

# MANDATORY HIV TESTING OF PREGNANT WOMEN: PUBLIC HEALTH POLICY CONSIDERATIONS AND ALTERNATIVES

ERIN NICHOLSON\*

## I. INTRODUCTION

Laws requiring mandatory Human Immunodeficiency Virus (HIV) testing for pregnant women have been contemplated by state legislatures since a ground breaking 1994 study showed that treating these women with antiretroviral drugs during pregnancy could decrease the chance of passing the disease to their children.<sup>1</sup> Approximately 477 HIV-positive pregnant women participated in the AIDS Clinical Trial Groups 076 (ACTG 076) study which showed a near sixty-seven percent decrease in transmission of HIV from mother to child when the mother was given zidovudine (AZT) during the last two trimesters of pregnancy and the child received AZT for the first six weeks after birth.<sup>2</sup> Shortly after the results of the study were released, mandatory HIV testing of pregnant women gained the support of the American Medical Association<sup>3</sup> and was defended by most of the physicians on the Committee for the Care of Children and Adolescents with HIV Infection.<sup>4</sup>

The Ryan White Care Act,<sup>5</sup> passed in 1990, originally made federal monetary support for state AIDS programs partially contingent on the patient's informed consent. In 1996, the Act was amended to make funding contingent on the state's efforts to test ninety-five percent of pregnant women, or else show that their numbers of newborn HIV cases were falling.<sup>6</sup> Despite this pressure to

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\* B.A., Boston College; J.D., Duke University School of Law, expected May 2003; Certificate in Health Policy, Terry Sanford Institute of Public Policy at Duke University, expected May 2003. The author would like to thank Carolyn McAllaster, Jason W. Maloney, Sarah Smith, and Margot and Larry Nicholson for their guidance and support throughout the writing and editing of this article.

1. Edward M. Connor, M.D. et al., *Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type-1 with Zidovudine Treatment*, 331 NEW ENG. J. MED. 1173, 1173-1176 (1994).

2. *Id.* at 1175-1176.

3. Jeremy Manior, *AMA Supports HIV Tests for All Pregnant Women: Critics Fear Some Will Avoid Prenatal Care*, CHI. TRIB., June 28, 1996, at 4.

4. Evans McMillion, *The Case Against Mandatory HIV Testing of Pregnant Women: The Legal and Public Policy Implications*, 5 DUKE J. GENDER L. & POL'Y 227, 229 (1998). In 1999, the American College of Obstetricians and Gynecologists and the American Academy of Pediatrics came out with a joint statement in support of "universal testing" as a component of prenatal care. American Academy of Pediatrics & American College of Obstetricians and Gynecologists, *Human Immunodeficiency Virus Screening*, 104 PEDIATRICS 128 (July 1999).

5. 42 U.S.C.A. § 300ff (West Supp. 1991).

6. 42 U.S.C.A. § 300ff-34(e) (West Supp. 1991).

make testing mandatory (or near mandatory), not a single state has gone so far as to order HIV testing for every pregnant woman.<sup>7</sup>

Arguments for and against mandatory testing for pregnant women seem to fall into one of three categories: (1) legal arguments, (2) ethical considerations, or (3) health policy. To make the distinction among these three does not mean that they are exclusive of each other. More often than not, an argument will overlap at least two of these groups. But for purposes of organization, it is helpful to consider both mandatory HIV testing and its alternatives from within these categories.

Examples of legal concerns surrounding the practice of mandatory testing include constitutional issues such as due process, equal treatment, informed consent, reasonable search and seizure, reproductive rights and privacy rights. When inquiring into the "legality" of imposing mandatory HIV tests, it is important to look at past precedent in other cases of related issues, but also to recognize the present state of legal uncertainty due to the fact that courts have yet to rule on this particular issue.

The ethical considerations of mandatory testing often go hand-in-hand with many of the legal issues. Is it right to compel a pregnant woman to have an HIV test? Is it right to allow a fetus to go untreated for a fatal disease if the treatment is proven and readily available? Would testing discriminate unjustly against particular racial or socioeconomic groups? Is it ethical to compel a pregnant woman to get an HIV test, and then allow her to decline treatment for herself and her baby if she tested positive for the virus?

While legal and ethical considerations are very important to the debate about mandatory HIV testing, they often lie at the edges of the discussion. Perhaps because the issue has yet to officially go before the courts or ethics boards, the main grounds for argument have been based in public and health policy, rather than law and ethics. Another reason that health policy will continue to be the most prevalent grounds for the debate is because as states and medical organizations decide what health measures should be taken to decrease the spread of AIDS (whether it be testing or prevention measures, education, etc.), their focus will likely be on whether the laws or policies will meet their goals. This type of utilitarian thinking certainly has both legal and ethical underpinnings, but really emphasizes the question: "Will this work?" rather than: "Is this right?" or "Is this legal?"

When applied to the problem of testing pregnant women, health policy looks at more than just whether or not mandatory testing will limit the spread of

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7. New York passed a law in 1996 that universalized HIV testing of newborns, a law that may have the same results as testing all pregnant women. N.Y. PUB. HEALTH § 2500-f (1996). Connecticut passed a law in 1997 which also mandates the screening of newborns for HIV. CONN. GEN. STAT. ANN. § 19a-55 (West 1997). Indiana passed a law in July of 1998 that allows doctors to test newborns without mother's consent if the mother was not herself tested. See *Indiana Allows Testing of Babies if Mothers Weren't Tested*, AIDS POL'Y & L., May 1, 1998, at 5. Other states have passed laws which order that pregnant women be tested *unless* they refuse to give consent, but there are no laws yet on the books that effectively force any woman seeking prenatal treatment to be subjected to an HIV test against her will. See Amanda Watson, *HIV/AIDS Issue Brief: Reducing Perinatal Transmission* (June 1, 1999), at <http://stateserv.hpts.org/public>.

