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Martha A. Field

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# Essays

## PREGNANCY AND AIDS

MARTHA A. FIELD\*

In this Essay, I discuss some of the points where pregnancy and the acquired immune deficiency syndrome (AIDS) come together—an intersection at which a wide range of important ethical issues exist. The subject illustrates that it is not possible to differentiate sharply between ethical and legal issues. Even subjects that today seem governed purely by ethical concerns can become legal issues as enterprising lawyers find ways to raise them in lawsuits.

Pregnancy and AIDS are an odd conjunction in one sense. We like to think of pregnancy as a happy event—and often are able to do so. AIDS never appears in that light. But both conditions have similar legal histories, and both may become occasions for government to make inroads upon areas previously left to individual choice.

In current litigation, both pregnancy and AIDS are advanced as justifications for allowing others to make decisions for the patient. For example, during pregnancy, others sometimes decide that a woman should undergo a Caesarean-section operation because that is safer for her fetus, or that a woman should not work in a particular environment or lead a particular lifestyle because it might compromise her fetus's development.<sup>1</sup> The AIDS issue has created a debate about criminalizing transmission—even by punishing sexual intercourse in some circumstances.<sup>2</sup> Attempts have also been made to

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\* Professor of Law, Harvard University. This Essay is a revised version of the 1992 Stuart Rome Lecture on Law and Ethics, delivered at the University of Maryland on April 15, 1992. Many thanks to Rebecca Winters and to Terry Perkins Mittman for excellent research assistance in connection with this Essay; and also to Dr. Robert Husson, pediatrician specializing in infectious diseases at Children's Hospital, Boston, Massachusetts, for keeping me up to date on technological developments and their impact on infant diagnosis and therapy.

1. See, e.g., *International Union, UAW v. Johnson Controls, Inc.*, 111 S. Ct. 1196, 1210 (1991) (finding discriminatory an employer's "gender-based fetal-protection policy" and warning that "[i]t is no more appropriate for the courts than it is for individual employers to decide whether a woman's reproductive role is more important to herself and her family than her economic role"). See generally Martha A. Field, *Controlling the Woman to Protect the Fetus*, 17 LAW, MED. & HEALTH CARE 114 (Summer 1989).

2. See generally Stephen V. Kenney, Comment, *Criminalizing HIV Transmission: Lessons from History and a Model for the Future*, 8 J. CONTEMP. HEALTH L. & POL'Y 245 (1992) (not-

exclude infected individuals from schools, jobs, insurance pools, and even to regulate living arrangements by implementing such extreme approaches as quarantine.<sup>3</sup>

A particularly thorny issue where pregnancy and AIDS converge involves the screening or testing of pregnant women for the human immunodeficiency virus (HIV).<sup>4</sup> I take no issue with voluntary testing, or with making AIDS testing available to anyone who wants it. (Any such testing should include honest counseling about the advisability of testing and again should provide follow-up counseling when the test results are in.) But some suggest that testing should be mandatory, either for pregnant women in general or for some subset of pregnant women.<sup>5</sup> Indeed, even those who reject

ing that an AIDS-specific criminal statute would serve punishment and deterrence goals but might also "exacerbate the public health crisis from AIDS"); Thomas W. Tierney, Note, *Criminalizing the Sexual Transmission of HIV: An International Analysis*, 15 HASTINGS INT'L & COMP. L. REV. 475 (1992).

3. See Wendy E. Parmet, *AIDS and Quarantine: The Revival of an Archaic Doctrine*, 14 HOFSTRA L. REV. 53, 53 (1985) ("An epidemic of fear has accompanied the spread of the disease and with it, public attention has turned to quarantine, one of the oldest tools of public health." (footnote omitted)); Edward A. Fallone, Note, *Preserving the Public Health: A Proposal to Quarantine Recalcitrant AIDS Carriers*, 68 B.U. L. REV. 441 (1988). But see David P.T. Price, *Between Scylla and Charybdis: Charting a Course to Reconcile the Duty of Confidentiality and the Duty to Warn in the AIDS Context*, 94 DICK. L. REV. 435, 446 (1990) ("[M]ost states have shunned the quarantine option."). For a discussion of the inappropriateness and ineffectiveness of quarantine and criminalization in response to the AIDS epidemic, see generally Kathleen M. Sullivan & Martha A. Field, *AIDS and the Coercive Power of the State*, 23 HARV. C.R.-C.L. L. REV. 139 (1988).

4. The human immunodeficiency virus (HIV) is transmitted, *inter alia*, by sexual intercourse, blood transfusions, and by maternal transmission to a fetus or infant. The virus manifests itself in various stages. First, it may lie dormant. A second stage, termed AIDS-Related Complex (ARC), includes people who are symptomatic but not fully so. Finally, there is the acquired immune deficiency syndrome (AIDS) itself, "characterized by HIV infection, severe immune deficiency, and a secondary illness that is potentially fatal." See Edward N. Brandt, Jr., *Health Care Workers and AIDS*, 48 MD. L. REV. 1, 3-4 (1989).

5. See *infra* note 19 and accompanying text (detailing Florida's requirement of prenatal testing of pregnant women for sexually transmitted diseases, including AIDS). Cf. Larry Gostin, *Hospitals, Health Care Professionals, and AIDS: The "Right to Know" the Health Status of Professionals and Patients*, 48 MD. L. REV. 12, 13 (1989) ("The Surgeon General has advocated HIV screening of all pre-operative patients. Some hospitals, irrespective of what the law may allow, already screen their patients without specific informed consent." (footnotes omitted)); A. Alyce Werdel, *Mandatory AIDS Testing: The Legal, Ethical and Practical Issues*, 5 NOTRE DAME J.L. ETHICS & PUB. POL'Y 155, 219 (1990) ("Mandatory testing is justifiable in the AIDS context because certain groups are known to be at high risk of carrying the disease. Based on this knowledge, the state has a duty to protect others not within these classes."). But see Taunya L. Banks, *Women and AIDS—Racism, Sexism, and Classism*, 17 N.Y.U. REV. L. & SOC. CHANGE 351, 370 (1989/1990) (warning that "routine HIV prenatal screening may prompt many HIV-infected women to forego needed prenatal care to avoid detection of their antibody status").

mandatory testing in most circumstances may favor testing pregnant women.

I believe that mandatory testing of pregnant women should be avoided. Moreover, testing of newborns at birth for HIV should not be undertaken without a parent's consent. Testing a newborn, like testing the pregnant woman herself, reveals whether the *mother* is HIV positive. Official receipt of this information suggests the further inquiry: Should government attempt to control pregnancy in women known to be HIV positive? Some, for example, would favor abortion and sterilization for AIDS-infected women, or government-supported encouragement of Norplant or Depo Provera.<sup>6</sup> How should one distinguish between encouragement and coercion, and is coercion permissible?

In this Essay, I review the law and the legal issues surrounding the particular intersection of pregnancy and AIDS and analyze, from an ethical and legal perspective, how the issues ought to be resolved. In general, I conclude that neither pregnancy, potential pregnancy, nor AIDS should serve as the occasion for government coercion.

The approach we take to the AIDS crisis, and to the regulation of pregnancy, may affect other, larger issues. For example: To what extent, and in what circumstances, is it permissible for government to decide who should and who should not reproduce or parent? Are there any circumstances where the government should encourage or even require abortion, contraception, or sterilization? Should it go further and adopt a *licensing* system for parenting, reserving permission to parent for those who can demonstrate themselves before the fact to be fit? Could the government go so far as to *criminalize* pregnancy by unauthorized persons? And, finally, as the biotechnological revolution continues, to what extent will *government* control new reproductive possibilities and to what extent will *individuals* exercise the new options?<sup>7</sup>

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6. See Banks, *supra* note 5, at 363 n.55 (noting that one commentator has argued "that it might be ethical to counsel women infected with HIV not to have children . . . [or] to abort"). Cf. Sandy Banisky, *City Officials Planning to Promote Norplant*, THE SUN (Baltimore), Dec. 3, 1992, at 1A (reporting city plan to promote use of the Norplant contraceptive among teenagers to combat "an adolescent pregnancy rate among the country's highest").

7. For example, as *in vitro* (or laboratory) fertilization becomes more widely available, ethical debates have begun to emerge. May parents select which embryo will be implanted based on its gender? Could they select its genetic characteristics, thereby screening out embryos having a prognosis of disability, or of being too short, or having brown eyes? Will the state be permitted to regulate the degree to which parents can "select" the characteristics of their future child? If the potential parent is not permitted

Some of these inquiries seem distant from current realities. But what we do with more immediate AIDS-related or pregnancy-related issues, like mandatory testing, may chart our course on larger questions like these—oftentimes without adequate reflection. We particularly need to guard against new intrusions upon individual decision making prompted either by a panicked response to AIDS or by political use of the AIDS epidemic.<sup>8</sup>

Our response to AIDS will be felt on many levels. The way we respond to AIDS-related issues—for example, patients' access to care and physicians' duty to treat—will affect our entire health care system and its regulation. It will also affect how our constitutional law develops, particularly in two ways: (1) how our Constitution protects the privacy of the individual to make major life decisions, in the face of twin onslaughts from government power and technology; and (2) how our Constitution protects the equality of all groups before the law. Because pregnancy and AIDS involve such difficult and far-reaching policy and ethical issues, it is essential that our response be a thoughtful, reflective one.

## I. THE FACTS CONCERNING VERTICAL TRANSMISSION

The process of transmitting HIV from mother to child is termed "vertical transmission." It is estimated that there are about 4000 cases of pediatric AIDS in the United States today; most infants acquire the virus from their mothers through vertical transmis-

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to make these determinations, will government itself be able to choose, or is no selection permissible at all?

8. See David I. Shulman, *AIDS Discrimination: Its Nature, Meaning and Function*, 12 NOVA L. REV. 1113, 1115-17 (1988) (arguing that the "panic response" to AIDS is due to the fear underlying societal taboos related to human sexuality, social stigma, helplessness, mental illness, and death). One commentator has summarized the problem as follows:

Politicians have reacted to the public's erroneous fear that AIDS is highly contagious by proposing numerous legislative programs intended to prevent the spread of the disease. Many of these proposals call for testing and quarantine programs under circumstances the scientific community has called unwarranted and absurd. As a result, the dangers posed by AIDS now stretch beyond its infectious and lethal nature and extend to the threat it poses to fourth amendment rights.

Bernadette P. Sadler, Comment, *When Rape Victims' Rights Meet Privacy Rights: Mandatory HIV Testing, Striking the Fourth Amendment Balance*, 67 WASH. L. REV. 195, 195 (1992) (footnotes omitted). Many of the same points could be made about reacting to the epidemic of crack-addicted babies by enacting legislation intended to regulate their mothers' drug intake.

sion.<sup>9</sup> One out of every 800 women in this country is estimated to be HIV positive, and women constitute about ten percent of all reported AIDS cases.<sup>10</sup> Most of these women acquired the virus through intravenous (IV) drug use or through sexual intercourse with an IV drug user.<sup>11</sup>

When a woman who is HIV positive becomes pregnant, there is a thirty percent or less chance that the baby she produces will also be infected.<sup>12</sup> Interestingly, it has not been proven that there is a greater chance of transmission if the pregnant woman actually has AIDS and therefore has a higher level of HIV in her body.<sup>13</sup> A newly infected woman who is not at all ill has the same chance of passing on the infection, even though she has a much lower level of the virus. Indeed, some researchers theorize that the fetus is most likely to become infected during the period when the mother first

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9. See Centers for Disease Control, *HIV/AIDS Surveillance Report*, 39 MORBIDITY & MORTALITY WEEKLY REP. 1 (1990) (noting that transmission from mother to child accounts for more than 80% of pediatric AIDS cases).

