Test Wars: Mandatory HIV Testing, Women, and Their Children

Michelle Oberman
Santa Clara University School of Law, moberman@scu.edu

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I. Introduction

The governmental power to act in defense of the public's health is vast, and yet, when it comes to fighting diseases, there are precious few weapons in its arsenal. Principal among these weapons is the power to combat epidemics by undertaking search and destroy missions in the general population. In the past, these missions have entailed the identification and treatment (or, in the absence of effective treatment, isolation) of infected individuals. For those who adhere to the belief that the government should not refrain from exercising the full range of its police powers whenever the public's health is threatened, the official response to the HIV epidemic has seemed like an incomprehensibly long stall tactic.

Ever since the early 1980s, when HIV first was identified, there has been a persistent debate over the exercise of the traditional public health power to identify infected individuals by screening the population or by testing selected subgroups. In virtually every context, advocates of non-anonymous mandatory HIV testing have been opposed and defeated by a broad coalition of opponents. In recent years, however, that coalition has begun to fray, and as a result, the debates over mandatory testing have intensified. The fragmentation of the anti-testing coalition has been precipitated by issues relating to the perinatal transmission of HIV. In particular, the 1994 discovery that HIV-infected pregnant women who take zidovudine ("AZT") are less likely to transmit the virus to their offspring, has led to widespread efforts to institute the mandatory HIV testing of pregnant women.

This Article seeks to situate the debates over mandatory testing in the broader context of public health policy by evaluating the underlying factual and policy assumptions that have informed both sides of the debate through-
out the epidemic. This analysis elucidates clear, if unexpected, answers to the challenges posed by those who claim that the possibility of preventing HIV infection in fetuses ought to alter the consensus against mandatory HIV testing with respect to pregnant women. It also casts considerable doubt upon the legitimacy, if not the legality, of the broadly construed police power to compel individual compliance in the name of the public’s health.

II. A Brief History of the HIV Test Wars

In 1985, two tests became available for identifying individuals who had been exposed to HIV. Almost immediately, the public health community engaged in a debate over mandatory HIV testing. The debate was informed by the following four underlying factual assumptions—assumptions whose validity persisted until November, 1994:

1. HIV infection is incurable and fatal, and the only thing the health care system can offer those infected with the virus is counseling and medicine to slow the inevitable, deteriorative process;
2. HIV is a virus transmitted by a limited number of well-established, private, intimate and/or illegal behaviors;
3. The diagnostic test for HIV is good, but not perfect, at identifying those who are infected and at excluding those who are not infected;
4. HIV is a stigmatizing condition, and those who test positive may experience negative consequences not only in terms of health status, but also in terms of personal and professional well-being.

In light of these assumptions, two opposing positions emerged: that of the “test zealots,” who advocated testing in order to identify infected individuals, and that of a broad coalition of “anti-coercionary forces,” who opposed

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1. Antibody tests (EIA and WB) do not always reflect the infection status of the test subject. There may be both false positive and false negative test results. False positive tests arise from a variety of circumstances: testing errors in handling and storage, biological errors involving other retroviral infections, and autoimmune diseases. False negatives are a more common problem than false positives. A person actually infected with HIV may nevertheless test negative because she has yet to develop HIV antibodies. Upon becoming infected, an individual may take anywhere from three weeks to three months (or, in rare cases, as long as 3 years) to develop antibodies. Several tests that minimize the false negative problem by identifying the virus, rather than the antibodies, are available. However, they are very sophisticated and expensive laboratory techniques that are difficult to perform accurately in a high-volume, clinical setting. See Helena Brett-Smith and Gerald H. Friedland, *Transmission and Treatment*, in Scott Burris, et al, eds, *AIDS Law Today: A New Guide for the Public* 31-32 (Yale 1993).


Obviously, many people fall somewhere in between these two positions. I have elected to address the topic of mandatory testing by focusing on the opposing positions because this dichotomization permits a thorough, critical analysis of the issue.
virtually any form of mandatory non-anonymous HIV testing that led to the identification of infected individuals.

The early HIV test zealots argued that mandatory testing constituted the best means of protecting the public's health because it was the only means by which the public might be forewarned against those individuals who carried the disease. Armed with knowledge of an individual's HIV status, members of the public could avoid contact with infected individuals, thus protecting themselves from acquiring the fatal virus. Of course, testing alone would not provide any protection to the general public—some further action would be necessary in order to halt the virus's progression.

Proponents of mandatory testing had several suggestions as to how this might be accomplished. First, there were those who favored the disclosure of information regarding HIV status—whether to selected individuals, such as those known to engage in one of the known modes of viral transmission, or to the public generally (giving rise to arguments favoring tattoos or "i.d. cards" for infected individuals). A smaller number of test zealots favored isolating HIV positive persons from society—much like those infected with tuberculosis had been relegated to sanitoria for the duration of the infectious periods of their illnesses.

The anti-coercionary coalition countered the test zealots with a variety of arguments. First, there were arguments based upon the validity of the HIV test itself. Even assuming that every individual could be tested—an assumption that is wholly untenable given that public health workers have never achieved universal compliance when testing for any disease—even when they had free

3. This concern took on various forms, from proposals to screen prostitutes, so that they might inform their customers of their HIV status, to proposals to screen all persons seeking marriage licenses, since presumably they would shortly begin engaging in high-risk behavior. Address by Dr. Jonathan M. Mann, AIDS: The Future of the Pandemic (Nov 30, 1995) (Delivered to the Ninth Annual Meeting of the International AIDS Education Society, Jerusalem, Israel. Unpublished manuscript on file with author.).

4. Note that police occasionally employ tattoo-like means to identify HIV positive individuals. See Jerry Thomas, Feeling the Sting of Heroin, Chi Trib 2:1 (Oct 10, 1995) (Photograph by Walter Kale, depicting an officer marking the arm of an individual arrested on a drug-related offense to indicate that the suspect is HIV positive). See generally, Jay M. Kohorn, Petition for Extraordinary Relief: If the LaRouche AIDS Initiative had Passed in California, 15 NYU Rev Law and Soc Change 477, 481 (1987) (describing Proposition 64, a failed California ballot initiative that would have mandated state reporting of all persons with HIV under the state's communicable disease laws, thereby triggering the state's public health quarantine powers and restricting access to schools and restaurants for HIV infected individuals).