HIV to newborns. It also asks: Do the health benefits of the AZT regimen<sup>8</sup> outweigh the risks to both mother and child? Might the policy of mandatory testing have the effect of driving women away from prenatal testing and prenatal care? Is such a policy going to significantly harm patient/provider trust and the overall patient/provider relationship? These are only a few of the many policy considerations that will be a part of this decision.

This note will primarily focus on the health policy considerations central to the proposal of mandatory HIV testing for all pregnant women. It will examine and weigh arguments both for and against mandatory testing and, as is appropriate in any policy discussion, it will briefly distinguish and consider several of the alternatives to mandatory testing. Finally, this note will argue for an alternative policy which combines both voluntary testing and programs to educate and counsel women and men about the spread of HIV.

## II. HEALTH POLICY ARGUMENTS FOR AND AGAINST MANDATORY TESTING

### A. Health of the Mother, Health of the Newborn

HIV and AIDS are very serious diseases for any infected person, but particularly for pregnant women and newborns. Newborns with HIV have suppressed immune systems and are therefore more highly susceptible to illnesses. Particularly dangerous to them is a strain of pneumonia which often occurs in HIV-infected infants between three and six months of age.<sup>9</sup>

Women with HIV typically have particularly difficult pregnancies.<sup>10</sup> While HIV does not usually affect the way a pregnancy progresses, it does increase a woman's chances of developing opportunistic infections and these illnesses may increase the likelihood of miscarriage and premature birth.<sup>11</sup> Further, even absent specific illnesses, a woman with a suppressed immune system (typically HIV-infected women with a low CD4 count) will be particularly weak during

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8. From this point on, "AZT" or "AZT regimen" will be the terms used when discussing the drug therapy given to pregnant women and infants to prevent the passing of HIV from mother to child during birth. At the time of this article zidovudine (AZT) is being used in combination with other drugs to heighten its effectiveness. For the purposes of this note, "AZT" or "AZT regimen" is intended to include these new drug formulations. For an example of one of these new formulations, see Laurent Mandelbrot et al., *Lamivudine-Zidovudine Combination for Prevention of Maternal-Infant Transmission of HIV-1*, 285 JAMA, 2083, 2083-2093 (2001).

9. R.J. Simmons et al., *Pneumocystis Carinii Pneumonia among US Children with Perinatally Acquired HIV Infection*, 270 JAMA 470, 470-73 (1993).

10. Project Inform, *Pregnancy and HIV 1-2* (Oct. 1999), available at <http://www.projinf.org/fs/mothertochild.html#basics>.

11. Project Inform, *supra* note 10.

pregnancy even with optimal nutrition and care.<sup>12</sup> It is thought that AZT treatment may boost her immune system and help her complete the pregnancy.<sup>13</sup>

The primary argument offered by most advocates of mandatory testing is that the detection of HIV in a pregnant woman is a first step in getting both her and her fetus on the treatment protocol so as to protect the mother's health and hopefully prevent the transmission of HIV to the baby before or during child birth. The testing then is used to identify those who should receive treatment.

The ACTG 076 clinical trials showed that mothers who received AZT treatment during the last two trimesters of pregnancy and whose babies then received AZT for six weeks after birth had an eight percent chance of transferring the HIV infection to the child, while those who were not treated had approximately a twenty-five percent chance.<sup>14</sup> The results of the study demonstrate that one's chances of protecting a baby from being born with HIV increased three-fold from what they might have been without the AZT treatment.<sup>15</sup> Further studies have shown that the incidence of HIV infection decreases even further when a mother has a Caesarian section rather than a vaginal delivery.<sup>16</sup> Finally, a woman who is aware of her HIV status can feed her newborn with formula rather than breast milk and further decrease the chances of infection after birth.<sup>17</sup>

All of this is promising news considering that the number of HIV positive children born in the U.S. rose at alarming rates throughout the early nineties.<sup>18</sup> After the release of the ACTG 076 study and the use of the AZT during pregnancy, the rate dropped forty-three percent between 1992 and 1996.<sup>19</sup> Of course, these improvements have not been achieved by testing alone. Testing has only been beneficial in situations where the mother, having been tested, has also agreed to treatment.

Many who argue for mandatory testing also argue that HIV-positive women should be given the choice whether or not to take AZT during pregnancy.<sup>20</sup> But with numbers like these, one could naturally assume that any pregnant woman would automatically choose to take AZT following a positive test—but the surprising answer is sometimes “no.” In fact, there are many reasons why, even given the current data, women who test positive may not want

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12. *Id.* “High viral load” and “low CD4 count” are both ways of indicating that a person with HIV has a particularly suppressed immune system. High viral load simply means that the woman is carrying an increased level of the virus in her blood and CD4 are lymphocytes which are essential for adaptive immunity. For more information on CD4 count and viral load, see RAMZI S. COTRAN, VINAY KUMAR, AND TUCKER COLLINS, *ROBBINS PATHOLOGIC BASIS OF DISEASE*, 245-247 (1999).

13. Nancy Karkowsky, *Advice From Counsel: Legal Implications of Neonatal and Fetal HIV Testing*, SPECIAL REPORT, at 9.

14. Connor, *supra* note 1, at 1175-1176.

15. *Id.*

16. N. Seppa, *Cesarean + AZT = Almost no HIV transmission*, SCIENCE NEWS, June 27, 1998, at 405.

17. George Kent, *HIV and Breastfeeding*, MOTHERING, May-June 1999, at 65-66.

18. *PHS Urges Simplified Pretest Counseling of Pregnant Women*, AIDS POL'Y & LAW, Nov. 24, 2000, at 3.