10. Centers for Disease Control National AIDS Hotline, Oct. 30, 1992. About 1800 AIDS-infected babies are born in the United States each year. Marta Gwinn et al., *Prevalence of HIV Infection in Childbearing Women in the United States*, 265 JAMA 1704 (1991).

11. See John a. Powell & Eileen B. Hershenov, *Hostage to the Drug War: The National Purse, the Constitution and the Black Community*, 24 U.C. DAVIS L. REV. 557, 602 (1991) (reporting that "[m]ore than sixty percent of the 4,000 women in New York City thus far diagnosed with AIDS are IV drug users"); Shawn M. Boyne, Note, *Women in Prison with AIDS: An Assault on the Constitution?*, 64 S. CAL. L. REV. 741, 752 (1991) (noting that "52% of the women with the HIV virus studied in research conducted by the Centers for Disease Control became infected through intravenous drug use").

12. Harvard AIDS Institute, *Nationwide Study Investigates Perinatal Transmission of HIV*, MONTHLY REP., Sept. 1989, at 10. Estimates of the rate of transmission have decreased over time, from about 40% in 1985, Centers for Disease Control, *Heterosexual Transmission of Human T-Lymphotropic Virus Type III*, 4 MORBIDITY & MORTALITY WEEKLY REP. 561 (1985), to the current figure, which some also believe is too high. The European Collaborative Study Group found a transmission rate of only 12.9%. European Collaborative Study, *Children Born to Women with HIV-1 Infection: Natural History and Risk of Transmission*, 337 LANCET 253 (1991). Some have theorized that the chance of transmission may increase for subsequent pregnancies. See Paul H. Black & Elinor M. Levy, *The HIV Seropositive State and Progression to AIDS: An Overview of Factors Promoting Progression*, 4 NEW ENG. J. PUB. POL'Y 97, 99 (1988).

13. See William Borkowsky & Keith Krasinski, *Perinatal Human Immunodeficiency Virus Infection: Ruminations on Mechanisms of Transmission and Methods of Intervention*, 90 PEDIATRICS 133 (1992). The authors do suggest, however, that the presence of AIDS or HIV-related secondary infections may increase the likelihood of transmission if these infections affect the mother's production of HIV-fighting antibodies or result in a "leaky placenta." *Id.* Moreover, some researchers have taken the position that the rate of transmission does increase as the mother's disease advances. See David D. Ho et al., *Quantitation of Human Immunodeficiency Virus Type 1 in the Blood of Infected Persons*, 321 NEW ENG. J. MED. 1621 (1989).

becomes infected.<sup>14</sup>

It is not entirely certain *how* or *when* the vertical transmission from pregnant woman to fetus takes place. Three different time periods are usually considered relevant—pregnancy, birthing, and breastfeeding—and it is agreed that infection may occur at different stages.<sup>15</sup> Some in the medical community speculate that the earlier the fetus is infected, the earlier the infant will develop AIDS from the HIV infection, and the earlier the infant will die. Researchers reason that very early transmission can result in interference with the development of the immune system, which hampers the infant's ability to produce her own HIV-antibodies.<sup>16</sup>

Interestingly, one-third of infants born infected with HIV develop AIDS within the first year; these infants generally die by age three. The other two-thirds who are infected do not immediately develop AIDS and can survive for many years. One child born with HIV is now fifteen.<sup>17</sup>

## II. MANDATORY TESTING AND INFORMED CONSENT

The usual rule in medicine—for testing as well as for operations and other treatments—is that the patient has the right to decide whether to consent.<sup>18</sup> The physician must persuade the patient to

14. See Phillip A. Pizzo & Karina M. Butler, *In the Vertical Transmission of HIV, Timing May be Everything*, 325 NEW ENG. J. MED. 652, 653 (1991).

15. While information on the timing of HIV transmission is unresolved, these three stages are the ones most commonly discussed. Some believe that most transmission takes place during birthing. See, e.g., Susanne Lindgren et al., *HIV and Childbearing: Clinical Outcome and Aspects of Mother-to-Infant Transmission*, 5 AIDS 1111 (1991); John Modlin & Alfred Saah, *Public Health and Clinical Aspects of HIV Infection and Disease in Women and Children in the United States*, in AIDS, WOMEN, AND THE NEXT GENERATION 41 (Ruth R. Faden et al. eds., 1991); John T. Repke & Timothy R.B. Johnson, *HIV Infection and Obstetric Care*, in AIDS, WOMEN, AND THE NEXT GENERATION, *supra*, at 94. Doctors Borkowsky and Krasinski, however, state that at least 50% of all perinatal infection occurs during gestation and, indeed, the virus has been detected in fetal material aborted as early as 18 weeks. See Borkowsky & Krasinski, *supra* note 13, at 133. There have been very few cases of transmission through breastfeeding. Even in those cases, doctors do not know if transmission occurred through the milk (which has been shown to contain the virus), through mother's blood which was in the milk, or through mother's blood that can collect around the nipple. The CDC currently recommends that HIV-positive women in the United States not breastfeed. Telephone Interview with Mary Jo O'Hara, National Pediatric HIV Resource Center (Oct. 21, 1992). The World Health Organization has declined to offer the same advice, on the theory that the risks of transmission through breastmilk are outweighed by risks of starvation without breastfeeding. *Id.*

16. Interview with Mary Jo O'Hara, *supra* note 15.

17. *Id.*

18. See *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 269-70 (1990) ("The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment."). Cf. *Union Pac. Ry. v.*



agree to any procedure that the physician wants to perform, and the patient retains the right to refuse. Most hospitals, physicians, and lawmakers have adhered to that principle in the context of AIDS testing and, for that matter, in the general context of testing pregnant women to detect fetal characteristics such as Down's Syndrome, spina bifida, and sickle cell anemia. A few statutes, however, have imposed mandatory testing of pregnant women for AIDS. Florida, for example, requires prenatal testing for AIDS as part of a requirement of testing pregnant women for all sexually transmitted diseases.<sup>19</sup>

Some hospitals also may engage in screening pregnant women, sometimes not openly.<sup>20</sup> Indeed, some state statutes explicitly allow physicians to test simply on the basis of the patient's consent to medical care, without even informing the patient that she is being tested for HIV.<sup>21</sup> In other places, courts can order testing of pregnant women. A Missouri statute, for example, allows courts to require testing when there "are reasonable grounds to believe that an individual is infected with HIV and there is clear and convincing evidence of a serious and present health threat to others posed by

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Botsford, 141 U.S. 260, 261 (1891) ("No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.").

19. FLA. STAT. ANN. §§ 384.23(3), 384.31 (West Supp. 1992). Similarly, a Mississippi statute allows physicians to make medical decisions for pregnant women, rejecting their ability to unreasonably refuse treatment. MISS. CODE ANN. § 41-41-3 (Supp. 1992).

For a discussion of the inappropriateness of including AIDS as a sexually transmitted disease under these statutes, see Sullivan & Field, *supra* note 3, at 171-72. In *New York State Society of Surgeons v. Axelrod*, 555 N.Y.S.2d 911 (1990), a group of medical societies that favored mandatory testing sued the New York State Commissioner of Health to have AIDS and HIV infection listed as sexually transmitted, communicable diseases so that they would be subject to mandatory testing under existing state law. The suit was not successful.

20. Keith Henry et al., *Human Immunodeficiency Virus Antibody Testing: A Description of Practices and Policies at U.S. Infectious Disease-Teaching Hospitals and Minnesota Hospitals*, 259 JAMA 1819, 1820 (1988) (noting that 34% of all United States Infectious Disease-teaching hospitals responding to a survey "estimated that the consent of the patient was rarely obtained when an HIV antibody test was ordered"). See Gostin, *supra* note 5, at 36 (warning that "[w]here patients are unaware that an HIV test will be given, their consent is fraudulently obtained" (footnote omitted)).

21. See ARK. CODE ANN. § 20-15-905(c) (Michie Supp. 1991) ("Informed consent, information, and counseling are not required for the performance of an HIV test when, in the judgment of the physician, such testing is medically indicated to provide appropriate diagnosis and treatment to the subject of the test, provided that the subject of the test has otherwise provided his or her consent to such physician for medical treatment.").

the individual if infected."<sup>22</sup> But to test without consent, and equally, to trick a woman into giving a paper "consent," is to abandon principles of informed consent that are basic to medical practice in this country and that many associate with individual freedom. The Supreme Court has said that the right to make one's own medical decisions is protected by the United States Constitution.<sup>23</sup>

### III. THE RIGHT NOT TO KNOW

Should someone have a right to refuse a test for HIV? After all, no treatment is required as a result of the test—at least not yet. Purely as a blood test, AIDS testing is not particularly intrusive. Should people have the right to object even to learning the truth?<sup>24</sup> One physician has called allowing "people at risk of being infected with HIV voluntarily to choose not to know [whether they are infected] a perversion of human rights and a formula for HIV disaster."<sup>25</sup>

Why would anyone refuse to consent to an AIDS test?<sup>26</sup> There are different types of considerations an individual might weigh against the benefits of testing in reaching a decision. First, there would be great and indisputable costs in having *other* people know that one is HIV positive. Even in places where, in theory, a test would be confidential, the reality may be that it is difficult to maintain total confidentiality once a person is found to be HIV positive.<sup>27</sup> And some states do not even afford a pretense of confidentiality,

22. MO. ANN. STAT. § 191.674(1) (Vernon Supp. 1992).

23. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) ("[A] constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.").

24. This proposition assumes that the result the test reveals is correct, as it usually—but not invariably—will be. For a discussion of the possibilities and causes of error in testing for HIV, and a description of the types of testing required to achieve maximum accuracy, see Martha A. Field, *Testing For AIDS: Uses and Abuses*, 16 AM. J. L. & MED. 33, 40-43 (1990).

25. Robert T. Jensen, *HIV Testing of Pregnant Women and Newborns*, 265 JAMA 1525, Mar. 27, 1991 (letter to the editor).

26. Larry Gostin, executive director of the American Society of Law, Medicine & Ethics, has explained, "As with many medical tests that predict grave or fatal diseases, some patients prefer to know the information, while others do not." Gostin, *supra* note 5, at 37-38. Gostin further noted that the informed consent doctrine generally "lays down a patient-oriented standard for the information that must be disclosed by the physician." *Id.* at 36.

27. *See id.* at 47 ("[B]y collecting sensitive health care data, hospitals may find themselves under great pressure to disclose that information. Another possibility is that the information may be disclosed intentionally or carelessly by persons with access to medical files."). Moreover, some scholars believe it would be a mistake even to attempt to ensure confidentiality, given the interest of other persons, such as lovers, insurers, and

instead requiring physicians to inform the state health department and then allowing the information to be subpoenaed.<sup>28</sup> Moreover, some insurance companies, potential employers, health maintenance organizations, and others now *ask* applicants whether they have ever been tested for AIDS, or whether they know if they are HIV positive.<sup>29</sup> Indeed Missouri's statute, for one, requires a person who knows she is HIV positive to inform any health care provider of that fact prior to receiving care.<sup>30</sup> It is sometimes therefore safer—even physically safer—not to be tested for AIDS. The test can jeopardize access to employment, health care, and housing.

