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Cheryl E. Amana

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## DRUGS, AIDS AND REPRODUCTIVE CHOICE: MATERNAL-STATE CONFLICT CONTINUES INTO THE MILLENNIUM<sup>1</sup>

CHERYL E. AMANA†

### INTRODUCTION

For more than a decade I have examined women's reproductive rights, paying particular attention to the role of the state, if any, in a woman's exercise of those rights. I have written and spoken about forced obstetrical intervention, intervention with substance dependent pregnant women, and reproductive choices of Human Immunodeficiency Virus (HIV) positive women. Issues that focus on pregnant women are often described in terms of "Maternal-Fetal" conflict. The tension, however, is not between a woman and her fetus, therefore making this description a misnomer. It would more appropriately be described as a conflict between a woman and the state regarding choices that she may make that the state decides may be injurious to the developing life that she carries. For purposes of this essay, I will refer to this conflict as "Maternal-State" conflict. State intervention in the lives of pregnant women has become more complex as the Supreme Court in both *Webster v. Reproductive Health Services*<sup>2</sup> and *Planned Parenthood of Southeast Pennsylvania v. Casey*<sup>3</sup> recognized a state's compelling interest in the potential life of a fetus so long as the woman chooses to continue her pregnancy.

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1. This essay has evolved from several presentations that I have made. I have decided to update it this year (2005) because now that Azidothymidine (AZT) has been used therapeutically for over a decade, I wanted to review some of the more recent data on AIDS and perinatal transmission, as well as changes, if any, in how society is responding to maternal-state conflict as we move into the new millennium. AZT, known generically as Zidovudine, is the only HIV drug that is fully approved for use during pregnancy. Although it is rarely used as a single drug therapy, it is used as a monotherapy during pregnancy because it does significantly reduce the chance of mother baby HIV transmission - see Part II of this article.

† Professor of Law, North Carolina Central University School of Law, JD-Pennsylvania; LLM-Columbia. I would like to thank first and foremost my research assistant, Amanda Maris. Amanda's assistance in gathering information, reminding me of deadlines and generally being available as needed has been invaluable in completing these updates. Thanks also to Professors Wright and Beckwith and my son and daughter-in-law Malik and Jill Morrison, who read and gave helpful critiques of earlier versions of this article. And finally, thanks to my husband, civil rights attorney John Burris, who has consistently lent a critical eye to my text and a critical ear to my ideas as I worked towards finding a useful framework to address these very important issues.

2. *Webster v. Reprod. Health Serv.*, 492 U.S. 490 (1989).

3. *Planned Parenthood of Se. Pa. v. Casey*, 510 U.S. 1309 (1994).

This essay will examine the reproductive choices of HIV positive women, particularly in light of Protocol 076,<sup>4</sup> the Azidothymidine (AZT) study, the National Institute of Child Health and Development (NICHD) study on perinatal transmission,<sup>5</sup> as well as several studies from developing countries. Common issues arising for the HIV positive woman include: whether she should become pregnant; if she becomes pregnant, whether she should carry the fetus to term or abort; and whether her infant should be tested for Acquired Immune Deficiency Syndrome (AIDS). There are also questions concerning whether all pregnant women should be tested for AIDS and, if they test positive, whether they should be treated with antivirals to protect the fetus.

Protocol 076 has shown that vertical transmission of the HIV virus from mother to child during pregnancy and shortly after birth can be dramatically reduced by a course of treatment with Zidovudine. The NICHD study predicts that vertical transmission can be reduced by half if delivery is done by elective cesarean section (c-section) before labor and prior to rupture of the membranes.<sup>6</sup> The implications of both studies could be far reaching and may involve "maternal-state" conflict. How, for instance, would women who want treatment be able to access it? Who would pay for it? Who would be informed of their HIV status? Would the husband of the woman and/or father of the fetus have a right to know? Would women who do not want treatment or surgery be forced to accept both or either? This essay will consider these issues and will offer a framework to assist policy makers and legal theorists as they face these and other questions relating to "Maternal-State" conflict.

Part I of this essay provides some background of state intervention in two contexts for pregnant women: medical care and substance dependency. Recognition and support of state intervention in these contexts have enabled states to intervene more easily in the lives of HIV positive women. Part II addresses AIDS generally in the African American Community, reviewing demographic information and risk factors for AIDS in the African American woman. Furthermore, I discuss vertical transmission of AIDS from mother to child particularly in light of Protocol 076, the NICHD study and recent international

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

5. NICHD press release Jan. 1, 1999, available at <http://www.niaid.nih.gov>. See also, <http://www.nih.gov/news/pr/nov96/niaid-27.htm> and [http://www.niaid.nih.gov/daids/therapeutics/research/2002PT\\_RA\\_sum.htm](http://www.niaid.nih.gov/daids/therapeutics/research/2002PT_RA_sum.htm) (last visited Nov. 1, 2005).

6. The International Perinatal HIV Group, *The Mode of Delivery and the Risk of Vertical Transmission of Human Immunodeficiency Virus Type1-A; Meta-Analysis of 15 Prospective Cohort Studies*, 340 NEW ENG. J. MED. 977 (1999).

studies. Part III examines calls for mandatory testing and treatment, and legal and ethical objections to both. Part IV concludes with recommendations for a positive, noncoercive community response to the problem.

## PART I

Recognition of a state's compelling interest in potential life and the need for modification of state dependency statutes to incorporate the fetus provided the groundwork for legislative and judicial intervention in the reproductive decision-making of pregnant women. This modification allows a state to monitor and regulate the conduct of a pregnant woman if it considers such intervention necessary to protect the fetus. The state is now assisted in this regulation by the woman's physician, who at one time considered the woman as her patient, but who now considers both the woman and the fetus as patients.<sup>7</sup> In many instances doctors are more than willing to place the interests of the fetus above that of the woman.<sup>8</sup> This is particularly true if they are dealing with women of color or women from a lower socioeconomic class.<sup>9</sup> Kolder & Gallagher in their study found that when court-ordered obstetrical intervention was sought, 81% of the women involved were African American, Asian or Hispanic. In 25% of the cases, the women did not speak English as their primary language. Intervention was ordered in 86% of the cases and 47% of the doctors polled said they would support forced intervention on behalf of the fetus, including forced confinement.<sup>10</sup> It is apparent from the Kolder and Gallagher study, and from other similar studies, that doctors tend to communicate with their private white patients when conflict arises during treatment, but are more inclined to use the courts for treatment conflicts when dealing with poor patients, patients of color and/or patients with language barriers.<sup>11</sup>

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7. Cheryl E. Amana, *Maternal-Fetal Conflict: A Call for Humanism and Consciousness in a Time of Crisis*, 3 COLUM. J. GENDER & L. 351, 353 (1992) (citing Jack A. Pritchard et al., *Williams Textbook of Obstetrics* at xi (1985)) ("Quality of life for the mother and her infant is our most important concern. Happily we live and work in an era in which the fetus is established as our second patient with many rights and privileges comparable to those previously achieved only after birth.").

8. See *id.* citing Veronika E.B. Kolder et al., *Court Ordered Obstetrical Intervention*, 316 NEW ENG. J. MED. 1192, 1193-94 (1987); see also Rosa H. Kim, *Reconciling Fetal/Maternal Conflicts*, 27 IDAHO L. REV. 223, 236-37 (1991); Lawrence J. Nelson & Nancy Milliken, *Compelled Medical Treatment of Pregnant Women: Life, Liberty and Law in Conflict*, 259 JAMA 1060 (1988).

9. Amana, *supra* note 7, at 354 (citing Nelson & Milliken, *supra* note 8).

10. Kolder, *supra*, note 8.

11. *Id.*; see also DOROTHY E. ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION AND THE MEANING OF LIBERTY* (1997) (hereafter "Killing the Black Body") (eloquently ad-

The same disparate treatment seen in the use of obstetrical intervention is observed with substance dependent pregnant women. For example, Dr. Ira Chasnoff, of the National Association for Perinatal Addiction Research and Education (NAPARE), conducted a study in Florida showing that although the rate of illicit drug use was similar across race and economic lines, African American women were ten times more likely to be reported to authorities.<sup>12</sup> Dr. Chasnoff also conducted a study in North Carolina for the Department of Human Resources, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. This study found that although the use of controlled substances and tobacco was roughly consistent between African American and European American women, African American women were more likely to have involvement with the criminal justice system and drug treatment programs.<sup>13</sup> The increased treatment numbers may result from the high incidence of reporting for African American women and the likelihood that one might be diverted to treatment once in the criminal justice system or as a condition of probation. Moreover, it is estimated that 70 to 80 percent of women prosecuted for prenatal drug use are Black.<sup>14</sup> Furthermore, Professor Dorothy E. Roberts has found that a greater percentage of African American than European American mothers who seek prenatal care are tested for drug use and lose custody of their children, often without hearings, investigations, or any semblance of due process.<sup>15</sup>

The response to substance dependency in pregnant women has been largely punitive rather than protective. Many states have redrafted their abuse and neglect statutes to incorporate the fetus.<sup>16</sup> In states

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addressing the many dimensions of governmental regulation in the lives of African American Women when it comes to reproductive choices).

12. Ira J. Chasnoff et al., *The Prevalence of Illicit Drug or Alcohol Use During Pregnancy and Discrepancies in Mandatory Reporting in Pinellas County, Florida*, 322 NEW ENG. J. MED. 1202, 1204 (1990). See also Dorothy E. Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right to Privacy*, 104 HARV. L. REV. 1419 (1991). Professor Roberts has written extensively about state intervention on reproductive choice. I have read many of her articles in preparation for my work. She was kind enough to review my first article in this area (see Amana, *supra* note 7).

13. Ira J. Chasnoff & Judith C. Burnison, *Drug and Alcohol Use in Pregnancy: A Study of Service Needs and Prevalence in the State of North Carolina* (1994) (on file with the author).

14. Lynn M. Paltrow, *Criminal Prosecutions Against Pregnant Women: National Update and Overview*, (ACLU/Reprod. Freedom Project) (April 1992); see also Roberts, *supra* note 11.

15. See Roberts, *supra* note 11 and Chasnoff, *supra* note 12.

16. See, e.g., FLA. STAT. ANN. § 39.01(g) (West, WESTLAW through Chapter 484 and H.J.R. No. 1 and S.J.R. No. 2394 (End) of 2004 Spec. 'A' Sess. of the Nineteenth Legislature) (defining "harm" for purposes of proceedings relating to children including "expos[ing] a child to a controlled substance or alcohol" where "[e]xposure to a controlled substance or alcohol is established by [in one way]: [1] Use by the mother of a controlled substance or alcohol during pregnancy when the child, at birth, is demonstrably adversely affected by such usage"); 705 ILCS 405/702-3 (2005) (amending the Juvenile Court Act's definition of neglected or abused minor to include "any newborn infant, whose blood or urine contains any amount of a controlled sub-

that have not made amendments, abuse and neglect statutes have often been interpreted to protect the fetus.<sup>17</sup> States have attempted to use criminal law to criminalize the behavior of mothers who are pregnant and substance dependent. "At least 200 women, in more than 30 states, have been arrested and criminally charged for alleged drug use or other actions during pregnancy."<sup>18</sup> For example, Florida, Michigan, South Carolina and Wisconsin have each addressed this issue with varying results. Prosecutors in both Florida and Michigan attempted to use drug delivery statutes to prosecute mothers with substance abuse problems.<sup>19</sup> The fact that the attempted prosecutions were ultimately

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stance. . . with the exception of controlled substances . . . [as] the result of medical treatment administered to the mother or the newborn infant."); IND. CODE § 31-34-1-10 (1997) (including a child born with fetal alcohol syndrome or an addiction to a controlled substance within its definition of a child in need of services). The statute specifically provides that a child is in need of services if it "needs care, treatment or rehabilitation that: [it] is not receiving; or [that] it is unlikely to be provided . . . without the coercive intervention of the court." *Id.* See also MINN. STAT. ANN. § 626.5561 (2) (West 1997) (defining child neglect as among other things prenatal exposure to drugs); N.J. REV. STAT. § 30: 4C-11 (1997) (providing that "the provisions of this section [a child endangerment statute] shall be deemed to include an application on behalf of an unborn child . . ."); N.Y. FAM. CT. LAW § 1012 (f)(I)(B) (McKinney 1979) (defining a neglected child as "one whose physical, mental or emotional condition has been impaired. . . as a result of the failure of his parent. . . to exercise a minimum degree of care. . . in providing the child with proper supervision or guardianship. . . or by misusing a drug or drugs or by misusing alcoholic beverages"); OKAL. STAT. ANN. tit. 10, § 7001-1.3.10.a. (3) (West 1997) (including in its definition of "deprived child" one "who is a child in need of special care and treatment," which entails "a child who at birth tests positive for alcohol or a controlled substance. . .").