19. Institute of Medicine, *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States* (Oct. 1998), at 1, available at <http://www.legacy.cdcnpin.org/broadcast/past/1999/0429/iomreport.pdf>.

20. Celia Farber, *AZT Roulette: The Impossible Choices Facing HIV-Positive Women*, MOTHERING, Sept./Oct.1998, at 53.

to receive treatment, and many of these are health reasons.<sup>21</sup> After learning of her positive test result, and before agreeing to the treatment protocol, a woman may want to know about the possible dangers to both herself and her fetus of receiving AZT treatment during pregnancy. There is evidence that the treatment may not be in the best interests of the mother's health and may even be dangerous to the fetus's health.<sup>22</sup>

The negative "knowns" as well as the "unknowns" of ACTG 076 are reason enough for many women to reasonably refuse the treatment. AZT drugs are known to have a host of side effects including severe headaches, anemia and bone marrow toxicity.<sup>23</sup> In addition to these physical side effects, a pregnant woman faces the danger of developing a resistance to the specific AZT combination given to her during pregnancy.<sup>24</sup> Should this happen, she may not respond well to later therapy. The fetus obviously may have much to gain should it happen to be one of those who would have otherwise been born with the virus. But what if the baby is one of the seventy-five percent who would have been born HIV-negative anyway? Could the regimen of AZT during birth and for several weeks afterwards have any dangerous side effects?

Most researchers and doctors who see infants that were previously exposed to the AZT regimen claim that there are few, if any, short term side effects on the infants and that these few discontinue if the baby ultimately tests negative and is taken off the drugs.<sup>25</sup> The evidence on long-term side effects is less conclusive. Very little is known because the treatment has only been given to fetuses and infants for the past six or seven years. Some scientists and researchers are concerned about the possibility of cancer and heart problems that may arise later in life.<sup>26</sup> The National Institute of Health has admitted that, for babies who were exposed to AZT but who are born HIV-positive anyway, the regimen may actually have the effect of "hastening illness and death."<sup>27</sup>

## B. Accuracy and Effectiveness

A second health policy consideration relating to the mandatory testing of pregnant women is the accuracy and effectiveness of testing. As many as sixty-four factors may affect the accuracy of an HIV test, one of which is pregnancy.<sup>28</sup> While there are only 4,000 or so known reports of false positive HIV tests,<sup>29</sup> it is

21. *Id.* at 57.

22. *Id.* at 61.

23. MARY J. MYCEK, RICHARD A. HARVEY, AND PAMELA C. CHAMPE, PHARMACOLOGY 369 (2000).

24. Theresa M. McGovern, *Mandatory HIV Testing and Treating of Child-Bearing Women: An Unnatural, Illegal and Unsound Approach*, 28 COLUM. HUM. RTS. L. REV. 469, 476 (1997).

25. Farber, *supra* note 20, at 57.

26. Elizabeth B. Cooper, *Why Mandatory Testing of Pregnant Women and Newborns Must Fail: A Legal, Historical and Public Policy Analysis*, 3 CARDOZO WOMEN'S L. J. 13, 19 (1996). For a new study offering at least some hope that the danger of cancer seems unfounded, see *Researchers Find No Cancers Among Children Exposed to AZT*, AIDS POL'Y & L., Feb. 5, 1999.

27. McGovern, *supra* note 24, at 478.

28. Christine Johnson, *Whose Antibodies are They Anyway? Factors Known to Cause False Positive HIV Antibody Test Results*, CONTINUUM, Sept.- Oct. 1996, available at <http://www.virusmyth.net/aids/data/cjtestfp.htm>; Farber, *supra* note 20, at 54.

29. Farber, *supra* note 20, at 60.

important that both doctors and women be aware that pregnancy could potentially cause a misleading test result which, if not double-checked, could lead to improper decision-making and increased health risks. (As a side note on the accuracy of HIV testing, it is important to recognize that all babies born to HIV-infected mothers initially test positive for HIV infection due to the baby's carriage of the mother's HIV antibodies in its blood stream.<sup>30</sup> Even without AZT treatment, almost seventy-five percent of these babies will "seroconvert" to HIV-negative after about twelve months.)<sup>31</sup> The realization that these false positives could encourage unnecessary treatment for a majority of fetuses and infants who will eventually test negative might make one wary to test pregnant women at all because treating a HIV-negative baby with AZT (a very strongly toxic drug) can cause many unnecessary health risks and possibly even death.<sup>32</sup>

One "effectiveness" problem that mandatory testing encounters is that the testing itself is unlikely to effect any reduction in the transmission of HIV in women who resist treatment after testing positive. Mandatory testing is likely to affect each pregnant woman very differently, but generally the responses of pregnant women fall into three categories. It is useful to compare how women would respond to mandatory testing in making treatment decisions and how this might vary from their response to voluntary testing.

The first group of women are those who would test regardless of whether the testing was mandatory or not. Because they are willing to take the test in order to get information on how to approach their prenatal care, many of these women will at least strongly consider treatment with AZT should their test come out positive.

The second group of women are those who may not have voluntarily agreed to a test because they did not consider themselves at risk,<sup>33</sup> but who, under a mandatory system, will be forced to test and will get HIV-positive results. It is possible that many of these women will also consider treatment, which they would not have considered, had they not been forced to be tested.

The final group of women are those who are resistant to testing because they do not wish to learn of, or have others learn of their HIV status.<sup>34</sup> Should mandatory testing be implemented, these women may make the decision to forego prenatal care, or they may give in to the test because they have decided that prenatal care is more important than their already-compromised rights to privacy and freedom of choice. It is quite likely, even after receiving their test results however, that these women may not wish to discuss their HIV status with their doctor or any health counselors and may be very resistant to AZT treatment.