In addition, there can be enormous social costs, especially for poor women. According to the Working Group on HIV Testing of Pregnant Women and Newborns, the extent to which HIV-positive women suffer because of their diagnosis has not been systematically documented, but "recent evidence suggests that poor, minority women risk the devastation of their personal and family relationships, the loss of social and medical services, the loss of control of their own medical decisions, and even the loss of their children."<sup>31</sup>

A different kind of reason to avoid AIDS testing—a reason much more important to some persons than to others—is a simple desire not to know the result. Such a reason might prevent some persons from being tested even if the results were not to be dis-

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treating physicians, in learning the information. See Harold Edgar & Hazel Sandomire, *Medical Privacy Issues in the Age of AIDS: Legislative Options*, 16 AM. J.L. & MED. 155 (1990).

28. See ARK. CODE ANN. § 20-15-906 (Michie Supp. 1992); IDAHO CODE §§ 39-602, 606 (Michie Supp. 1991); MO. ANN. STAT. § 191.653(3) (Vernon Supp. 1992).

29. After disclosure is made, companies may act on the information. For example, in *McGann v. H & H Music Co.*, 946 F.2d 401 (5th Cir. 1991), *cert. denied*, 113 S. Ct. 482 (1992), the court held that ERISA did not forbid an employer from changing an existing insurance policy that otherwise provided lifetime medical benefits up to \$1,000,000, to limit lifetime coverage for AIDS-related benefits to \$5000. The change was instituted after an AIDS-afflicted employee filed claims for reimbursement. The company's desire to avoid the expense of paying for AIDS treatment was considered a sufficient justification. *Id.* at 404.

30. MO. ANN. STAT. § 191.656(5) (Vernon Supp. 1992). Arkansas has a similar provision. ARK. CODE ANN. § 20-15-903 (Michie Supp. 1990).

31. Working Group on HIV Testing of Pregnant Women and Newborns, *HIV Infection, Pregnant Women, and Newborns: A Policy Proposal for Information and Testing*, 264 JAMA 2416, 2418 (1990). In one study conducted in a high-incidence area of New York City, for example, only one-half of the women who gave birth without having received prenatal care agreed to submit to voluntary testing. See David Chambers, *Public Policies Regarding Families*, in THE SOCIAL IMPACT OF AIDS 18, 19 (National Academy of Sciences 1991). See also Banks, *supra* note 5, at 370 ("The stigma of a positive HIV antibody test—loss of employment, insurance, housing, and other economic or social harm—provides another reason for women who suspect they are infected with HIV to avoid routine prenatal screening.").

closed to anyone else, as would be the case at anonymous testing sites, which are an available alternative in some states.<sup>32</sup> The wish not to know will often, though not always, be stimulated by a fear that the result could be positive.<sup>33</sup> People differ greatly concerning whether they would want to face a terrible disease. Such reactions are not limited to AIDS, by any means.

Huntington's Disease provides another example. It is an incurable neurological disorder that gradually destroys the brain cells over a period of twenty years from the onset of the illness, usually sometime during middle age. The disease is hereditary; a person who carries the gene for the disease has a fifty percent chance of passing it on to her or his children. In 1986, researchers first developed a test enabling people whose parents had the gene, and who therefore had lived with the uncertainty of knowing they had a fifty percent chance of developing Huntington's Disease in their own middle age, to determine whether in fact it had been passed to them. During the first five years following the development of the test, however, only 200 of the 125,000 persons at risk had taken the test. Many of the persons involved agonized about whether or not they preferred to know their actual status.<sup>34</sup>

A right not to know in situations like these should be seen as part of the constitutionally protected liberty interests that the current Supreme Court has recognized in *Cruzan v. Director, Missouri Department of Health*<sup>35</sup> and *Planned Parenthood of Southeastern Pennsylvania v. Casey*.<sup>36</sup> The right not to know also bears a relationship to Justice Brandeis's pivotal justification for recognizing a fundamental privacy interest in a democracy: "the makers of our Constitution . . . conferred, as against the government, *the right to be let alone*—the most comprehensive of rights and the right most valued by civilized men."<sup>37</sup>

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32. For a discussion of the desirability of anonymous testing and how it works, see Field, *supra* note 24, at 51-53.

33. See Gostin, *supra* note 5, at 52 (stating that "[s]tudies indicate that positive HIV test results can cause severe psychological distress, including an increased risk of suicide").

34. Giovanna Brea, *For a Family Facing Incurable Huntington's Disease, Finding Out is Better Than the Dread of Suspicion*, TIME, Nov. 5, 1990.

35. 497 U.S. 261 (1990) (stating that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment).

36. 112 S. Ct. 2791 (1992) (stating that the Constitution places limits on a state's right to interfere with a citizen's "most basic decisions" about family, parenthood, and bodily integrity).

37. *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting).

Whether or not exercise of this right is the “correct” approach is another question—the answer to which might be affected by the availability of early and effective treatment for people carrying the virus. But whether or not the right choice seems clear, making the choice reflects and is part of one’s evolving individuality. It is the right of personal autonomy, the right to develop such individuality, that is at the heart of the freedom that the Fourteenth Amendment protects.<sup>38</sup> Like the decisions involved in *Cruzan* (the “right to die”), *Casey* (the right that previability abortion not be made criminal), and *Griswold v. Connecticut*<sup>39</sup> (the right to use contraception), deciding whether or not to know one’s medical diagnosis is a subject on which there are “intimate views with infinite variations, [which have a] deep, personal character.”<sup>40</sup> Like abortion and other decisions protected by Fourteenth Amendment rights to privacy and liberty, these decisions involve “the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy.”<sup>41</sup>

Even on a more basic level, cases like *Cruzan* and *Casey* are applicable here, because what is at issue is the right to make one’s own medical decisions. Whether we speak of the right to refuse medical treatment, as in *Cruzan*, or the right to obtain it, as in *Casey*, we are dealing with a constitutionally protected liberty interest. Mandatory testing eviscerates a woman’s right to make her own medical decisions, and requires instead that she submit to medical decisions made by the state.

The state should not be permitted to impose testing for disease, forcing a person to confront her health status, especially when the government has no compelling need for the information that the test will reveal. In the case of AIDS, a positive test will fundamentally and dramatically affect a mother’s life without serving any compelling or even important need of government.<sup>42</sup> Testing will not

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38. U.S. CONST. amend. XIV.

39. 381 U.S. 479 (1965). Justice Douglas concluded his opinion by recognizing that when the Court confronts family issues, “[w]e deal with a right of privacy older than the Bill of Rights—older than our political parties, older than our school system.” *Id.* at 486.

40. *Casey*, 112 S. Ct. at 2808.

41. *Id.* at 2807.

42. See Gostin, *supra* note 5, at 53 (“Compulsory screening in health care facilities . . . would not be an efficacious public health policy: there is little documented risk of occupational transmission; knowledge of a patient’s HIV-antibody test result would be unlikely to further decrease the already low risk; and screening would pose wholly disproportionate psychological and social burdens on the individual, and financial burdens on the [health care professional] and the health care facility.”).

prevent vertical transmission. A basic difficulty with the case for forcing testing, or even strongly encouraging it, is that no particular treatment may result from the diagnosis, and little direct benefit flows from learning the result.<sup>43</sup> Of course, that may change, and it was truer in the past than it has been recently. Today, treatments such as AZT and other drugs have become available that might be helpful to the mother during or directly after pregnancy. But such treatments are not available even to everyone who wants and needs them; they will not necessarily follow upon a diagnosis of AIDS, even in cases where they would be medically advisable.

#### IV. GOVERNMENT NEEDS AND PURPOSES

Why then does government take the position that it is better for persons to know their status if they are HIV positive? One common supposition is that persons will take greater precautions to avoid spreading infection if they know they are positive than if they do not. But that is not necessarily the case. Some people react to learning they carry AIDS with anger at being infected and a willingness or even desire to spread it to others.<sup>44</sup> There are stories like that of the notorious Gaetan Dugas, a Canadian airline steward also known as Patient Zero, who reportedly told his doctors that he would not give up unprotected sexual intercourse even though he knew he was HIV infected.<sup>45</sup> At the other extreme, many others who do *not* know their status *do* take precautions—both to avoid infecting themselves and to protect others from any infection they might carry. Indeed, many believe that such an attitude of universal precautions, to be exercised in all circumstances and without regard to one's HIV status, is the safer approach to adopt in confronting the AIDS dilemma. Public promotion of such an approach for all would accomplish far more than mandatory testing—either of the general population or of subgroups.<sup>46</sup>

Of course, when the subject of testing is pregnant women, government can argue it has purposes, and that testing has effects, which do not exist when the test is imposed on others in the popula-

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43. See Banks, *supra* note 5, at 369 (finding "[t]he practical value of routine HIV prenatal screening [to be] questionable").

44. See Marshall Forstein, *Understanding the Psychological Impact of AIDS: The Other Epidemic*, 4 NEW ENG. J. PUB. POL'Y 159, 166 (1988).

45. See Sullivan & Field, *supra* note 3, at 153 n.48.

46. See Field, *supra* note 24, at 59-60; see also Larry Gostin et al., *The Case Against Compulsory Casefinding in Controlling AIDS—Testing, Screening and Reporting*, 12 AM. J.L. & MED. 7, 20-21 (1987).

tion. And for some, pregnancy is indeed the special case that warrants mandatory testing.<sup>47</sup>

The principal effect one would expect from testing pregnant women is that those who learn they are HIV positive will consider whether to abort. Many health professionals and others believe that a woman should abort upon learning she is HIV positive, rather than take the approximately thirty percent chance of giving birth to a child who is infected.<sup>48</sup> The woman herself may, however, see things in a different light.<sup>49</sup> Indeed, when a woman learns that she has tested positive, she may look to the seventy percent chance of having a child who is not infected as a wonderful opportunity.<sup>50</sup> She may be encouraged in this attitude because it does not appear that pregnancy is harmful to the health of the HIV-positive woman.<sup>51</sup>

There is no evidence, then, that compelled testing will encourage abortion—an especially ironic state interest anyway, given the vehemence of the government's effort to discourage abortion in other contexts. As long as there continue to be no significant therapies or treatments for improving the life of the fetus or mother-to-

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47. See Jensen, *supra* note 25. Others favor routine, but not necessarily mandatory testing. See Marcia Angell, *A Dual Approach to the AIDS Epidemic*, 324 NEW ENG. J. MED. 1498, 1499 (1991).

48. The CDC, for example, has long taken the position that HIV-positive women should "delay" pregnancy. Centers for Disease Control, *Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome*, 34 MORBIDITY & MORTALITY WEEKLY REP. 721 (1985); see also Ronald Bayer, *Perinatal Transmission of HIV Infection: The Ethics of Prevention*, 32 CLINICAL OBSTETRICS & GYNECOLOGY 497, 499 (1989); John D. Arras, *AIDS and Reproductive Decisions: Having Children in Fear and Trembling*, 68 MILBANK Q. 353, 353-54 (1990).

