a right to bodily integrity.58 The right to informed consent includes the right to refuse or forego medical treatment59 and remains intact even if the intrusion is for the benefit of another, including a fetus.60 Moreover, the state may not promote an identified interest in potential life by providing misleading information; rather, the “validity of a state’s informed consent requirement rests on its interest in ensuring that the mother’s consent is fully informed.”61

54 Id.; Roe v. Wade, 410 U.S. 113 (1973); Thornburgh v. Am. College of Obstetricians and Gynecologists, 476 U.S. 747, 770 (1986) (holding that a woman cannot be forced to undergo any procedures that increase the risk to her life and health for the sake of her fetus).
57 N.Y. PUB. HEALTH LAW §§ 2780(7), 2782.
60 See In re A.C., 573 A.2d at 1235 (emphasizing that fetus does not have rights superior to the mother); Bonner v. Moran, 126 F.2d 121, 122 (D.C. Cir. 1941) (requiring consent for “a surgical operation not for the benefit of [that] person but for another”). See also Thornburgh v. Am. College of Obstetricians and Gynecologists, 476 U.S. 747 (1986).
61 Correspondence from the Center for Reproductive Law and Policy to Members of the New York State Legislature, May 16, 1994 (citing Akron v. Akron Center for Reproduc-
At least one court has acknowledged that testing for HIV without informed consent "would actually have a negative impact on the epidemic because those individuals will be deterred from seeking medical treatment. . . . [I]t will create an atmosphere of distrust in the physician and patient relationship. . . ."62 For each of these reasons, the exclusion of pregnant or parturient women as a class from the parameters of informed consent protocols, or, a reduction in the protections afforded by such protocols, would be difficult to defend.63

The Right to Make Medical Decisions on Behalf of One's Children. This right, also essentially part of one's rights to privacy and due process, lies in parents' interest in raising their children without undue state interference.64 The implicit presumption that parents will act in the best interest of their children generally is upheld, unless there is some indication that a parent is refusing life-saving or curative treatment to the child — a concept not so applicable with regard to a fetus.65 Although prophylaxis is available that may help prevent PCP in infants, it is neither uniformly effective nor universally implemented.66 As important, the state first would have


63 Attempts to mandate testing of pregnant or delivering women or their newborns — or to reduce counseling and consent requirements prior to testing — under the guise of an emergency exception to the informed consent doctrine similarly is unavailing. See, e.g., N.Y. St. Reg., I.D. No. HLT-50-95-00009-P (to be codified at N.Y. Comp. Codes R. & Regs. tit. 10) (proposed Dec. 13, 1995). First, virtually any HIV-related health emergency can be treated without an HIV diagnosis. The presenting symptom is attended to, and, if appropriate, a presumption of HIV infection is made. Counseling to encourage HIV testing is continued. Still, care cannot be denied on the basis of an individual's refusing to be tested. Second, newborns tend not to be at risk for opportunistic infections, specifically PCP pneumonia, until age 3-6 months; the CDC recommends that PCP prophylaxis not commence until age one month. Therefore, a substantial window exists for continued HIV-related counseling of the mother following the birth of the child. Third, should a parent not be competent to consent or refuse to consent to testing, the care provider has a number of options. For example, if the child has been removed to foster care, the consent process is likely to change significantly, facilitating access to testing should the state find it necessary. In another example, if a parent acts in a manner perceived by careproviders to be not in the child's best interest, the provider can take advantage of existing legal mechanisms to ensure that the child receives appropriate care. For each of these reasons, particularly considered in light of the overwhelming consent-to-testing rates found when care and confidentiality are assured, it is nigh impossible to construe an appropriate "emergency" exception to existing consent requirements prior to administering an HIV-related test.


66 For example, infant medical records in New York City revealed that of 29 seropositive infants born who were later diagnosed with PCP, only seven had received prophylaxis.
the obligation to seek the consent of the mother, through counsel-
ing, with regard to both testing and treating the child. As has been
shown, women consistently consent to testing in this context.

