

Winter 1995

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### Recommended Citation

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# MANDATORY NON-ANONYMOUS TESTING OF NEWBORNS FOR HIV: SHOULD IT EVER BE ALLOWED?

JEAN R. STERNLIGHT\*

## INTRODUCTION

Since it was first reported over a decade ago,<sup>1</sup> AIDS has now become one of the leading causes of death in the United States. As the spread of HIV-AIDS reaches epidemic proportions, the public and medical community have become increasingly concerned with the possibility and implications of vertical or perinatal transmission: the transmission of HIV from mother to newborn child.

Tragically, thousands of children will contract HIV from their HIV-positive mother via vertical transmission. Approximately 1800 HIV-infected babies are born in the United States each year,<sup>2</sup> and vertical transmission accounts for 87% of all HIV transmissions to children.<sup>3</sup> While some HIV-infected infants do not immediately develop AIDS, one-third of the infected infants die by age three.<sup>4</sup>

In response to cries from both the public and the medical community for increased research and improved treatments with respect to pediatric AIDS, some state legislatures have attempted to enact legislation that would require routine mandatory testing of newborns for HIV on a non-anonymous basis.<sup>5</sup> For example, in

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1. The Centers for Disease Control (CDC) first reported the identity of Acquired Immune Deficiency Syndrome (AIDS) in July of 1981. See, CDC, *Pneumocystis Pneumonia — Los Angeles*, 30 MORBIDITY & MORTALITY WKLY. REP. 250 (June 5, 1981).

2. Marte Gwinn et al., *Prevalence of HIV Infection in the United States*, 265 JAMA 1704 (1991). See 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 29-31 (Ruth R. Faden, et al. eds. 1991) (hereinafter AIDS, WOMEN AND THE NEXT GENERATION).

3. PEDIATRIC HIV INFECTION ON THE INCREASE, HIV/AIDS PREVENTION 2 (DC, July 1991).

4. Martha A. Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402, 407 (1993).

5. Although no states currently mandate routine non-anonymous HIV testing, a few offer non-anonymous testing indirectly by requiring physicians to inform the state health department, and by making the HIV-information subject to subpoenas. See, e.g., ARK. CODE ANN. § 20-15-906 (Michie Supp. 1992); MO. ANN. STAT. § 191.653(3) (Vernon Supp. 1992). For a discussion of a spec-

1993, the New York state legislature narrowly defeated a bill which would have permitted such "unblinded" testing.<sup>6</sup> Such proposals have created fierce political controversy.<sup>7</sup> Central to this issue is the reality that revealing the HIV status of a newborn reveals the HIV status of the mother as well.<sup>8</sup> A newborn will test HIV-positive only if its mother is positive.<sup>9</sup>

Those who favor mandatory testing of newborns contend that such testing is necessary in order to protect the health of newborns and to ensure that the newborns' doctors provide them with adequate care.<sup>10</sup> Moreover, testing advocates argue that because most hospitals already screen anonymously, failing to inform parents of the test results is inappropriate and perhaps immoral.<sup>11</sup>

Opponents of mandatory testing argue that the possible negative consequences of AIDS testing to the child, mother and public far outweigh its few conceivable benefits.<sup>12</sup> Given current testing inaccuracies for newborns,<sup>13</sup> and the fact that there is at present no cure for AIDS, mandatory testing arguably provides little or no medical help to the child.<sup>14</sup> Instead, opponents argue that testing

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trum of testing alternatives short of routine mandatory tests, see Ruth R. Faden et al., *Warrants for Screening Programs: Public Health Legal and Ethical Framework*, in AIDS, WOMEN AND THE NEXT GENERATION, *supra* note 2.

6. The proposed legislation was Assembly Bill 6747 and Senate Bill 5617A. An Assembly Committee narrowly defeated the bills and asked for a panel of experts to study the issue. N.Y. A.B. 6747, 215th Gen. Ass., 1st Sess. (1993); N.Y. S.B. 617A, 215th Gen. Ass., 1st Sess. (1993). These bills both require the Department of the Health in the State of New York to disclose to the parents (whether biological or adoptive) the HIV status obtained from testing done on the newborn by the Department or any other entity. *Id.*

7. John Riley, *Focus on Mandatory AIDS Tests*, NEWSDAY, Aug. 25, 1993, at 15; Mireya Navarro, *Testing Newborns for AIDS Virus Raises Issue of Mothers' Privacy*, N.Y. TIMES, Aug. 8, 1993, at A1; *Infants' Rights Give HIV Test to Mothers*, NEWSDAY, June 9, 1993, at 46.

8. See Field, *supra* note 4, at 402.

9. MICHAEL L. CLOSEN ET AL., AIDS: CASES & MATERIALS 490-93 (1987).

10. Taunya L. Banks, *Women and AIDS — Racism, Sexism, and Classism*, 17 N.Y.U. REV. L. & SOC. CHANGE 351, 367-68 (1989-90). See generally Nancy Hutton & Lawrence S. Wissow, *Maternal and Newborn HIV Screening: Implications for Children and Families*, in AIDS, WOMEN AND THE NEXT GENERATION, *supra* note 2, at 105-18. Other arguments in favor of such testing include: saving public money by reducing health care costs, allocating resources fairly, improving society's general health, and protecting the helpless. *Id.*

11. See, e.g., Keith Henry et al., *Human Immunodeficiency Virus Antibody Testing: A Description of Practices & Policies at U.S. Infectious Disease—Teaching Hospitals and Minnesota Hospitals*, 259 JAMA 1819 (1988) (indicating that many hospitals engage in testing for public policy reasons without obtaining consent of the patient).

12. See Larry Gostin, *Hospitals, Health Care Professionals and AIDS: The "Right to Know" the Health Status of Professionals and Patients*, 48 MD. L. REV. 12, 52 (1989) (noting the negative aspects of testing, including the psychological distress and increased risk of suicide placed on the tested HIV person).