In looking at these three groups of women, and recognizing not every woman will easily fall into one of these three categories, it seems that the two

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30. Catherine H. McCabe, *Ryan White Care Amendments: Mandatory HIV Testing of Newborns and a Woman's Right to Privacy*, 1 DEPAUL J. HEALTH CARE L. 373, 386 (Winter 1996).

31. *Id.*

32. *Id.* at 387.

33. *US Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women*, 44 (No. RR-7) MORBIDITY & MORTALITY WKLY. REP. 6 (1995) [hereinafter "*US Public Health Service*"].

34. *Id.* at 7.

latter groups are most likely to be affected by mandatory testing. When we ask about the effectiveness of testing, we should consider whether testing will lead to better and increased treatment. While there may be increased treatment in the second group, it is very possible that the third group will have decreased treatment as fewer of these women will seek prenatal care at all.<sup>35</sup> In addition, at a certain utilitarian level, it may make sense to mandate the tests and the treatment for all women whose tests come back positive. However, the impressive decrease in numbers of HIV-infected infants thus far has been obtained with HIV counseling, voluntary testing and voluntary treatment.<sup>36</sup> While in theory it seems that if all pregnant women were tested and treated this number could decrease even further, in actuality it is possible, for some of the behavioral reasons described above, that mandatory testing may in fact result in more HIV-positive births.

The third point on effectiveness is not directly related to testing, but rather to treatment. A main argument for mandatory testing is increasing the numbers of HIV-infected women who take AZT during pregnancy,<sup>37</sup> thus the effectiveness of the AZT treatment should be accounted for when considering testing. There are some studies that suggest that AZT treatment does not significantly reduce transmission of HIV from woman to child in women who have a low viral load at the time of birth. Of course, a woman would not be able to gauge what her health is likely to be during childbirth so this argument may have little effect. There may also be reason to believe that the treatment is not as effective in women who have a more advanced stage of HIV or AIDS.<sup>38</sup> Furthermore, the ACTG 076 trial was also conducted on women who had never taken AZT in the past, so there may be a danger that the treatment will not be as effective for those who had taken it to pregnancy.<sup>39</sup> There may also be problems with effectiveness for women who do not complete the AZT treatment or who skip doses due to drug use or other problems with commitment or access to the therapy.<sup>40</sup> It should also be noted that the most effective formula for treatment following a positive HIV test is AZT + caesarian section + formula feeding.<sup>41</sup> The possible push towards mandating a combination of these will be explored in a later section of this note.

### C. Public Health Concerns

Another policy reason that supports mandatory testing is that the testing will help stem the spread of AIDS in general. States are given power under the federal constitution to “legislate and enforce regulations to preserve the public

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35. *Id.* at 6.

36. *Id.*

37. Part of the plan advocated by the Institute of Medicine is that, “[t]esting should be seamlessly linked to treatment for women found to be infected.” See *Panel Urges Universal Testing of Pregnant Women for HIV*, AIDS POL’Y & L., Oct. 30, 1998, at 13.

38. McGovern, *supra* note 24, at 478.

39. *Id.*

40. *Id.* at 480.

41. Daniel Q. Hanley, *C-section plus AZT cuts AIDS infection*, ORANGE COUNTY REG., Jan. 29, 1999, at A6.

health and safety.”<sup>42</sup> Public health and safety is certainly at stake when it comes to the AIDS virus so it makes sense that state legislatures take reasonable measures to contain and perhaps someday eradicate the disease. The relevant question then is whether mandatory testing of pregnant women is a reasonable step to take.

The data on HIV-positive newborns in the various states in the U.S. has shown a decline in cases in the last several years.<sup>43</sup> This certainly could be the result of greater numbers of women being tested, and could also be supported either by the position that many of the women who test positive are choosing to take AZT during pregnancy, or are choosing to abort the possibly-infected fetuses prior to birth. It is likely that a combination of these testing-related choices is producing the decline. But is the reduction in HIV-positive children necessarily a significant step in putting an end to the disease in the general public? And is the public made safer by the decrease in HIV-infected newborns?

The decrease in infections in newborns is certainly a factor in eliminating AIDS, but when we realize that very few infants with HIV survive childhood, and that most of these infants are not spreading the disease to others in the first several years of life, it becomes obvious that reducing HIV in newborns is not significantly changing the growing numbers of total individuals with HIV in the United States. Educating those who are actually putting large numbers of people at risk—those who engage in unprotected sex and needle-sharing - is more useful to the goal of curbing the spread of AIDS. While reducing the number of pediatric AIDS cases is certainly a noble goal, we should recognize that as far as public health is concerned, infants have little to do with the spread of HIV in this country. Even the few HIV-positive infants who may reach adolescence will likely have very little impact on the overall spread of HIV.

The issue of public health seems to raise at least one more question. If we are serious about diagnosing currently unknown cases of HIV in order to prevent the spread of the disease, it would be more effective to mandate testing of everyone, or at least specific high risk individuals who, on occasion, seek medical attention for other reasons. (For example, intravenous drug users who arrive in the ER after an overdose, or any person who comes in to be treated for a sexually transmitted disease?) These groups of individuals have an overall higher rate of undiagnosed HIV infection than pregnant women, and are in at least as good a position to spread the disease to others. From the standpoint of public health policy and its presumed reliance on cause and effect, there is no reason that pregnant women who come in for prenatal care should be singled out for mandatory testing while others who stand an even better chance of infecting others are not.

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42. Linda Farber Post, *Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?*, 16 CARDOZO L. REV. 169, 199 (1994).