The Right to Equal Protection. As a rule, the government cannot
adopt policies that treat women, as a class, differently from the
manner in which it treats all others, unless it can establish that this
differential classification serves an important governmental objec-
tive and that the discriminatory policy is substantially related to the
state’s articulated goal. The prohibition on treating members of
racial minorities in a discriminatory manner is even more exacting.
Although these are theoretically appealing and sound claims, in
practice, they are least likely to be availing in a court of law.

* * *

Based on the foregoing, mandatory testing HIV programs may
well be found to violate many of a woman’s constitutional and stat-
utory rights. Similarly, it would be highly unethical — and illegal —
to force a woman to take AZT without her full voluntary and
informed consent. First, all women must be counseled with re-
gard to the possible risks and benefits (to herself and her child) of
this potentially toxic treatment. Attendant to the obligation to pro-
vide counseling is the understanding that the patient has the right
to refuse even recommended treatment. This right is not eviscer-

Also, FCP occurs in approximately 30% of newborns receiving prophylaxis. New York
State AIDS Advisory Council, supra note 16, at 16-17. See also B.W. Levin, J.M. Discoll,
A.R. Fleischman, Treatment Choice for Infants in the Neonatal Intensive Care Unit at Risk for
HIV status may negatively affect provider decision-making about treatment for non-HIV-
related conditions for critically ill infants, including those not actually infected).

Reed v. Reed, 494 U.S. 71 (1971); see Schlesinger v. Ballard, 419 U.S. 498, 506-07 (1975) (requiring heightened scrutiny because danger that government policies may be
reflective of “archaic and overbroad” generalizations about gender).

Washington v. Davis, 426 U.S. 292, 298 (1976); Loving v. Virginia, 388 U.S. 1, 11
(1967); Wygant v. Jackson, 476 U.S. 267 (1986); see also Richard v. Croson Co., 488 U.S.
469, 493 (1989) (noting the difficulty of distinguishing “benign” or “remedial” classifications
from those motivated by discrimination of race).

69 The currently-proposed regulation in New York State, see supra note 63, designed to
reduce counseling and lessen or eliminate consent procedures for delivering women, is
also subject to significant legal challenge. Indeed, principles of bodily integrity and in-
fomed consent are put at-risk in the proposal. The New York statute regarding HIV test-
ing, see supra note 57, would be effectively vitiated for pregnant and delivering women. As
explained supra note 63, the exceptions for testing in an “emergency” are inconsistent with
both medical knowledge concerning HIV and existing legal standards. Moreover, to the
extent such “emergency” testing is predicated on perceptions of risk, the state is likely to
Dist. LEXIS 19878, at *27 (M.D. Ala. Oct. 7, 1993). Finally, based on the actual mechanism
for testing and processing test results, the proposal runs afield of state and federal statutory
protections found in the respective human subjects laws.

tion into a nonconsenting person's body represents a substantial interference with that
person's liberty").
ated for pregnant women. In fact, absent extraordinary circumstances — not present in this context — a woman legally cannot be forced to accept medical intervention she does not wish to have.\(^{71}\)

It would be inappropriate to yield to the expectation of some that every HIV-infected pregnant woman should take AZT regardless of her own risk assessment for taking this potent drug.\(^{72}\)

**Perspectives of Women Living with HIV**

Regardless of the construct of the analysis of mandatory testing programs, one always must return to the reality of life for the HIV-infected woman. One cannot ignore the anecdotal reports of numerous HIV-positive women that implementation of a mandatory testing program would result in more women avoiding pre-natal care and avoiding hospital deliveries;\(^{73}\) this likely would be particularly true for immigrant and undocumented women, for whom a positive HIV-antibody test may provide grounds for deportation, as it is grounds for barring non-citizen aliens entry to the United States.\(^{74}\) We also cannot ignore that implementation of a mandatory testing program would make the receipt of health care contingent on an individual’s being tested for HIV, a principle uniformly rejected until now. Indeed, it seems odd to establish a barrier requiring a pregnant woman to be tested as a pre-requisite for getting health care, including pre-natal care.