17. See e.g., *In re Ruiz*, 500 N.E.2d 935, 939 (Ohio C. P. 1986) (holding that a viable fetus is a child under its child abuse statutes); *Brown v. Dept. of Health and Rehab. Services*, 582 So.2d 113, 115 (Fla. Dist. Ct. App. 1991) (finding evidence of drug abuse to be a sufficient basis to support prospective neglect); *In re Stefanel Tyesha C.*, 556 N.Y.S.2d 280 (App. Div. 1990) (positive toxicology sufficient to support a cause of action for neglect); *In re Troy D.*, 215 Cal.App.3d 889 (Cal. Ct. App. 1989) (allowing positive toxicology to establish juvenile court jurisdiction). *Cf.* *People ex rel. H.*, 74 P.3d 494 (Colo. App. 2003) (holding that an unborn child does not fall within the definition of child for the purpose of a child dependency or neglect proceeding); see also Michelle Oberman, *Sex, Drugs, Pregnancy and the Law: Rethinking the Problems of Pregnant Women Who Use Drugs*, 43 HASTINGS L.J. 505, 520-21 (1991) (recognizing that some states such as Illinois revoke maternal custody immediately if the newborn is reported with a positive toxicology screen); and Rorie Sherman, *Keeping Babies Free of Drugs*, NAT'L. L.J., Oct. 16, 1989 ("In some jurisdictions women whose newborns' urine tests positive for drugs immediately lose custody for months until they can prove to a court that they are fit mothers.").

18. Center for Reproductive Law and Policy, *Punishing Women for Their Behavior During Pregnancy: An Approach That Undermines Women's Health and Children's Interests*, (CRLP Press Sept. 2000). Women have challenged the criminal charges for drug use during pregnancy in 22 states. South Carolina has been the only state to sustain the charges. Some states that have brought charges against pregnant women include, Arizona, California, Florida, Georgia, Indiana, Kentucky, Massachusetts, Michigan, Nebraska, New Jersey, New York, Nevada, North Carolina, Ohio, Oklahoma, Pennsylvania, South Carolina, Texas, Virginia, Washington, Wisconsin and Wyoming. *Id.*

19. See *Johnson v. State*, 602 So. 2d 1288 (Fla. 1992) (concluding that the state legislature never intended the drug trafficking laws to be used against a woman for giving birth to a drug exposed infant); *People v. Hardy*, 469 N.W.2d 50 (Mich. Ct. App. 1991), *appeal denied*, 471 N.W.2d 619 (Mich. 1991) (rejecting the use of drug trafficking statutes to prosecute pregnant women).

unsuccessful in those instances does not mean that criminalization has had no substantive impact. Many women charged under these statutes pled guilty, thereby precluding an appeal.<sup>20</sup>

South Carolina has been at the forefront of prosecuting women for maternal drug use and has prosecuted the largest number of women for prenatal drug use.<sup>21</sup> The Supreme Court of South Carolina has affirmed the legality of prosecuting women for maternal drug use and the United States Supreme Court has upheld the decision.<sup>22</sup> Prosecutors in South Carolina have vigorously enforced the existing child abuse and neglect statutes against pregnant women addicted to crack cocaine.

*Whitner v. South Carolina* involved Cornelia Whitner, a twenty-eight-year-old woman addicted to crack cocaine, who had been prosecuted and sentenced to eight years in prison for fetal abuse. The South Carolina Supreme Court reinstated Ms. Whitner's eight-year sentence that had been vacated by the court of appeals. The court held that a viable fetus is covered by the state child-abuse statutes.<sup>23</sup> The court found that punishing fetal abuse furthers the state's interest in protecting children.<sup>24</sup> The court reasoned that "[t]he consequences of abuse or neglect after birth often pale in comparison to those resulting from abuse suffered by the viable fetus before birth,"<sup>25</sup> thus recognizing the fetus as covered by the child-abuse statutes furthers the statute's aim of preventing harm to children.

Litigation on this issue has continued. In March of 2001 the United States Supreme Court addressed the issue of whether the Medical University of South Carolina Hospital's (MUSC) policy of searching pregnant women for evidence of drug use, without a warrant or con-

20. See *Mother Cleared of Passing Drug to Babies*, N.Y. TIMES, July 24, 1992, at B7.

21. See Lynn M. Paltrow, *Criminal Prosecution Against Women: National Update and Overview* (ACLU/Reprod. Freedom Project) (April 1992). Attorney Paltrow and the Center for Reproductive Law and Policy have been instrumental in challenging states that seek to prosecute women for maternal drug use. They have been particularly active in South Carolina, understandable given the aggressive prosecutions there, and they have compiled state by state case summaries of criminal prosecutions against pregnant women. Attorney Paltrow has written numerous articles on this issue. Likewise, Wyndi Anderson and Susan Dunn from the South Carolina Advocates for Pregnant Women have consistently represented women in challenging South Carolina's repressive policies. See also Angela L. Knutson, *South Carolina Supreme Court Sends the Wrong Message: "If You are Pregnant and Addicted Tell Your Doctor and You Will Go to Jail"*; Whitner v. State, No. 24468, 1996 WL 393164 (S.C. July 15, 1996), 20 HAMLINE L. REV. 207 (1996) (giving a compelling call for a "restorative justice" approach to the problem of prenatal substance abuse and describes in a thoughtful discussion how that approach could have worked in South Carolina. See *id.* at 253-56.).

22. See *Whitner v. South Carolina*, 328 S.C. 1 (1997); *cert. denied*, May 26, 1998, *Whitner v. South Carolina*, 523 U.S. 1145 (1998).

23. *Id.* at 1.

24. *Id.* at 3.

25. *Id.*; see also Chasnoff, *supra* note 12.

sent, violated the Fourth Amendment's prohibition against unlawful searches.<sup>26</sup> Concerned about an apparent increase in the use of cocaine in patients receiving prenatal care, a task force made up of MUSC representatives, police and local officials developed a policy setting out procedures for identifying and testing pregnant patients suspected of drug use.<sup>27</sup> The policy required that a chain of custody be followed when obtaining and testing patients' urine samples; provided for education and treatment referrals for patients testing positive; and contained police procedures and criteria for arresting patients who tested positive and prescribed prosecutions for drug offenses and/or child neglect, depending on the stage of the defendant's pregnancy.<sup>28</sup>

MUSC's policy remained in place for nearly five years. However, instead of using the information obtained to provide medical care and treatment, the staff provided the information to the police who then arrested the women.<sup>29</sup> MUSC justified the policy as one that fit within the category of "special needs" which would allow for constitutionally permissible suspicionless searches.<sup>30</sup> The issue, as framed by Justice Stevens, was "whether the interest in using the threat of criminal sanctions to deter pregnant women from using cocaine can justify a departure from the general rule that an official nonconsensual search is unconstitutional if not authorized by a valid warrant."<sup>31</sup> The Court concluded that "the gravity of the threat alone cannot be dispositive of questions concerning what means law enforcement officers may employ to pursue a given purpose."<sup>32</sup> The Court found that the policy was in violation of the Fourth Amendment.<sup>33</sup> In reaching its decision,

26. See *Ferguson v. City of Charleston*, 532 U.S. 67 (2001).

27. The 12 page document adopted is known as "Policy M-7" dealing with the subject of "Management of Drug Abuse During Pregnancy."

28. *Id.*

29. All but one of the 30 women reported and arrested were African American. See Statement of South Carolina Advocates for Pregnant Women (on file with author).

30. This category described by the court as "closely guarded" was first articulated by Justice Blackmun in a concurring opinion in *New Jersey v. T.L.O.*, 469 U.S. 325, 351 (1985) where he concluded that such a test would only be warranted in "those exceptional circumstances in which special needs beyond the need for law enforcement make the warrant and probable cause requirement impracticable . . . ." *Id.* The Court ultimately adopted the terminology in subsequent cases. (See e.g. *O'Connor v. Ortega*, 480 U.S. 709, 720 (1987)). The Court distinguishes *Ferguson* from other cases where the special needs doctrine has been applicable such as *Skinner v. Railway Labor Executives' Assn.*, 489 U.S. 602 (1989) where tests were allowed to assist the Railways in preventing accidents resulting from employees impaired by alcohol or drugs; and *Treasury Employees v. Von Raab*, 489 U.S. 656 (1989) where the Customs Service was allowed to test employees seeking promotion to identified sensitive positions.

31. *Ferguson*, 532 U.S. at 70.

32. *Id.* at 86 quoting *Indianapolis v. Edmond*, 531 U.S. 32, 42-43 (2000).

33. U.S. CONST. AMEND. IV ("The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no



the Court concluded that the nine criteria<sup>34</sup> used to identify the women to be searched would not provide probable cause or a reason to believe that they were using cocaine.<sup>35</sup>

Since *Ferguson v. City of Charleston*, the Supreme Court of South Carolina has addressed the issue of prenatal drug use in two related cases—*South Carolina v. Peppers*<sup>36</sup> and *South Carolina v. McKnight*.<sup>37</sup> In *Peppers*, Brenda Peppers was charged with violating South Carolina's child endangerment statute.<sup>38</sup> She entered a guilty plea that was subsequently reversed by the Supreme Court of South Carolina. Peppers entered the plea on the condition that she be able to appeal her case to the South Carolina Supreme Court. The Supreme Court, in overturning the plea, held that South Carolina did not recognize conditional pleas. If an attempt is made to attach a condition to the plea, the trial court must enter a plea of not guilty.<sup>39</sup>

However, the Court did not address the underlying issue of the constitutionality of allowing pregnant women to be prosecuted under child abuse laws if they take drugs during pregnancy. This issue was focused on more clearly in *McKnight*. Regina McKnight was convicted of homicide by child abuse and sentenced to twenty years in prison. She is an indigent African American woman, with limited education, who had an ongoing addiction to crack cocaine. On May 15, 1999, she gave birth to a stillborn baby girl weighing five pounds.<sup>40</sup> It was estimated that the gestational age of the infant was between 34 and 37 weeks, and that she was viable. A subsequent autopsy showed the presence of benzoylecgonine (a cocaine metabolite). The cause of death was determined to be "intrauterine fetal demise with mild chorioamnionitis, funisitis and cocaine consumption."<sup>41</sup> However, no expert could say, with any degree of certainty, that cocaine was the cause of the infant's death.

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warrants shall issue, but upon probable cause, supported by oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized").

34. The listed criteria were: No prenatal care; late prenatal care after 24 weeks gestation; incomplete prenatal care; abruptio placentae; intrauterine fetal death; preterm labor "of no obvious cause"; IGUR (intrauterine growth retardation) "of no obvious cause"; previously known drug or alcohol abuse; and unexplained congenital anomalies. (See Policy M-7, *supra* note 27.).

35. *Ferguson*, 532 U.S. at 77, *see* Kolder, *supra* note 11.

36. *South Carolina v. Peppers*, 552 S.E.2d 288 (S.C. 2001).

37. *South Carolina v. McKnight*, 576 S.E.2d 168 (S.C. 2003); *cert. denied*, 540 U.S. 819 (2003).

38. S.C. CODE ANN. § 20-7-50 (Supp. 1995).

39. *Peppers*, 552 S.E.2d at 289 *quoting* *State v. O'Leary*, 393 S.E.2d 186, 187 (S.C. 1990).

40. *McKnight*, 576 S.E.2d at 171.

41. *Id.* Chorioamnionitis and funisitis are the terms used for the placenta and umbilical cord when they are inflamed. Most fetuses with this condition have live births. An infant would have benzoylecgonine in its system rather than pure cocaine because of the rapid breakdown of pure cocaine.

A number of issues were raised on appeal in *McKnight*.<sup>42</sup> The court determined that there was either no error in addressing each issue or that the issue had not been raised in the lower courts or was not preserved. Relying on several law journal articles,<sup>43</sup> the court concluded that it is incumbent on the woman to stop using drugs once a decision has been made to carry the child to term. The court stated, "Once the mother has made a choice to have a child, she must accept the consequences of that choice. One of the consequences of having children is that it creates certain duties and obligations to that child. If [the] woman does not fulfill those obligations, then the state must step in to prevent harm to that child."<sup>44</sup> The court's position on the equal protection claim is particularly telling. The court refused to consider this claim concluding that it was procedurally barred and not preserved even though Ms. McKnight had filed a pretrial motion to dismiss based on equal protection and renewed that motion at trial.<sup>45</sup> As Justice Moore stated in his dissent "it is for the legislature to determine whether to penalize a pregnant woman's abuse of her own body. It is not the business of the Court to expand the application of a criminal statute to conduct not clearly within its ambit. To the contrary we are constrained to strictly construe [criminal] statutes in the defendant's favor."<sup>46</sup> Nevertheless the court applied the homicide by child abuse statute which carried a punishment of twenty years to life, rather than the criminal abortion statute which carried a maximum penalty of two years, and which would have been applicable had she intentionally killed her viable fetus.