43. *E.g.*, *Maternal-infant HIV transmission drops sharply in wake of 076 findings*, INFECTIOUS DISEASE NEWS, March 1996, available at <http://www.infectiousdiseaseneews.com/199603/frameset.asp?article=maternal.asp> (discussing a North Carolina study showing a decline in mother to infant HIV transmission from 21% to 8.5% after the release of the 1994 ACTG 076 study).

#### D. Stereotyping Patients

This leads us to another interesting point that might support mandating HIV testing in pregnant women. Advocates of universal testing point out that under current voluntary testing, the only women who are counseled and urged to test are those who are thought to be in high-risk categories.<sup>44</sup> Often this corresponds to particular racial and socioeconomic groups who, in certain regions, have higher incidences of HIV infection. Many point to this stereotype-driven testing and consultation and argue that universal testing would prevent this type of discrimination and better help identify HIV-positive women in low-risk categories.<sup>45</sup> It is a point well taken, as any woman who has become pregnant by means of sexual intercourse could possibly be infected with HIV. Would universal testing bring an end to the stereotyping and possibly save many potentially HIV-infected babies who are born to low-risk mothers?

It is possible that a program that tests uniformly would at least end the singling-out of certain races and classes, and yet there may be ways to create a program that offers testing universally without forcing the test.

#### E. Other Policy Concerns of Mandatory Testing

##### 1. Domestic Violence

Beyond pressure to take a potentially dangerous drug, women may also have numerous other concerns about how an HIV-positive test result could affect her and her child. Researchers have found that HIV-positive women are exposed to greater risk for spousal abuse or domestic violence than are other women.<sup>46</sup> And while one may argue that the testing itself is not the cause of this increased risk (indeed there may be no cause-effect correlation), health policy should consider this factor nonetheless when weighing the risks and benefits of mandating HIV tests.

##### 2. Prenatal Care

As has been briefly discussed, there are also concerns that mandatory testing may result in increased numbers of abortions in HIV-positive mothers, or potentially a decrease in the amount, if any, of prenatal care that is sought by those who are concerned about their HIV status and do not wish to be tested for various reasons.<sup>47</sup> Mandatory HIV testing programs in general have a history of driving people away from services.<sup>48</sup> There is reason to believe that the women for whom prenatal care and the HIV test are most important, may be the very women who do not come in for care if they know it is predicated by an HIV

44. American Academy of Pediatrics & American College of Obstetricians and Gynecologists, *Human Immunodeficiency Virus Screening*, 104 PEDIATRICS 128 (July 1999).

45. *Id.*

46. McMillion, *supra* note 4, at 231; Project Inform, *supra* note 10.

47. Because no mandatory systems currently exist, data on this trend is unavailable. For "anecdotal evidence," see Cooper, *supra* note 26, at 26; see also Eileen Hansen, *The Historionic Push for Mandatory Perinatal HIV Testing*, 11 (No. 7/8) GMHC TREATMENT ISSUES 34 (1997).

48. For example, when Illinois required HIV testing prior to issuance of marriage licenses, "approximately 40,000 people left the state to marry elsewhere." Cooper, *supra* note 26, at 21.

test.<sup>49</sup> Thus, mandatory testing may in fact have the unintended consequence of driving up the number of births of HIV-infected infants.<sup>50</sup> The issue of access to prenatal care is important and will be explored further in a later section of this note.

### 3. Nature of the Patient-Provider Relationship

There is also much concern in the medical community about the effects that mandatory testing may have on the patient-provider relationship. It is often expressed that providers should have the role of facilitator, not enforcer.<sup>51</sup> Most cases of health professionals imposing treatment rather than patient choosing it (i.e. treatment without consent) break down any bit of trust that may have existed in the relationship. Alan Fleishman and Ana Dumois identify this possible danger to the provider/patient relationship in their 1994 article on the impact of mandatory HIV testing of all patients stating, "mandatory testing will create an atmosphere of fear. It will alienate the mothers from the health-care system and compound the distrust many already feel toward those who are presumably there to help—namely, health-care professionals who practice at hospitals and community health centers."<sup>52</sup> A woman who may already feel the most vulnerable in the medical care environment, may feel even less respect for and trust in a system that refuses to let her be in charge of the decision of whether or not to have an HIV test. All health care, but prenatal care in particular, relies on a high level of trust in one's doctor and in an open dialogue in between doctor and patient. Almost all benefits of a prenatal care program rely upon mother's compliance with the care that is determined to be best for her and her baby. This compliance will be much more likely when the care decided upon is mutually acceptable. A forced test will, in some cases, put a woman at odds with her doctor from the start. A positive test result without the mandate to treat may drive a particular wedge in the doctor-patient relationship if the mother and doctor are of differing opinions about whether to treat.

There is no question that some women will forgo prenatal care and instead rely on a pregnancy test and their own judgment, rather than be faced with a mandatory HIV test. This wouldn't be such a particular problem in many cases, but for the fact that so many HIV-positive women also use and abuse drugs—a behavior which puts the pregnancy at additional risk. A prenatal visit is an opportune time to give these women counseling about drug abuse, STDs and anything else she and her child may need. These avenues may be restricted if we replace HIV counseling and voluntary tests with a mandatory universal test.

### F. Possible 'Snowball' Effects of Laws Mandating HIV Testing

A final concern facing many who oppose mandatory HIV testing of pregnant women is the possibility that once women can be compelled to submit to

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49. Amanda Watson, *HIV/AIDS Issue Brief: Reducing Perinatal Transmission*, (June 1, 1997), at <http://stateserv.hpts.org/public>.

50. McMillion, *supra* note 4 at 230.

51. *Id.* at 231.