5. Ironically, the only model for those favoring these highly restrictive measures was that of Cuba, which adopted a policy of forcible isolation for HIV-infected individuals. See Ronald Bayer and Amy Fairchild-Carrino, AIDS and the Limits of Control: Public Health Orders, Quarantine, and Recalcitrant Behavior, 83 Am J Public Health 1471 (1993). See also, Michael L. Closen and Mark E. Wojcik, International Health Law, International Travel Restriction, and the Human Rights of Persons with AIDS and HIV, 1 Touro J of Transnational L 285, 289 (1990).
Roundtable treatment rather than stigma to offer those who were infected—it was far from obvious that the public would be fully protected by the dissemination of these test results. The nature of an antibody test was to identify those who had been exposed to the virus at some time in the past, and whose bodies had developed antibodies against the virus. Because antibodies develop slowly, some individuals who test negative for HIV antibodies are in fact infected with, and capable of transmitting, the virus. Moreover, the validity of even a truly negative HIV test is of limited duration, because an individual who tests negative for HIV but continues to engage in any of the behaviors associated with transmission (such as sexual intercourse) might subsequently acquire the virus at any time. Finally, the HIV antibody test’s accuracy, particularly in populations otherwise at low-risk for HIV, is problematic at the opposite end of the spectrum in that it yields a disturbing number of false positive results. Thus, any form of mandatory testing risks conveying a false sense of security, while at the same time stigmatizing perfectly healthy members of the public.

Second, the anti-coercionary coalition argued that, in an environment in which HIV remains both incurable and stigmatized, mandatory testing becomes a punitive public health strategy. Outside of an altruistic desire to protect others, those most likely to test positive have few conceivable motives for being tested. They may therefore choose to avoid contact with any system, including the health care system, that would force them to be tested. This would in effect drive the HIV epidemic underground, and deprive health care workers of the opportunity to counsel at-risk individuals about modes of transmission, and about ways in which they might avoid behavior linked to HIV infection.

The final, and perhaps most dispositive of the arguments against mandatory testing proposals was that the cost of these plans was absolutely prohibitive. For example, no one could seriously contemplate a program involving the routine testing and isolation of HIV infected persons—how could society afford it? The same also proved true even for testing programs that lacked any accompanying proposal for isolation or stigmatization. Illinois’s brief attempt to mandate premarital HIV testing is but one example of the high costs of “case finding” through mandated HIV testing. Even the costs of routine tests...


7. The time necessary to develop antibodies ranges from three weeks to three years, although most individuals seroconvert within three to six months following exposure to HIV. Brett-Smith and Friedland, Transmission and Treatment at 32-33 (cited in note 1).

8. Low-risk groups are characterized by a prevalence rate of disease of 0.1% or less. James M. Steckelberg and Franklin R. Cockerill III, Serologic Testing for Human Immuno-deficiency Virus Antibodies, 63 Mayo Clinic Proceedings 373, 373 (1988).


10. The Illinois law was repealed after 20 months. In the first six months after the
HIV screening of well-defined populations that posed clear risks to others, such as hospital patients, seemed wastefully high when one recognized that the indeterminate nature of the test meant that health care workers needed to take precautions against transmission even from patients who tested negative.

Thus, a strategy of voluntarism—encouraging individuals through counseling to ascertain their HIV status and/or to take precaution against transmission—dominated the public health response to the first decade of HIV. Several exceptions were made to the widespread consensus against mandatory non-anonymous testing: the federal government provided for the screening of new recruits to the armed forces; prisoners in federal and many state prisons were tested, as were accused sex offenders; and prior to transplantation and/or transfusion, organs, tissues, or body fluids were screened. At least theoretically, however, none of these HIV tests truly was mandatory, in that those who sought to avoid testing could “elect” not to participate in behaviors that might ultimately cause them to be subjected to testing.

III. The Test Zealots and “Innocent Victims”

Perhaps it was inevitable that society would respond to the fearsome HIV epidemic by distinguishing the “innocent” from the “guilty” victims. True to our Puritanical roots, the innocent victims became those who had acquired the disease “unwittingly,” as through a blood transfusion, rather than through sexual intercourse or other objectionable activity. By the time society was confronted with evidence of perinatal transmission, the lines were easily drawn. HIV infected women, most of whom had acquired the virus through sexual intercourse or injection drug use, were “guilty,” and the fetuses they might law went into effect, only eight people with HIV were discovered among 70,846 individuals who applied for marriage licenses. Many persons applied for marriage licenses in bordering states in order to avoid the costs and risks of testing. Charlotte Silverman, Letter to the Editor, in John R. Dykers, et al, Mandatory Premarital HIV Testing: The Illinois Experience, 263 JAMA 1917 (1990).

11. “Almost every jurisdiction statutorily requires or otherwise endorses the view that HIV testing must be voluntary or that consent be obtained. Although most states require ‘consent,’ ‘informed consent,’ or ‘written and informed consent,’ at the very least the voluntary nature of the procedure must be communicated to the individual.” Note, Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?, 16 Cardozo L Rev 169, 189 (1994). See also, Bayer, 324 New Eng J Med at 1501 (cited in note 2).

12. Major exceptions to privacy rules and laws contain exceptions responsive to genuine, and not so genuine “needs to know.” Examples include: funeral directors, emergency medical technicians, health care workers and mental health personnel. For a detailed discussion, see Scott Burris, Testing, Disclosure and the Right To Privacy, in Scott Burris, et al, eds, AIDS Law Today 115, 124 (Yale 1993).

13. For example, by choosing abstinence, or by choosing activities that might lead to one’s incarceration, etc.

14. In 1990, I was asked by the Illinois Judicial Conference to organize a continuing education program on HIV for state judges. The coordinating committee, made up of many senior judges, indicated that the audience was really only interested in learning about “the innocent victims of AIDS.”
perchance be carrying were, without a doubt, the quintessential innocent victims of the epidemic.

Much has been written about the systematic neglect of women's health in the HIV epidemic, but the one aspect of women's health that has received considerable attention involves women's capacity to transmit HIV.\textsuperscript{15} Whether it be through heterosexual or perinatal transmission, there is no dearth of research on the dangers women pose to men and to fetuses as "vectors" of viral transmission.\textsuperscript{16} Current scientific knowledge suggests that, as vectors of heterosexual transmission, HIV infected women are far less dangerous to men than HIV infected men are to women.\textsuperscript{17} However, there is no question that pregnant HIV infected women pose a risk of transmission to their fetus. Although the actual percentage of babies who contract HIV from their mothers is far lower than it was originally feared to be, as the virus works its way into the heterosexual population, there are growing numbers of babies born with HIV every year.\textsuperscript{18} Estimates for the mid-1990s are that 7000 HIV infected United States women give birth annually, and that approximately 1000-2000 of their offspring will have HIV.\textsuperscript{19} These numbers will undoubtedly increase

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15. See, for example, Taunya Lovell Banks, \textit{Women And AIDS—Racism, Sexism, And Classism}, 17 NYU Rev L & Soc Change 351, 352 (1990). But see 44% of Doctors Report Test for AIDS on Donated Semen, NY Times A23 (late ed Aug 11, 1988). There is one reported case of female to female sexual transmission. However, women who have sex exclusively with women are not currently considered at great risk of HIV infection unless they are injection drug users or have been exposed to HIV positive semen through prior sexual intercourse with a man, or through artificial insemination.