Not all states agree that a fetus is covered by child abuse statutes. Wisconsin for example, said that a fetus is not covered. In *State ex rel. Angela M.W. v. Kruzicki*,<sup>47</sup> the Supreme Court of Wisconsin consid-

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42. *Id.* Issues included whether the court erred in refusing a directed verdict on grounds that there was insufficient evidence of the cause of death and no evidence of criminal intent or that the baby was viable when she ingested the cocaine; whether the court erred in refusing to dismiss the homicide by child abuse indictment on the grounds that the more specific criminal abortion statute should govern, the statute did not apply to the facts in her case and the legislature did not intend for the statute to apply to fetuses; whether application of the homicide by child abuse statute violated her constitutional right to privacy or her due process right of adequate notice; whether the court erred in refusing to dismiss the indictment on eighth amendment cruel and unusual punishment grounds and whether application of the homicide by child abuse statutes violated equal protection.

43. See Marilyn L. Miller, *Fetal Neglect and State Intervention: Preventing Another Attleboro Cult Baby Death*, 8 CARDOZO WOMEN'S L.J. 71 (2001); Nova D. Janssen, *Fetal Rights and the Prosecution of Women for Using Drugs During Pregnancy*, 48 DRAKE L. REV. 741 (2000) and James R. Schueller, *The Use of Cocaine By Pregnant Women; Child Abuse or Choice?* 25 J. LEGISL. 163 (1999).

44. *McKnight*, 576 S.E.2d at 175, n. 5, relying on Janssen, *supra* note 43 at 762-63.

45. *Id.* at 177.

46. *Id.* at 180 referencing *State v. Blackmon*, 403 S.E.2d 660 (S.C. 1991).

47. *State ex rel. Angela M.W. v. Kruzicki*, 561 N.W.2d 729 (Wis. 1997).

ered whether the statutory definition of child included a viable fetus for the purpose of juvenile court jurisdiction. In this case, which involved a pregnant woman who tested positive for cocaine use on more than one occasion, the trial court ordered the unborn child to be detained, recognizing that “[s]uch detention will by necessity result in the detention of the unborn child’s mother. . . .”<sup>48</sup> A divided court of appeals determined that the juvenile court had not exceeded its jurisdiction.<sup>49</sup> The state supreme court, in reversing the court of appeals, recognized that “the essence of this case is one of statutory construction.”<sup>50</sup> The court concluded, “the legislature did not intend to include fetus within the definition of ‘child’.”<sup>51</sup> The Wisconsin Supreme Court and other state courts that have interpreted child abuse statutes similarly, appropriately recognized that the courts are not the most productive forum for addressing the complex public policy issues inherent in maternal drug use.<sup>52</sup>

It is apparent from the previously mentioned cases that neither the criminal law nor the child abuse and neglect statutes provide the answers to maternal drug use. Focusing only on this problem out of context diverts attention from the equally harmful, if not more harmful, effects of other variables such as the use of alcohol or tobacco or poor diet during pregnancy. It also ignores the significant negative impact of poverty on fetal health. Studies have shown that the harmful effects of crack, cocaine and alcohol can be mitigated by proper prenatal care and nutrition.<sup>53</sup>

Rather than campaigning for punitive measures against these mothers, states should provide access to prenatal care, prevention pro-

48. *Id.* at 732 (quoting from the trial court record).

49. *State ex rel. Angela M. W. v. Kruzicki*, 197 Wis.2d 532, 541 N.W.2d 482, (Wis. Ct. App. 1995).

50. *State ex rel. Angela M.W. v. Kruzicki*, 561 N.W.2d at 732.

51. *Id.* at 733.

52. *Id.* at 739. See also Helen A. Cole, *Legal Interventions During Pregnancy: Court Ordered Medical Treatment and Legal Penalties for Potentially Harmful Behavior by Pregnant Women*, 264 JAMA 2663 (1990). In this Trustees’ Report the American Medical Association agrees that courts are not the best forum for addressing appropriate intervention with pregnant women on behalf of the fetus. The report indicates that “courts are ill equipped to resolve conflicts concerning obstetrical interventions. The judicial system ordinarily requires that courts’ decisions be based on careful, focused deliberation and the cautious consideration of all the facts and related concerns.” *Id.* at 2665. Such a system cannot respond with the speed necessary given the time constraints of pregnancy. *Stare decisis* does not provide the court with guidance in addressing these complex policy driven conflicts.

53. See, e.g., Ira J. Chasnoff et al., *Cocaine/Polydrug Use In Pregnancy: Two Year Followup*, 89 Pediatrics 337 (1992); Scott N. MacGregor et al., *Cocaine Abuse During Pregnancy: Correlation Between Prenatal Care and Perinatal Outcome*, 74 Obstetrics and Gynecology 882 (1989); Nesrin Bingol et al., *The Influence of Socioeconomic Factors on the Occurrence of Fetal Alcohol Syndrome*, 6 ADVANCES IN ALCOHOL & SUBSTANCE ABUSE 105 (1987); and Bonnie Baird Wilford & Jacqueline Morgan, *George Washington University, Families at Risk: Analysis of State Initiatives to Aid Drug Exposed Infants and Their Families* 11 (1993).

grams, education and treatment. Though the need for treatment is recognized, resources are not allocated to ensure that the need is met. For example, in North Carolina, significant gaps in service have been identified. More than ninety percent of substance abuse treatment programs say they will accept pregnant women, but the services provided are extremely limited.<sup>54</sup> Substance dependent pregnant women commonly identified a need for halfway houses that will accept women and children.<sup>55</sup> These women also indicated a need for transportation, support systems and child care services.<sup>56</sup> Similar needs for prenatal care, prevention and treatment models are seen beyond North Carolina.<sup>57</sup>

Coercive intervention has tremendous potential for deterring women, who are most in need, from obtaining prenatal care.<sup>58</sup> Moreover, there is little evidence that criminal sanctions prevent in utero drug exposure<sup>59</sup> or that using drugs while pregnant indicates an inability to parent.<sup>60</sup> The hysteria surrounding pregnant women's drug use has resulted in a number of decisions that are clearly not in the child's best interest. For example, a woman in California lost custody of her children for three months based on a positive drug test, which resulted

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54. Less than three percent of substance abuse treatment programs provide obstetric or pediatric care; only 12 programs provide any HIV related services. Although forty-two programs state that they have residential rehabilitation services, none accept the women's children. Children's services are limited with only five programs having day care available. Chasnoff & Burnison, *supra* note 13, at 48-49. See also T. Weisdorf et al., *Comparison of Pregnancy Specific Interventions to Programs for Cocaine Addicted Women*, 16 J. SUBSTANCE ABUSE TREATMENT 39 (1999) (indicating that many interventions used today were designed using male based recovery models, which are not as suited to the needs of pregnant women).

55. *Supra* note 54.

56. *Supra* note 54.

57. See e.g. Wendy Chavkin & Stephen R. Kandall, *Between a Rock and a Hard Place: Perinatal Drug Abuse*, 85 PEDIATRICS 223 (1990); Kary L. Moss, *Forced Drug or Alcohol Treatment for Pregnant or Postpartum Women: Part of the Solution or Part of the Problem?* 17 NEW ENG. J. ON CRIM. & CIV. CONFINEMENT 1 (1991) and Kary L. Moss, *Substance Abuse During Pregnancy*, 13 HARV. WOMEN'S L.J. 278 (1990) (noting that liability problems created by high-risk pregnancies and lack of obstetrical services cause many pregnant women to be excluded from treatment centers).

58. Chavkin & Kandall *supra* note 57, at 224. The American Public Health Association in an amicus brief filed on behalf of Angela Carder (*In re AC*, 573 A.2d 1235 (D.C. 1990)) stated "[r]ather than protecting the health of women and children, court ordered caesareans erode the element of trust that permits a pregnant woman to communicate to her physician —without fear of reprisal— all information relevant to her proper diagnosis and treatment. An even more serious consequence of court ordered intervention is that it drives women at high risk of complications during pregnancy and childbirth out of the health care system . . ." See *supra* note 17.

59. See Committee on Substance Abuse of the American Academy of Pediatrics, *Drug Exposed Infants*, 86 PEDIATRICS 639, 641 (1990).

60. See SUSAN C. BOYD, *MOTHERS AND ILLICIT DRUGS: TRANSCENDING THE MYTHS* 14-16 (1999) (discussing multiple studies showing that women who use illicit drugs can be adequate parents).

from a sedative administered during labor.<sup>61</sup> There were also instances in Texas and New York of children removed from their mothers based on a single positive test for marijuana with no evidence of harm to the children.<sup>62</sup> While the crisis of drug exposed babies has increased the need for residential and outpatient treatment for addicted women, the availability of such treatment remains limited.<sup>63</sup> For example, only eleven percent of pregnant addicts obtain treatment and one in four infants are born to mothers who have not received early prenatal care.<sup>64</sup> This number will continue to rise as public health funding is decreased. Nine percent, or 433,000 pregnant women at any given time, are without health insurance coverage.<sup>65</sup> The number of children in foster care is steadily rising, child protective services are under siege, and the child welfare system is collapsing under the weight of children reported as abused and neglected due to allegations of drug using mothers.<sup>66</sup>

There is hope, however. North Carolina is at least attempting to address the problem. Federal and state programs such as Healthy Babies/Healthy Start, Baby Love and WIC (Women, Infants, and Children) are attempting outreach, education and preventive services in

61. See *Woman Given Labor Sedative Loses Custody of Children*, SACRAMENTO BEE, Feb. 11, 2000.

62. See LONG ISLAND MONTHLY, Jan. 1990 at 46 ; TIMES RECORD NEWS (Wichita Falls, Texas) Nov. 11, 1999 and HOUSTON PRESS, Nov. 4, 1999 at 8.

63. See Deborah J. Krauss, *Pregnant Cocaine Addicts Facing Harsher Sentences in the Courts*, N.Y.L.J., May 1, 1992, at S-10; see also Wendy Chavkin, *Help Don't Jail Addicted Mothers*, N.Y. TIMES, July 1989 at A21; Wendy Chavkin, *Mandatory Treatment for Drug Use During Pregnancy*, 266 JAMA 1556 (1991) and Elaine W. v. Joint Diseases N. Gen. Hosp. Inc., 613 N.E.2d 523, 524 (N.Y.) (illustrating a New York Hospital's refusal to admit pregnant women into its drug detoxification program).

64. See NATIONAL COMMISSION ON CHILDREN, BEYOND RHETORIC: A NEW AMERICAN AGENDA FOR CHILDREN AND FAMILIES 119, 123 (1991) [hereinafter BEYOND RHETORIC]. It should be noted that although the number of drug infected newborns increased more than 300% between 1979 and 1987, drug use among child-bearing age women has been reported to be slowly declining from 15% in 1985 to 8% in 1990. (See American Academy of Pediatrics, Committee on Drugs report, *Neonatal Drug Withdrawal*, 101 PEDIATRICS 1079, n.6 (June, 1998)).

65. BEYOND RHETORIC, *supra* note 64, at 137.

66. This is apparent anecdotally to anyone who is involved in the child welfare system. For example, in Durham, N.C. prevention monies were jettisoned from the social services budget several years ago. In Philadelphia, Pa. where I have practiced, the outlook is equally poor with insufficient resources and burgeoning caseloads. See also Barry M. Lester et al., *Keeping Mothers and Their Infants Together: Barriers and Solutions*, 22 N.Y.U. REV. L. & SOC. CHANGE 425 (1996). The author notes that between 1983 and 1992 the number of children in foster care increased from 269,000 to 442,000. *Id.* at 435. He suggests that given the state of the foster care system, foster care may prove more detrimental to drug exposed children than remaining with their mothers. *Id.* at 433-35. Child abuse and neglect reports more than doubled in the 1980s, from 1.15 million in 1980, to 2.4 million in 1989. From June 1987 to June 1990, foster care cases increased by 29% (from 280,000 to 360,000). *Id.* Federal law requires periodic review (usually at least every six months) for each child in foster care. See THE ADOPTION ASSISTANCE AND CHILD WELFARE ACT OF 1980: THE FIRST TEN YEARS 58-59 (North American Council on Adoptable Children, ed. 1990).

community settings and several states have model programs.<sup>67</sup> Education should be initiated prior to a woman's childbearing years and continued throughout. There must be consistent support for these programs to be continued and replicated. The outcome will be worth the effort for both pregnant women and society.<sup>68</sup>

## PART II

Many of the issues affecting substance dependent women also impact HIV positive women. These populations overlap considerably because those most at risk for HIV are intravenous drug users, prostitutes (who are often drug dependent) and partners of intravenous drug users (who may also have a history of drug use).<sup>69</sup> Ninety-three percent of HIV positive women are of childbearing age (between 13 and 49).<sup>70</sup> Eighty percent of reported cases of HIV positive women are women of color.<sup>71</sup> In 1999, HIV infection was the third leading cause of death among African American women aged twenty-five to forty-four. It became the leading cause of death among African American women aged twenty-five to thirty-four in 2001.<sup>72</sup> HIV in-

67. See L.R. Metsch et al., *Implementation of a Family-Centered Treatment Program for Substance-abusing Women and Their Children: Barriers and Resolutions*, 27(1) J. PSYCHOACTIVE DRUGS 73 (1995) (describing an eighteen month residential treatment program in Florida); S. Burman, *A Model for Women's Alcohol/Drug Treatment*, 9(2) ALCOHOLISM TREATMENT QRTLY. 87 (1992) (describing an intensive outpatient treatment program in Illinois that has treatment staff and child welfare professionals working collaboratively); Amy Goldstein, *Fresh Start and a New Life: State Funded Center Melts Drug Treatment, Prenatal Care to Help Recovering Addicts and Their Babies*, WASH. POST, June 11, 1992 at M1. (describing a successful model in Baltimore, Md. that combines treatment, prenatal care and child care) and Kathleen Teltsch, *In Detroit, a Drug Recovery Center That Welcomes the Pregnant Addict*, N.Y. TIMES, Mar. 20, 1990, at A14 (describing a successful program in Detroit, Michigan).