13. See *infra* text accompanying notes 24-32.

14. See Gostin, *supra* note 12, at 50-52 (discussing negative aspects of testing).

could harm both parent and child by labeling them HIV-positive<sup>15</sup> and, thus, endangering their access to a variety of life's necessities.<sup>16</sup>

In analyzing the arguments supporting and opposing mandatory testing of newborns, it is important to note that approximately 70% of American women affected with AIDS are African-American or Latino.<sup>17</sup> Thus, one must constantly be wary of the role racist or classist views may consciously or unconsciously play in this debate.<sup>18</sup>

This Article analyzes whether, as a matter of both constitutional law and public policy, a state can or should require the routine testing of newborns for HIV on a non-anonymous basis absent the parent's consent. First, this Article briefly explains vertical transmission and HIV testing. Second, this Article examines the legal principles applicable to the issue. Third, this Article considers whether, as a matter of public policy, a state should require non-anonymous testing of newborns absent a parent's consent. Lastly, this Article considers whether mandatory non-anonymous testing would be appropriate considering that tests are flawed and treatments are currently limited. Additionally, this Article considers whether mandatory testing might be appropriate in the future world.

To assess the desirability of mandatory non-anonymous testing in the future world, this Article employs an analytic model which examines potential changes in such variables as: the accuracy of the HIV test, the availability of a cure for AIDS in terms of medical knowledge, economics, and feasibility, and the availability of protections for those determined to be HIV-positive with regard to confidentiality, discrimination and stigmatization. Upon analysis of all these factors, this Article concludes by stating that non-anonymous, non-consensual testing of newborns is unwise as a matter of policy. Rather, this Article proposes that a state should focus on creating conditions so that reasonable mothers will voluntarily choose to have their newborns tested for HIV, and thus make testing a desired choice, rather than forcing it on reluctant parents.

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15. For example, the stigma of an HIV-positive test could lead to loss of housing, employment, or insurance coverage. Banks, *supra* note 10, at 370. Unfortunately, HIV-status has also led to suicide. See Glass, *AIDS and Suicide*, 259 JAMA 1369 (1988).

16. See generally, Banks, *supra* note 10, at 370-71 (explaining that discrimination laws, both state and federal, inadequately protect HIV-infected individuals).

17. Banks, *supra* note 10, at 352. However, it is also possible that the prevalence of AIDS among whites in higher socioeconomic classes has been inappropriately undercounted. *Id.* at 354-55.

18. See generally Banks, *supra* note 10, at 361-65 (discussing history of racist medicine in this country).

## I. HIV VERTICAL TRANSMISSION: TESTING AND TREATMENT

### A. Vertical Transmission of AIDS: From Parent to Child

Vertical transmission is the transmission of HIV from mother to child. When a woman who is HIV-positive bears a child, there is a likelihood of 30% or less that she will pass on the HIV virus to her child.<sup>19</sup> It is not entirely clear at what point vertical transmission takes place. The strongest evidence supports a theory of transmission during pregnancy.<sup>20</sup> Other evidence demonstrates transmission during the birthing process itself.<sup>21</sup> Some studies even indicate that transmission may occur after birth through breast feeding.<sup>22</sup> Although the exact method of vertical transmission from mother to child is unclear, it is clear that the virus can not be transmitted directly from the father to the fetus through the insemination process.<sup>23</sup>

### B. HIV Testing of Newborns

The two tests most frequently used to determine whether a person is infected with the HIV virus are the Enzyme-Linked Immunosorbent Assay (ELISA),<sup>24</sup> and the more expensive and accurate Western Blot test.<sup>25</sup> Both tests examine the blood for the presence of antibodies produced by the body to fight HIV, rather than for the presence of HIV itself.<sup>26</sup>

These tests are far more accurate when administered to adults than when they are administered to newborns. When used on adults, the two tests are more reliable because an adult possesses the HIV antibodies only if he has been exposed to the virus. By contrast, when given to newborns, these tests will produce approximately seven false positives for every three positive results. This inaccuracy occurs because a newborn receives virtually all its mother's antibodies while it is in the womb. The newborn will retain these antibodies for as long as a year and a half after birth, at

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19. See Field, *supra* note 4, at 406.

20. See William Borkowsky & Keith Krasinski, *Perinatal Human Immunodeficiency Virus Infection: Ruminations on Mechanisms of Transmission & Methods of Intervention*, 90 PEDIATRICS 133 (1992).

21. See Susanne Lindgren et al., *HIV and Childbearing Clinical Outcome and Aspects of Mother-to-Infant Transmission*, 5 AIDS 1111 (1991).

22. See generally Field, *supra* note 4, at 407.

23. See *id.*; see generally Modlin & Saah, *supra* note 2, at 41. The father can, however, indirectly infect the fetus by first infecting the mother.

24. See CLOSEN, *supra* note 9, at 148.

25. *Id.*

26. *Id.* at 149. Testing errors may nonetheless occur with adults due to such problems as heating the serum, improper storage, mixing of specimens, mixing of reagents, improper washing, and improper labeling. *Id.* Biological errors in testing include the existence of other infectious diseases, the presence of certain illegal drugs, and other causes of antibody deficiency. *Id.*

which time the mother's antibodies disappear and the child is dependent on the antibodies which have been produced by its own immune system.

Thus, virtually *all* newborn babies born to HIV-positive mothers will test positive for the virus at birth.<sup>27</sup> However, because of the fact that approximately 70% of newborns will seroconvert to negative after their first year when they lose their mother's antibodies, less than a third of such babies are actually infected by the HIV virus.<sup>28</sup> In short, when the current tests are applied to newborns, they are far more accurate with respect to the mother's status than they are with respect to the newborn's status.