52. Alan Fleischman & Ana Dumois, *New York Forum About Newborns HIV Testing Is Not Health Care*, N.Y. NEWSDAY, Jan 18, 1994, at 84.

testing against their will, the floodgates may open and legislatures and hospitals will be able to justify even further violations and limitations on choice. Perhaps these fears are unwarranted—it is possible that laws can be put into place that only mandate HIV testing of pregnant women and go no further. But given the history of regulatory systems, there is probably good reason to think that if a system chooses “public health” over “individual choice” in one case, there is at least the possibility that advocates of other types “care absent consent” will be able to use the same rationale to their ends. Regardless of whether these fears are unfounded, the fact that they exist is still important to a public policy discussion because often fear and emotion drive an individual’s health care decisions just as strongly as reason (i.e., a woman’s fear about the possibility of having her children removed from her care should she test positive may drive her decision to not go to the hospital prior to delivery). The following are a few of the potential extensions of mandatory HIV testing in pregnant women that are feared by its opponents.

First is the fear that mandatory testing may be only a precursor to the mandate of care for HIV-infected persons.<sup>53</sup> A positive test in many states is followed by a person from the state health department visiting a home and asking the woman numerous questions about her private life.<sup>54</sup> The individual is generally counseled to look into treatment for his or her disease and to refrain from any high-risk activities that might put others at risk. A pregnant woman might also fear that because her pregnancy puts another at high risk, that the next step could be mandating HIV treatment during pregnancy and then perhaps mandating HIV treatment for her child. Women may fear that they will not only lose the right to choose whether to be tested, but will also lose the right to choose whether to treat themselves and their children.

A woman may also fear that the consequences of declining treatment could extend to culpability and associated criminal sanctions.<sup>55</sup> The decision not to receive treatment, particularly with the knowledge of a twenty-five percent chance of transmission, could constitute criminal neglect in some jurisdictions. Might a woman’s child be taken from her if she “knowingly” or “recklessly” exposes it to HIV during or after childbirth? Criminal law already applies in cases of knowing or reckless exposure or transmission of the virus during sexual intercourse.<sup>56</sup> Women may then rationally fear that the next step after losing her

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53. The Institute of Medicine believes that “testing should be seamlessly linked to treatment for women found to be infected.” *Panel Urges Universal Testing of Pregnant Women for HIV*, 13 AIDS POL’Y & L., Oct. 30, 1998, at 8.

54. Almost forty states now keep names of individuals who test positive for HIV (some of which send state officials to the homes of the infected individuals for the purpose of informing them of test results and trying to persuade them to speak to others whom they may have put at risk). See Randy Dottinga, *HIV Patients Lose Privacy in Oregon*, HEALTHSCOUTNEWS REP., Oct. 9, 2000, available at [http://healingwellaids.subportal.com/health/Diseases\\_and\\_Conditions/Sexually\\_Transmitted/AIDS\\_HIV/501980.html](http://healingwellaids.subportal.com/health/Diseases_and_Conditions/Sexually_Transmitted/AIDS_HIV/501980.html).

55. Cooper points out that the possibility of criminal prosecution currently exists in at least four states. Cooper, *supra* note 26, at 27.

56. Melinda Madison, *Tragic Life or Tragic Death: Mandatory Testing of Newborns for HIV—Mothers’ Rights Versus Children’s Health*. 18 J. LEGAL MED. 361, 374-75 (1997).

right to choose to test is losing her right to choose treatment, or worse, losing custody of her child.<sup>57</sup>

A woman might also fear that should HIV testing be made mandatory, the next logical step will be to make many more prenatal tests mandatory, particularly those which might inform of a health risk to the child. With the current development of the human genome project, some tests for genetic diseases already exist and the creation of tests for others are likely to be developed in the near future. If the justification for mandatory testing is that the woman will have information with which she may decide to end her pregnancy or take precautions so as to keep her child from developing a disease, it may just as well apply to diseases other than AIDS. It is important to keep in mind that a test (HIV, genetic or other) that may be justified to protect or help treat an unborn child will typically reveal the status of the mother as to the disease as well. There are many reasons that a woman may not want to know her status as to a genetic disease or HIV. The ultimate policy question then is whether or not we should protect this inclination of a woman to remain ignorant of her status, when it may mean that her child's status will also go unknown and untreated?<sup>58</sup>

A final fear held by many people is that pregnant women are just the first of several groups who may be forced to take an HIV test when accessing health care. It would make sense that if the rationale for testing pregnant women is that they may put another at high risk for transmission of HIV, that other groups who also put others at risk may be tested for HIV upon entering the hospital in the name of public health.<sup>59</sup>

### III. ALTERNATIVES

It is important to understand that in this debate about testing there are not just two irreconcilable choices: mandatory testing or no testing. Nor, as Professor Paris R. Baldacci points out, does this have to be a strict choice between mother's rights and child's welfare.<sup>60</sup> There may be alternatives to mandatory testing that allow protection of the interests of both mother and child.

#### A. Testing Newborns

Much has been written about the alternative of testing a newborn rather than testing the mother prior to delivery, and this paper will give it only brief attention in so far as it is an alternative to mandatory testing. *In theory*, this alternative protects both mother's and child's interests, but *in fact* it fails to protect

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57. See Hansen, *supra* note 47, at 11 ("HIV infected women have been threatened with the loss of their children.").

58. This gets into some legal and ethical topics which are not the direct focus of this paper, but which are discussed in Julie D. Levinson's *While Ignorance May Not Be Bliss, It is a Mother's Right: Constitutional Implications of Testing Newborn Babies For HIV*, 3 CARDOZO WOMEN'S L.J. 71 (1996).

59. See McMillion, *supra* note 4, at 229 ("Gay Men's Health Crisis and New York Civil Liberties Union oppose mandatory testing because each fears it will set a precedent that erodes the statutory basis of confidentiality in one's HIV status.").