16. It was not until 1994, with ACTG Protocol 076, that researchers consciously enrolled a large number of HIV infected women in an AIDS clinical trial. This study did not involve a long-overdue evaluation of the short- or long-term effects of the various HIV chemo-therapeutic agents on women's health, but rather, the impact that such drugs might have on fetal well-being. Daniel DeNoan, \textit{AZT and Pregnant Women: One Answer, Many Questions}, AIDS Weekly 2 (Dec 19, 1994).

17. Studies have demonstrated repeatedly that the receptive partners have the highest risk. One cause may be that the penetrating partner's body fluids remain deposited. Moreover, rectal penetration may tear mucosal tissues creating increased exposure. See Nancy S. Padian, et al, \textit{Female-to-Male Transmission of Human Immunodeficiency Virus}, 266 JAMA 1664 (1991).

18. Early estimates of transmission ranged from 50% to 80%. As of 1995, most experts estimate that only 25% of the offspring will contract the virus. Studies from Europe demonstrate a 15% transmission rate, and some recent U.S. research involving relatively healthy HIV infected women indicate a transmission rate as low as 13.6%. European Collaborative Study, \textit{Natural History of Vertically Acquired Human Immunodeficiency Virus-1 Infection}, 94 Pediatrics 815, 818 (1994); U.S. Department of Health and Human Services, The Women and Infants Transmission Study (WITS), 109 Pub Health Rep 694-699 (Sept-Oct 1994).

19. Internationally, the picture is far more grim. The World Health Organization estimates that by the end of the century developing countries will account for more than 90% of all people with HIV infection. The worldwide cumulative number of infected women is expected to reach fifteen million by the year 2000. \textit{WHO’s Primer on AIDS}, 111 Pub Health Rep 7, 7 (Jan/Feb 1996). Certain African nations report that 24% of women of reproductive age have HIV. Douwe A.A. Verkuyl, \textit{Practising Obstetrics and
as the epidemic increases among women of reproductive age. Given the rising numbers of "innocent victims," it is not surprising that the temptation to test pregnant women for HIV has proved irresistible for test zealots.

A. NEWBORN SEROPREVALENCE STUDIES

Pressure to institute the mandatory HIV testing of women began in 1993 in response to the Centers for Disease Control's blind seroprevalence study in newborns. This study, which entailed performing anonymous ("needlestick") tests on every infant born in a given locality, yielded invaluable information about the prevalence of HIV in women of reproductive age. Although the HIV tests were performed on infants, the study revealed little about the ultimate HIV status of the newborns, because until they develop their own antibodies, between fifteen and eighteen months of age, babies simply reflect the antibody status of their mothers. Thus, 75 percent to 85 percent of infants who test positive for HIV will actually be virus-free by the time their own immune system is operative. The mothers of those infants, however, are most certainly infected. Thus, the "newborn" seroprevalence study actually was a misnomer—in reality, it was a "women" seroprevalence study.

The seroprevalence studies provided useful, if not critical, information to epidemiologists and health care planners. They documented evidence of the speed and severity of HIV's migration into the female population, and yielded a more accurate estimate of the epidemic, allowing policymakers the opportunity to better allocate health care resources. Despite these laudable results, from its inception the newborn seroprevalence study carried with it two problematic, internally inconsistent ethical dilemmas.

First, in order to obtain accurate information, the newborn HIV screening had to be universal. It therefore was performed on all infants, shortly after birth, and without prior consent from the infants' mothers. Although the test itself was harmless, and thus one might reason that maternal consent to testing her child's blood was not necessary, in reality the test and particularly the test results posed a serious threat to the mother. By administering an HIV test without counseling...
and without even seeking the woman's consent, the study jeopardized a host of fundamental medical ethical principles—autonomy, confidentiality, justice—in addition to all of the public health principles that had been invoked in rejecting earlier mandatory testing proposals.\footnote{23} The only manner in which to insulate women from these risks was to secure absolute anonymity of test results—a goal which is elusive even without numerous constituents vying for the information. Testing women without their consent, simply because they are accessible, by virtue of delivering a child, strips them of the rights to liberty and bodily integrity enjoyed by every other individual in society.

The gravity of this threat to women led the Centers for Disease Control to structure the study with full anonymity—the test results were not linked to individual newborns nor to their mothers. Thus, although the study revealed the actual number of HIV infected babies born in any participating locality in 1994, one could not, on the basis of the data collected, identify the HIV infected infants or their mothers. This situation gave rise to the second ethical dilemma: how can a just society simply release these potentially dying infants to the care of their dying mothers and without informing the mothers or without attempting to care for the infants?

In response to this dilemma, the test zealots renewed their demands for mandatory, non-anonymous HIV testing—this time for newborns. Joining the chorus were some rather surprising voices: legislators who introduced bills requiring the "unblinding" of the CDC study, the New York Times, which called the ethical concerns on behalf of the mothers "theological," and various state branches of the American Academy of Pediatrics.\footnote{24} The new test zealots claimed that the anonymous nature of the CDC study was depriving newborns of early medical intervention and treatment for HIV, and that neither law nor ethics required that a mother’s privacy rights be honored at the expense of her child’s well-being.\footnote{25} Even if the test zealots were correct in their legal analysis, there was widespread consensus among medical experts that, "despite advances in the management of HIV disease, early treatment could do little to affect the life


\footnote{24. The Congressional bill, H.R. 4507, was introduced by Representative Gary Ackerman (D-NY). Newborn Infant Notification Act, H 4507, 103d Cong, 2d Sess (May 26, 1994) in 140 Cong Rec H 4164 (May 26, 1994). See also, Ron Bayer, Ethical Challenges Posed by Zidovudine Treatment to Reduce Vertical Transmission of HIV, 331 New Eng J Med 1223, 1224 (1994).}

expectancy of HIV-infected children." Therefore, the principal non-punitive benefit derived from mandating testing and identifying HIV-infected mothers and their potentially-infected newborns would be the ease with which the state could identify them in order that they might be notified and encouraged both to look after their own medical care and also to bear in mind their HIV status when contemplating behavior linked to HIV (such as future pregnancies).

Obviously, this reasoning applies with equal force to any individual in society (and presumably, to any medical condition for which a cure is being sought), and if accepted, should lead to a call for mandatory HIV screening for the entire population. Not surprisingly, this justification for mandatory screening was raised and rejected early on in the HIV test wars. In the context of a society that does not guarantee health care to its citizenry, this use of testing, with its concomitant risks of harm to those identified, is an absurd misuse of state funds and state power.