Through a mandatory testing program, the state would insert itself between the mother and her child with the message that the state is a better caretaker than the mother. This mode of state intervention sets the stage for broader intrusions of the government into the lives of women and their children. Concern over such intrusions, particularly the removal of children to foster care, historically has worked to discourage women from seeking services that might otherwise be beneficial to them or their families.\(^{75}\) Also outstanding is the concern that a state might prosecute HIV-infected women for transmitting HIV, in much the same way that women have been charged with violating drug statutes when their children

\(^{71}\) *In re A.C.*, 573 A.2d 1235, 1246 (D.C. Cir. 1990).

\(^{72}\) *Institute for Family-Centered Care*, *supra* note 41.


\(^{75}\) Breibtart et al., *supra* note 46.
are born with drug metabolites;\textsuperscript{76} indeed, such HIV-related prosecution already is at least technically possible in four U.S. states.\textsuperscript{77}

\textbf{A Policy Proposal}

Based on the foregoing analysis, or elements thereof, many experts have concluded that access to care for women and their children is best facilitated through universal HIV-related education and counseling, with an offer of testing.\textsuperscript{78} Moreover, although it is useful for a woman to learn her serostatus after delivery, learning it before she becomes pregnant or during pregnancy will give her a wider range of prevention, treatment, and reproductive options. And, although early identification is important, alone it is not enough; counseling and testing must be linked to care, services, and confidentiality to have value.\textsuperscript{79} Moreover, as we encourage routine counseling with the offer of testing, this must not be interpreted as an implicit invitation to mandatory testing. Finally, we must ensure that the quality of care a woman receives is not linked to her decision to be tested or not tested.

This is not a matter of babies' rights versus women's rights: we cannot forget that perhaps the most important factor in a baby's health care is the mother.\textsuperscript{80} By building policy on the borne-out societal assumption that a pregnant woman, including an HIV-positive pregnant women, is interested in giving birth to a healthy baby, we foster, rather than undermine, the critical provider-patient trust relationship.\textsuperscript{81} This more comprehensive approach both respects

\textsuperscript{76} Telephone Interview with Nina Lowenstein, Aaron Diamond Fellow, Center for Reproductive Law and Policy (Apr. 1995).


\textsuperscript{78} This approach has been endorsed by the American Medical Association, American Nurses Association, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, American Public Health Association, and the Institute of Medicine, among others. \textit{See also} preceding discussion concerning the success of universal counseling and voluntary programs.

\textsuperscript{79} Having a testing program in place does not ensure the availability of a treatment and care program. Wendy Chavkin, MD, MPH, Testimony to the New York State Advisory Council Subcommittee on Newborn Screening (Nov. 8, 1995). \textit{See also} New York State AIDS Advisory Council, \textit{supra} note 16, at 16-17 ("Among infants in New York City identified as HIV-positive prior to diagnosis . . . 22 of 29 had not received prophylaxis").

\textsuperscript{80} Indeed, when care for newborns replaces care for both mother and child, a woman's role narrows falsely to that of carrier and deliverer of newborn.

\textsuperscript{81} If it is determined that a parent is acting in a manner that would constitute abuse or neglect, mechanisms currently exist in the law for health care providers, child welfare agencies, or other appropriate parties to pursue means of improving the welfare of the child, including, if necessary, the removal of the child from the home.
individual autonomy and protects the public health — benefiting both mother and child.\textsuperscript{82}

It is disturbing that proposals to mandatorily test newborns and pregnant women are being considered seriously by many state legislatures. In fact, it is alarming when any arm of the government (legislative, executive, or judicial) chooses to pursue a path of policy development that not only has not been endorsed by, but in fact has been rejected outright, by virtually every well-respected medical, scientific, and public health organization.\textsuperscript{83}

Most policy makers seeking to implement mandatory testing programs assert that there is a countervailing and compelling reason to ignore this virtual medical consensus: the welfare of the children. Yet, implicit in the argument that we must mandate testing to preserve the health and well-being of our children is the belief that mothers will not act to best preserve the welfare of their children. In most circumstances, this notion would have family-rights advocates and many others up in arms. Therefore, we must question why the response of some policy-makers to the development of critical medical interventions is to seek to eliminate or decrease the HIV-related counseling and consent, essentially reducing the degree of information and autonomy afforded pregnant and delivering women. We also must question the apparent ease with which policy-makers are willing to establish a different degree of HIV-related consent from pregnant and delivering women than is required from all other people.