49. Evidence suggests that HIV-positive women are not more likely to abort than others. See Peter A. Selwyn et al., *Knowledge of HIV Antibody Status and Decisions to Continue or Terminate Pregnancy Among Intravenous Drug Users*, 261 JAMA 3567 (1989).

50. Women who are HIV positive may desire to spend their final days producing a new life, even when childbirth may result in their death. For discussions of the issues involved when HIV-positive women consider abortion, and the different roles that race, class, and education can play in these deliberations, see Leroy Walters, *Ethical Issues in HIV Testing During Pregnancy*, in AIDS, WOMEN, AND THE NEXT GENERATION, *supra* note 15, at 274, 277-278; Ruth R. Faden et al., *Prenatal Screening and Pregnant Women's Attitudes Toward the Abortion of Defective Fetuses*, 77 AM. J. PUB. HEALTH 288 (1987).

51. Marie Louise Newell, *HIV-Infection in Pregnancy*, 4 AIDS 5111, 5112 (1990). *But cf.* Lindgren et al., *supra* note 15, at 1115 (opining that pregnancy has no effect on asymptomatic HIV but may accelerate HIV disease). At Newark Children's Hospital, physicians maintain that pregnancy is not dangerous to an HIV-positive woman if her T-cell count is high enough, but if the count is below 200, pregnancy is risky to her. Telephone Interview with Mary Jo O'Hara, National Pediatric HIV Resource Center (Nov. 3, 1992).

be when the pregnant woman is diagnosed as HIV positive, such testing will remain purposeless.

One of the problems with discussing the connection between mandatory testing and therapies that may help the pregnant woman and her fetus is that women have, until recently, been excluded from various AIDS studies.<sup>52</sup> Prior to 1990, those women who were permitted to participate were prohibited from being or becoming pregnant. Therefore, the treatment of pregnant women—either to preserve their own health or to reduce the rate of transmission to the fetus—was largely unexamined. In 1990, in response to criticism of this clear bias, a protocol study called AIDS Clinical Trial Group protocol was developed. Originally, the trial involved only treating newborns with AZT because of a reluctance to administer AZT to pregnant women. But thereafter the trial was altered so women in their third trimester of pregnancy would be given AZT, and the infant would continue to receive the drug for six weeks after birth.<sup>53</sup>

Women's groups harshly criticized this modification, claiming that women were only permitted to use AZT while pregnant if investigators felt the fetus would not be harmed.<sup>54</sup> Some elements of the scientific community agreed that the focus of the test should be on preserving maternal health, regardless of the effect on the fetus. The FDA reviewed the new proposal and decided that the focus of these tests should indeed be on women and not on risks to the fetus. Accordingly, Clinical Protocol 076 currently enables all pregnant participants to receive AZT. Moreover, all receive the drug throughout their pregnancy, rather than some merely receiving a placebo.<sup>55</sup> The effect of the AZT on either the woman or the fetus, however, has not yet been conclusively determined.

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52. See Ilise L. Feitshans, *Confronting AIDS in the Workplace: Balancing Employment Opportunity and Occupational Health Under Existing Labor Laws*, 1989 DET. C.L. REV. 953, 960 (noting that women "have been ignored by AIDS studies in the United States until recently"); Roy G. Spece, Jr., *AIDS: Due Process, Equal Protection, and the Right to Treatment*, 4 ISSUES L. & MED. 283, 309 (1988) ("Women and children might be excluded from AIDS studies because of possible tort liability concerns.").

53. See Deborah Cotton, *AIDS Clinical Research and Drug Regulation*, in *THE SOCIAL IMPACT OF AIDS* 31, 35 (National Academy of Sciences, 1991).

54. *Id.* In a preliminary study of 40 women given AZT during the third trimester, there were no cases of birth defects.

55. See FDA Clinical Protocol 076, *Phase 3 Randomized Placebo Controlled Trial to Evaluate the Efficacy, Safety and Tolerance of Oral AZT in Pregnant HIV-Infected Women and Their Infants* (19xx). (As of Mar. 3, 1993, only 642 of the expected 1496 patients had been found for the study.)



This is not to say that if therapies develop that could benefit the fetus—a drug that helped protect it from infection, for example—the pregnant woman should lose her right to decide whether to consent to treatment. Different issues would be posed if the therapy appeared harmless to the pregnant woman than if it seemed risky for her, but in either event, the mother's right to decide on appropriate treatment should continue unabated. A woman's right to control medical decisions that implicate her body and her health does not end because she is pregnant. She should be treated as an individual in her own right, and not simply as a vessel for fetuses. Nor should she be conceptualized as simply the conveyor of disease.<sup>56</sup>

Another possible scenario would exist if AZT or another drug administered during pregnancy to HIV-positive women proved beneficial to the mother but detrimental to the developing fetus. Again, I would contend that the choice whether to proceed belongs to the pregnant woman, and that the physician's obligation is simply to give her full and fair information to guide her decision. But if such a conflict between the interests of mother-to-be and developing child were shown actually to exist, some would doubtless favor taking account of the interests of the child-to-be in order to limit the pregnant woman's options. In any event, such an approach is inappropriate when no conflict between mother and child has been demonstrated.

When medicine develops a way to put the information that the patient is seropositive to good use—for the benefit of the patient or, in the case of a pregnant women, of her fetus—and when that medical advance is available to the poor as well as the rich, there will be more reason to encourage pregnant women to undergo testing. But even then, the choice should always remain with the pregnant woman.

## V. EUGENICS

Some would argue, however, that the government's usual anti-abortion stance is wrong, and that it should not be ashamed even to encourage abortion when the fetus has approximately a thirty percent chance of acquiring AIDS. The government would be "pro-

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56. See generally Field, *supra* note 1 (proposing a flat rule that women not be subject to governmental coercion because of pregnancy); Martha A. Field, *Pitting the Fetus Against Its Mother*, in 1 EMERGING ISSUES IN BIOMEDICAL POLICY: AN ANNUAL REVIEW (Robert H. Blank & Andrea L. Bonnicksen eds., 1992). See also Planned Parenthood of Southeastern Pa. v. Casey, 112 S. Ct. 2791, 2810 (1992); *In re A.C.*, 533 A.2d 611, 615-16 (D.C. 1987).

tecting" the child in the odd sense that it would be preventing it from being born, despite its seventy percent chance of being uninfected. Such a position would also save the substantial costs, usually borne by the government, that are associated with a child who has been born with AIDS.<sup>57</sup>

Indeed, some would favor even greater controls. Sterilization of HIV-positive women might also be encouraged,<sup>58</sup> or use of Norplant (an implanted contraceptive that prevents conception for about five years), or Depo Provera (a newly-approved and comparatively inexpensive contraceptive involving a shot that prevents pregnancy for about three months).<sup>59</sup> And why focus simply on *encouraging* abortion, sterilization, or the use of Norplant? Is there any reason that government could not *require* such measures, at least for the subset of HIV-positive women, if it is convinced that they should not reproduce? And if government can control HIV-positive women and prevent them from having children, then perhaps there *is*, after all, a use for mandatory testing and the information it would yield.<sup>60</sup>

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57. The cost of caring for HIV-infected infants has been estimated at one billion dollars annually. Howard L. Minkoff, *AIDS in Obstetrics*, 32 CLINICAL OBSTETRICS & GYNECOLOGY 421 (1989).

58. See Banks, *supra* note 5, at 371-72 (warning that "HIV-infected women may be coerced or directed to abort if pregnant or to be sterilized if of childbearing age"). Professor Banks also asserted that "[a] government policy which advocates sterilization through directive counseling of fertile HIV-infected women . . . is precisely the kind of interference with private decision making that *Skinner* and *Roe* attempt to prevent." *Id.* at 379.

59. See *supra* note 6 and accompanying text. Recent efforts to discourage poor and minority women from having children include the Bush administration's proposed policy of cutting off welfare for single mothers who have another child, announced in April of 1992 with the avowed aim of improving Bush's electability. Then-Governor Clinton as well, during the presidential campaign, spoke of a two-year limit on welfare and indicated that he would be willing to allow states to "experiment" with their welfare programs even by cutting off aid to poor women who continued to have children. See Linda C. Rehkopf, *Playing Politics of Resentment*, ATLANTA CONST., Apr. 18, 1992.

The stance of the former Bush administration on "encouraging smaller families" is especially ironic given its simultaneous campaign to deny legal abortions to poor people. In many cases, the result of these policies will not be preventing single mothers from having another child, but rather reducing the level of payments to her growing family. As long ago as 1970, the Supreme Court upheld a statute that had a similar effect on poor women. In *Dandridge v. Williams*, 397 U.S. 471 (1970), the Court upheld a limitation on the amount that families could receive under the Aid to Families with Dependent Children program regardless of family size.

60. Criminalization is another method that might be employed to coerce HIV-positive women not to have babies, or to punish them if they did. While it seems almost incredible that pregnancy could be made criminal for any subset of women, there are criminal transmission statutes today that would seem literally applicable to pregnancy. For example, Idaho's statute makes it a felony, punishable by up to 15 years in prison

In this way, mandatory AIDS testing is a step in the direction of government control of eugenics, and a step we should be reluctant to take. It represents our government inserting itself into decisions of reproductive choice—not in the *anti*-abortion stance we were most familiar with during the Bush and Reagan administrations, but as a promoter of abortion for reasons of cost efficiency and eugenics. This is a step toward a policy, increasingly a matter of concern as possibilities for allowing government control increase, of allowing government bureaucrats and statisticians to decide who can and who cannot parent.<sup>61</sup>

If persons with AIDS cannot parent, who else should be precluded? Surely drug addicts and incurable alcoholics would seem vulnerable to control, for their habits can and do harm their offspring, even before birth. Should persons who have abused children in the past also be excluded from parenting?<sup>62</sup> Persons with serious hereditary conditions such as cystic fibrosis or Huntington's Disease, and poor people, who, after all, might not be expected to provide as well for children as persons with a secure source of income?

A serious question to consider in connection with mandatory testing, then, is whether we want government participating in the

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and a \$5000 fine, to "expose another [to HIV] in any manner with the intent to infect." IDAHO CODE § 39-608 (Supp. 1992). While the statute was not enacted with pregnancy in mind, a woman could arguably be prosecuted under it if the pregnancy was intended. The defense, of course, would be that there is, presumably, no specific intent to *infect* the offspring, but only an intent to procreate. Still, a prosecutor might contend that knowingly exposing a fetus to the risk of HIV satisfies that element of the offense. Further, even if the pregnancy was not intended, the woman might possibly be prosecuted on the theory that when she *continued* the pregnancy knowing she was HIV positive, she satisfied the intent requirement. Missouri's statute explicitly uses a lower *mens rea* requirement, making it criminal to "deliberately create a grave and unjustifiable risk of infecting another with HIV through sexual or other contact when an individual knows that he is creating that risk." MO. ANN. STAT. § 191.677.1 (Vernon Supp. 1992).