### C. HIV Medical Treatment

Although there is presently no cure for persons infected with HIV, many doctors believe that they can offer substantial and beneficial medical treatment to HIV-positive babies. Pediatricians contend that preventative medical treatment exists both to extend the lives of HIV-positive children and to improve the quality of those lives.<sup>29</sup> For example, HIV-infected children can be treated with Bactrim, an antibiotic, which will assist such children in fighting off pneumocystis pneumonia (PCP).<sup>30</sup> In addition, HIV-positive children can also receive AZT treatment which some argue can provide a substantial benefit.<sup>31</sup> With the benefit of these and other medical treatments, a few children born HIV-positive have lived up to age nine, whereas children not known to be HIV-positive (and, thus, not treated for the disease or watched carefully for opportunistic infections) may die as early as their first year.<sup>32</sup>

As the technology surrounding HIV advances, improvements in both testing<sup>33</sup> and medical treatment are likely.<sup>34</sup> Clearly, far more work needs to be done in order to produce a "cure" for AIDS or

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27. Field, *supra* note 4, at 424. See Modlin & Saah, *supra* note 2, at 30, 38.

28. Field, *supra* note 4, at 424. A year and a half after birth only one-third of the infants who test positive for the antibody will actually be positive. *Id.*

29. Field, *supra* note 4, at 430-31. The author notes that the availability of therapy that enhances an HIV positive infant's life makes the decision concerning mandatory testing more troublesome.

30. PCP is the most frequent lethal complication of pediatric HIV. Field, *supra* note 4, at 430.

31. Field, *supra* note 4, at 430. Although doctors do not administer AZT to asymptomatic infants, AZT is given to infected infants who have below average T-4 cell counts.

32. See, e.g., John Riley, *Focus on Mandatory AIDS Tests*, NEWSDAY, Aug. 25, 1993, at 15. Of course, some would argue that it is not clearly beneficial to extend the life of an HIV positive child who will eventually die at an early age.

33. With regard to testing, some have already begun to develop tests which far more accurately determine the HIV status of the newborn, rather than merely that of the mother. See Field, *supra* note 4, at 424. While none of these tests are yet very accurate until the child is approximately three months old, and while all of them are problematic in terms of expense, time lag, or unrelia-

even to develop better treatment, absent a cure. However, some progress in the area of treatment is likely, and all but the most pessimistic among us believe that somehow, some time, there will be a cure or at least a vaccine to prevent the spread of the virus.

## II. LEGAL PROTECTIONS

### A. Statutory and Common Law Protection

#### 1. The Requirement of Informed Consent

It is generally well established that, pursuant to statutory and common law principles, a person may not be subjected to medical testing without their consent.<sup>35</sup> However, this general rule has been overcome in a variety of situations, such as where the patient is unable to consent or where compelling societal interests outweigh the individual's refusal to consent.<sup>36</sup>

#### 2. Consent for Medical Treatment with Respect to Minors

Children who are too young to provide their own consent may not generally, pursuant to statute and common law, be subjected to medical tests or treatment without the consent of one of their parents.<sup>37</sup> However, the parent's refusal to consent may be overridden not only to protect compelling societal interests (parallel to overriding of adult consent), but also to protect the child where the parent has effectively neglected the child by substantially failing to act in the child's best interest.<sup>38</sup> Nonetheless, a court will not override a

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bility, it is probable that more accurate testing of newborns will be possible in the near future. *Id.* at 424-25.

34. See Field, *supra* note 4, at 424.

35. In *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 270 (1990), the Supreme Court stated: "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." *Cruzan* further stated that this common law right gives rise to "a constitutionally protected liberty interest in refusing unwanted medical treatment . . ." *Id.* at 278. Where a person is tested without her consent, she may be able to assert such common law claims as battery, negligence, invasion of privacy, or intentional infliction of emotional distress. See generally, Anita L. Allen, *Legal Issues in Nonvoluntary Prenatal HIV Screening, in AIDS, WOMEN AND THE NEXT GENERATION*, *supra* note 2, at 183-87.

36. See generally, Michael L. Closen, *Mandatory Disclosure of HIV Blood Test Results to the Individuals Tested: A Matter of Personal Choice Neglected*, 22 *LOY. U. CHI. L.J.* 445, 449-51 (1991).

37. See *Hodgson v. Minnesota*, 497 U.S. 417, 454 (1990) ("[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"); *Bonner v. Moran*, 126 F.2d 121, 122-23 (D.C. Cir. 1941) (physician may be subjected to liability for operating on child without parent's consent).

38. See, e.g., *State v. Perricone*, 181 A.2d 751, 759 (N.J. 1962) (holding parents' sincere and religiously based refusal to allow child to be treated by a blood transfusion amounted to neglect and could therefore be overridden), *cert. denied*, 371 U.S. 890 (1962). See generally Field, *supra* note 4, at 425-431. The rule that state public health interests may overcome even a religiously-based

parent's refusal to consent merely because the court disagrees with the parent's assessment of what is best for the child. Rather, a court will intervene only where it perceives the situation to be very serious or drastic.

Hospitals do frequently screen newborns on a mandatory non-consensual basis for phenylketonuria (PKU), a highly treatable disease causing mental retardation.<sup>39</sup> Such screening has been widely accepted and subject to few if any successful legal challenges. However, the differences between AIDS and PKU highlight the issues surrounding whether HIV tests should be imposed on a mandatory basis. Unlike AIDS, PKU is highly treatable on a relatively low-cost and simple basis.<sup>40</sup> Also, PKU is not transmitted vertically, meaning a positive PKU result makes no revelation regarding the status of the mother. Nor does our society discriminate or stigmatize on the basis of PKU status. As discussed below, these factors are relevant to our assessment of whether mandatory HIV tests may be imposed with respect to newborns.