68. For each dollar spent on providing prenatal care to low-income, poorly educated women, society saves three dollars and twenty eight cents in medical care for the infants of these women in the first year of life. David Chavkin, *"For Their Own Good:" Civil Commitment of Alcohol and Drug Dependent Pregnant Women*, 37 S.D.L. REV. 224, 245 & n.136 (1992) (quoting Ira J. Chasnoff, *Drugs, Alcohol, Pregnancy, and the Neonate: Pay Now or Pay Later*, 266 JAMA 1568, 1568 (1991) and sources cited therein).

69. See A. Alyce Werdel, *Mandatory AIDS Testing: The Legal, Ethical and Practical Issues*, 5 NOTRE DAME J.L. ETHICS & PUB. POL'Y 155, 165-69 (1990).

70. See Centers for Disease Control and Prevention, *HIV/AIDS update: A Glance at the HIV Epidemic* (2000) at <http://www.cdc.gov/hiv> (Dec. 2000).

71. Centers for Disease Control and Prevention, *Status of Perinatal HIV Prevention: U.S. Declines Continue* (1999) (relying on 1998 statistics that identify African American and Hispanic women as eighty percent of reported AIDS cases) available at <http://www.cdc.gov/hiv/pubs/facts/perinat1.pdf> (Nov. 1999).

72. Centers for Disease Control and Prevention, *HIV/AIDS Among African Americans* (citing excerpts from the 2003 National Vital Statistics Reports, 52(9) National Vital Statistics Reports 1, 27-33 (2003) available at [http://www.cdc.gov/nchs/data/nvsr/nvsr52/nvsr52\\_09.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr52/nvsr52_09.pdf)). See also, Centers for Disease Control and Prevention, *Young People at Risk: HIV/AIDS Among America's Youth*, at <http://www.cdc.gov/hiv>; Robert N. Anderson et. al., *Deaths: Leading Causes for 2001*, 52(9) National Vital Statistics Reports 27-33 (2003) available at [http://www.cdc.gov/nchs/data/nvsr/nvsr52/nvsr52\\_09.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr52/nvsr52_09.pdf).

fection was among the top four causes of death for African-American women aged twenty to fifty-four in 2001.<sup>73</sup> From 2000 to 2003 the HIV/AIDS rate of infection for African American females was nineteen times the rate of White females and five times the rate for Hispanic females.<sup>74</sup> Moreover, AIDS is now the sixth leading cause of death among fifteen to twenty-four-year-olds.<sup>75</sup> The proportion of total AIDS cases attributable to women is increasing. From 1985 through 1996, the proportion of women reported to the Centers for Disease Control and Prevention (CDC) with AIDS increased from seven percent to twenty percent.<sup>76</sup> The total number of female AIDS cases attributable to heterosexual contact is also increasing. In 1994, AIDS cases in women attributable to transmission via heterosexual contact surpassed the number attributable to transmission via intravenous drug use.<sup>77</sup> This is particularly troubling when one considers that although African American women are most likely to become infected as a result of sex with men, many are unaware of their male partners' risks for HIV infection.<sup>78</sup> Even though new HIV infections have declined from a peak in the mid-1980's of more than 150,000 to approximately 40,000 annually in the 1990s, poor African American women are still at great risk for infection based on a number of factors. For example a recent study of African American women in North Carolina found that women with HIV infection are more likely than non-infected women to be unemployed, to receive public assistance, to have a life time history of genital herpes infections, to have

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73. *Supra* note 72.

74. Centers for Disease Control and Prevention, *Diagnoses of HIV/AIDS-32 States, 2000-2003*, 53(47) MMWR 1106-10 (2004) available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5347a3.htm> (Nov. 1, 2005). Furthermore, the rate of AIDS diagnoses for African American women was 25 times the rate for White women. See Centers for Disease Control and Prevention, *Cases of HIV Infection and AIDS in the United States, 2003*, 15 HIV/AIDS Surveillance Report 1-46 (2005) available at <http://www.cdc.gov/hiv/stats/2003surveillancereport.htm>.

75. CDC Report Shows Drop in Sexual Risk Behaviors Among U.S. Teens, *INFECTIOUS DISEASES IN CHILDREN*, at 88 (Oct. 1998) (noting that although the number of sexually experienced teenagers dropped from 54.1% in 1991 to 48.4% in 1997, there are still too many youth at risk – nearly half of all HIV infections in the United States occur among young people under 26).

76. *Id.*

77. *Id.* See also Centers for Disease Control and Prevention, *Cases of HIV Infection and AIDS in the United States, 2003*, *supra* note 74.

78. Such male risks include unprotected sex with multiple partners, bisexual behavior, and/or injection drug use. In a recent study of HIV infected and non-infected African American men who have sex with men (MSM), approximately 20% of the study participants reported having had sex with a female in the preceding six months. Centers for Disease Control and Prevention, *HIV Transmission Among Black College Student and Non-student Men Who Have Sex with Men – North Carolina, 2003*, 53(32) MMWR 731-34 (2004) available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5332a1.htm>. Equally telling is a study showing that of HIV infected persons, thirty-four percent of African American MSM reported having sex with women, even though only 6% of African American women reported having sex with a bisexual man. (See JP Montgomery et al. *The Extent of Bisexual Behavior in HIV-infected Men and Implications for Transmission to their Female Sex Partners*, 15(6) AIDS Care 829-37 (2003)).

more than twenty lifetime sexual partners, to have used crack or cocaine, or to have traded sex for drugs, money or shelter.<sup>79</sup> We are indeed concerned with a very fragile population of women.

Consistent with the increased number of HIV positive women of childbearing age, there is an increased number of pediatric AIDS cases.<sup>80</sup> The majority of these children are HIV positive because of "vertical transmission" in which the virus passes from mother to fetus before or during birth. Vertical transmission can occur during gestation, during delivery or from breast-feeding.<sup>81</sup> When twins are born, the first born is likely to be infected. Absent medical intervention, vertical transmission rates are fairly consistent at twenty-five to thirty percent.<sup>82</sup> As a result, seventy to seventy-five percent of infants born to positive mothers will not be infected. It is currently not possible to determine whether a fetus is infected with the virus prior to birth. It also is not clear how many infants who test positive at birth will seroconvert to negative once their immune systems have developed and their mothers' antibodies are no longer in their systems.<sup>83</sup> For infants who do not seroconvert, the disease will progress much more quickly than in adults. According to early CDC data, children diagnosed with AIDS lived a median of nine months<sup>84</sup> and seventy percent died within two years.<sup>85</sup>

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79. Centers for Disease Control and Prevention, *HIV Transmission Among Black Women—North Carolina, 2004*, 54(4) MMWR 89-93 (2005), available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5404a2.htm>.

80. From 1993 to 1994 the number of pediatric AIDS cases increased by 8%. At the end of 1994 a total of 6209 pediatric AIDS cases were reported to the Centers for Disease Control and Prevention. *Id.* AIDS is currently the fifth leading cause of death among children under the age of 15 in the United States. *Id.*

81. Pamela J. Boyer et al., *Factors Predictive of Maternal-Fetal Transmission of HIV-1. Preliminary Analysis of Zidovudine Given During Pregnancy and/or Delivery*, 271(24) JAMA 1925 (1994). According to the Centers for Disease Control and Prevention, 91% of all AIDS cases reported among U.S. children result from mother to child transmission, either during pregnancy, labor and delivery or by breast feeding. Centers for Disease Control and Prevention, *Status of Perinatal HIV Prevention: U.S. Declines Continue* (2005) at <http://www.cdc.gov/hiv/pubs/facts/perinat1.htm>. Reduction in perinatal transmission based on zidovudine (AZT) therapy continues to be striking. For example, the Centers for Disease Control and Prevention's Perinatal AIDS Collaborative Transmission Study (PACTS) shows that AZT use has contributed to a drop in perinatal transmission from 21% to 11%. The PACTS study included women from four urban cities—New York City, Newark, Baltimore and Atlanta.

82. Connor, *supra* note 4, at 1173.

83. While all infants born to an HIV positive woman will test positive as a result of the mother's antibodies seventy to seventy-five percent of the babies will seroconvert to negative within fifteen to eighteen months after birth. John Modlin & Alfred Sabb, *Public Health and Clinical Aspects of HIV Infection in Women and Children in the United States*, in *AIDS, Women and the Next Generation* (Ruth R. Faden et al. eds. 1991).

84. *Id.*

85. Michael A. Grizzi, *Recent Developments: Compelled Antiviral Treatment of HIV Positive Pregnant Women*, 5 UCLA WOMEN'S L.J. 473, 480-81 (1995).



More recent studies seem to indicate that infants who have acquired HIV perinatally follow one of two patterns: Rapid Disease Progression (RPD), which occurs in ten to thirty percent of infected infants, and Non-Rapid Disease Progression (NRPD), occurring in seventy to ninety percent of infants.<sup>86</sup> Infants with RPD experience an impairment of immunologic depletion within the first few months of life. On the other hand, those infants with NRPD experience gradual impairment of immunologic function over a number of years and a disease progression more like that of infected adults.<sup>87</sup> Infants who are exposed to Zidovudine perinatally are significantly more likely to exhibit RPD.<sup>88</sup> Children generally are not included in clinical trials though, and it is unclear how some of the success with antivirals and protease inhibitors will impact the progression of their disease. As would be expected, given the incidence of AIDS in African American and Hispanic women, studies have shown that children of color are disproportionately affected. Of the 382 cases reported with AIDS in 1998, 84 percent were African American or Hispanic children.<sup>89</sup> Together, these two demographics make up only thirty percent of children under thirteen in the United States.<sup>90</sup>

In 1994 the National Institutes of Health (NIH) conducted the AIDS clinical trial Protocol 076 which studied 477 HIV positive pregnant women in their fourteenth to thirty-fourth weeks of pregnancy.<sup>91</sup> Half of the women were randomly assigned to a treatment arm where they received AZT during the last two trimesters of their pregnancies and intravenously during labor and delivery. The other half received placebos. The infants were treated for six weeks after birth. Neither the women nor the researchers knew which women were receiving AZT and which were receiving placebos. During the trial period, 409 women gave birth to 415 infants. Some infants were excluded from the results because their HIV status was not known at the time the data was analyzed or because treatment was not started due to neonatal death or withdrawal from the study.<sup>92</sup> Of the 363 infants whose HIV

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86. Ricardo S. de Souza et al., *Effect of Prenatal Zidovudine on Disease Progression in Perinatally HIV-1-Infected Infants*, 24 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 154 (2000)

87. *Id.*

88. *Id.* at 157. This increased risk is another consideration when considering intervention with ZDV.

89. See CDC Status report, *supra* note 81.

90. M.F. Rogers, *Epidemiology of HIV/AIDS in Women and Children in the USA*, 86 ACTA PAEDIATRICA 15 (supp. 421 1997).

91. Connor, *supra* note 4.

92. *Id.*

status was known, 25.5 percent of the placebo group were HIV positive, while 8.3 percent of the AZT group tested positive.<sup>93</sup>

In the NICHD study, the largest, most comprehensive analysis of its kind, researchers found that HIV positive pregnant women could reduce the risk of transmitting the virus to their infants by elective c-section, if performed before labor and before their membranes ruptured. The study included 8,533 mother and child pairs from five European and ten North American studies. Mothers participating in the study were divided into four groups: those who had elective c-sections; those who had c-sections after rupture of their membranes and/or after labor began; those who delivered vaginally with assistance from forceps or vacuum suction; and those who delivered vaginally with neither forceps nor vacuum suction.