60. Paris R. Baldacci, *An Introduction to "Mandatory HIV Screening of Newborns: A Child's Welfare in Conflict with its Mother's Constitutional Rights?"—False Dichotomies Make Bad Law*, 3 CARDOZO WOMEN'S L.J. 1, 5 (1996).

either. Those who advocate newborn testing point out that the woman is not subjected to the testing of her body without her consent, and at the same time the infant's status can be known so that it may be treated.<sup>61</sup> However, those who believe that most women who reject HIV tests do so because they are averse to merely an invasion of a prick of a needle are missing the point. The HIV test is most likely unwanted because it will reveal the mother's HIV status which either she would rather not know, or, in states where testing is confidential rather than anonymous, would rather the state not know. If the child is tested upon delivery, the mother's status is immediately known as well. Furthermore, the baby, if born with HIV, may only get minimal help from the AZT therapy after birth.<sup>62</sup> Testing after birth actually gives more information about the mother's HIV status than the baby's, due to the "seroconversion" of most HIV-positive newborns.<sup>63</sup> So the process of newborn testing actually manages to combine the bad effects of both forcing the mother to test and not having the test done at all, and thus is not a very good alternative.

#### B. One Dose of Nevirapine for Mothers and Babies at High Risk for HIV

A possible way to treat *without* testing is currently being considered in Africa and in other countries where conditions exist so as to make it difficult for women to receive prenatal care or to fund long-term AZT treatment. A study of a new drug, Nevirapine, shows that giving a HIV-positive pregnant woman a dose of the new drug at the onset of labor and also giving a dose to the baby at birth, may reduce transmission of HIV by forty-seven percent.<sup>64</sup> This is not quite as effective as the AZT treatment (about sixty-seven percent) in the ACTG 076 study, but may be a good alternative if the mother identifies that she is at high risk of having HIV and would agree to this simple treatment, but refused testing earlier in her pregnancy. There are few side effects of the treatment, and the mother's privacy and baby's health are both taken into consideration. This treatment may be considered "substandard" care by some, but seems a viable alternative where the mother will not comply with the more complex AZT treatment. If the health system can also identify high-risk patients, there may be a justification for offering the drug without the test.<sup>65</sup> Of course, if a woman is HIV positive she still risks transmitting the virus to baby through breast milk, and thus the treatment is not optimal unless the woman is willing to make some lifestyle changes after the birth of the child.

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61. Nina Lowenstein, *Mandatory Screening of Newborns For HIV: An Idea Whose Time Has Not Yet Come*, 3 CARDOZO WOMEN'S L.J. 43 (1996).

62. For this reason, many doctors do not treat HIV positive infants with antiretroviral drugs unless the test result is also corroborated by symptoms of HIV infection. See McCabe, *supra* note 30, at 387-88.

63. All babies born to HIV infected mothers are positive at birth and 70-80% of babies who test positive at birth will sero-convert to negative at fifteen months of age. Juliet J. McKenna, *Where Ignorance Is Not Bliss: A Proposal For Mandatory Testing of Pregnant Women*, 7 STAN. L. & POL'Y REV. 133, 135 (1996); see also Anna Quindlen, *The Baby Bill*, N.Y. TIMES, June 8, 1994, at A25.

64. Kevin M. De Cock, M.D. et al., *Prevention of Mother-to-Child HIV Transmission in Resource-Poor Countries*, 283 JAMA 1175 (March 1, 2000).

65. R. Curtis McNeil, *Prenatal HIV Testing Under Ohio Revised Code Section 3701.242: The Doctor's Dilemma and the State's Shame*, 22 U. DAYTON L. REV. 301, 306 (1997).

### C. Focus on Preventing the Rise of HIV Infection in Women of Childbearing Age

Some opponents of mandatory testing address the issue of the spread of HIV to infants from a different perspective. These individuals argue that if the focus is shifted from preventing the infant from getting HIV from the mother, to preventing the woman from getting HIV to begin with, we will move much more quickly towards the goal of eradicating AIDS altogether.<sup>66</sup> They argue not for mandatory testing, but for more progressive programs promoting “safe sex,” discouraging intravenous drug use and encouraging needle exchange. They would also focus on testing women *before* they become pregnant, and not single out only women of child-bearing age, but also men of the same generation—to promote overall awareness of the disease and its outcomes.<sup>67</sup> The counseling of young people about the health risks associated with unsafe sex and drug use would be important, just as would be testing individuals and couples before they become sexually active.

Of course this might seem all very naively optimistic. After all, the United States has worked on AIDS education for years and it seems to barely have made a dent in the number of new infections each year (particularly among young women).<sup>68</sup> However, the argument here is that we should not give up on education and awareness as a way of protecting newborns from HIV, and that it is a much more empowering option than forcing all pregnant women to be tested for the disease. Years of experience have shown, however that education alone will not keep the disease from spreading. That is why many who advocate this alternative realize that it must be combined with testing programs of some sort in order to be of any use.

### D. Voluntary Testing

Most states’ legislatures, doctors, hospitals, patient advocate groups, and civil liberty groups favor a policy of combining voluntary HIV screening with effective counseling and education.<sup>69</sup> There are two main types of voluntary testing—one which I will refer to as true voluntary testing,<sup>70</sup> and another which is a policy of testing with the option to refuse.<sup>71</sup> If done well, either of these

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66. Hansen, *supra* note 47, at 34.

67. McMillion, *supra* note 4, at 242.

68. Three-fourths of all HIV infected women are of childbearing age. Mary A. Crossley, *Of Diagnosis and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581, 1591 (1993).