### B. Constitutional Protection

The extent to which the United States Constitution provides additional protection beyond the common law or statute is unclear. Several arguments may, however, be raised with regard to non-consensual testing. First, non-consensual tests may constitute an unreasonable search and seizure in violation of the Fourth Amendment.<sup>41</sup> Second, non-consensual tests may impinge on a person's right to substantive or procedural due process under the Fourteenth Amendment.<sup>42</sup> Third, non-consensual testing may im-

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refusal to accept treatment on behalf of one's child is well established. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1943).

39. Field, *supra* note 4, at 426 (noting that parental consent is not always mandatory for PKU screening). 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 although the risk of PKU striking any one child is 1 in 12,000, all states currently require PKU screening for infants).

40. Field, *supra* note 4, at 426.

41. Compare *Glover v. Eastern Neb. Community Office of Retardation*, 867 F.2d 461 (8th Cir. 1989), *cert. denied*, 110 S. Ct. 321 (1989) (finding mandatory testing of employees of all state mental health facilities unreasonably intrusive under the Fourth Amendment) with *Leckett v. Board of Comm'rs of Hosp. Dist. No. 1*, 714 F. Supp. 1377 (E.D. La. 1989), *aff'd*, 909 F.2d 820 (5th Cir. 1990) (finding hospital may mandate disclosure of HIV status by staff) and *Hill v. Evans*, No. 91-A-626-N, 1993 WL 439966, at \*14 (M.D. Ala. Oct. 7, 1993) (rejecting Fourth Amendment challenge to statute mandating HIV tests for patients whose care might be modified or where test is necessary to protect hospital staff).

42. See generally Robert Craig Waters, *Florida's Involuntary AIDS Testing Statutes*, 19 FLA. ST. L. REV. 369 (1991); Scott H. Isaacman, *Neonatal HIV Testing: Governmental Inspection of the Baby Factory*, 24 J. MARSHALL L. REV. 571 (1991). An argument can also be made that non-consensual testing violates the Equal Protection Clause. In *Hill v. Evans*, No. 91-A-626-N, 1993 WL 439966, at



pinge on the right to privacy which is protected by the penumbra of various amendments.<sup>43</sup> Lastly, similar arguments may also be made under state constitutions, particularly those which contain an explicit clause protecting privacy rights.

However, while these constitutional arguments are colorable, none seem sufficiently strong to prevent mandatory non-anonymous testing of newborns. Historically, states have successfully justified measures, such as mandatory testing and quarantines, if they are supported by legitimate state interests.<sup>44</sup> Moreover, the Supreme Court's decision in *Skinner*<sup>45</sup> authorizing governmental drug testing made it clear that mandatory blood and urine tests are permissible, notwithstanding the Constitution, provided the government can point to supposedly special or compelling interests.<sup>46</sup> For example, in *Skinner*, the Court both denigrated the individual's interest in the privacy of his blood and also said that any such privacy interest was outweighed by the government's supposed compelling interest in preventing work-related accidents.<sup>47</sup> Thus, the constitutional analysis largely blurs into a policy analysis of whether the government can establish a strong case to compel mandatory testing of newborns.

Additionally, the state may conceivably be able to escape constitutional strictures by resorting to such steps as testing fetal tissue which would otherwise be discarded; thus, eliminating the need for an independent needle stick which would more clearly constitute a search. Finally, United States constitutional provisions only

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\*14 (M.D. Ala. Oct. 7, 1993) the court struck down part of Alabama's HIV testing statute which allowed non-consensual testing of persons deemed "upon reasonable medical judgment, as high risk for HIV infection" on the grounds that it failed the rational basis test (rejecting Fourth Amendment challenge to statute mandating HIV tests for patients whose care might be modified or where test is necessary to protect hospital staff).

43. See *Griswold v. Connecticut*, 381 U.S. 479 (1965).

44. E.g., *Johnetta J. v. Municipal Court*, 267 Cal. Rptr. 666 (Cal. Ct. App. 1990) (allowing forced testing of woman who bit a deputy). See also Anita A. Allen, *Legal Issues in Non Voluntary Prenatal Screening, in AIDS, WOMEN AND THE NEXT GENERATION*, supra note 2, at 168-82 (concluding that the constitutionality of mandatory testing of pregnant woman is also unclear); Kathleen M. Sullivan and Martha A. Field, *AIDS and the Coercive Power of the State*, 23 HARV. C.R.-C.L. L. REV. 139 (1988).

45. *Skinner v. Railway Labor Executives' Ass'n*, 489 U.S. 602 (1989). The *Skinner* Court noted "society's judgment that blood tests do not constitute an unduly extensive imposition on an individual's privacy and bodily integrity." *Id.* at 625 (quoting *Winston v. Lee*, 470 U.S. 753, 762 (1985)).

46. See also *National Treasury Employees Union v. Von Raab*, 489 U.S. 656, 679 (1989) (once the government shows a special need for the information sought, the court looks only to whether the public interests outweigh personal interests); *New York v. Burger*, 482 U.S. 691 (1987) (permitting search of premises of certain highly regulated businesses); *New Jersey v. T.L.O.*, 469 U.S. 325 (1985) (permitting school search of student purses).

47. *Skinner*, 489 U.S. at 625, 628.

apply to "state" action and, therefore, only restrict testing by state controlled entities.

Therefore, in light of the uncertain future of HIV testing under constitutional provisions, it is essential to evaluate the possible justifications for non-consensual, non-anonymous testing of newborns based on general policy considerations. To the extent that valid constitutional arguments are successfully made, they will, in any event, turn on the policy considerations discussed herein.<sup>48</sup>

### III. MANDATORY NON-ANONYMOUS TESTING OF NEWBORNS: POLICY CONSIDERATIONS INVOLVING BOTH MOTHER AND CHILD

#### A. *Testing: Is It in the "Best Interest of the Child"?*

Advocates of mandatory non-anonymous testing argue primarily that the testing will result in a health benefit to the *child*, and that because mothers<sup>49</sup> cannot be trusted to act in their children's best interest, such testing may be imposed by the state. A corollary to this argument is the idea that once society or doctors learn of a child's HIV status through anonymous screening, it would be immoral not to convey that information to the parent, so that the child can receive adequate treatment. In addition, advocates of mandatory testing sometimes assert that such testing will benefit *society* by preventing the spread of the disease, by helping us determine the cause of the disease, or perhaps by decreasing treatment costs.