After adjustment for receipt of antiretroviral therapy, maternal stages of the disease and infant birth weight, the likelihood of vertical transmission decreased by approximately 50 percent with elective c-section as compared with other methods of delivery.<sup>94</sup> With both elective c-section and antiretroviral therapy during prenatal, interpartum, and neonatal periods, the likelihood of transmission was reduced by approximately 87 percent as compared with other methods of delivery and the absence of therapy.<sup>95</sup> Two more recent studies have shown compelling evidence that the prime risk factor for transmitting the virus perinatally is the mother's viral load. This was confirmed by the Pediatric AIDS Clinical Trials Group (PACTG) study. Researchers measured HIV levels in stored blood samples from HIV infected women enrolled in PACTG 185, a study which was stopped early, but that compared the effectiveness of AZT alone versus AZT plus immune globulin containing HIV-1 antibodies.<sup>96</sup>

As a result of the remarkable reduction in transmission with AZT treatment, bills were introduced in Congress and in some state legislatures calling for mandatory testing of pregnant women and for unblinding of seroprevalence tests conducted on infants in forty-five

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93. *Id.*

94. See International Perinatal HIV Group, *supra* note 6. Elective cesarean section is defined as cesarean section before rupture of the membranes and before the beginning of labor. *Id.*

95. *Supra* note 94.

96. Lynne Mofenson et al., *Risk Factors for Perinatal Transmission of Human Immunodeficiency Virus Type 1 in Women Treated With Zidovudine*, 341 NEW ENG. J. MED. 385-93 (1999); The second article with similar findings was by Patricia M. Garcia et al., *Maternal Levels of Plasma Human Immunodeficiency Virus Type 1 RNA and the Risk of Perinatal Transmission*, 34 NEW ENG. J. MED. 394-402 (1999). Other risk factors include: Mother's low CD4 count; her water breaks at least four hours before delivery; she has a vaginal delivery; a difficult labor requiring episiotomy or forceps; mother has a genital infection such as Chlamydia; illicit drug use during pregnancy. See <http://www.aidsmap.com/en/docs/8766F941-6A4C-4F13-B5BE-A936138D4546.asp> (last visited Nov., 1, 2005).

states.<sup>97</sup> There was some apprehension among health care professionals with this response. Given the very real stigmatization and discrimination that results from a positive HIV status, most professionals recognized that testing would have to be conducted with appropriate care and caution.<sup>98</sup> In July of 1995, the Centers for Disease Control recommended routine, voluntary testing of all pregnant women.<sup>99</sup> As the calls for testing were made, some understanding of testing policy was required. Mandatory is not the same as routine testing, and voluntary testing may not be routine. The CDC's recommendation of voluntary testing for all women verges on being mandatory. Routine testing usually requires little communication and counseling, while voluntary testing may involve some counseling.<sup>100</sup> Routine testing will probably not work for HIV. It is not like other sexually transmitted diseases. There is no cure and there is still a valid concern with discrimination.<sup>101</sup> It also may result in differing responses from the medi-

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97. See Centers for Disease Control National AIDS Clearinghouse (testing conducted in all states other than Idaho, Nebraska, North Dakota, South Dakota and Vermont and conducted in Puerto Rico, the Virgin Islands and the District of Columbia).

98. Carol B. Barnett, *The Forgotten and Neglected: Pregnant Women and Women of Childbearing Age in the Context of the AIDS Epidemic*, 23 GOLDEN GATE U. L. REV. 863 (1993).

99. The 1996 amendment to the Ryan White Care Act, codified at 42 U.S.C. § 300ff-33, requires the States to adopt the guidelines issued by the Centers for Disease Control and Prevention concerning recommendations for human immunodeficiency virus counseling and voluntary testing for pregnant women. It became effective October 20, 2000. A New York Assembly Bill (AB 6747) requiring that the anonymous seroprevalence test performed on newborns be unblinded and parents notified of the result was defeated in the July 1994 Legislative session. The author of AB 6747, Assemblywoman Nettie Mayersohn of Albany, N.Y., was not deterred by the bill's defeat. She introduced a new bill (AB 6684-B) in the 1995-96 session that would include HIV testing as one of the routine tests performed on newborns and that would provide for mandatory counseling and voluntary HIV testing for pregnant women (this bill was referred to the Assembly's Health Care Committee, where it died in committee). See Lenardo Renna, *New York State's Proposal to Unblind HIV Testing for Newborns: A Necessary Step in Addressing a Critical Problem*, 60 BROOK. L. REV. 407 (1994).

100. All Things Considered: "Voluntary AIDS Testing for Pregnant Women Urged by CDC" (NPR radio broadcast, Feb. 22, 1995).

101. Linda Farber Post, *Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?*, 16 CARDOZO L. REV. 169, 227 n.67 (1994). The American Civil Liberties Union (ACLU) reported on several studies documenting such discrimination: (1) In a survey of more than 500 dentists, 63% did not want to treat patients considered at risk for AIDS; (2) Another study of 1000 surgeons showed that 90% endorsed a policy of refusing to operate on a person who is HIV positive; (3) In a Virginia study of paramedics 40% said they were unwilling to administer treatment to HIV positive patients; (4) In a study of nursing home administrators, 47% said they would refuse to accept a patient with AIDS; (5) In a study of hospitals, 20% reported that in at least one instance a staff member refused to care for an HIV infected person and 25% had a policy of immediately transferring any such patient. (ACLU/AIDS Project, N.Y., N.Y. 1990 "Epidemic of Fear" at 31, 78-80) (on file with the author). See Winifred J. Pinch, *Caregivers' Perspectives on Confidentiality for Mothers and Newborns With HIV/AIDS*, 4 PEDIATRIC AIDS AND HIV INFECTION: FETUS TO ADOLESCENT 123 (1993). The questionnaire results recording frequencies of discrimination against women with HIV showed the following:

cal community.<sup>102</sup> HIV testing historically has required both pre and post-test counseling.<sup>103</sup> If a move to routine testing is considered, a review of genetic testing, including sickle cell testing, might prove instructive.

As genetic testing has become more readily available, concern about privacy and discrimination has increased.<sup>104</sup> Genetic testing has been shown to affect one's relationship with insurers, employers and other third parties. Accordingly, people have been deterred from being tested because of a fear of consequences.<sup>105</sup> Such beliefs may be well founded where studies show that 31 percent of families with a known genetic condition were denied insurance whether they were sick or not.<sup>106</sup> There has also been an instance where a normal healthy

Type of Discrimination	% Often	% Sometimes	% Never
Employment	34	63	3
Housing	26	69	5
Physical Abuse	13	76	11
Psychological Abuse	36	61	3
Rejection by Families	35	65	
Rejection by Friends	37	63	
Rejection by Neighbors, Coworkers And Others	39	62	

102. *Supra* note 101.

103. See Mike McKee, *Testing HIV Policy*, RECORDER, May 17, 1995, at 1.

104. See Juliet J. McKenna, *Where Ignorance is Not Bliss: A Proposal for Mandatory HIV Testing of Pregnant Women*, 7 STAN. L. & POL'Y REV. 133, 137 (1996). Ms. McKenna's article is well written and although we start out with some of the same premises and same sources, we end up with slightly different positions. I cannot agree with her call for mandatory testing of all pregnant women and I do not think my disagreement is one of semantics. She calls for mandatory testing but not mandatory treatment. Although I recognize that the constitutional issues between testing and treatment may be heightened, the moral issues are implicated in both. It would seem to me that mandatory, non-directive counseling would reach the same results that she suggests and address her concern that only poor and minority women would be tested absent a mandatory scheme. See Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109 (1991); See also Lori B. Andrews, *Prenatal Screening and the Culture of Motherhood*, 47 HASTINGS L.J. 967 (1996). Professor Andrews has written extensively in the area of reproductive rights and societal control of women during pregnancy.

105. Caryn Lerman et al., *Interest in Genetic Testing Among First-degree Relatives of Breast Cancer Patients*, 57 AM. J. MED. GENETICS 385, 389 (1995). Caryn Lerman cites a 1995 Harris poll that found 86% of people were concerned that employers and insurers would use the results of genetic tests in hiring and insurance decisions. In one study of women's interest in genetic testing for breast cancer, 15% of women declined testing because they worried about losing their insurance. According to Senator Olympia Snowe, who introduced a genetic privacy bill in the Senate this year (2005), when the National Institutes of Health offered women genetic testing for breast cancer risk, nearly 32% of those receiving the offer refused to be tested because of concerns about insurance discrimination. See *infra* note 113.

106. See COMMITTEE ON ASSESSING GENETIC RISKS, NATIONAL ACADEMY OF SCIENCES, ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY at 270 (Lori B. Andrews et al. eds. 1994).

child who had been diagnosed with Phenylketonuria (PKU)<sup>107</sup> at birth and successfully treated, was denied coverage under her father's group health plan when he changed jobs,<sup>108</sup> and where women with a family history of breast cancer have been told they could be insured but not for breast cancer treatment.<sup>109</sup> Dr. Herbert Nickens has been especially concerned about the implications of genetic testing for African Americans. He has called genetics "a science of inequality" that "entwines society's racial, ethnic and economic biases with genetic differences that can be detected, particularly if any of these differences are differentially distributed by race, ethnicity or class."<sup>110</sup>

Similar discrimination has occurred in employment. In the early 1970's, as routine sickle cell testing became common, employers' discrimination against African American employees and job applicants who were carriers of the disease increased, despite the fact that carrier status has no impact on one's health or job performance.<sup>111</sup> In 1995, the San Francisco Legal Services Office filed a class action suit against the federally funded Lawrence Berkeley Laboratories at the University of California-Berkeley. The suit alleged that the laboratory tested African American employees for sickle cell without their knowledge or consent and secretly maintained the testing results in its files.<sup>112</sup> Also of concern, but beyond the scope of this paper is whether information gleaned from genetic testing should be shared with family members.

107. *Id.* This genetic condition affects one's ability to process phenylalanine, an amino acid commonly found in most proteins. Left untreated the disease causes severe mental retardation. Retardation can be avoided by modifying the mother's diet during pregnancy and raising the child until age four on a diet low in phenylalanine.

108. See Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476 (1992).

109. *Id.* at 478; See also Julie Holland, *Should Parents Be Permitted to Authorize Genetic Testing for Their Children?*, 31 FAM. L.Q. 321 (1997) (describing a number of types of discrimination associated with genetic disorders).

110. Herbert Nickens, *The Genome Project and Health Services for Minority Populations*, in THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE (Thomas Murray et al. eds., 1996) (describing Genetics as sometimes a "racialized science" where stereotypes, and biases may frame its interpretation, management and use).

111. *Id.* There are a number of comprehensive articles on genetic testing and some of the legal and ethical concerns associated with testing. In addition to Dr. Nickens' article, I would recommend Deborah Gridley, *Genetic Testing Under the ADA: A Case For Protection From Employment Discrimination*, 89 GEO. L.J. 973 (2001); and Mark A. Rothstein, *Employee Selection Based on Susceptibility to Occupational Illness*, 81 MICH. L. REV. 1379 (1983).

112. *Norman-Bloodsaw v. Lawrence Berkeley Nat'l Lab.*, No. C95-03220 V.R. Walker, J. (N.D. Cal.1995) The court for the Northern District of California ruled in favor of the defendant and the plaintiff appealed (Ct. of App. No. 96-16526 (1996)). The appeal was heard in 1997, *Norman-Bloodsaw v. Lawrence Berkeley Nat'l Lab.*, 135 F.3d 1260 (9th cir. 1998), and an agreement was finally reached between the class of plaintiffs represented by the suit and the lab in 2001 (2001 WL 764473 (N.D. Cal. 2001)). Samples were not only tested for sickle cell but were also tested for syphilis and pregnancy.

AIDS testing has as much a potential for abuse and discrimination as genetic testing. As protocols for testing are developed, they must be undertaken with the same concerns for confidentiality and protection against abuse. The concern with abusive use of genetic information is reflected in numerous attempts by state and federal legislatures to enact legislation to deal with the issue. The most recent attempt at the federal level was in February of 2005 when the United States Senate approved without opposition the Genetic Information Nondiscrimination Act.<sup>113</sup> At the state level 41 states have passed health insurance laws and 31 states have passed workplace laws in an attempt to limit discrimination and misuse of genetic information.<sup>114</sup> Some state legislation is more comprehensive than others. The Americans with Disabilities Act (ADA) of 1990 provides some protection from discrimination that is based on a disability or perceived disability. Additionally, while in office President Clinton signed an executive order prohibiting genetic discrimination.<sup>115</sup> Because of the unevenness in protection provided from state to state and the lack of any protection in some states, a federal statute is warranted. Even then companies with fourteen or fewer employees would be exempted.