61. Current issues involve whether the government should license surrogacy, as the state has traditionally done in the context of adoption, and whether the state should regulate who may parent through artificial insemination or *in vitro* fertilization. The United States government has generally avoided regulation in these areas, although the medical profession sometimes has provided its own controls that just as substantially limit parental choice. In other countries, Denmark for example, government limits who may use even simple reproductive technology like artificial insemination, although there are no government-imposed limits upon who can parent "naturally." Discussion with Danish participants at the Seventh World Conference of the International Society on Family Law, Motherhood and Fatherhood in a Changing Society, May 15, 1991, held at Opatija, Yugoslavia.

62. Cf. *People v. Pointer*, 199 Cal. Rptr. 357 (Cal. Ct. App. 1984) (holding that a condition of probation that included prohibition of conception for a woman convicted of child endangerment was overbroad).

abortion decision at all. In fact, this is a serious and troubling issue even when it is only government *encouragement* that is contemplated. And those who would strike the balance by favoring encouragement but not force must further decide at what stage encouragement slides into forbidden coercion.<sup>63</sup>

Government control could extend even beyond choosing who may parent. Genetic studies and other analyses may be performed on the fetus itself, and "inferior" fetuses can be flushed out, while "superior" ones are promoted. Through so-called advances in reproductive technology, the medical profession is achieving greater opportunities for knowledge about, and control over, what kind of persons will be brought into the world. Society is acquiring the opportunity to reduce the element of chance and replace it with planning and deliberation. Should we welcome these developments, or are they more threatening than beneficial? Even if they do present a welcome opportunity, how should we justly decide what types of people to allow or to encourage?

It is an interesting exercise to take a moment to contemplate what kind of people you would encourage if you were the decision-maker. Linus Pauling, a nobel laureate in chemistry, found it problematic

that the majority of donors [of semen for artificial insemination] are from a professional group [physicians] that, on the average, may have some desirable qualities, but that . . . is not the professional group that leads in intelligence (average IQ), and that failure to discuss the question of selection of donors may well be causing us to . . . reject[] an opportunity to improve the human race in a small but nevertheless significant way.<sup>64</sup>

Pauling called for legislation setting "certain minimum standards of health, desirable characteristics, and family history for donors."<sup>65</sup> But should there be only minimum standards? And how should any standards be chosen? Even if "intelligence" could be gauged, would that be the right measure? Happiness, or perhaps generosity, might be preferable, although we would have to research and de-

63. See *supra* note 62 and accompanying text. If the prohibition against conception had not been overturned on appeal and Pointer became pregnant, could the state have insisted on abortion?

64. Linus Pauling, *Reflections on the New Biology*, 15 UCLA L. REV. 267, 271-72 (1968). Pauling's comment on the medical profession was drawn from an observation of Hermann Muller.

65. *Id.* at 272.

bate whether those characteristics have any genetic component. Others doubtless will think of other characteristics they consider more important still.

These issues concerning positive eugenics may still seem remote today. *Negative* eugenics—eliminating the “unfit”—is, however, part of the current landscape.<sup>66</sup> For nearly two decades, controversy has raged over elimination of newborns who have disabilities.<sup>67</sup> The issue usually posed is whether parents have the right to decide not to provide treatment, on the theory that the child will have a poor quality of life and is essentially “better off dead.” During the Reagan administration, the White House attempted to eliminate parental and medical discretion not to treat a newborn for reason of its disability,<sup>68</sup> a move that was only partially successful.<sup>69</sup>

In other ways, however, government has encouraged elimination of newborns with handicaps. It has promoted prenatal diagnosis of some disabilities, especially those associated with mental retardation, by funding amniocentesis.<sup>70</sup> Moreover, public funds have been available for abortion more readily when the fetus is

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66. See John R. Harding, Jr., *Beyond Abortion: Human Genetics and the New Eugenics*, 18 PEPP. L. REV. 471, 478 (1991) (explaining that “[n]egative eugenics seeks to reduce or eliminate deleterious genes, while positive eugenics encourages desirable or superior traits”).

67. See generally Martha A. Field, *Killing “the Handicapped,”* 16 HARV. WOMEN’S L.J. — (forthcoming 1993).

68. The Reagan administration’s Baby Doe guidelines tried to accomplish this by applying § 504 of the Rehabilitation Act of 1973, 29 U.S.C.A. § 794 (West Supp. 1988), to the treatment of newborns with handicaps. See *Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers*, 47 Fed. Reg. 26,027 (1982); *Nondiscrimination on the Basis of Handicap, Interim Final Rule*, 48 Fed. Reg. 9630 (1983) (invalidated by *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983)); *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 49 Fed. Reg. 1622 (1984) (invalidated on technical administrative law grounds by *Bowen v. American Hosp. Ass’n*, 476 U.S. 610 (1986)). For a thorough discussion of the Reagan Guidelines, see U.S. COMM’N ON CIVIL RIGHTS, *MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES* 61-78 (1989). The Child Abuse Amendments of 1984, Pub. L. No. 98-457, and its implementing regulations, see 50 Fed. Reg. 14,878, extended and amended the Child Abuse Prevention and Treatment Act of 1978, to cover denial of medical treatment to disabled infants.

69. See U.S. COMM’N ON CIVIL RIGHTS, *supra* note 68, at 103-10 (finding a “likelihood of widespread denials of lifesaving treatment to children with disabilities that have continued since implementation of the Child Abuse Amendments of 1984 [*supra* note 68] on October 1, 1985”).

70. One recent study found that all 50 states pay for amniocentesis through their Medicaid programs. *Study Tracks Medicaid Payments for Abortions*, MOD. HEALTHCARE, June 4, 1990, at 12, 14.

handicapped.<sup>71</sup>

Even though the United States government has not *required* abortion when prenatal testing shows that the fetus will have disabilities, the steps it has taken to encourage prenatal diagnosis and abortion cross the line forbidding government interference in reproductive choice through encouragement of abortion. Our government has also thereby discriminated against persons who have disabilities, in violation of the Equal Protection Clause of the Fourteenth Amendment<sup>72</sup> and the Americans with Disabilities Act.<sup>73</sup> But although I consider such government conduct illegal and unconstitutional, it is widely practiced and has been little challenged to date.<sup>74</sup>

One issue therefore is whether government should ever get involved in reproductive control, either for the purpose of producing persons who are genetically "better," or in order to eliminate those it considers least fit. Moreover, if wholesale governmental involve-

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71. By labeling abortion for disability as "medically necessary"—defined to include those where "the fetus is physically deformed, mentally deficient, or afflicted with a congenital illness"—Iowa provides otherwise unavailable funding to cover such abortions. 1991 Iowa Legis. Serv. 270 § 103 (West). Virginia pays for abortions through its state medical assistance fund when "the fetus will be born with a gross and totally incapacitating physical deformity or with a gross and totally incapacitating mental deficiency." VA. CODE ANN. § 32.1-92.2 (Michie 1982). Similar provisions have been proposed, but not yet passed, by several other state legislative bodies. See, e.g., 1991 Mo. H.B. 75 (authorizing Medicaid payment for abortion when there is "severe fetal deformity" or when the pregnant woman tests positive for HIV); 1991 Tenn. H.B. 1522. A 1988 study predating the Iowa law found that 13 states paid for abortion for fetal handicap. See *Study Tracks Medicaid Payments for Abortions*, *supra* note 70.

72. U.S. CONST. amend. XIV, § 1.

73. 42 U.S.C. §§ 12101-12213 (Supp. II 1990). See Field, *supra* note 67.

74. Indeed, more persons have objected to government *restrictions* on the ability to abort fetuses deemed disabled than to government encouragement of abortion in this context. Some have argued that a state that bans postviability abortion must nonetheless make an exception when the pregnant woman learns her fetus will have a serious disability and that such a woman has a constitutional right to abort and to choose not to have a disabled child. See Curt S. Rush, Note, *Genetic Screening, Eugenic Abortion, and Roe v. Wade: How Viable is Roe's Viability Standard?*, 50 BROOK. L. REV. 113, 142 (1983). My position, by contrast, is that the state cannot permissibly make abortion for disability any easier to obtain than any other elective abortion, and that to do so violates both the Equal Protection Clause and the Americans with Disabilities Act. Field, *supra* note 73. This position would invalidate even rather common statutory rules allowing abortion for "fetal deformity." While the position was crafted with other disabilities in mind, it suggests as well that any rules making it easier to abort HIV-infected fetuses than others would be unconstitutional; if government wants women to be allowed to abort because they are HIV positive, it must make elective abortion available to all. Only in those cases where the pregnancy poses a risk to the health of the mother-to-be, see *supra* text accompanying notes 54-56, should the abortion be considered a "therapeutic" one that must be available to the pregnant woman.

ment is eschewed and few are to be encouraged or forced to abort, why should AIDS-infected women be the group that is controlled? After all, a person in that group has a seventy percent chance of having a noninfected baby. Furthermore, she may have a partner who is willing and able to provide well for their offspring, even when she becomes ill or dies.

## VI. THE INEFFICACY OF MANDATORY CONTROLS

Even apart from issues of the rights of the women who would be tested, a powerful argument against imposing testing on particular groups, like pregnant women, is that testing will not work to slow the spread of HIV, or to accomplish any other legitimate government purpose. Not only is universal precautions a more effective approach than the vain effort to sort the population into infected and uninfected segments, but also the attempt to impose testing on women who do not want it will be counterproductive. If forced testing becomes part of prenatal care, it will drive pregnant women who do not want to be tested away from the other components of prenatal care as well. They will be less able to make intelligent decisions during pregnancy and protect the health of their potential offspring.<sup>75</sup> If testing is a condition of admission to the hospital, when women learn of that fact, then women who do not want to be tested will simply give birth elsewhere under less safe conditions.

Indeed, money spent on imposing mandatory testing could be put to much better use by providing free prenatal care for women who cannot otherwise obtain it, and on developing other prenatal health strategies.<sup>76</sup> Such steps would do far more to protect the health of the next generation than mandatory testing of pregnant women ever could.

Accordingly, it is difficult to justify imposing testing—either upon pregnant women, or upon other populations that might be targeted. Even apart from any civil liberties concerns, forced testing is a misuse of resources and is counterproductive. In deciding whether to impose testing, society is not choosing *between* the public health and our civil liberties, although the issue is often so framed

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75. See Banks, *supra* note 5, at 370-72.

76. In other contexts, screening infants for diseases has actually thwarted continued research on the disease, as public funds were channeled instead into the testing. See Katharine L. Acuff & Ruth R. Faden, *A History of Prenatal and Newborn Screening Programs: Lessons for the Future, in AIDS, WOMEN, AND THE NEXT GENERATION*, *supra* note 15, at 59, 66 (discussing effects of mandatory screening programs for syphilis, PKU, sickle cell disease, Tay-Sachs, neural tube defects, and Hepatitis B).

by proponents of coercive controls. Both public health *and* civil liberties are harmed by coercive state action. In addition to the futility of mandatory controls, the threats to civil liberties are enormous. These range from abandoning informed consent and coercing medical testing or treatment, to making special regulations to govern AIDS, and to promulgating special rules to govern pregnant women, to name but a few of the varied possibilities.<sup>77</sup> The threats loom even larger when one bears in mind the slippery slope that exists, not only between the different groups of people who might be subjected to AIDS testing, but also concerning the variety of conditions or traits that might be tested for—or even forcibly treated.<sup>78</sup>

The right time to cut off this movement toward coercive governmental decision making, and the concurrent loss of individual decision making, is at the outset. Individuals should not be subject to coercion concerning medical decisions—*no* individuals.<sup>79</sup> Nor should AIDS or pregnancy be the occasion for special coercive legal rules.