Because the test zealots were unable to demonstrate convincingly why revealing HIV status would benefit a newborn, the entire debate over maternal versus newborn "rights" in this round of the HIV test wars became essentially theoretical. Nevertheless, despite the defeat of all of the early efforts at "unblinding" the seroprevalence studies, the threat posed by this debate yielded a most astonishing result: in May, 1995, the CDC halted the collection of newborn seroprevalence data. It seems that once the HIV test zealots evoked the powerful image of a newborn "innocent" victim, the anti-coercionary coalition lost its nerve. Rather than articulating the anti-testing position as sound public health policy, the Centers for Disease Control chose to call the whole thing off, leaving the test zealots and others with the impression that public health forces had capitulated to women's rights, rather than the conclusion that public health goals were most easily attainable through honoring women's rights. In a scientifically dynamic environment, this "duck and run" strategy was doomed to failure. The seeds of that failure were sown by ACTG Protocol 076.

27. There is a minimal risk of viral transmission through breast milk. See Margaret J. Oxtoby, Human Immunodeficiency Virus and Other Viruses in Human Milk: Placing the Issues in Broader Perspective, 7 Pediatric Infectious Dis J 825, 825 (1988); D.T. Dunn, et al, Risk of Human Immunodeficiency Virus Type I Transmission Through Breastfeeding, 340 Lancet 585, 587 (1992). Therefore, an HIV-infected woman who did not transmit the virus to her offspring through gestation and delivery still poses a risk to the child if she elects to breast feed. However, because the vast majority of cases involving vertical transmission occur during gestation, labor and delivery, the test zealots seldom offer it up as justification for newborn screening. See, for example, Nat Henthoff, Discrimination in its Cranelest Form—How Mothers of HIV-Positive Babies Are Not Being Told of Their Child's Condition, Wash Post A15 (July 5, 1994).

Of course, this information might be put to other uses. For example, if a mother's HIV-positive status is thought to implicate her ability to parent, then the state's child protective services might be called to intervene and evaluate her before the child is released to her custody. See, infra, at note 48, and accompanying text regarding the reality of this risk.

B. AZT AND FETUS WORSHIP

In November, 1994, researchers halted a study known as ACTG Protocol 076 before its anticipated date of completion in order to disseminate the exciting findings: Offspring born to HIV infected women who were given AZT while pregnant are less likely to have an HIV infection than those born to HIV infected women who did not take AZT.29 This study presented the first truly good news in the decade and a half battle against HIV. In fact, it was the first breakthrough to alter any of the four underlying factual assumptions that had, to date, framed HIV-related policy debates. It now seemed evident that there was a way to inhibit viral transmission in one type of exposure to HIV.

Understandably, those who had been calling for mandatory non-anonymous HIV testing throughout the epidemic viewed this breakthrough as providing indisputable justification for implementing a testing scheme for pregnant women. Because AZT offered some protection to a fetus, and because this benefitted not only the fetus, but also society at large (by limiting future costs), many began to question the conventional position that mandatory testing was punitive and yielded no benefit. The temptation to help the most innocent of American victims was so powerful that, despite the lack of an articulated plan as to what would be done with the test results, the anti-coercionary coalition began to shrink, and defectors joined the burgeoning ranks of the test zealots.

Before analyzing the opposing positions in the reinvigorated test wars, however, it is important to understand the scope of Protocol 076 and the limited nature of its findings.30 The HIV infected women who participated in Protocol 076 were carefully selected.31 All were in the early phases of HIV infection, and had only mild to moderate levels of immunosuppression. Participants were limited to those with minimal or no prior use of AZT. The women were given a daily regimen of five doses of AZT during the second and third trimesters of pregnancy, intravenous AZT during labor, and additional AZT for both woman and child in the postpartum period. Along with the care rendered as clinical trial participants, the women also received excellent prenatal care.32 Statistics from a variety of U.S. studies indicated that had there been no medical intervention, approximately 25 percent of the Protocol 076 babies would have acquired HIV infection. Instead, upon verifying the infant's serostatus, only 8.3 percent of the Protocol 076 infants were infected.

These results are indisputably encouraging. They are not, however, unequivocally positive. First, there are many reasons to doubt whether this particular

30. Id at 1173 (explaining that the data from protocol 076 suggested some reduced transmission in certain populations but did not completely prevent it).
31. Provisional Committee on Pediatric Aids, 95 Pediatrics at 303-04 (cited in note 25).
32. Id at 304.
33. Id.
group of women, given their early stage of infection and the quality of prenatal care they received, had the same chances of transmitting the virus to their fetuses as the general population of HIV-infected women. Additionally, AZT is a powerful, destructive chemotherapeutic agent. Its use by pregnant women raises uncertain risks for the women and their offspring. Even if we assume that 25 percent of these children would have inherited HIV, a policy mandating the ingestion of this potentially toxic agent needlessly risks harming the large majority of children who would have been born healthy and uninfected. Moreover, this early use of AZT may carry long-term consequences for the woman’s well-being. Many experts fear that by using AZT early in her infection, the woman must not only endure the drug’s miserable side effects during her pregnancy, but also may find that AZT will no longer work to prolong her life when she resumes using it later in her own illness.

Armed with the evidence that AZT helps to reduce perinatal transmission rates, the reinvigorated test zealots have, for the first time, won the support of the federal government. A federal law passed in May, 1996, requires that by the year 2000, states that have not invoked mandatory HIV testing for pregnant women must demonstrate either (1) that they have reduced by 50 percent the number of newborns who develop AIDS as a result of maternal infection, or (2) that 95 percent of pregnant women who make at least two prenatal visits are tested for HIV. If states do not satisfy at least one of these requirements, they will be required to test all newborns whose mothers’ HIV status is unknown or risk losing their Ryan White AIDS funding. The test zealots support their edict demanding mandatory HIV testing for pregnant women via three basic argu-

34. The most recent findings of the on-going U.S. study called the WITS (Women, Infants Transmission Study) indicate that HIV transmission rates may be higher among pregnant women whose HIV disease is more advanced. Michelle Oberman, Interview with Mildred Williamson, Program Administrator for Cook County Hospital Women and Children with AIDS Project (Nov 15, 1995) (unpublished). This result supports the findings of studies demonstrating diverging transmission rates among wealthy European and poor African nations. In countries like France and Switzerland, where health care is free and women discover their HIV infection early, transmission rates average around 14.4%. European Collaborative Study, Risk Factors for Mother-to-Child Transmission of HIV-1, 339 Lancet 1007, 1007 (1992). However, in several African nations, studies reveal a transmission rate ranging from 28% to 42%. Verkuyl, 346 Lancet at 294 (regarding vertical transmission by women in Zimbabwe, Zambia, Zaire, Uganda, Kenya, Tanzania, Malawi, and Mozambique) (cited in note 19).