However, while these latter arguments have occasionally been asserted, advocates of mandatory, non-anonymous testing have generally failed to show how testing newborns, absent extreme measures such as quarantine, would in fact prevent the spread of HIV. Nor have such advocates explained how the non-anonymous testing would provide us with any useful information beyond that which we can already obtain from anonymous screening to assist in

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48. One additional and interesting potential constitutional issue might arise if the father consented to have the newborn tested, but the mother did not. Generally, of course, a single parent's consent is sufficient. Here, however, where a positive test on the newborn would reveal the mother to be positive, the mother might have an independent claim. Cf. Ruth R. Faden & Judith Areen, *Screening Newborns for HIV: Ethical and Legal Aspects*, in AIDS, WOMEN AND THE NEXT GENERATION, *supra* note 2, at 262 (concluding that the apparent conflicts between mother's and child's interests might be deemed sufficient to support a requirement of paternal notification).

49. Throughout this Article, I will generally assume that it is the mother, rather than the father, who is being asked to consent to the testing of the child. I employ this shorthand because, as a matter of practical logistics, it is more often the mother who is asked to consent. She, of course, is in the hospital delivering the child, whereas the father may be present, if at all, for far less time.

tracing the spread of the disease. Thus, this Article focuses primarily on whether non-anonymous, mandatory testing is now necessary and appropriate to serve the "best interest of the child."

*B. Reasons for a Mother's Refusal to Consent to Newborn's HIV testing*

My analysis starts with the premise that mothers love their children and would choose to act in their children's best interest, all else being equal. Stated in this fashion, the assumption that mothers love their children may seem so obvious as to be absurd. Nonetheless, it is important to set out the assumption, because many persons who write or speak about compulsory testing seem to assume, at least implicitly, that mothers do not necessarily act in their children's best interest.<sup>50</sup>

Even with this basic assumption, there are a number of reasons a reasonable and loving mother might refuse to have her newborn tested for HIV. First, in the world as it exists today, a mother might quite rationally conclude that submitting to an AIDS test is not in the child's best interest. The mother might determine that the child has little to gain and much to lose by being tested. Considering the potential benefits, the mother might reasonably conclude that medical technology, particularly as made available under our current economic system,<sup>51</sup> has relatively little to offer the HIV-positive child in order to improve its life.

There are potential negative implications of testing the child that might influence the reasonable mother's decision to consent. They are the likelihood of false positive identification<sup>52</sup>; possible loss of medical care<sup>53</sup>; possible loss of day-care and educational op-

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50. See generally Ruth R. Faden & Judith Areen, *supra* note 48, at 265 (surveying some moral philosophers' views on parent-child relationships). I believe that some commentators' refusal to assume that mothers love their children is one way in which conscious or unconscious racism and classism may factor into the discussion. See *supra* text accompanying note 18. Middle class and upper class White America seem all too ready to believe that poor African American or Hispanic mothers may act against the children's best interest. See Allen, *supra* note 44, at 174 (discussing the role stereotypes of poor female minority group members may play in HIV analysis).

51. See Kenneth Bogel, *Discrimination on the Basis of HIV Infection: An Economic Analysis*, 49 OHIO ST. L.J. 965 (1988-89). Evidence shows the average person with HIV-AIDS will acquire \$100,000 or more medical costs over his remaining lifetime. *Id.* at 986. It can be very difficult for a person infected with HIV to obtain health insurance. *Id.* at 988. For example, health insurance companies usually will not provide coverage for preexisting conditions. *Id.* Therefore, someone who has developed symptoms of AIDS will not be able to find affordable private health insurance. *Id.*

52. See *supra* text accompanying notes 26-28. Approximately 70% of newborns are false positive if mother is positive.

53. Ruth R. Faden et al., *HIV Infection, Pregnant Women & Newborns: A Policy Proposal for Information and Testing*, in AIDS, WOMEN AND THE NEXT

portunities<sup>54</sup>; possible loss of housing<sup>55</sup>; possible loss of food and support for the entire family<sup>56</sup>; and possible breakup of the family.<sup>57</sup>

In addition, while my analysis begins with the premise that mothers love their children, mothers may have other factors to consider beyond the best interest of one particular child. Thus, the loving mother must sometimes balance against the single child's interest such considerations as other children's interests, the mother's own interests, and the interests of others in her family. For example, a reasonable and loving mother might conclude that the relatively slight medical gain to one child from revelation of his or her HIV-positive status would be far outweighed by the effects of stigmatization and discrimination. Stigmatization and discrimination not only affect the HIV-positive child, but also affect others in the family, including the mother herself. Moreover, even to the extent economically affordable treatment exists, they may be costly in terms of feasibility. To obtain or administer certain medical treatment, for example, the mother may have to sacrifice substantial time and energy that she cannot take away from other causes. Thus, the premise that only a selfish or unloving mother could possibly refuse to have her child tested for HIV is unacceptable. Rather, a reasonable and loving mother might well, given today's medical, economic and legal realities, choose not to have her child tested for HIV.

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GENERATION, *supra* note 2, at 336 (citing NAN D. HUNTER, REPORT OF THE ACLU AIDS PROJECT (1990)).

54. See generally *Doe v. Dolton Elem. Sch. No. 148*, 694 F. Supp. 440 (N.D. Ill. 1988) (ordering a 12-year old HIV-positive student to be returned to school).