## VII. TESTING THE NEWBORN

Even if the pregnant woman's right not to know does protect her from having testing forced upon her, the issue of whether she can prevent the testing of her newborn at birth still remains. One consequence of the test will be that it reveals *her* HIV status. In fact, testing the mother is the *only* immediate effect of tests performed

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77. See generally Gostin, *supra* note 5, at 35-42. Professor Gostin concluded: [T]he justifications for fully informed consent to HIV testing, then, are that it respects a patient's autonomy and privacy in law, it complies with the well-accepted clinical standards of care, and it maintains the ethical integrity of the medical profession and the dignity and worth of the patient.

*Id.* at 42.

78. For the moment, most fetal conditions that can be detected are either not treatable during pregnancy, or treatment is highly experimental and, accordingly, could not be forced upon a woman who declined to consent to it. But unless the law embodies principles protecting women's rights to make their own medical decisions during pregnancy, such women may become subject to forced operations as science develops ways to treat the fetus *in utero*. Society should be able to develop medical knowledge and the opportunity for the treatment of fetuses without thereby coercing women to submit to it.

79. What about "the incompetent"? I believe far too many individuals are considered to be in that category and that more persons should have control of more of their own decisions. However, there are some who cannot in any way understand the decisions being made or express any preference. Whether the state or a substitute decision-maker should then have control of the decision is a matter of hot dispute. See *Conservatorship of Valerie N.*, 707 P.2d 760 (Cal. 1985) (en banc) (holding that a state law barring sterilization of persons under a conservatorship impermissibly interfered with their privacy and liberty interests).



shortly after birth. All babies born of HIV-positive mothers test positive for the virus at birth,<sup>80</sup> even though less than a third of them will ultimately prove to be infected.

The only tests much in use until very recently check for the presence of HIV-related antibodies in the individual's blood. During the third trimester of pregnancy, however, the mother transmits her antibodies to the fetus in order to provide it with the protection from infection it will need once born. These antibodies remain in the infant for as long as fifteen to twenty-four months after birth. Therefore, a test for this antibody in the infant (usually the enzyme-linked immunosorbent assay or ELISA test) will be positive until the mother's antibodies disappear. Under that test, the infant will test positive at birth and for approximately a year and a half thereafter, regardless of whether the infant is one of the thirty percent actually infected with the virus.<sup>81</sup>

Recently, several tests have been developed that can determine much earlier whether an infant has the virus, although still not reliably until a few months after birth.<sup>82</sup> Current technology is develop-

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80. See Martha M. Curley, Note, *Establishing Relief for the Most Innocent of All AIDS Victims: Liability for Perinatal Transmission of AIDS*, 28 J. FAM. L. 271, 275 (1989/1990) ("Antibodies are transmitted to the fetus in every case, and half of the babies who test positive to HIV are born with visible signs of clinical illness.").

81. See Field, *supra* note 24, at 98-99.

82. There are currently several other kinds of tests—for markers other than HIV seropositivity. They still cannot detect whether the infant has the virus immediately after birth, but they can as early as three to six months.

First, the *HIV Culture Test* works by extracting blood from the infant and then using this blood to attempt to grow the virus. If the virus is detected, the infant is infected. (The specificity of the culture is almost 100%.) If the result is negative, however, there is still at least a 5-10% chance that the infant may be infected. When this culture is taken at birth, the sensitivity drops to less than 50%. Moreover, results are generally not available for two or three weeks, because it takes that long to grow the virus. The chief problems with the HIV Culture Test are this time lag and its expense.

A second test, called the *Polymerase Chain Reaction* (PCR), works by determining whether or not viral DNA exists in the infant's blood; if viral DNA is detected, the child is almost certainly infected, as long as the test has been performed in an experienced laboratory. This test also is usually conducted when the infant is three to six months old. Like the HIV Culture, it is less sensitive during the first few months of life but highly sensitive (greater than 90%) by three to six months of age. The PCR is quicker to perform than the HIV culture; the results can be obtained within forty-eight hours. Because samples are often batched, however, the turnaround time is typically several days.

The PCR is likely soon to become the preferred method of early diagnosis. It is already becoming more widely used and can be performed by some commercial laboratories. Within the year, a kit for HIV diagnosis using PCR is likely to be available.

The *P-24 Antigen Test* is a third test. It works by looking at the infant's blood for the presence of P-24, a protein component of HIV. This test is limited by rare false positive results that can occur in the first few weeks after birth, and by its low sensitivity. A recent modification of the P-24 Test has significantly improved the test's sensitivity,

ing rapidly. At present, nearly all infected infants can be identified by the time they are three to six months old.<sup>83</sup> Moreover, the new types of tests—once both prohibitively expensive and capable of being performed only at a limited number of laboratories—are becoming more generally available. Unless an infant has received a transfusion or another procedure that could have transmitted the HIV virus, these tests will still have the effect of indirectly revealing the HIV status of the mother. (Fewer mothers will be shown to be positive than previously, because only the infants actually infected will test positive, so the status of only about thirty percent of the mothers who are themselves positive will be revealed.)

Some would require the testing of newborns even during the period when the test would disclose only the mother's HIV status (a period ranging from the first three months to the first fifteen months of the child's life, depending on the test utilized). After all, the arguments for the mother's bodily integrity and for her right to decide her own medical course, which weighed toward deferring to her during pregnancy, no longer apply after the child is born. The mother is no longer the one on whom the test will be performed.

But the right a mother has traditionally had that *does* require deference to her at this stage is her right to decide upon the medical treatment of her child.<sup>84</sup> Usually parents are asked to consent to medical procedures performed on an infant, and physicians who treat children without parental consent expose themselves to liabil-

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without apparent loss of specificity. See Steven A. Miles et al., *Rapid Serologic Testing with Immune-Complex-Dissociated HIV p24 Antigen for Early Detection of HIV Infection in Neonates*, 328 NEW ENG. J. MED. 297 (1993).

Another test, called the *IGA Antibody Test*, works by detecting a particular type of antibody which the infant herself will begin to develop to combat the virus; it is an antibody that does not cross the placenta. This test is hopeful because it can be easily performed at commercial laboratories—rather than only at university research facilities—and can be performed more inexpensively than the others. The test is not useful before six months of age, however. Though IGA detection is very specific, it is also highly insensitive in the first few months of life. Interview with Mary Jo O'Hara, *supra* note 15; Conversations with Dr. Robert Husson, Children's Hospital, Boston, MA, Feb. 1993.

83. See Conversations with Dr. Husson, *supra* note 82.

84. If the father is involved in the decision-making process and he disagrees with the mother, the state might accept his consent in place of the mother's in order to test and protect the child. See *Hodgson v. Minnesota*, 497 U.S. 417, 454 (1990) (stating that "[i]n virtually every state, the consent of one parent is enough . . . to submit [a child] to any medical or surgical procedure other than an abortion" and to permit the child to participate as a subject in most forms of medical research); see also 45 C.F.R. §§ 46.404-05 (1988).

ity.<sup>85</sup> A parental refusal to consent to a proposed medical procedure will be overridden only if the procedure is greatly needed by the infant and the withholding of parental consent is highly unreasonable.<sup>86</sup>

Proponents of AIDS testing of newborns, however, point to mandatory programs for screening newborns for phenylketonuria (PKU), which are widely accepted. Parental consent has not always been considered necessary for PKU screening. PKU is a hereditary metabolic disorder that has an incidence of approximately 1 in 12,000 to 15,000 live births.<sup>87</sup> It is characterized by the development of severe mental retardation; ninety-five percent of those affected have IQs of less than fifty. Unlike HIV, PKU is not fatal; nor is it transmitted vertically.

Most significantly, unlike HIV, early treatment of PKU actually prevents the development of retardation in ninety-five percent of the infants treated.<sup>88</sup> Moreover, the treatment is comparatively simple. It involves restricting the infant's intake of phenylalanine (found in a few foods, like fava beans) beginning before the infant is four weeks old. Given the low cost, safety, and accuracy of the PKU test, as well as the availability of very simple and effective treatment for this disease, forty-three states established mandatory testing programs during the decade following the development of PKU testing.<sup>89</sup>

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85. *Bonner v. Moran*, 126 F.2d 121, 122-23 (D.C. Cir. 1941) (remanding an assault and battery action for new trial so that the jury could be instructed that the consent of a parent, not that of her 15-year-old son, was necessary before the defendant plastic surgeon could legally remove a skin patch from the son for the benefit of his cousin).

86. *See, e.g., State v. Perricone*, 181 A.2d 751, 759 (N.J. 1962) (finding that while the "appellants evidenced sincere parental concern and affection for their child [...] courts have held that the refusal of parents, on religious grounds, to submit their infant child to a blood transfusion necessary to save its life or mental health amounted to statutory neglect"), *cert. denied*, 371 U.S. 890 (1962); *People ex rel. Wallace v. Labrenz*, 104 N.E.2d 769, 774 (Ill. 1952) ("Neglect . . . is the failure to exercise the care that the circumstances justly demand. It embraces wilful as well as unintentional disregard of duty."), *cert. denied*, 344 U.S. 824 (1952).

87. *See Lori B. Andrews, Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 *Hous. L. Rev.* 149, 168 (1992) (noting that "all states have newborn screening programs which screen every infant for phenylketonuria" and reiterating the risk of the disorder actually striking any particular child as, at most, 1 in 12,000).

88. *See Acuff & Faden, supra* note 76, at 64.

89. *Id.* at 65. The first state to begin a voluntary screening program was Massachusetts. That early effort was very successful. Yet, in spite of the widespread testing that was conducted during the voluntary regime, Massachusetts was also the first state to adopt a mandatory screening program, due largely to pressure from the National Association for Retarded Children and certain state health officials.

In many respects, PKU screening serves as the paradigm for a procedure to which parents cannot effectively withhold consent. Early treatment is simple and works to eliminate the harm associated with the disease, while nontreatment of the infected child results in a near-certainty of serious disability.

It is a much more difficult judgment whether AIDS testing, on the other hand, satisfies requirements for overriding parental refusal of consent. The current balance of benefits and burdens that will result from a mandatory test suggests that it is still reasonable for a parent to refuse AIDS testing and early treatment—more reasonable than it would be in the case of PKU.

As benefits of early knowledge of HIV status increase, many more mothers will consent voluntarily to testing, as long as care is available for their children. When therapy is both effective and available, society will have to face the question whether denial of the medical benefits that would result from testing is abusive, so that parents are not permitted to deny consent.<sup>90</sup> We are not yet there, in terms of either effectiveness or availability of therapy, but there are more benefits from early detection than there were a few years ago.

In making judgments about how reasonable it is for parents to refuse consent to testing, it is important to weigh in negative social and economic effects of learning HIV-positive status. We also must differentiate between the period, shrinking though it is, in which the test will reveal only the mother's HIV-infection status and the period when the infant's own status can be tested. The important difference is that, *as a group*, newborns who test positive during the first period (about seventy percent of whom are not really infected) will not benefit from aggressive treatment from birth. Indeed, AZT—the most frequently used treatment for AIDS—can cause severe toxic effects.<sup>91</sup> Thus, it is both dangerous and wholly without benefit to those infants who are not infected but still test positive.