35. Recall that it is precisely the indeterminate risks of harm to the fetus that lead us to caution pregnant women against consuming aspirin and other analgesics, tobacco, caffeine, and virtually all FDA-approved prescription drugs.


ments: ethical, practical, and legal. The following subsections will analyze the strengths and weaknesses of each of these arguments.

1. The Ethics of Mandatory Testing for Pregnant Women

The ethical justification for mandatory testing is that the values of privacy and autonomy are outweighed by the countervailing duty to preserve life. Proponents of this position include renowned bioethicist Arthur Caplan, who asserts that, “[D]espite all the rhetoric . . . this isn’t such a complicated moral call. If you can prevent a young child from being infected, it would seem to me that you are under an obligation to take the steps necessary to prevent that harm.”

The analysis underlying this ethical justification is limited. No effort is made to explain the scope of the permissible infringement upon the pregnant woman’s rights to privacy and autonomy. It is unclear whether the test zealots’ support is limited to compulsory testing, or rather, would include the compulsory treatment of women who wanted to refuse AZT treatment. Of course, it is difficult to imagine rendering treatment according to Protocol 076 absent patient compliance. The daily regimen of five doses administered over the course of six months led one commentator to query, “Would anything short of incarceration make such treatment possible?”

When forced to consider the woman as an individual, rather than as a potentially lethal fetal transport mechanism, the test zealots acknowledge that a positive HIV test result may have an impact on her physical and psychological well-being. Nevertheless, they maintain that mandatory testing “would promote the psychological well-being of the mother. HIV still is laden with stigma and controversy. Assuming that she plans to carry the child to full term, the mother can use the advance knowledge that her child may be infected to adjust to the news and receive counseling and support.” This cheery platitude not only fails to acknowledge the woman as anything more than a mother, but is also based upon a false conception of reality. Counseling and support services for HIV infected parents of HIV infected children, or even for HIV infected persons themselves, are scarce. Moreover, even assuming that a parent might have

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39. In fact, privacy and autonomy concerns often are dismissed as “political.” One newspaper editorial called on doctors and hospitals to implement mandatory testing without waiting for government authorization. “That would avoid the controversy that would be associated with a governmentally imposed test. It also would remove the decision about mandatory HIV testing for babies and their mothers from the political arena.” AIDS and Infants: Mandatory HIV Testing of Expectant Mothers Can Save Lives,” Pittsburgh Post-Gazette A14 (Aug 9, 1995) (editorial).
41. AIDS and Infants, Pitt Post-Gazette at A14 (cited in note 39).
42. In one study, medical sociologist Rose Weitz found that “Nongay PWAs [people with AIDS] (especially women) . . . are far less likely to have networks of fellow sufferers to whom they can turn for advice and information . . . .” Carol Levine and Nancy N.
access to these services, this hardly offsets the potentially negative implications of the HIV test results for the lives of parent and child alike.

If mandatory HIV testing of pregnant women is to be justified by virtue of the ethical benefit of enabling the parent to prepare to care for themselves, as well as to plan for the future guardianship of their offspring (whether healthy or sick), this justification certainly applies with equal force to all parents. The test zealots have yet to issue a call for the mandatory HIV testing of all men who have fathered children. Obviously, even when couched in terms of parental benefit, the “ethical” arguments in favor of HIV testing for pregnant women are about benefitting the fetus, regardless of the risks of harm to the pregnant woman. An ethical analysis requires an honest and thorough exploration of the risks and benefits of a proposed course of action to the individual involved.

From the perspective of the pregnant woman, there are both positive and negative consequences to learning that one has acquired HIV. Although the positive consequences have been well-rehearsed by advocates of mandatory testing, the negative consequences have been largely ignored. First, an HIV diagnosis remains tantamount to a death sentence, and therefore carries with it devastating psychological consequences.  

In addition to psychological consequences, the pregnant woman who tests positive for HIV may face all of the well-documented forms of discrimination exhibited by landlords, employers, insurers, family and friends.  

However, pregnant women who test positive for HIV face an additional, and perhaps even more menacing risk: an HIV infected test result may jeopardize a woman’s access to her child. Given that a substantial majority of HIV infected women acquire the virus either through injection drug use, or through heterosexual intercourse with an injection drug user, there is a possibility that the children of HIV infected women may be at risk of abuse and neglect. 

The majority of HIV infected women have at least one child, and according to Mildred Williamson, the administrator of Chicago’s first and largest hospital-based program for women and children with HIV, the majority of HIV infected women have had at


43. There is considerable documentation of the negative psychological consequences of HIV testing, particularly when completed without adequate pre- and post-test counseling. See Richard M. Glass, AIDS and Suicide, 259 JAMA 1369, 1370 (1988); Samuel Perry, et al, Suicidal Ideation and HIV Testing, 263 JAMA 679, 681 (1990).


45. “HIV-infected women are mainly young, in their twenties and early thirties... Over half are IVDUs [intravenous drug users].” Levine and Dubler, 68 Milbank Q at 331 (cited in note 42).
least one encounter with the state child welfare agency. There are many reasons why it is inappropriate for state officials to use HIV status as a proxy for child abuse and neglect. Nevertheless, because child protection workers seldom are criticized for having acted too vigilantly, there is a powerful incentive to intervene in these families, even if there is no evidence that the child is at risk.

Moreover, once a child has been removed from a parent’s custody, even temporarily, it is remarkably difficult for the parent to convince the state to reunite them. As Richard Goldstein, an investigative reporter for the Village Voice observes:

No one [among those who advocate HIV testing for pregnant women and newborns] has written about how easy it is for a poor black woman’s positive HIV status to become known, or how hard it is for such women—80 percent of whom have a history of IV-drug use—to hold onto their children once it is. No one has described how difficult it is for such women to get their children out of foster care, even if they’ve been placed there because the mother has a serious infection from which she will recover.