55. Although discrimination on the basis of HIV status is prohibited in public housing by the new Americans with Disabilities Act, 42 U.S.C. § 12101, and although some states prohibit discrimination in private housing as well, such discrimination still may occur.

56. Identification of the mother as HIV-positive might well lead to her being fired from her job, even though the American With Disabilities Act (hereinafter "ADA"), 42 U.S.C. § 12101 (1992) outlaws certain discrimination. It provides:

[t]he term "qualified individual with a disability" means an individual with a disability who, with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires.

*Id.* § 12111(8).

57. A recent study concluded "evidence suggests that [upon testing positive], poor, minority women risk the devastation of their personal and family relationships, the loss of social and medical services, the loss of control of their own medical decisions, and even the loss of their children." Working Group on HIV Testing of Pregnant Women and Newborns, *HIV Infection, Pregnant Women, and Newborns: A Policy Proposal for Information and Testing*, 264 JAMA 2416, 2418 (1990).

IV. UNDER WHAT CIRCUMSTANCES IS IT APPROPRIATE TO  
OVERRIDE A MOTHER'S REFUSAL TO HAVE HER CHILD  
TESTED FOR HIV?

A. *Factors a Mother Will Consider in Determining Whether to  
Consent to Have Her Child Tested*

Given my assumption that mothers love their children and will act in their children's best interest, all else being equal, my thesis is that a mother will fail to act in a particular child's best interest only when outside factors lead the mother to place other interests, such as the welfare of another child or the mother's own interests, ahead of the particular child's interests. Consciously or unconsciously, the mother will weigh three primary, and to some extent, interrelated factors to determine whether to consent to HIV-testing: (1) *the accuracy of the proposed test*; (2) *the availability of medical care for the child and the mother*, not only in terms of medical technology, but also in terms of budgetary constraints, and the practical feasibility of obtaining the necessary medical care; and (3) *the anti-discrimination and anti-stigmatization protection available to both mother and child*. Such potential anti-discrimination/stigmatization protection could include confidentiality afforded to a positive result; anti-discrimination protection available to protect mother and child from discrimination with respect to such necessities as housing, employment, insurance and medical care; and protection from stigmatization which might, for example, lead to the child being taken away from the mother by the state welfare agency.

I use this multi-factor model to address two questions. First, under what current or foreseeable future circumstances, if any, may society compel testing of a child for HIV, absent the mother's consent? Second, how can society ensure that there is minimum divergence between the child's interests and the other interests that the mother will consider, such that a mother will consent to have her child tested for HIV, where such consent is in the child's best interest?

B. *All Else Being Equal, Mandatory Testing Is Undesirable*

I also assert that unless mandatory testing is shown to achieve substantial benefits which cannot be achieved as effectively through voluntary means, mandatory testing should be avoided. First, mandatory testing infringes on individuals' and families' rights of autonomy and is in that sense inherently undesirable. Second, mandatory testing would inevitably be difficult and costly to administer. If mothers did not wish their newborns to be tested they would seek, and no doubt often find, ways to avoid the tests. Third, imposition of mandatory testing would likely lead to an increase in the incidence of a variety of medical problems, in that

some mothers who did not wish to have their newborns tested for the virus would avoid hospital deliveries and follow-up medical care.<sup>58</sup> The question remains, however, whether the benefits of mandatory testing of newborns outweigh its inherently negative aspects. Thus, in the sections which follow, I analyze whether, given these inherently negative aspects, mandatory testing of newborns is nonetheless justifiable or desirable.

*C. Given the Current Situation, Should We Require Non-Anonymous Testing of Newborns?*

In today's world it is quite reasonable for a mother to refuse to have her newborn tested for HIV. Both child and mother have much to lose and relatively little to gain if the child tests positive. Although some medical treatment is technologically available for the potentially HIV-positive mother and child, there is no cure for AIDS. Even our best treatments are unsuccessful in staving off many fatal opportunistic diseases and infections. Moreover, those infected by HIV are by no means guaranteed access even to the existing technology. As an economic matter, very few members of our society can afford AIDS treatments through personal savings, health insurance, or government benefit. In addition, the available treatments are often costly in terms of feasibility. To obtain or administer certain medications, for example, the mother may have to sacrifice substantial time and energy she can ill afford to take away from other children, her job, or her own well being.

At the same time, those who are labeled HIV-positive are placed at substantial risk. Even those states that attempt to provide strong HIV confidentiality protection often fail to prevent the dissemination of this information. When the news of an HIV-positive test result does leak out, discrimination on the basis of housing, employment, insurance, and medical care is common. The possibility of such discrimination is aggravated by the fact that under current testing of newborns, there are many false positive results. Thus, the family will run the risk of substantial discrimination even though the child is in fact HIV-negative and thus needs no HIV treatment.

Given these factors, it is currently inappropriate to say that a mother has acted unreasonably in refusing to consent to have her child tested. Moreover, as discussed above, mandatory testing is inherently undesirable. Thus, we should not substitute a governmental assessment of these risks for the choice made by the mother. By virtue of this same analysis, it would at present be very difficult for the government to show that mandatory non-anonymous testing

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58. See generally Banks, *supra* note 10, at 370.

was supported by a compelling government interest and thus constitutional.

*D. Given Conditions That Might Exist In The Future, Are There Any Circumstances Under Which We Should Require Non-Anonymous Testing Of Newborns?*

In this section, I will hypothesize a number of changes which might occur in the future, and then assess whether, given these changes, it would be appropriate to mandate HIV testing of newborns absent parental consent. The exact scenarios I describe are not necessarily likely to occur. Nonetheless, they are useful for analytical purposes in that they elucidate a range of possible outcomes. Although I ultimately conclude that mandatory testing would not be appropriate under any of the scenarios, the analysis also helps us consider the type of care, protection and resources which need to be provided to parents of HIV-positive newborns.