Part of the puzzle about whether HIV-positive parents should be compelled to consent either to testing or to immediate treatment

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90. And if consent to testing is to be forced, should it be forced upon all parents of newborns—or only on women known to be HIV positive? See *infra* Part IX.

91. See Douglas D. Richman et al., *The Toxicity of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-Related Complex: A Double-Blind, Placebo-Controlled Trial*, 317 *NEW ENG. J. MED.* 192, 193 (1987) (finding treatment-associated toxic effects, including nausea, headaches, myalgias, and anemia); Rhoda S. Sperling et al., *A Survey of Zidovudine Use in Pregnant Women with Human Immunodeficiency Virus Infection*, 326 *NEW ENG. J. MED.* 857 (1992). Cf. Tierney, *supra* note 2, at 482 (noting that “people taking AZT often show increasing viral resistance to the drug”).

for their newborns is the traditional position of our legal and medical systems that parents should not even be able to consent to medical procedures to be performed on their child when any expected benefit is not really for the child herself. It is considered inappropriate to use the child for the benefit of another person or for the benefit of society as a whole.<sup>92</sup> Adults can and often do consent on their own behalf to be research subjects out of altruistic motives—or to donate bone marrow or a kidney to a loved one—but it is much more troublesome when a parent agrees for her child to be so used.<sup>93</sup>

But the relevance of that doctrine is not obvious in the context of neonates with HIV-positive mothers. There is, after all, a thirty percent chance that the child will benefit from current treatment. Perhaps the uncertainty and the gambling character of whatever decision is made during this period suggest the wisdom of adhering to traditional practice and deferring to parental discretion.

In 1990, one set of authors summarized the balance of considerations thus:

Currently, and for the foreseeable future, programs of newborn screening are de facto programs testing for HIV

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92. For a sampling of the debate surrounding this issue, see generally PAUL RAMSEY, *THE PATIENT AS PERSON* 14-15 (1970) (arguing that while no one should be able to give consent for a child to undergo “[n]ontherapeutic, nondiagnostic experimentation,” parents may have consented to Salk polio vaccine testing of a healthy child because it was a potentially “therapeutic” procedure used to combat “epidemic conditions”); Richard McCormick, *Proxy Consent in the Experimental Situation*, in 18 *PERSPECTIVES IN BIOLOGY AND MEDICINE* 2, 14 (Autumn 1974) (maintaining that “when a particular experiment would involve no discernible risks, no notable pain, no notable inconvenience, and yet hold promise of considerable benefit,” vicarious consent is permissible. But consider that, under this analysis, parental consent to a kidney transplant from one three-year-old to another lacks moral justification). See also Charles Fried, *Children as Subjects for Medical Experimentation*, in *RESEARCH ON CHILDREN* 107 (J. van Eys ed., 1978); Additional Protections for Children Involved as Subjects in Research, 48 Fed. Reg. 9814 (1983) (discussing regulations governing research on children).

93. See *Curran v. Bosze*, 566 N.E.2d 1319 (Ill. 1990) (surveying decisions of several states regarding whether consent by court, parent, or guardian to the removal of a kidney from a child or an incompetent person for transplantation to a sibling is legally effective, and finding that the key inquiry is whether or not such removal is in the donor’s best interest). The position taken in *Curran* is not necessarily decisive in the AIDS context, though. A parent might decide that testing may be of some benefit to her child since her child does have a 30% chance of being infected. The parent might reason that the benefit that would adhere if this 30% probability became a reality outweighs the harms that would occur if the child were not infected. It is the significance of these opposing factors that makes the parent’s decision a reasonable one whatever she decides, and prevents such parental choices from being overridden. If the parental motive were purely altruistic, and without possible benefit to the child, parental consent would probably not be considered legitimate.

infection in the mother, not the infant. . . [N]ewborns and their mothers are a family unit; when HIV-infected mothers experience social or institutional discrimination, their infants suffer as well. Human immunodeficiency virus-positive newborns—70% of whom are not themselves infected—face the further risk of being abandoned by their mothers, difficulties with adoption and foster home placements, and difficulties in access to day care.

At present, the expected benefits to newborns from HIV testing do not clearly outweigh these risks or the privacy and autonomy interests of their mothers. Although there are few experimental data on this point, we are persuaded that for the approximately 30% of newborns who are infected, the prospects for medical benefits are significant and would be enhanced by early identification of “at risk” status. Currently available benefits include the prevention or delay of death through *Pneumocystis carinii* pneumonia prophylaxis and the prospect that antiviral treatment may lengthen and improve the quality of life, particularly with regard to cognitive development. However, for the approximately 70% of newborns who would be identified as being at increased risk because maternal antibodies are detected but who turn out not to be infected, the benefit-to-harm calculus may well tip in the opposite direction. For both groups of newborns, access to adequate medical care is by no means guaranteed. Where the interests of newborns are so difficult to discern and evaluate, there is no moral justification for substituting the judgment of the state or the health professional for that of the parent.<sup>94</sup>

But even at that early date, some balanced the risks differently. At least one state provided by statute that parental consent rules change when HIV is at issue. In 1989, Rhode Island enacted a law providing that, despite its requirement of particularized informed consent for HIV testing in most settings, an HIV test may be performed at the discretion of the health care provider on any patient less than one year old without any consent.<sup>95</sup> North Carolina allows such testing but only when a “parent or guardian has refused to consent to such testing and there is reasonable suspicion that the minor has AIDS virus or HIV infection or that the child has been

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94. Working Group on HIV Testing of Pregnant Women and Newborns, *supra* note 31, at 2418-19.

95. See R.I. GEN. LAWS § 23-6-14(a) (1989).

sexually abused."<sup>96</sup>

Even if it is accepted that parents have discretion to refuse consent to testing or treatment during the period when it is not possible to tell whether the particular infant is actually infected, the dilemma becomes more difficult when the child can be accurately tested for her *own* status. Perhaps the most crucial variable bearing upon the reasonableness of a parent's refusal to consent even at this stage is the degree of medical benefit that will flow from the intervention. Not only advances in diagnosis but also advances in therapy have been occurring rapidly.

Today we know there are clear benefits to neonates from early detection and treatment. More early therapy is administered than in the past. Asymptomatic infants do not receive AZT,<sup>97</sup> but infected infants with below age-normal T-4 cell counts usually are treated with AZT.<sup>98</sup> Moreover most infants born to women known to be HIV infected are given different types of inoculations than other children, and their T-cell count is monitored regularly. These treatments carry little risk to infants who are not in fact HIV positive while they benefit those who are infected.

In addition, most infants born to women known to be HIV infected do receive Bactrim, an antibiotic, until the HIV-infection status and immune status of the infant are determined. The purpose is to help those who are infected ward off pneumocystis pneumonia (PCP). This type of pneumonia is the major lethal complication of pediatric HIV infection. An ethical dilemma concerning mandatory testing does exist because PCP is highly preventable with treatment, but treatment is only administered when the mother or child is identified as HIV infected. Moreover PCP prophylaxis seems clearly sound and beneficial. Improved neurologic function has clearly been demonstrated in response to antiretroviral treatment. Most agree that antiretroviral therapy prolongs life and prolongs the period without disease in asymptomatic adults. Measurable effects of AZT have been the same in children as in adults, although placebo-controlled trials in children have not been done (and will not be).<sup>99</sup>

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96. N.C. GEN. STAT. § 130A-148(h) (1989 & Supp. 1991). *See also* LA. REV. STAT. ANN. § 40:1300:13(F)(6) (West Supp. 1992) (allowing testing of children without parental consent when the attending physician deems it necessary to properly diagnose or treat the child).

97. *See supra* notes 53-55 for a discussion of FDA Clinical Protocol 076, in which infants born of HIV-infected women do receive AZT for the first six weeks of life.

98. *See* Conversations with Dr. Husson, *supra* note 82.

99. *Id.*

These facts about available therapies increase pressure to cut off the requirement that parents consent before identified testing occurs. The availability of therapy makes decisions about mandatory testing more difficult than they were a few years ago. Moreover, the balance of advantages may change rapidly. At some point the medical profession may be able to demonstrate that the clear benefits available to the child who tests positive outweigh the economic and societal disadvantages that such a diagnosis may impose upon him. Certainly, if treatment options develop so that reasonable persons would not differ as to whether it was to the clear advantage of the child to know her status and proceed with available treatment, parents might not be permitted to block testing and resulting treatment,<sup>100</sup> just as they cannot block PKU testing. But we have not yet arrived at that scenario.

As long as reasonable persons can differ as to the proper course of treatment, the state should not intrude on the decisions of parents. It is important to note that it is *a* reasonable decision that is required here—not *the* reasonable one, or the one that seems best. The decision need only be within the realm of rational choice, for the parent's choice to be followed. It is only in extreme circumstances that government choice replaces parental choice. Pediatric AIDS is a serious problem and needs to be combated, but this fact should not be used to make inroads upon our longstanding rules concerning parental authority. Today the medical benefits deriving from testing are not so compelling that a parental decision not to take the risks involved is an abusive decision, warranting forcible displacement of parental authority under prevailing principles of child abuse.

#### VIII. DEVELOPING APPROPRIATE TREATMENTS

In part *because* parental refusal of consent is so reasonable, it has been difficult to develop conclusive information about which treatments *will* be beneficial to newborns. It is crucial to know both what will help those who are infected and which procedures will be harm-

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100. Most courts have refused to intervene to override parental objections when the health problem at issue is not life threatening. Compare *In re Seiferth*, 127 N.E.2d 820, 823 (N.Y. 1955) (finding that a court "has power in *drastic* situations to direct [an] operation over the objection of parents" (emphasis added)) with *In re Sampson*, 317 N.Y.S.2d 641, 654 (N.Y. Fam. Ct. 1970) (concluding that the court's power is not limited to "drastic situations"), *aff'd*, 328 N.Y.S.2d 686 (1972). Similarly, an advantage that comes to the child from treatment but that will not actually save or very significantly prolong the child's life might not be considered significant enough to warrant the extraordinary step of overriding parental consent.



ful to the seventy percent who are seropositive but not in fact infected. Moreover, we need to develop knowledge and strategies to avoid those harms.

Without testing and experimentation on newborns and their use as research subjects, it is difficult for drugs to be approved for infants. And if the drugs are not approved, doctors may risk personal liability in prescribing those drugs for infants, even if parental consent has been given. Without such experimentation, it is difficult to accumulate medical knowledge that could be beneficial to such children. The research already done in the AIDS area involves primarily gay, white, adult males, and may or may not be applicable in this very different context.