Perhaps boldly, I suggest that this aberration may well adhere to the demographics of the epidemic. Advocates for mandatory testing frequently appear to yield to an assumption that HIV-infected women — the vast majority of whom are poor or have low incomes, are women of color, and some of whom have a history of drug use — do not adhere to an otherwise intact societal assumption that women will act in their children's best interest. Ironically, as noted above, when women are provided with information — when they are told of the advantages and the disadvantages of being tested including non-biased information about possible intervention and treatment, and when care and services are available to them — women overwhelmingly consent to testing. And, it is in

\textsuperscript{82} \textsc{New York State AIDS Advisory Council}, \textit{supra} note 16; \textsc{Gorman}, \textit{supra} note 50; \textsc{Lindsay, Determinants}, \textit{supra} note 51; \textsc{Lindsay, Screening}, \textit{supra} note 51; \textsc{Centers For Disease Control, Questions and Answers}, \textit{supra} note 51; \textsc{The Association of the Bar of the City of New York, Prenatal/Newborn HIV Testing (1994)}; \textsc{Cohen Interview, supra} note 49; \textsc{HIV Infection in Women Conference, supra} note 18.

\textsuperscript{83} \textsc{See supra} note 66.
this context that both they and their children are brought into critical and appropriate HIV-related health care.

Therefore, I fear false perceptions concerning race, class, HIV, and the role of health care providers, underlie good-hearted, but misguided policies concerning mandatory HIV testing of pregnant women and newborns. In almost every other context, as a society, we support the provision of information to the patient and we support patient and familial decision-making autonomy. Yet, here, proponents of mandatory testing seek to carve out an exception to these well-founded presumptions — presumptions that have been repeatedly validated in the context of HIV counseling, testing, and care.\[^{84}\] There is no doubt that medical interventions are critically important developments in our efforts to reduce the prevalence and virulence of HIV/AIDS. However, as a society, we must remain vigilant that policies are developed in a manner that facilitates access to these interventions, if they are desired.

**PART III - CONCLUSION AND STEPS FOR THE FUTURE**

The construction of valid, useful, respectful policies concerning women living with HIV/AIDS necessarily requires that our policy-makers, be they legislators, judges, government administrators, or hospital administrators, listen more attentively to the voices of these women. Indeed, a review of our history and an analysis of our present circumstances compel but one conclusion: despite the soaring numbers of women infected with HIV,\[^{85}\] policy frequently is developed without the input of those who will be most affected by its development. The invisibility of women living with HIV must be corrected if we are to have hope for the development of sound AIDS policy. Consider the following: had women been recognized earlier on in the epidemic, we would have had the opportunity to develop more-effective prevention and treatment mechanisms; we would have had a chance to develop more-appropriate clinical trials; we would have given more people a chance to rightfully obtain

\[^{84}\] New York State AIDS Advisory Council, *supra* note 16; Gorman, *supra* note 50; Lindsay, *Determinants, supra* note 51; Lindsay, *Routine, supra* note 51; Centers for Disease Control, *Questions and Answers, supra* note 51; Semba Study, *supra* note 56; HIV Infection in Women Conference, *supra* note 18.

\[^{85}\] The World Health Organization ("WHO"), focusing its attention on the worsening impact of HIV disease on women, has predicted that by the end of the 1990s the number of women infected with HIV will be double what it was at the beginning of the decade. WHO estimates that AIDS will kill at least 2 million women this decade. U.S. Dep't Health & Hum. Serv., *AIDS Among Women to Double by 2000*, 106 U.S. Pub. Health Rep. 216 (1991).
government benefits that others could more easily obtain. Fundamentally, the epidemic would not have developed as it has.

Many of our policymakers are tired of the epidemic. They want it to go away. So do we. But making the epidemic go away does not mean shunning people who have HIV/AIDS. Instead, it means bringing all of us closer together: listening, talking, building trust, and building policies and programs that will help, not hurt, women living in the HIV/AIDS epidemic.