*1. World One: 100% Testing Accuracy, 100% Effective Cure*

Imagine a world in which newborns could be tested for HIV with 100% accuracy and in which a 100% successful, low-cost, highly feasible cure to AIDS were available to all adults and children. In this hypothetical world, there would be no need to require non-consensual testing of newborns. Parents would have no reason not to permit their child to be tested. If the child tested HIV-positive, thereby revealing both child and mother to be HIV-positive, both could be cured at low cost, in terms of money and feasibility. Thus, the mother's personal incentives would coincide with the best interests of the child, favoring early testing so as to secure an early cure. Even if society did not provide particularly good confidentiality or anti-discrimination protection, the mother would in all likelihood consent to testing. The availability of a low-cost cure would render virtually irrelevant the problems of non-confidentiality or discrimination in that any AIDS victim could easily be cured and take himself or herself out of the category of persons who would be discriminated against.<sup>59</sup> Given the inherent undesirability of mandatory testing, it would not be justifiable in such a world. Nor, in my view, would it be constitutionally defensible as supported by

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59. Of course, if a cure technically existed, but were not made available on a low-cost and otherwise feasible basis, a mother would have far better reasons not to consent to the testing. In such a world, a reasonable mother would recognize that she and her child might be found to be HIV-positive but not able to obtain the cure. If the world also failed adequately to protect confidentiality, and prevent discrimination and stigmatization, the reasonable mother might deny consent. In such a world, while some might wish to compel the testing absent parental consent, the more appropriate solution would be to provide better access and protection such that the reasonable parent would have incentives to consent to the testing.

a compelling government interest.<sup>60</sup>

## 2. *World Two: 100% Testing Accuracy, 50% Effective Cure*

Imagine a world in which newborns could be tested with 100% accuracy and in which a 50% successful low-cost highly feasible cure were available to all. In this world the mother, both on her own behalf and on her child's behalf, would weigh the likely negative consequences of disclosure versus the 50% likelihood of a low-cost highly feasible cure. In a world which provided strong protection with respect to confidentiality, anti-discrimination, and anti-stigmatization, the parent would likely grant consent in return for the 50% likelihood of cure. On the other hand, in a world in which the results were likely to leak out and in which anti-discrimination protections were weak, the parent might hesitate to consent.

Some, perhaps appalled at the possibility that a mother might refuse to risk disclosure in return for a 50% likelihood of cure, would argue that it would be appropriate to mandate testing in this world. My position, however, is that there is no valid reason to mandate testing in such a world. Here, the parent's own incentives closely parallel those of the child. The costs and benefits the mother will weigh on her own behalf, specifically the risks of disclosure and discrimination versus the possible benefits of the 50% likelihood of cure, are essentially the same costs and benefits that we would have had the mother weigh on behalf of the child. If the mother makes a decision we would deem inappropriate, it is not because the mother is placing her own interests or someone else's interests above those of the child. Rather, the decision would be deemed inappropriate because the mother has not based her decision on full or accurate information. Given the inherent undesirability of mandatory testing, the proper, and I believe the constitutional solution to such a problem is not to compel testing, but rather to provide more complete information and better counseling to the mother so that she can make a fully informed decision.

## 3. *World Three: 50% Testing Accuracy, 100% Effective Cure*

Imagine a world in which newborns could be tested with 50% accuracy and in which a 100% successful low-cost highly feasible cure were available to all. In this world, there would be no strong argument for compelled testing. In all likelihood, most mothers would consent to have their newborns tested. With a 100% success-

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60. Some may protest that I am improperly assuming the mother is both rational and well informed. However, if the problem is lack of information rather than a true conflict of interest between mother and child, then the best answer is better education and counseling, not mandatory testing. The conceivably irrational, but well-informed mother as an appropriate justification for mandatory testing is discussed *infra* note 62.



ful low-cost highly feasible cure for AIDS available, mothers would have little reason to fear a HIV-positive diagnosis for either themselves or their children. In a world where cure was possible, there would presumably be little or no discrimination on the basis of AIDS, so confidentiality also would not be an important issue. While the 50% testing inaccuracy surely would not thrill most parents, in that they would have to deal with the high possibility of false positive and perhaps false negatives, this risk would appear to be worthwhile in a world in which a cheap feasible cure were available. Most important, in this scenario, once again, the mother's incentives would not diverge from those of the child. The mother's choice on whether or not to have the child tested would parallel the mother's choice on whether to get herself tested. Thus, apart from fearing that the mother may not make a sufficiently well-informed decision, the state has no legitimate reason to intervene.

#### 4. *World Four: 100% Testing Accuracy, 100% Effective Cure For Newborns Only*

Imagine a world in which newborns could be tested with 100% accuracy and in which a 100% successful low-cost, highly feasible cure were available to all children, but no cure were available for adults. This scenario<sup>61</sup> exemplifies the strongest case for mandatory testing because the personal interests of the mother and the child diverge. A mother who knows that the likelihood of her own cure is nonexistent may hesitate to have her HIV status revealed through the testing of the child. While many altruistic mothers would elect to have their child tested, regardless of possible negative consequences for the mother and other children, other mothers might rationally hesitate to consent to such testing. Such a non-consenting mother might, of course, fear not only knowledge of her own imminent death but also, depending on the degree of confidentiality and protection available in the society, fear discrimination with respect to various benefits and also fear possible loss of the child due to allegations of parental neglect.

At the same time, we would likely all agree that if the child's chance of recovery is 100%, it would be in the child's best interest to be tested. Thus, this scenario, which potentially pits the mother's personal self-interest against the best interest of the child, presents the strongest case for mandatory testing. There is a societal justification for overriding the parental objection not only because we fear that the mother may be making an ill-informed decision, but also

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61. The scenario, while unlikely in this extreme version, is not entirely impossible. Many diseases affect adults and children differently, and cure rates for children are, in certain instances, much higher than cure rates for adults.

because we see that the mother's personal interests potentially conflict with those of the child.