Once one begins to factor the pregnant woman’s lived reality into the ethical debates on mandatory testing, it becomes difficult to see why compulsory testing should be any more acceptable among pregnant women than among the popula-

46. Oberman, Interview with Mildred Williamson (cited in note 34).

47. First, HIV is a medical condition, not an indicator of parental ability. (One would not consider presumptively taking children away from mothers dying of cancer.) Furthermore, even if there is evidence that the woman acquired the virus through injection drug use, she may have stopped using drugs many years ago. Moreover, there is no societal mandate that equates even current substance abuse with an inability to parent. It is worth noting, however, that in many states, the law permits drug-testing of newborns in order to detect maternal substance abuse. Although I have criticized this policy elsewhere as both under- and over-inclusive, at least it is tailored to the specific issue of current substance abuse and the ability to parent. See Michelle Oberman, Sex, Drugs, Pregnancy and the Law: Rethinking the Problems of Pregnant Women Who Use Drugs, 43 Hastings L Rev 504, 520-21 (1992). Finally, one must consider the services available to the children who are taken from their mothers. At least in major metropolitan areas, child protective services are so overburdened that they are incapable of assuring the safety of their wards. These agencies clearly are necessary as a last resort, but there is little reason to idealize their capacity to ameliorate a difficult situation. For a detailed discussion of the problems plaguing state child protection agencies, see id at 524-25.

48. A somewhat extreme example of this is suggested by Cook County Public Guardian Patrick Murphy, who advocates prosecuting parents for the abuse of unborn children. According to his rationale, a woman who tested positive for HIV, and then elected to avoid further contact with the health care system, might be seen as having abused her child, even if the child was born uninfected. Patrick Murphy, Protect the Innocent, NY Times A11 (July 30, 1996).

49. Richard Goldstein, Unintended Consequences, Village Voice 6 (June 6, 1995) (quoting Ms. Terry McGovern, an attorney at the HIV Law Center, who notes that, “It’s practically impossible to get those kids back once they’re taken.”). McGovern’s agency has handled over 100 discrimination cases involving women with HIV in the past two and a half years.
tion as a whole. This does not mean that pregnant women never should be tested. Quite the contrary—all pregnant women should be counseled as to the risks and benefits of knowing their HIV status. This sound ethical directive should be fully acceptable to both sides of the testing debates, particularly in light of several studies documenting that between 90 and 95 percent of pregnant women who receive adequate HIV-related counseling consent to testing. Therefore, at its core, the entire debate about mandatory testing is far less about ethical concerns than it is about pragmatic considerations of resource allocation.

2. Pragmatic Arguments Regarding HIV Testing for Pregnant Women

Proponents of mandatory testing for pregnant women acknowledge that programs involving well-trained health care providers who counsel pregnant women regarding the benefits of HIV testing achieve test rates of 90 percent or more, but they correctly observe that these programs are not easily replicated in health care facilities which, driven by concerns of cost containment, elect to minimize counseling tailored to needs of specific populations. Therefore, they argue that mandatory testing is needed as a practical matter, in order to insure that women who do not receive sufficient counseling are not “deprived” of the opportunity to learn their infants’ HIV status.

This is a strange argument. Pregnant women, like all other people, have a fundamental right to autonomy which is secured by requiring that they give their informed consent to medical treatment and testing. Thus, one would expect the test zealots to demand mandatory HIV counseling, rather than mandatory HIV testing for this population. Instead, the test zealots argue that the successful programs are costly and impractical, implicitly asserting that the price tag on liberty for pregnant women should be cheaper than it is for any other individuals. Aside from the ethical and legal problems inherent in subordinate-


51. One well documented example of counseling’s success is at New York’s Harlem Hospital, where an intensive counseling program has resulted in a 90% HIV test rate for pregnant women. Nicholas Goldberg and Manuel Pérez-Rivas, AIDS Test Disclosure, Newsday 23 (Feb 10, 1994). For other studies documenting comparable test rates, see Susan Holman, et al, A State Program for Postpartum HIV Counseling and Testing, 109 Pub Health Rep 521, 523 (Jul-Aug 1994). The Women and Children with AIDS Project at Cook County Hospital reports a 95% HIV test rate for pregnant women. Oberman, Interview with Mildred Williamson (cited in note 34).


ing fundamental rights in the name of pragmatism, the test zealots' position fails to take into consideration the likely practical consequences of a mandatory test policy.

History teaches us that universal compliance with compulsory testing and treatment programs is a myth, and that those whose fear of the negative consequences associated with detection outweighs their desire for treatment will avoid public health officials at all costs. The fact that, in the absence of adequate counseling, as few as 50 percent of pregnant women elect an HIV test does not bode well for the success of a compulsory testing program. It reveals that as many as 50 percent of all pregnant women prefer not to be tested. It stands to reason that some of these women are strongly opposed to testing and will take steps to avoid being tested no matter the official policy.

If prenatal care is linked to HIV testing, this portends disastrous consequences, as the lack of prenatal care jeopardizes both the women's and the fetus' well-being. This is particularly true for those women whose health status already may be compromised by the effects of poverty. This specter is all the more troubling when one considers that the vast majority of the babies placed at risk by the lack of prenatal care, including at least 75 percent of those born to HIV infected mothers, would otherwise have been born uninfected and healthy.

There is little reason to believe that any compulsory testing policy could achieve the 95 percent test rates reported by the best voluntary HIV counseling programs. At its heart, the "pragmatic" debate about HIV testing for pregnant women is a struggle over whether society is obligated to invest the resources necessary to bring high quality HIV counseling to all pregnant women. From a public health perspective the answer is clear: investing in mandatory HIV counseling is the safest and most effective way to encourage the greatest possible number of women to be tested. From a fiscally conservative perspective, mandating testing alone might seem more attractive, but only if one is both cavalier about the rights of pregnant women, and blind to the foreseeable negative consequences such a policy may bring about.

3. The Legal Justifications for Mandating HIV Testing for Pregnant Women

As a result of the fact that we are living in an era that is unsympathetic towards the allocation of resources to marginalized populations such as those perceived to be at risk of HIV, it is perhaps unsurprising to find that the practical debate over HIV testing has been subsumed by a legal one. Rather than

56. For a thorough description of the importance of prenatal care in enhancing the health of both pregnant women and fetuses, see Sarah S. Brown, ed, Prenatal Care: Reaching Mothers, Reaching Infants 17-25 (Natl Acad Press 1988).
57. Mildred Williamson notes that a trust-based relationship with patients is critical to treating the HIV-infected woman, and central to the success her institution has experienced in terms of HIV-test rates. Oberman, Interview with Mildred Williamson (cited in note 34).
focusing on instituting broadscale HIV counseling programs designed to permit pregnant women to make informed choices about testing and treatment, the test debate has been framed in terms of rights. The test zealots correctly argue, that the right to informed consent is not absolute, in that pregnant women routinely are screened, without their specific consent, for a host of medical conditions. Indeed, the public health laws of various jurisdictions permit, and often require, that pregnant women be tested for Rh factor, syphilis, gonorrhea, and other conditions that have a bearing on their own health, and on the health status of their fetuses. HIV tests, they argue, might be added to the list without much complication.