### PART III

If a woman is HIV positive and AZT/antiviral treatment is considered, her cooperation will be vital for her treatment to be successful. Similarly, if a c-section is indicated she would have to consent to such surgery. Care must be taken to ensure that those most in need of treatment are not driven underground and that they receive the treatment without coercion.<sup>116</sup> With careful counseling, mandatory testing and treatment should be unnecessary. As initial surveys of hospitals that have instituted voluntary testing found, properly counseled pregnant women agree to testing ninety-six percent of the time.<sup>117</sup>

Given the ability to significantly reduce vertical transmission with antiviral treatment, it would seem logical to argue for mandatory test-

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113. See S. 306, 109th Cong. (2005) (passed Senate February 17, 2005). It still must pass in the House, and that is by no means assured. A similar bill passed by a 95-0 vote in 2004 to no avail because it was never taken up by the House.

114. See THE HUMAN GENOME PROJECT: EXPLORING OUR MOLECULAR SELVES; see also THE STATE OF LEGISLATION-WHAT'S PROTECTING US? available at the North Carolina Center for Genomes and Public Health.

115. Exec. Order No. 13, 145, 65 Fed. Reg. 6877 (February 8, 2000).

116. See Cole, *supra* note 52.

117. See McKee, *supra* note 103. Later studies have indicated that of 90% of women offered AZT prophylaxis 90% were compliant. See *Universal Testing, Counseling Critical to Reducing Perinatal HIV Infection*, INFECTIOUS DISEASES IN CHILDREN, Feb. 1999; but cf. Andrew A. Wiznia et al., *Zidovudine Use to Reduce Perinatal HIV Type 1 Transmission in an Urban Medical Center*, 275 JAMA 1504 (1996) asserting that 25% of HIV positive pregnant women refused treatment and of those who agreed to treatment 33% were noncompliant. *Id.* at 1505.

ing and treatment. However, when one considers what such treatment would entail, it is apparent that mandatory treatment would not be feasible unless one were willing to confine a woman for the duration of her pregnancy.<sup>118</sup> It is important to note that treatment would require the mother to take the medicine five times a day, every day, during the last two trimesters of her pregnancy, and would require that she receive the drug intravenously during labor and delivery. She would also have to give it to her newborn for six weeks postnatally.<sup>119</sup> Even if the testing is voluntary, the consent would have to be informed.<sup>120</sup>

Informed consent assumes that an individual should be free to exercise her free will when making important decisions concerning her medical treatment and care. The doctrine of informed consent as received from the common law required that consent to health care be voluntary, knowing and competent. Constitutional support for informed consent was recognized by the Supreme Court in *Cruzan v. Director, Missouri Department of Health*.<sup>121</sup> The court held "the notion of bodily integrity has been embodied in the requirement that

118. See Paltrow, *supra* note 21.

119. See Connor, *supra* note 4.

120. The following states have enacted statutes that require informed consent prior to conducting an HIV antibody test: ALA. CODE SEC. 22-11A-51 (1991 & Supp. 1996); ARIZ. REV. STAT. ANN. § 36-663 (West, WESTLAW through the 2nd Reg. and 2nd Spec. Sess.'s of the Forty-Sixth Legislature 2004); CAL. INS. CODE § 799.03 (West, WESTLAW through Ch. 1 of 2005 Reg.Sess.); COLO. REV. STAT. § 25-4-1401 (West, WESTLAW through the end of the 2004 2nd Reg. Sess. of the 64th General Assembly); CONN. GEN. STAT. ANN. § 19a-582 (West, WESTLAW through Gen. St., Rev. to 1-1-05); DEL. CODE ANN. tit. 16 § 1202 (1995); D.C. CODE ANN. § 31-1606 (West, WESTLAW through November 29, 2004); FLA. STAT. ANN. § 381.004 (West 1993 & Supp. 1997); HAW. REV. STAT. § 325-16 (West, WESTLAW through 2003 Reg. and Spec. Sess.'s); ILL. STAT. ANN. Ch. 410 305/4 ¶ 7304 (West's Smith-Hurd, WESTLAW through P.A. 93-1084 of the 2004 Reg. Sess.); IND. CODE ANN. § 16-41-6-1 (West, WESTLAW through 2005 Public Laws approved and effective through February 8, 2005); IOWA CODE ANN. § 141A.6 (West, WESTLAW through laws effective July 1, 2004); KY. REV. STAT. ANN. § 214.625 (West, WESTLAW through end of 2004 First Extraordinary Sess.); LA. REV. STAT. ANN. § 40:1300.13 (West 1992 & Supp. 1997); ME. REV. STAT. ANN. tit. 5 § 19203-A (West 1989 & Supp. 1996); MD. CODE ANN., Health-Gen. I § 18-336(b)(1) (1989); MASS. GEN. LAWS ANN. Ch. 111, § 70F (West 1992); MICH. COMP. LAWS ANN. § 333.5133(2) (West Supp. 1991); MINN. STAT. ANN. § 144.7407 (West, WESTLAW Current with 2005 Reg. Sess. laws through Ch. 2); MISS. CODE ANN. § 41-41-16 (1993); MONT. CODE ANN. §§ 433.045, 433.075 (1995); N.H. REV. STAT. ANN. § 141-F:5 (1993); N.M. STAT. ANN. § 24-2B-2 (Michie 1996); N.Y. PUB. HEALTH LAW § 2781 (McKinney 1996); N.C. GEN. STAT. § 130A-148(h) (West, WESTLAW through the 2004 Reg. and Extra Sess.'s); N.D. CENT. CODE 23-07.5-01, -02 (1991 & Supp. 1995); OHIO REV. CODE ANN. § 3701.242 (Baldwin Supp. 1995); OR. REV. STAT. §§ 433.045, 433.075 (1995); PA. STAT. ANN. tit. 35 § 7605 (a), § 7606, 7608 (supp. 1993); R.I. GEN. LAWS § 23-6-12 (1996); TEX. HEALTH & SAFETY CODE ANN. § 81.105 (West 1992); VT. STAT. ANN. tit. 18, § 1128(a) (1996); VA. CODE ANN. § 32.1-37.2 (Michie 1992 & Supp. 1996); WASH. REV. CODE ANN. § 70.24.325 (West, WESTLAW through Chapter 2 of 2005 Regular Sess.); W. VA. CODE § 16-3C-2 (1995); WIS. STAT. ANN. § 252.15 (West, WESTLAW through 2003 Act 327, published 6/11/04).

121. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261 (1990).

informed consent is generally required for medical treatment.”<sup>122</sup> The Centers for Disease Control has recognized the importance of informed consent in its recommendations for voluntary testing. Included in the recommendations are the following:

Pretest counseling should be linguistically, culturally and educationally appropriate;

Counseling should be done as early in pregnancy as possible so that informed therapeutic and reproductive decisions can be made in a timely fashion;

Post-test counseling should take into account the woman's psychological needs, social support structures and risk of discrimination and domestic violence and doctors should make referrals to psychological, social or legal services if the need arises;

Uninfected pregnant women who continue to have unprotected sex or use injection drugs should be encouraged to avoid further HIV exposure and be retested in the third trimester of the pregnancy to rule out recently acquired HIV infection;

Physicians should explain the possible benefits and possible risks of AZT therapy in a nonjudgmental manner and let patients make their own decisions;

HIV positive women should get information on all reproductive options, but without coercion;

Doctors should evaluate a woman's need for anti-microbial drugs to ward off infections;

HIV positive women should be advised against breast feeding and support services should be enlisted to find breast milk substitutes for infant feeding;

Health care providers should keep track of the needs of infected women and children and make referrals to medical and social services as needed.<sup>123</sup>

Providing the information necessary for a woman to make an informed decision encourages her to participate in her medical care. By exchanging information, asking questions and indicating specific is-

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122. *Id.* at 270. The court stated that “a constitutionally protected liberty interest in refusing unwarranted medical treatment could be inferred” from its prior decisions.) Other courts have recognized the doctrine. *See, e.g.,* *United States v. Williams*, 754 F.2d 672, 674 (6th Cir. 1985) (defining informed consent as “unequivocal, specific and intelligently given, uncontaminated by any duress or coercion”).

123. Recommendations (supported by the CDC) of the U.S. Public Health Service on the Use of Zidovudine to Reduce Perinatal Transmission of the Human Immunodeficiency Virus. *See also supra* note 99; 42 U.S.C. § 300ff-33 (additional guidelines promulgated by the CDC).



sues of concern, the patient is permitted to acknowledge her own autonomy and to make choices consistent with her belief system.<sup>124</sup>

The same concerns presented when considering mandatory treatment with AZT are also present with the use of elective c-section to reduce vertical transmission of the virus. The woman ultimately must consent to treatment if it is to occur. And she will have every right to refuse treatment after she is provided with all the relevant information. Ensuring that a woman's consent is truly voluntary and informed will require skill on the part of health professionals. They will have to recognize that poor people and women generally have been more willing to let doctors make decisions for them believing that the doctors "know best."<sup>125</sup> Until women's relationships with their doctors change, there will be a disparate power relationship that will hinder true consent.

Even if an argument could be made for mandatory testing, the same argument would have to be stretched to support mandatory treatment.<sup>126</sup> In addition to the concerns discussed above with informed consent, mandatory treatment must be considered in light of a woman's right to privacy, liberty and bodily integrity. Treatment, whether in the form of medicine or surgery, must comport with substantive due process protections. People do not lose their rights simply because they become pregnant or HIV positive. Competent adults have the right to refuse medical treatment even if the refusal would result in their deaths.<sup>127</sup>

The right to physical liberty and bodily integrity implicated in medical treatment decisions has been recognized and protected by our courts for more than a century.<sup>128</sup> In *Union P. R. Co. v. Botsford*, the Court said "[N]o right is held more sacred, or more carefully guarded under the common law than is the right of every individual to the possession and control of his own person . . ."<sup>129</sup> That right has re-

124. Doctors Faden and Beauchamp describe this approach to structuring medical decision-making in their book. RUTH FADEN & TOM BEUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* (1986). Lori Andrews also addresses this issue in her article: Lori Andrews, *Informed Consent Statutes and the Decisionmaking Process*, 5 J. LEGAL MED. 163 (1984).

125. See e.g. Lisa Napoli, *The Doctrine of Informed Consent and Women: The Achievement of Equal Value and Equal Exercise of Autonomy*, 4 AM. U. J. GENDER & LAW 335 (1996) and Nsiah-Jefferson, *Reproductive Laws, Women of Color, and Low Income Women*, 11 WOMEN'S RTS. L. REP. 15 (1989) Professor Nsiah-Jefferson points out that women, regardless of color or education level are less likely than men to question the doctor's orders. She cites to Martha Eliot's Health Center, *Reproductive Health Report* (1985) which discusses the impact of the classism and racism of health care providers.

126. See McKenna, *supra*, note 104.

127. See Schloendorff v. Society of N.Y. Hosps., 105 N.E. 92, 93 (N.Y. 1914) ("Every human being of adult years and sound mind has a right to determine what shall be done with his own body. . .").

128. *Union P. R. Co. v. Botsford*, 141 U.S. 250 (1891).

129. *Id.* at 251.

ceived consistent recognition and protection by the Supreme Court and state courts in a number of cases since *Botsford*.<sup>130</sup> The right is broad based, applying to prisoners as well as patients involuntarily committed to mental institutions.<sup>131</sup> The right is protected by the Fourteenth Amendment's guarantee of due process and the Fourth Amendment's prohibition against unreasonable search and seizure.<sup>132</sup>

A competent adult has the right to refuse treatment and cannot be forced to submit to treatment for the benefit of a third person, even if treatment involves little pain or inconvenience and even if the third person is one's own child. For instance, a mother is not legally required to donate a kidney if her child needs it; nor would an identical twin be forced to donate bone marrow to a sibling in need.<sup>133</sup> Courts have found generally that society is not diminished by the refusal to compel an individual to submit to medical intervention for the benefit of another.

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130. See, e.g., *Cruzan v. Director of Mo. Dep't of Health*, 497 U.S. 261 (1990); *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986); *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977); *In re Conroy*, 486 A.2d 1209 (N.J. 1989); *In re Quinlan*, 355 A.2d 647 (N.J. 1976), cert. denied, 429 U.S. 291 (1976). For more recent treatment see also *In re Guardianship of Schiavo*, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001). This controversial case, involving termination of life prolonging procedures for a patient in a persistent vegetative state and without an advance directive, spanned thirteen years and all three branches of government at both the state and federal level. It returned to the Florida Court of Appeals twice in 2001 alone. See also *Bush v. Schiavo*, 851 So.2d 182 (Fla. App. 2003) (*Schiavo IV*); *Bush v. Schiavo*, 861 So. 2d 506 (Fla. App. 2003); and *Bush v. Schiavo*, 866 So. 2d 136 (Fla. App. 2004).