### *E. Addressing Counter Arguments*

#### *1. The Expense of Testing: Is Mandatory Testing Cheaper?*

Nonetheless, even in this situation, the strongest imaginable scenario supporting mandatory non-anonymous testing, I conclude that mandatory testing is unnecessary. Rather than resorting to mandatory testing, we should seek to establish a set of social constraints such that the mother will have the incentive to act in her child's best interest. Specifically, we need to provide social support in terms of confidentiality, anti-discrimination and anti-stigmatization protection, as well as caretaking assistance to the mother, such that she will not be so fearful of disclosure of her own HIV-positive status that she will refuse to have her child tested for the virus. That is, we must revise the social parameters so that the mother's incentives more closely parallel those of the child.

Some might argue that it would be less expensive and therefore more efficient simply to mandate testing, rather than to attempt to revise social conditions to the point where the mother would voluntarily elect to have her child tested for HIV. However, this argument fails for several reasons. First, whereas such an argument may well be based in part on an implicit assumption that a mother who refuses to consent to her child being tested is a selfish or a "bad" mother, this is not the case. As discussed above, there are many reasons why a reasonable mother, concerned for *all* of her children, would take steps not to reveal her own possibly HIV-positive status. Nor should a mother be called selfish merely because she takes into account her own concerns, as well as her child's concerns. In economic terms, the mother is in a better position to assess *all* the relevant costs than is the government. Second, while revising the various social conditions may in fact be somewhat more expensive in dollar terms than imposing mandatory testing, it will also yield substantial benefits in that it would be less intrusive on personal liberties and less difficult to police, and perhaps most significantly, in that it would not lead mothers of newborns to avoid needed medical treatment for their newborns. That is, the seemingly cheaper solution is, in fact, expensive once all costs are considered. Third, providing the improved confidentiality protection against discrimination and stigmatization, assistance to HIV-positive mothers would, of course, provide additional independent positive benefits for the mother and many others in the society.

## 2. *What About an Irrational Mother?*

Some might also argue that I have failed to adequately address paternalism, specifically the possibilities of ignorance or irrationality as a justification for mandatory testing. That is, an argument can be made that a loving but ignorant or "irrational" mother, acting out of what most of us would view as unbased fears or religious beliefs, may fail to act in her child's best interest, by consenting to testing some would argue that mandatory testing can be justified on this basis, particularly where the testing is clearly in everyone's best interest, such as in the first scenario. However, I believe that such paternalism is a very weak justification for the extreme measure of mandatory testing. First, as a general rule, it is not wise to make a broad policy rule based on a very unlikely and rare scenario. Second, in a situation such as this, where there are no apparent systematic psychological factors at work (such as a taste for dangerous sport) which would lead many parents to reject testing, such conceivable ignorance and irrationality is better addressed through education and counseling than through mandatory testing.<sup>62</sup>

Third, if our goal is to achieve maximum testing, voluntary measures are more likely to work than mandatory measures. Even if we mandate testing, the truly ignorant or irrational mother may simply refuse to seek medical treatment, and thus avoid mandatory testing. Therefore, better education, counseling, and protection are our best hope for encouraging this mother to have her child tested. Fourth, as a practical matter, if a mother really did ignorantly or irrationally refuse to allow her child to be tested in the hypothetical world in which newborns could be tested with 100% accuracy and assured a cure, the parent's refusal could probably be overridden by a legal finding of parental neglect.<sup>63</sup> Although some may now argue that I have reintroduced mandatory testing under a different guise, I don't believe I have. A world in which the vast majority of testing occurs voluntarily, with the very few outlying irrational mothers being ordered to have their newborns tested, is far different from a world in which all mothers are compelled to have their newborns tested. My point is that we should focus on creating con-

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62. Alternatively, for those who are more swayed than I by the paternalistic arguments, my analysis shows mandatory testing should be allowed on this basis only where testing and cure technology are such that the test would very clearly be in all of society's best interest. See, e.g., Faden & Areen, *supra* note 48, at 259-73 (stating that mandatory testing of newborns is not currently justifiable but would be, under certain future circumstances); Faden, *supra* note 53 (while noting that mothers can generally be trusted to act in their children's best interest, *id.* at 352-53, the report nonetheless concludes that mandatory testing of newborns would be acceptable under certain circumstances, *id.* at 351).

63. See *supra* text accompanying note 38.

ditions such that the vast majority of mothers will *voluntarily* have their children tested, rather than legislating mandatory testing of all newborns to meet the problem of a very small number of irrational mothers.

#### CONCLUSION

In sum, I conclude that mandatory, non-anonymous testing of newborns is not justifiable from either a policy or constitutional standpoint. Such mandatory testing cannot be justified given the medical technology and social factors which exist today. Nor can it be justified under any other imaginable set of facts. Rather, the analytic model of hypothetical worlds discussed in this Article demonstrates that our societal interests would be best served by creating a set of societal conditions so that a mother will voluntarily consent<sup>64</sup> to have her newborn tested for HIV. Instead of viewing non-consenting mothers as bad people who are against their children's best interest, we should recognize that mothers can instead be counted on to do that which is best for their children, all else being equal. Our job then is to provide accurate tests, effective and available treatment, confidentiality, and anti-discrimination protection so that mandatory testing will be rendered unnecessary by voluntary consent to testing.

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64. Additional work must be done to spell out what type of consent should be required and what kind of counseling should accompany the solicitation of such consent. *See generally*, Banks, *supra* note 10, at 372-76 (discussing directive versus non-directive counseling). *See also* Nancy E. Kass, *Reproductive Decisionmaking in the Context of HIV: The Case for Nondirective Counseling*, in AIDS, WOMEN AND THE NEXT GENERATION, *supra* note 2, at 312-24 (discussing directive and non-directive counseling in the context of HIV-related decisions to be made by pregnant women).