The legal response to this is complex, because the governmental power to act on behalf of the public health is extraordinarily broad and ill-defined. As a policy matter, mandatory testing of any sort usurps women's autonomy as a class by treating them on the basis of their status as women, rather than as a result of specific behaviors or symptoms. In principle, this is offensive, yet the tests permitted under public health laws are far more defensible than are HIV tests. Although the extent of physical intrusiveness is the same in all cases (a blood test), no one can argue that an HIV test and an Rh factor test carry identical social, legal, and even medical meanings. None of the permissible prenatal public health screenings open women to social and legal discrimination. Moreover, because safe and effective treatments are readily available for the targeted public health conditions, the knowledge gained from testing is unequivocally useful. Thus, although there is precedent for mandatory testing, it is debatable whether the law should, or in fact could, permit mandated HIV tests in this particular instance. Unlike the other conditions for which pregnant women are tested, HIV/AIDS is recognized as a disability. The law protects those who carry the virus, as well as those suspected of carrying it, against unlawful discrimination. Additionally, many states have laws forbidding the administration of an HIV test absent an individual's specific, informed consent.

There is a tension inherent in the government's desire to control infectious disease while simultaneously defending individual rights. Presently, the government may impinge upon privacy and bodily autonomy in the name of the compelling state interest of safeguarding public health and welfare, but only to the extent that no less restrictive alternatives are available.

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60. For example, New York state law currently prohibits HIV testing without specific written and informed consent, as does Illinois. See 1993 NY Laws 2781 and 410 ILCS 305.
61. When fundamental individual rights are affected by state actions, the current standard of review requires that the state demonstrate the existence of a compelling purpose for action, and that no less restrictive means of achieving its goal exist. Scott
Involuntary HIV testing of pregnant women clearly constitutes an invasion of privacy and bodily autonomy. Although the test reveals information relevant to the health of the woman and the fetus, it is difficult to cast the state's desire to ascertain HIV status as a compelling state interest. Unless the state intends to compel those women who test positive to undergo AZT therapy, merely knowing which pregnant women are HIV infected does little to further the state's interest in public health.

The legal debate therefore raises the issue of compulsory treatment of pregnant women—one which makes little sense as a practical matter, given the logistics and costs entailed in forcing women to endure this protocol. As a legal proposition, forcing a competent adult to undergo such treatment would be unprecedented. A considerable body of law guarantees to individuals the right to be free from unwanted medical treatment, even if such treatment is necessary to preserve their lives. Although some courts have attempted to impose treatment on pregnant women for the benefit of the fetus, these decisions have been roundly criticized and rejected as legally unsound. Moreover, there remains considerable scientific uncertainty about the short and long-term effects of AZT on the woman and the fetus. A reasonable woman well might conclude that any benefit gained by taking AZT during her pregnancy is outweighed by the associated risks to herself and her fetus. Thus, despite the argument that the state

Burris, *Fear Itself: AIDS, Herpes and Public Health Decisions*, 3 Yale L & Policy Rev 479, 483 (1985) (“It is the least restrictive means if it is the medically justified response that entails the least infringement on individual rights.”).

62. For a description of perinatal AZT treatment, see text accompanying notes 29-32, supra.

63. These rights are both Constitutional and common law in nature. See, for example, *Cruzan v Director of Mo Dept of Health*, 497 US 261, 277 (1990); *In Re Estate of Brooks*, 32 Ill 2d 361, 205 NE2d 435, 442 (1965); Laurence H. Tribe, *American Constitutional Law* 1363 (Foundation 2d ed 1988).

64. See, for example, Nancy K. Rhoden, *The Judge in the Delivery Room: The Emergence of Court-Ordered Cesareans*, 74 Cal L Rev 1951, 1952 (1986); 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, 749 (1986). See also *In re A.C.*, 573 A2d 1235, 1254 (DC App 1990) (Court holds that a pregnant woman, whether competent or incompetent, has the right to refuse medical treatment, even if such treatment is believed to be necessary to save the live of her fetus. The court does not foreclose the possibility that a conflicting state interest may be so compelling that the patient's wishes must yield, but noted that "such cases will be extremely rare and truly exceptional.").

To date, there is no case in which a court has ordered a pregnant woman to take AZT. Nevertheless, given that AZT therapy extends over the course of several months, and is therefore both longer in duration and less certain to protect fetal well-being than is a cesarean section, it stands to reason that a court could not legally compel a pregnant woman to undergo AZT treatment against her will.

65. Although the health care community has been quick to endorse the use of AZT by HIV-infected pregnant women, (see, for example, *US Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women*, 44 Morbidity & Mortality Weekly Report 1 (July 7, 1995)), AZT is far from a risk-free therapy. It is a toxic chemotherapeutic agent with serious side effects. The
may have a compelling interest in protecting the fetus’s life, this interest does not subsume the competent woman’s right to refuse treatment.

Moreover, even if the state’s goal is to ensure that all pregnant women know that AZT treatment is available and may protect their fetuses from acquiring the virus, surely mandatory HIV counseling is as effective, and less invasive, a means of communicating this information. Therefore, neither the state interest in fetal life, nor the state interest in protecting the public health generally, justify the imposition of mandatory HIV testing on pregnant women.

IV. Reconsidering Compulsion as a 21st Century Public Health Strategy

Although the law clearly requires the government to honor pregnant women’s choices regarding HIV testing and treatment, the rights-based arguments from which this requirement derives are somewhat sterile and distracting. The legal debate forces both sides to posit extreme scenarios, and to argue in a manner that is wholly removed from reality. In this case, the debate requires us to imagine a pregnant woman with access to the health care system, who is informed of the risks of HIV, of the benefits of testing and the availability of treatment, and who nevertheless elects to refuse testing. Yet, it is common knowledge that one of the most significant barriers to treating HIV in women is that women lack access to care—they seek medical assistance late in their disease when it is too late to extend their lives via therapies like AZT, and that the length of time between diagnosis and death in women is years shorter than it is in men.

full range of effects of this agent on a developing fetus have yet to be evaluated (see, supra, notes 35-36 and accompanying text).

Even a cursory review of twentieth century approaches to prenatal care reveals that one generation’s recommended medical treatments during pregnancy have often produced the next generation’s medical disasters. Lisa Ikemoto refers to this pattern as “defaulting to science,” which she defines as “the practice of letting developments in science and technology define the issues in a way that creates an imperative to use these developments.” Lisa Ikemoto, The Code of Perfect Pregnancy: At the Intersection of the Ideology of Motherhood, the Practice of Defaulting to Science and the Interventionist Mindset of Law, 53 Ohio St L J 1205, 1286 (1992). To illustrate this pattern, she notes later-discredited “innovations” ranging from the late nineteenth and early twentieth century practice of using anesthesia and forceps during delivery to later twentieth century endorsements of DES, X-rays, and diuretics. Id at 1237, 128.