131. *Washington v. Harper*, 494 U.S. 210 (1990) (holding that a prison inmate has a liberty interest, under the due process clause, in refusing to take anti-psychotic drugs); *Mills v. Rogers*, 457 U.S. 291 (1982); *Youngberg v. Romeo*, 457 U.S. 307 (1982) (finding that the due process clause creates a liberty interest in involuntarily committed patients to be free from unreasonable bodily restraints.).

132. See *Winston v. Lee*, 470 U.S. 753 (1985) (forcing a criminal to undergo surgery to recover bullet as evidence violates the Fourth Amendment); *Rochin v. California*, 342 U.S. 165 (1952) (pumping the stomachs of criminal suspects constitutes an unreasonable search under the fourth amendment) but cf., *Schmerber v. California*, 384 U.S. 757 (1966) (forcing an accident victim to submit to blood test to determine blood alcohol level not violative of Fourth Amendment prohibition against unreasonable search and seizure) and *Skinner v. Railway Labor Executives' Ass'n*, 489 U.S. 602 (1989) (finding as reasonable under the Fourth Amendment a drug test of railroad workers - the government's compelling interest in safety outweighs the worker's interest in privacy).

133. W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 56, at 375 (5th ed. 1984) (indicating that even in cases of special relationships there is no obligation to render aid where to do so would endanger one's self); see also *McFall v. Shimp*, 10 Pa. D. & C.3d 90 (1978) (Alleghany County Court 1978) (refusing to compel a man to donate bone marrow to his terminally ill cousin even though he was the only compatible donor. The court questioned whether the cousin's decision was morally sound but recognized there was no legal duty). But cf. *Hart v. Brown*, 289 A.2d 386 (Conn. Supp. Ct. 1972) (permitting the parents of a seven year old to consent to a kidney transplant to save the life of her twin sister) and *Little v. Little*, 576 S.W.2d 493 (Tex. Civ. App. San Antonio 1979) (permitting a mother-guardian of a fourteen year old with Down's Syndrome to consent to the removal of a kidney from her daughter's body to be transplanted into the body of her son who was suffering from end stage renal disease).

There are arguments for and against treating a pregnant woman differently when it comes to treatment decisions. A woman should not be treated differently based on her pregnancy, but that does not mean that she will not be.<sup>134</sup> Some courts have authorized performance of c-sections and interuterine blood transfusions over the pregnant woman's objection, holding that such intervention was necessary to preserve the life or health of the fetus.<sup>135</sup> These cases provide significant precedent for physicians who would argue for elective c-sections with all HIV positive pregnant women, whether they choose such treatment or not.

Some states automatically invalidate or limit the enforceability of advance directives such as living wills if the patient is pregnant.<sup>136</sup> Some argue that a pregnant woman who continues her pregnancy has a moral obligation to submit to treatment on behalf of her fetus.<sup>137</sup> As with *McFall v. Shimp*, it is difficult to change the questionable moral obligation into a legal one.<sup>138</sup>

One's interest in refusing medical treatment is not absolute, however. We have seen in the cases discussed above some instances

134. See Lawrence J. Nelson et al., *Forced Medical Treatment of Pregnant Women: "Compelling Each to Live as Seems Good to the Rest,"* 37 HASTINGS L.J. 703 (1986).

135. See, e.g., *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 S.E.2d 457 (Ga. 1981). The Georgia Supreme Court affirmed a juvenile court opinion ordering a woman to undergo a Cesarean section. The woman was in her thirty-ninth week of pregnancy, and she was diagnosed with placenta previa. The operation was ordered to save the life of both the mother and child. Mrs. Jefferson, who refused to consent to the operation for religious reasons, seemed to have her prayers answered. Although the doctors said "there is a 99 to 100 percent certainty that the unborn child will die if she attempts a vaginal delivery," she delivered a healthy baby vaginally. See also *Around the Nation: Pregnant Woman Believes Prayers Obviated Cesarean*, N.Y. TIMES, Jan. 26, 1981, at A12; *In re Jamaica Hosp.*, 491 N.Y.S.2d 898 (Sup. Ct. 1985) (ordering a blood transfusion to a woman in her eighteenth week of pregnancy who objected to the transfusion for religious reasons and holding that the state's interest in the not yet viable fetus outweighed the patient's interest.); but cf. *Taft v. Taft*, 446 N.E.2d 395 (Mass. 1983) (vacating an order requiring a woman in her fourth month of pregnancy to undergo a "purse string" operation to prevent miscarriage. The court found no compelling circumstances to outweigh the women's religious objections and her privacy interest.) See also *supra* notes 8-10 and accompanying text.

136. See, e.g., The Uniform Rights of the Terminally Ill Act § 6(c) (1989) which reads "Life sustaining treatment must not be withheld or withdrawn pursuant to a declaration from an individual known by the physician to be pregnant. . . so long as it is probable that the fetus will develop to the point of live birth with continued application of life sustaining treatment." See also MINN. STAT. ANN. § 145B.13 (West 1997) (providing "in the case of a living will of a patient that the attending physician knows is pregnant, the living will must not be given effect as long as it is possible that the fetus could develop to the point of live birth with continued application of life-sustaining treatment").

137. John A. Robertson, *Procreative Liberty and the Control of Conception, Pregnancy and Child Birth*, 69 VA. L. REV. 405 (1983); Margery Shaw, *Conditional Prospective Rights of the Fetus*, 5 J. LEGAL MED. 63 (1984). Professor Shaw has argued for policies to prevent the birth of children with genetic diseases, suggesting that the prevention of genetic disease is so important that parents who decide to give birth to a child with a serious genetic disorder should be criminally liable for child abuse. See also *supra* note 43, articles cited and accompanying text.

138. See *supra* note 133; see also Susan Goldberg, *Medical Choices During Pregnancy: Whose Decision is it Anyway?* 41 RUTGERS L. REV. 591 (1989).

where a state has intervened. The state has an interest in intervening to preserve life, prevent suicide, protect the integrity of the medical profession and to protect innocent third parties.<sup>139</sup> State intervention is warranted when the state's interest outweighs the individual's interest in being free from intrusion.<sup>140</sup> Some factors the court will consider in balancing the interests include: the relationship between the intervention sought and the state interest set forth to justify it; whether the intervention is necessary to protect innocent third parties; whether the intervention benefits the individual; and whether there are less restrictive alternatives to protect the state's interest and to accommodate the rights of the individual.<sup>141</sup> As mentioned above, the Supreme Court has recognized a compelling state interest in the potential life of the fetus throughout the pregnancy.<sup>142</sup> But the Supreme Court also has said the fetus is not a person under the Fourteenth Amendment of the Constitution.<sup>143</sup>

As such, protecting the fetus as an innocent third party could be problematic. A state attempting to compel treatment using its *parens patriae*<sup>144</sup> powers and basing it on the best interest of the child would have to view the fetus as a child for this purpose. In doing this, the state will encounter the same issues that were raised in Part I when considering whether the fetus is a child under the abuse and neglect statutes. Even if a state gets over that hurdle and considers the fetus an innocent third party, it must acknowledge that intervention cannot occur without actively involving the pregnant woman. She has a constitutionally protected liberty interest in her own body and in rejecting treatment, and at least one court has upheld the right of a HIV infected mother to refuse treatment for her HIV infected son. If a mother can refuse treatment for a living child, she surely should be able to refuse it on behalf of an unborn child.<sup>145</sup>

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139. See Grizzi *supra* note 85, at 488; see also *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

140. See *Skinner*, 489 U.S. 602 (1989), *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990) (finding the patient's right to refuse treatment must be balanced against the state's interest in protecting life); *Jacobson v. Massachusetts*, 197 U.S. 11 (1905) (holding that the individual's right to refuse a vaccination must be balanced against the state's interest in public health).

141. See Carol Gosain, *Protective Custody for Fetuses: A Solution to the Problem of Maternal Drug Use?* *Casenote on Wisconsin ex. rel. Angela v. Kruzicki*, 5 GEO. MASON L. REV. 799 (1997).

142. See *supra* notes 2 & 3.

143. *Roe v. Wade*, 410 U.S. 113 (1973).

144. See 67A C.J.S. *Parens Patriae* §195 (1978). ("The doctrine of *parens patriae* expresses the inherent power and authority of the state to provide protection of the person and property of a person *non sui juris*, and under the doctrine the state has sovereign power of guardianship over persons of disability.")

145. See *In re Nikolas E.*, 720 A.2d 562, 566 (Me. 1998) (holding that the mother's decision to delay drug therapy was rational and reasoned). The court further reasoned that "with the relative uncertainty of the efficacy of the proposed treatment, it can only reasonably be left up to the parent to make an informed choice in this regard." *Id.* at 566.

It is too soon to tell if treatment with AZT will preserve life and protect the fetus. We know that it impacts the vertical transmission rates, but we still do not know about long term effects. Preliminary data question whether administering it to a woman before it is medically indicated will jeopardize her health if she develops an antiviral resistant virus, thus limiting her treatment options.<sup>146</sup> Additional trials are also necessary to determine the most effective time period and duration for treatment. Must it start at fourteen weeks or could it start later?<sup>147</sup> Is the IV infusion necessary during labor and delivery? Would that alone be effective? Is the treatment for six weeks postnatally useful?<sup>148</sup> Without treatment, a fetus has a seventy-five percent chance of being HIV negative. There is limited data on whether the HIV negative infant will suffer any effects from the intrauterine exposure.<sup>149</sup> Treatment will not cure the underlying disease in either the mother or the child who remains HIV positive.

It is still unclear whether the findings from Protocol 076 will be useful with a different population of HIV positive women. The women in this study were asymptomatic. Their CD4 T-lymphocyte counts were

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146. See Grizzy, *supra* note 85, at 492.

147. Very preliminary studies with two to four years of additional data indicate: between 3.2 & 6.1 percent rate of transmission if treatment is begun prenatally; between 10 & 10.7 percent if treatment is given in the intrapartum period; between 9.3 & 12.5 percent if treatment is begun within the first 48 hours of life and between 18.4% & 42.9% with treatment begun 3 to 42 days after birth. See Nancy A. Wade et al., *Abbreviated Regimens of Zidovudine Prophylaxis and Perinatal Transmission of the Human Immunodeficiency Virus*, 339 N. ENG. J. MED. 1409 (Oct. 1998) and Susan Fiscus et al., *Trends in HIV Counseling, Testing, and Antiretroviral Treatment of Human Immunodeficiency Virus-Infected Women and Perinatal Transmission in North Carolina*, JOURNAL OF INFECTIOUS DISEASES, 180:99-105 (1999).

148. Some more recent studies suggest that a shorter regimen may be more feasible in reducing mother-to-child transmission in developing countries. It is currently possible to reduce transmission by 66% with treatment throughout pregnancy at a cost of roughly \$1,000 or by 51% beginning at 36 weeks gestation at a cost of \$50. See *Short Course of AZT Reduces Rate of Perinatal HIV Transmission*, INFECTIOUS DISEASES IN CHILDREN, Mar. 1999 at 24. Another issue that arises is what intervention, if any, there should be with HIV positive mothers, who breast feed, in developing countries. It is currently estimated that 5% of infants born to mothers with HIV who live in developing countries become seropositive through postnatal breast-feeding. Transmission rates appear to be related to the length of time the infant is breast-fed. There are still unanswered questions about whether the infants could be latently infected with the virus, with the infection surfacing during breast-feeding. See *Infants Born to HIV Positive Mothers at Greater Risk to Become Seropositive*, INFECTIOUS DISEASES IN CHILDREN, Oct. 1998 at 80.