69. The U.S. Public Health Service recommends “routine HIV counseling,” “voluntary testing,” and education about risks for “uninfected women.” *US Public Health Service*, *supra* note 33, at 8. Also, as noted before, the Gay Men’s Health Crisis and New York Civil Liberties Union both support voluntary testing. See *supra* note 59 and accompanying text.

70. All states except Texas, Michigan, Tennessee and Arkansas have policies of testing only with the woman’s consent. See Amanda Watson, *HIV/AIDS Issue Brief: Reducing Perinatal Transmission* (June 1, 1999), at <http://stateserv.hpts.org/public>.

71. Texas, Arkansas, Michigan and Tennessee have statutes which allow health professionals to test unless the woman refuses to give consent. This is also the plan advocated by the Institute of Medicine. See *Panel Urges Universal Testing of Pregnant Women for HIV*, 13 AIDS POL’Y & L., Oct. 30, 1998 at 1.

methods of voluntary testing with counseling as to the risks and benefits of possible treatments could save more babies than mandatory testing.

#### IV. WHY A COMBINATION OF VOLUNTARY TESTING AND INCREASED AWARENESS IS BEST

There are various reasons why a policy of voluntary testing and education is the preferred alternative, but in focusing on public health policy, the plan would seem to have four main advantages.

##### A. Keeping Women in Prenatal Care

First, in an era of confidential, rather than anonymous, testing a pregnant woman may have several reasons not to want her HIV status known, either by herself or others. A system that informs her of the benefits of testing but still leaves the final decision in her hands will encourage some of those who might not otherwise test to do so, but will allow women who, after hearing all of their options still wish to forego the test, to receive prenatal care. A more comprehensive voluntary approach that places prenatal care as woman's ally rather than as a foe will encourage women to seek out prenatal care initially and may have a better chance of getting them, once tested positive, to understand and accept the benefits of treatment. If a woman feels that she will lose control over her body if she is to seek prenatal care—she may choose not to, or at least refuse treatment after an HIV-positive result so as to exert any remaining control over her own health and her own pregnancy. Evans McMillion argues to this effect stating, “any benefits to be realized by testing depend upon the continued cooperation and involvement of the mother” and that “identification alone is not good without trust and willingness to go forward with care.”<sup>72</sup>

If, as a matter of public policy, we want such cooperation and willingness, it follows that a program of mandatory testing which places women at odds with their providers from the start would not be a good one. If instead a provider says, “this is your decision, I will give you all of the information about testing and treatment and help answer your questions,” a woman is much more likely to ask the provider for advice, in which case the provider may or may not advocate the testing. This type of environment and provider-patient interaction will certainly bring more women to the hospital than one which forces a test without consent.

##### B. Universal Voluntary Testing and Education Prevents Stereotyping

If the counseling is done universally, and is done universally well, concerns about racial profiling and socioeconomic stereotyping need not be a problem. Well-trained counselors and/or providers will understand that every pregnant woman is at risk (at least to some extent) for HIV. If the program of education and voluntary testing is encouraged and understood by the patient to be a routine part of every pregnancy exam, and even perhaps routine for all those who

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72. McMillion, *supra* note 4 at 243.

have become sexually active, there is little reason to believe that this will have a more prejudicial effect than mandatory testing.

### C. Unknown Health Risks Necessitate Choice of Care

A very important health policy reason for HIV testing to remain voluntary is the fact that very little is known about the long-term side effects of AZT on a newborn. Though initial studies give hope that the treatment is relatively safe and effective, there still may be some cause for concern. Pregnant women are generally cautioned against taking any toxic medication during pregnancy unless absolutely necessary.<sup>73</sup> To some, a two-thirds decrease in the likelihood that they will transmit HIV to their child may be enough reason to believe the treatment to be necessary. For others, particularly mothers who have low viral load, a pregnancy that ends in Caesarian section may be preferable and have as effective a decrease in risk. When patients are counseled on any other type of care, be it chemotherapy, surgery, radiation, and various drug therapies, they are always given the pros and the cons. With other health conditions where there is uncertainty about care, the health system does not compel someone to be tested nor to receive treatment they do not want. HIV should be no different. Hopefully, with a program that educates and informs about the dangers of HIV infection, all women who are at some risk, pregnant or not, will be tested. The same applies to men who are at risk for the disease. But so long as there remains no cure for AIDS, so long as the treatments have some potentially harmful side effects, and so long as the information about the test result is released to both infected individual and the state in which he or she lives, we must make do with a process that will allow individual choice, rather than make mandatory HIV testing a requisite to medical care.

### D. The Programs Work

Public policy tends to go with programs that clearly meet their intended goals. Here the goal is getting women and their unborn babies the medical care they need. There is no better advocate for voluntary testing than the programs at NYC's Harlem Hospital, Chicago's Cook County Hospital, and Baltimore's Johns Hopkins Health System. They are all extremely good examples of how HIV testing has the best outcome when women are strongly urged to get tested by good counseling, but not forced to get tested against their will.<sup>74</sup> There is no reason that with increased education and better counseling we would not see even better results and we would not see them in hospitals and clinics across the country. While the main basis for the argument for mandatory testing is that it will work even better than these programs, there is significant reason to believe that it will have the effect of decreasing the number of women who seek prenatal care, thus decreasing the number who are tested and therefore increasing the numbers of infants born with HIV. The better policy is to work with the volun-

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73. Farber, *supra* note 20, at 54.

74. Cooper, *supra* note 26, at 22. Note that North Carolina also has had success with voluntary testing. See *Most HIV-Positive Pregnant Women Effectively Identified and Treated in North Carolina*, SCIENCE NEWS UPDATE (May 15, 1996), at <http://www.ama-assn.org/sci-pubs/sci-news/1996/snr0515.htm>.

tary programs that we currently have to make them an environment of empowerment and choice for women who wish to seek prenatal care.