66. See Roe v Wade, 410 US 113, 162 (1973). (Note that this holding has not been interpreted to require a pregnant woman to risk her own health in order to protect her fetus.)

67. This calculus shifts once the child is born. Should the state determine that treatment is in a child’s best interest, it may override a parent’s refusal of treatment. See, generally, Tribe, American Constitutional Law at 1363 (cited in note 63).

68. After months of debate over a mandatory HIV testing bill, the New Jersey state legislature ultimately determined that a law mandating HIV counseling for pregnant women would better meet their public health goals. Bob Groves, Whitman Signs Bill to Advance HIV Testing, The Record A3 (July 8, 1995).

69. This combination of late diagnosis, misdiagnosis, and lack of access to health care
The entire legal debate over individual rights and the permissibility of mandatory testing has the perverse effect of eclipsing the far more important dialogue about how best to remedy the public health problem itself. Time and again in the short history of HIV/AIDS, policymakers have squandered precious resources and energy arguing the merits of compulsion.\textsuperscript{70} Despite its high costs and inefficacy, the power to compel individual compliance has proven to be an irresistible lure for policy-makers facing a public health threat. It is all but inevitable that, as the HIV epidemic continues to spread among the poorest members of society, and as the scientific world offers up more treatments, there will be new calls for mandatory testing and treatment. Perhaps it is not premature then, to conclude by re-thinking the permissibility of this broad governmental power. When, if ever, is compulsion the best course of action?

Imagine that there was an affordable cure for persons infected with HIV—but that it only could be administered by physicians. Certainly, such an innovation would engender calls for mandatory testing and treatment—proposals which, at first blush, would seem to be the best way to cure the infected, as well as to protect the uninfected public. In order to consider the merits of these proposals, however, it is imperative to consider whether compulsion would be the best way to cure the greatest number of infected individuals. The key question would be whether there are those who would resist HIV testing and treatment even if a cure were available.

Although any answer to this question is purely speculative, one can imagine several sub-groups among the population who might resist HIV testing and treatment. First, there would be those who objected to testing and treatment on religious grounds. The relatively powerful lobby of the Christian Scientists has secured the right of its followers to be free of medical treatments including vaccinations, that other citizens are legally required to undergo.\textsuperscript{71} The laws that permit these individuals to avoid vaccination for some contagious diseases pose at least a theoretical risk to the population, although as long as everyone else is vaccinated, this risk is confined to members of their own community. It is not clear whether the Christian Scientist lobby would be sufficiently strong to obtain

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  \itemgrass results in the disturbing reality that, “HIV positive women generally experience a decreased length of survival after a diagnosis of AIDS relative to HIV positive men.” Grizzi, 5 UCLA Women's L J at 473 (1995) (cited in note 36). Specific survival statistics vary, but one comparison suggests that a woman infected with HIV in New Jersey lives an average of 15.5 \textit{weeks} following diagnosis, compared to a white gay male in the northeast, who lives, on average, 20.8 \textit{months} following diagnosis. Risa Denenberg, Unique Aspects of HIV Infection in Women, in Cynthia Chris and Monica Pearl, eds, Women, AIDS and Activism 31, 31 (South End 1990).
  \itemgrass 71. See Note, Faith Healing Exemptions to Child Protection Laws: Keeping the Faith Versus Medical Care for Children, 12 J Legis 243, 244 (1985) (noting that more than forty states provide some form of exemption in their child protection laws for spiritual treatment, and that “church-supported lobbyists actively work to ensure continued religious carte blanche”).
\end{itemize}
exemptions for its followers to any HIV testing and treatment laws, but the
debate would be an intense one.

A far more troublesome group of resisters would be those whose desire to be
cured would be pitted against their fear of the negative consequences that might
follow from their contact with the health care system. There are many persons
who perceive the health care system as a potential threat to their civil status.
Those who are undocumented fear exposure and deportation, both for them-
selves and their families. Those who are addicted to illegal drugs fear disclo-
sure and arrest. Those who are mothers fear losing custody of their children.
These fears may seem irrational to those not similarly situated. And yet, it is a
tragic truth of our times that some individuals are so marginalized and vulnera-
ble that they would prefer death to the consequences of detection.

Those who fear detection do not have an organized lobby. If a mandatory
testing scheme was enacted, there would be no exception for those who have
reason to fear contact with the health care system. Instead, these individuals
would do what powerless peoples have been doing for decades, or even for
centuries: they would avoid testing and treatment, even if it threatened their own
lives and the lives of their children.

Seen from this vantage point, mandatory testing is as much an exercise of
privilege as a gesture of protection. Rightly understood, the debate over manda-
tory testing is about discerning the extent to which a subordinated population,
in this case, pregnant, HIV-infected women, is entitled to the same rights of
autonomous medical decision-making guaranteed to other members of society; it
is a debate over the degree to which society is prepared to use their ill-health and
vulnerability as an excuse to usurp their moral and legal standing.

In the face of any curable epidemic, the public health goal must be to treat
the largest number of persons vulnerable to the disease. When those most
vulnerable to a disease happen to be those most vulnerable in society at large,
the temptation to override individual rights in favor of community welfare is
overwhelming. It is also counter-productive. The rational public health strategy
would be one that created incentives to be treated, rather than incentives to
avoid treatment. Although the law permits the subordination of individual rights
to the collective good, it seems fair to conclude that what is legal is not always
wise, prudent, or effective policy.

The public health arsenal was stocked in an era in which society knew no
fear greater than epidemics and natural disasters. The powerful and imprecise
weapon of compulsion, like the cannonball, inspired confidence among those

72. See League of United Latin American Citizens v Pete Wilson, 908 F Supp 755,
771 (CD Cal 1995) (holding unconstitutional the provisions of California's Proposition 187
that sought to deny undocumented immigrants access to non-emergency health care services
by requiring health care personnel to verify a patient's immigration status prior to
rendering treatment). Although the court struck down this provision, the fact that it was
passed into law certainly justifies a fear on the part of undocumented individuals.

73. I am indebted to Timothy F. Murphy, Ph.D., for helping me to elucidate this
argument.
who felt threatened. Like societies in the past, we share a fear of epidemics and natural disasters. Unlike them, we must recognize that certain individuals among us have fears born of poverty and desperation that far surpass these abstract fears. Until we can assuage their concerns, any efforts to compel these individuals to undertake actions that further jeopardize their status, even if those in power intend these actions to be purely beneficial, are destined to fail. The military analogy in public health discourse presupposes and legitimizes fighting disease "to the death." When disease resides in individuals, there is precious little difference between fighting the disease and fighting the individuals who carry the disease. This tired metaphor has no place in a civilized society.