Today many children are enrolled in clinical trials concerning treatment for HIV. Better medical treatment is expected to develop as a result, which will benefit seropositive infants as a group. Nonetheless, a reluctance to experiment with newborns or to consent to yet-untried treatments on one's own child is extremely understandable and is well within parental authority.<sup>101</sup>

Developing appropriate drug treatments and other therapies for infants poses yet another ethical dilemma. Many children who test positive for HIV are abandoned or orphaned and then are placed in group homes or in foster care. Often the state acts *in loco parentis* for these children. Should the government be permitted to consent to aggressive treatment of those children? One advantage is development of more information on the proper medical course for seropositive children. However, there are obvious objections to government harvesting a population of research subjects by way of the foster care system. Drug testing using children as subjects must not be limited to or consist primarily of this group of children, as might occur with broad governmental consent for its wards. Certainly, during the period when there is a seventy percent chance that

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101. Similarly, comparatively little research has been done on the effect of various treatments on HIV-positive pregnant women because of a reluctance to experiment at a time when the fetus might be harmed and when medical personnel might subject themselves to liability. On current efforts to include consenting pregnant women in more clinical trials, especially those involving drugs that might prevent transmission of the virus to the fetus, see Deborah Cotton, AIDS, Clinical Research and Drug Regulation (work in progress for the National Academy of Sciences Panel on the Social Impact of AIDS).

For an excellent discussion of the myriad ways in which the needs of women, pregnant or not, in relation to the AIDS epidemic have been neglected, see Nan D. Hunter, *Complications of Gender: Women and HIV Disease*, in AIDS AGENDA EMERGING ISSUES IN CIVIL RIGHTS 5 (Nan D. Hunter & William Rubenstein eds., 1992).

any treatment will not be beneficial to the particular child, governmental consent to such experimental treatments is problematic.

### IX. TARGETING

Another extremely difficult issue has been raised in the development and administration of our AIDS policies—the issue of targeting. The economic impossibility of universal, identified testing or even of large-scale identified testing of low-prevalence groups, and the consequent necessity of targeting in any such testing, are still further reasons why mandatory testing is unacceptable.

There is an alternative: universal, *anonymous* testing. Some states have tested all infants on an anonymous, unidentified basis, thereby compiling useful data about the incidence of AIDS.<sup>102</sup> It is not the universal testing itself that is economically impossible but the post-test counseling. In addition, pre-test counseling imposes very large costs when informed consent is required. Anonymous, unidentified testing avoids these costs and can be administered even universally,<sup>103</sup> but those tested also do not obtain treatment benefits.

Universal identified testing for HIV infection, where those tested will learn of their status and have opportunities for treatment, could not work efficiently.<sup>104</sup> Indeed, any large-scale identified testing of low-prevalence populations is unlikely to work. Money spent in such testing would be much better spent in some other way to fight the AIDS epidemic.

The experience in Illinois, when the state required AIDS testing as a precondition to obtaining a marriage license, illustrates this point. The Illinois statute required that both members of a couple be informed of either one's HIV status, but it did not prohibit marriage based on a positive result.<sup>105</sup> During 1988, the program's first

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102. See, e.g., Lawrence Feinberg, *D.C. to Test Newborns, Clinic Patients for AIDS*, WASH. POST, Aug. 18, 1988, at D5 (noting a District of Columbia plan to conduct mass, anonymous testing for AIDS of all infants born in the city during one month, as part of a federally financed, multistate program to track the spread of the disease); Robert Steinbrook, *State Proposes Anonymous Testing of Infants for AIDS*, L.A. TIMES, Jan. 15, 1988, at 1 (noting similar testing in California and New York).

103. See Conversations with Dr. Husson, *supra* note 82.

104. See Price, *supra* note 3, at 446 (noting that universal testing might be "a methodology for ensuring precise and accurate data on the developing epidemiology of the disease" but admitting that "[r]ealistic proposals, however, are targeted at specific populations"); H. Rutherford Turnbull, III et al., *Mandatory AIDS Testing for Persons with a Developmental Disability in Residential Facilities*, 39 U. KAN. L. REV. 585, 602-03 (1991) (finding universal testing "inappropriate" as "both under and over inclusive").

105. ILL. ANN. STAT. ch. 40, para. 204(b) (Smith-Hurd 1934 & Supp. 1992).

year in existence, only one in 7000 people tested was found to be HIV positive, at an estimated total capital cost of \$5.6 million.<sup>106</sup> This translated into a cost of \$243,000 in order to identify each person testing HIV positive through that program.<sup>107</sup> The effect of the Illinois law, and the fact that the cost of the testing was passed on to the individuals who were tested,<sup>108</sup> discouraged some people from marrying at all, and encouraged others to marry out of state.<sup>109</sup> After a year and a half, Illinois repealed the statute.<sup>110</sup>

There is no evidence that pregnant women have any higher percentage of AIDS than the general population. There is no reason to think mandatory testing of that group would be any more effective than the mandatory premarital testing in Illinois. When politicians argue otherwise, it is invariably for political reasons, not for any real health care objective. Accordingly, even when a statute provides for mandatory testing of pregnant women, as does the Florida statute,<sup>111</sup> in practice it is applied only to so-called high-risk groups.<sup>112</sup>

106. Telephone Interview with Jeff Johnson, Legislative Liaison, Illinois Department of Public Health (Jan. 20, 1989).

107. *Id.* The Chicago Tribune estimated the cost at \$228,000 per positive test result. *Repeal the Premarital AIDS Test Law*, CHI. TRIB., Jan. 6, 1989, at 18, col. 1. (editorial).

108. While the average cost per test was \$35, the Illinois Department of Health has anecdotal information that physicians were charging as much as \$125 for testing and certification. Interview with Jeff Johnson, *supra* note 106.

109. See Field, *supra* note 24, at 75-76.

110. Daniel Egler & Rick Pearson, *Premarital AIDS Test Law Repealed*, CHI. TRIB., Sept. 12, 1989, at 1, col. 5.

Because universal identified testing does not work in the area of AIDS research, and because it wastes money, almost no programs attempt it or force testing on low-prevalence populations. The exception is the United States military, which has, by far, the largest HIV testing program in the world. It spends hundreds of millions of taxpayer dollars to test applicants and active duty personnel, finding a 1.4 and 1.3 per thousand seroprevalence rate, respectively. For a discussion and critique of the military testing program, see Field, *supra* note 24, at 75-76 (citing Centers for Disease Control, *Trends in Human Immunodeficiency Virus Infection Among Civilian Applicants for Military Service—United States, October 1985-March 1988*, 37 MORBIDITY & MORTALITY WEEKLY REP. 677 (1988)); Centers for Disease Control, *Prevalence of Human Immunodeficiency Virus Antibody in U.S. Active-Duty Military Personnel, Apr. 1988*, 37 MORBIDITY & MORTALITY WEEKLY REP. 461 (1988).

111. See *supra* note 19.

112. Such discrimination in application is unconstitutional to the same extent as if the discrimination were part of an enacted statute, according to the venerable precedent of *Yick Wo v. Hopkins*, 118 U.S. 356 (1886). However, such discrimination may be hard to prove because the Supreme Court often requires a showing of intent to discriminate if the discrimination is not apparent on the face of the statute. The Court also requires a desire to discriminate on the part of the government before unconstitutionality will be found. See, e.g., *Personnel Adm'r of Mass. v. Feeney*, 442 U.S. 256 (1979); *Village of Arlington Heights v. Metropolitan Housing Dev. Corp.*, 429 U.S. 252 (1977); *Washington v. Davis*, 426 U.S. 229 (1976).

Targeting high-risk groups for mandatory testing makes more sense economically than universal mandatory identified testing, but brings with it problems of its own. In the context of pregnancy, the groups who would be targeted would be poor and minority populations living in the inner cities of a few metropolitan areas, because those are the groups of women where the concentration of HIV infection is the highest.<sup>113</sup> Targeting by such socioeconomic criteria is common in the context of AIDS, but it is also highly discriminatory.<sup>114</sup> Targeting poor women of color is unjust for many reasons. First, huge personal costs can accompany testing. Moreover, while race, geography, and socioeconomic status do define the group of women that currently has the highest HIV prevalence, none of those factors is the "fault" of the women in the group, and most of the group is not and never will be HIV infected. To impose mandatory testing only on this group not only encourages a false sense of security in other women regarding their risk of infection, but also unfairly and inaccurately labels the targeted women as "sources of contagion."<sup>115</sup> It is difficult to justify adding such stigma to a group who is already oppressed.

Given the high cost of testing low-prevalence populations of pregnant women and the discrimination inherent in testing targeted groups of pregnant women, the better way to combat vertical transmission of HIV is through education, counseling, and prenatal care.<sup>116</sup> Many women, including a great many in groups most vulnerable to AIDS, either receive no prenatal care or none until late in pregnancy.<sup>117</sup> There is no question that, because of both AIDS and the interest in newborns' health generally, prenatal care should be made available to all pregnant women, and information concerning AIDS should be offered in conjunction with it.

Questions concerning targeting have also been raised apart from testing or other government coercion. There is concern about targeting even in connection with providing information, education, counseling, and even free voluntary testing. If government concen-

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113. Over 72% of the women in the United States who have AIDS are either black or Hispanic, while only 19% of all U.S. women are black or Hispanic. Centers for Disease Control, *AIDS in Women—United States*, 39 MORBIDITY & MORTALITY WEEKLY REP. 845 (1990).

114. See Working Group on HIV Testing of Pregnant Women and Newborns, *supra* note 31, at 2419.

115. *Id.*; see also Field, *supra* note 24, at 61-63.

116. See Field, *supra* note 24, at 96-97.

117. See GEORGE WASH. UNIV., 1 INTERGOVERNMENTAL HEALTH POLICY PROJECT AIDS: A PUBLIC HEALTH CHALLENGE 2-2, 2-28 (M. Rowe & X. Ryan eds., 1987).

trates its outreach efforts on particular groups, the same risk exists of government branding those groups as "sources of contagion." At the same time, it is understandable that government would want to use its limited resources to benefit those most in need. Of course, it would be best to educate and inform everyone and to provide free and voluntary testing to all who desire it.<sup>118</sup> But where that cannot be done, targeting, though problematic, is considerably less troublesome when applied to outreach efforts that do not involve coercion.

Any such targeting that occurs should be undertaken with great care to avoid stigmatization to the extent possible. Moreover, it is important that sound epidemiologic research—not simply racial or social class prejudice—guide which populations will be targeted.<sup>119</sup>

### CONCLUSION

Vertical transmission of AIDS is a serious problem, but mandatory testing, either of pregnant women or of newborns, is not the appropriate solution to try. Not only does it violate established rights of pregnant women or mothers of newborns to test without their consent. It also would be counter-effective to societal efforts to control the spread of HIV. Coercion does not work in this context. Those who urge coercive methods are frequently motivated by political or self-interested rather than health objectives, or are moved by panic concerning the AIDS epidemic rather than a reasoned and informed response. The grave concern that the AIDS epidemic justifiably causes should not be the occasion for imposing new coercive controls on pregnant women, on parents of newborns, or on others.

We must not lightly abandon well-established standards of informed consent in a panicked response to the AIDS epidemic. Nor should we abandon our tradition that decisions concerning the appropriateness of childbearing belong to parents and not to the state. Altering such fundamental principles in the context of the AIDS crisis would contribute nothing to controlling the epidemic. The thoughtless adoption of such a course would, in addition, have serious repercussions throughout our jurisprudence and our society.

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118. Working Group on HIV Testing of Pregnant Women and Newborns, *supra* note 31, at 2416-17.

119. See Robert M. Wachter et al., *HIV Testing of Pregnant Women and Newborns*, 265 JAMA 1525 (1991).