149. Early data is uncertain. There have been early reports that there is no risk at least for cancer. (See *Zidovudine, Cancer Link not Found in Treated Infants*, INFECTIOUS DISEASES IN CHILDREN, Feb. 1999); There have also been reports of some danger. See Mitchell L. Zoler, *Vertical Transmission of Multidrug-Resistant HIV*, PEDIATRIC NEWS, at 23 Mar. 1999 (indicating that a neonate whose mother had received treatment during pregnancy appeared to inherit a viral strain resistant to two different classes of anti-HIV drugs and within a few months developed a strain that was resistant to a third class of drugs). The article further reported that 2 of 203 infants born to HIV infected mothers who received combined treatment with zidovudine and lamivudine during pregnancy developed a rare, fatal complication called mitochondrial dysfunction. It should be noted that with the neonate who became multi-drug resistant, the mother had a history of treatment and noncompliance with several types of anti-HIV drugs. *Id.*

relatively high (forty-one percent had counts between 200 and 500, and fifty-nine percent had counts over 500). None had undergone previous antiretroviral treatment.<sup>150</sup> Physicians have also found that AZT treatment can cause some "severe toxic side effects."<sup>151</sup> What we do know is that treatment outcomes have improved markedly in the past few years. The so called "AIDS cocktail" which uses combination antiretroviral therapy shows real promise in depressing viral loads and extending life that has some quality to it. Being treated at a medical facility with experience in AIDS treatment is critical. For example one study of 887 women covered under Medicaid showed that seventy-one percent of those treated at high volume treatment facilities were alive twenty-one months after diagnosis, while only fifty-one percent had the same results if treated at a facility with less experience.<sup>152</sup> Generally the outlook for women who are HIV positive is good, but even with improved therapies they are fifteen times more likely to die within a six year period than women who are HIV negative.<sup>153</sup>

There are also unresolved issues associated with elective c-sections. For example, some data indicate that the risk of complications in HIV positive women may be higher than in negative women.<sup>154</sup> Moreover, cesarean delivery, both non-elective as well as elective, is associated with significant morbidity in infected women.<sup>155</sup> Even though the initial reports on the protective effect of elective c-sections are promising, the choice to undergo this surgery, given the risk to the HIV positive women, must be their own. The decision should be made by the woman in consultation with her treating physician. State intervention would be ill advised. The decline in perinatal transmission without state intervention has been remarkable. Reported cases decreased in children younger than one year by 79 percent and in children between one and five years by 67 percent in the years from 1993

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150. Deborah H. Pinkney, *AZT Found to Reduce Perinatal HIV Transmission Risk*, 37 AM. MED. NEWS 4 (1994) (preliminary results from studies currently being conducted of women with lower CD4 counts seem to indicate the transmission rates may still be lowered). See Boyer, *supra* note 81.

151. See Martha A. Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402 (1993). This article cites a New England Journal of Medicine study that found AZT treatment related side effects include nausea, headaches, myalgias and anemia. *Id.* at 427.

152. See JOURNAL AIDS (March 1998); see also <http://www.aegis.com/news/re/1998/RE980303.html> (last visited Nov. 15, 2005).

153. *Id.*

154. Lynn M. Mofenson, *Can We Eradicate Perinatal HIV Transmission in the US?*, presented at 6th Conference on Retroviruses and Opportunistic Infections, Jan. 1999; see also abstract from Dr. Jennifer S. Read, National Institute of Child Health and Human Development (on file with author); and *infra* note 169.

155. *Supra* note 154.

to 1997.<sup>156</sup> We certainly do not need to do anything coercive which could result in noncompliance and failure to seek treatment.

Some states have enacted criminal statutes to allow prosecution of those who engage in conduct that creates a risk of transmission.<sup>157</sup> Without clarification it is foreseeable that some states may attempt to use these statutes against pregnant women who refuse treatment and who have HIV positive children just as they attempted to use drug delivery statutes and criminal child abuse statutes against pregnant women who bear children with positive drug toxicologies.<sup>158</sup> We are already seeing calls for civil commitment.<sup>159</sup> Will an HIV positive child be able to sue her parents?<sup>160</sup>

We have also begun to see further state intervention in the lives of HIV positive women, even after the birth of the child. In Eugene, Oregon, a juvenile court judge has prohibited an HIV positive woman from breast feeding her infant son.<sup>161</sup> The State intervened within hours after the birth of the child after a doctor expressed concern about the mother breast-feeding the baby. The family remained under regular supervision of the state, which retained legal custody of the child. A social worker visited the home weekly to ensure that the baby was bottle fed.<sup>162</sup> Interestingly, the attorney for the mother in

156. *Id.*

157. See e.g. GA. STAT. § 16-5-60 (West, WESTLAW through 2005 Special Sess.); MISS. STAT. tit. XII, Chapt. 191 § 191.677; ILL. COMP. Chapt. 720, § 5/12-16.2 (yr.) and INN. ANN. CODE tit. 35, art. 38 § 35-36.1-7.1.

158. See *supra* notes 11-25 and accompanying text.

159. In the context of substance abuse, see e.g. Mara Lynn Krongard, *A Population at Risk: Civil Commitment of Substance Abusers After Kansas v. Hendricks*, 90 CAL. L. REV. 111 (2002).

160. In California proposition 64 was placed on the ballot in 1986. The proposition, which was defeated, would have required public officials to quarantine anyone who was HIV positive and would have forbidden anyone with AIDS from teaching or attending public school. See Martha A. Field, *Testing for AIDS: Uses and Abuses*, 16 AM. J.L. & MED. 34 (1990). One example of potential state intervention into the lives of pregnant HIV women was North Carolina Senator Jesse Helms advocacy for quarantine as a means of controlling the spread of AIDS. See also Sandra Anderson Garcia & Ingo Keilitz, *Involuntary Civil Commitment of Drug- Dependent Persons with Special Reference to Pregnant Women*, 15 MENTAL & PHYSICAL DISABILITY L. REP. 418, (1991). This article reports that twenty-four states and the District of Columbia have specific detailed provisions for involuntary commitment of drug dependent persons and eleven have limited provisions. Fifteen have no specific provisions, but eleven of that group would allow commitment under their general commitment statutes. There also have been suggestions that a child should be able to bring a wrongful life action against a physician or medical professional for failure to test and disclose to a pregnant woman that she is HIV positive. See John F. Hernandez, *Perinatal Transmission of HIV: Cause for the Resurrection of Wrongful Life*, 27 J. MARSHALL L. REV. 393 (1994). Wrongful life actions are not favored in most jurisdictions and there is no reason to believe it would be viewed anymore favorably in the case of AIDS.

161. See *HIV-Infected Mother Can Keep Baby but Must Bottle-Feed*, SEATTLE TIMES, Apr. 21, 1999 at B8.

162. *Id.*; See also Robin Power Morris, *The Corneau Case, Furthering Trends of Fetal Rights and Religious Freedom*, 28 NEW ENG. J. ON CRIM. & CIV. CONFINEMENT 89 (2002) (detailing a case in which a pregnant woman, Rebecca Corneau, was held in custody until she gave birth because she was refusing prenatal care). During a previous pregnancy Ms. Corneau's child, Jer-

this case also represented the mother in *In re Nikolas E.*<sup>163</sup> There are currently several studies to assess the HIV transmission rate in the breast-feeding period.<sup>164</sup> Most are being conducted in developing countries where the majority of infants are breast fed. If a strong correlation is established, will we be facing anti-breast feeding police who monitor the homes of HIV positive mothers to ensure that their infants are bottle-fed? As unappealing as that would be, the Oregon case clearly indicates that it is not far fetched. And, what alternatives do we offer women in developing countries without the resources and support for bottle feeding? The issue of AIDS in developing countries is of continuing concern. The future is not particularly bright. Most new cases of HIV infection in children occurs in developing countries. Nearly ninety percent of all HIV infected babies are born in Africa. UN AIDS estimates that there were 1.4 million children worldwide under age fifteen and living with HIV/AIDS at the end of 2000. Of these children, almost all acquired the virus from their mothers, before or during birth or during breast feeding.<sup>165</sup> Clinical trials are being conducted in developing countries, but certainly not on the same level as in the United States and other more developed countries. Because of the lack of infrastructure to support clinical trials and research, researchers have had to be more innovative. In Uganda, for instance, a clinical trial reported a marked reduction in mother to child transmission with a single dose of nevirapine.<sup>166</sup> Three phase III randomized placebo controlled trials using short course AZT regimes were conducted in Thailand and the Ivory Coast. The estimated transmission rate was 9.4 percent at two and six months compared with 18.9 percent in the placebo arm.<sup>167</sup> A similar trial in a breast feeding

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emiah, died at birth from what authorities believe was a lack of adequate medical care. She was refusing medical care during pregnancy because she belonged to a cult that shunned science and medicine as a form of blasphemy. She was held in protective custody until her baby was born on October 16, 2000. See David Abel, *Pregnant Sect Member in State Custody*, BOSTON GLOBE, Sept. 1, 2000 at A1.

163. See *supra* note 145.

164. See, Joseph Saba, abstract S7, *The results of the PETRA Intervention Trial to Prevent Perinatal Transmission in sub-Saharan Africa*, Address at the Sixth Conference on Retroviruses and Opportunistic Infections in Chicago, Illinois, (Jan. 31 – Feb. 4, 1999); see also Andrea Ruff, abstract S8, *Breastfeeding Correlates of Transmission and Prevention*, Address at the Sixth Conference on Retroviruses and Opportunistic Infections in Chicago, Illinois, (January 31 - February 4, 1999).

165. See <http://www.unaids.org/en/Resources/epidemiology/epicore.asp> (last visited Nov. 1, 2005).

166. See <http://www.unaids.org>.

167. N. Shaffer, R. Chuachoowong, P.A. Mock, et al., *Short-course Zidovudine for Perinatal HIV-1 Transmission in Bangkok, Thailand: A Randomised Controlled Trial*, 353 LANCET 773 (1999); S.Z. Wiktor, E. Ekpini, J.M. Karon, et al., *Short Course Oral Zidovudine for Prevention of Mother-to-Child Transmission of HIV-1 in Abidjan, Côte d'Ivoire: A Randomised Trial*, 353 LANCET 781 (1999); and F. Dabis, P. Msellati, N. Meda, et al. *Six-month Efficacy, Tolerance, and Acceptability of a Short Regimen of Oral Zidovudine to Reduce Vertical Transmission of HIV in*



population in the Ivory Coast was conducted by the Ivory Coast government and the CDC.<sup>168</sup> These successful trials provide some hope for developing countries where the ACTG 076 regimen is neither affordable nor feasible.

We know that transmission rates can be reduced significantly using delivery by c-section. Again the lack of adequate resources for the procedure as well as the increased risk of infection would have to be addressed. Studies to date have shown that cesarean births in developing countries have a relatively high risk of post operative mortality. There is also a concern with complications which are increasingly common among HIV positive women, particularly if they have a severely suppressed immune system.<sup>169</sup> The special challenges in developing countries must be considered as we craft a response to HIV infection among the poorest of the poor.

There is an ongoing concern among public health professionals and some members of the legal community that doctors and states may attempt to restrict an HIV positive woman's reproductive choice by encouraging that she abort if pregnant, or be sterilized if she is not.<sup>170</sup> It is conceivable that a woman would choose to abort to avoid prosecution under the criminal statutes mentioned above. It is also conceivable that a state concerned with the cost of foster care and health care for these infants would encourage abortion, sterilization or contraception for HIV positive women. Some still view an HIV positive woman's decision to become pregnant or to continue her pregnancy as being selfish, or to categorize her as a bad mother. The sentiment is that no HIV positive woman would voluntarily get pregnant. Surely she would not want her child to be born with AIDS or be orphaned. Racism exacerbates the lack of respect for the reproductive choices of HIV positive women, of poor women, and of African-American women generally.<sup>171</sup>

During the last decade, as the availability of long term birth control has become common, and as it has become possible to sterilize a woman on an outpatient basis, we have seen a significant increase in

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*Breastfed Children in Côte d'Ivoire and Burkina Faso: A Double-blind Placebo-controlled Multicentre Trial*, 353 LANCET 786 (1999).

168. *Id.*

169. M. Bulterys, A. Chao, A. Dushimimana, et al., *Fatal Complications After Cesarean Section in HIV Infected Women*, 10(8) AIDS 923 (1996).

170. See *infra* note 171; see *supra* note 137.

171. See Roberts, *supra* note 11; *supra* notes 8-12. See also Dorothy E. Roberts, *Unshackling Black Motherhood*, 95 MICH. L. REV. 938 (1997) and Taunya L. Banks, *Reproduction and Parenting*, in AIDS LAW TODAY 216 (Scott Burris et al. eds., 1993). See also Walker v. Pierce, 560 F.2d 609 (4th Cir. 1977), *cert. denied*, 434 U.S. 1075 (1978). Dr. Pierce's practice of sterilizing Medicaid patients after the birth of their third child was upheld as his publicly and freely announced policy. This was so even though the policy was based on economic factors rather than on the health of the mother.

courts ordering women to be sterilized, to practice contraception or to otherwise limit their reproductive capacity.<sup>172</sup> It is not difficult to envision judges who feel that an HIV positive woman's choice to have a child is socially irresponsible and morally reprehensible, and should therefore be controlled. We should reject this "Good mom-Bad mom" construct. HIV positive women and poor women of color who become pregnant and choose to continue the pregnancy are vilified, yet society seems invested in creating and preserving genetic ties between caucasian parents and their children. Time and again, we see limits placed on African-American women when it comes to procreative choice.<sup>173</sup> The choices of both women should be respected. We would not encourage a pregnant woman with a terminal disease to abort, nor would we require a woman who is carrying a child with a potentially fatal or crippling genetic condition to do so.<sup>174</sup> Why should we feel or reason differently if the woman is HIV positive? With proper treatment there is a good prognosis for an HIV positive woman to have a number of healthy years before the onset of symptoms and society is searching feverishly for a cure.<sup>175</sup> "Knowing that her own prognosis is bad, or even anticipating a short life expectancy, may provide a very strong reason for a woman to seek fulfillment in motherhood."<sup>176</sup> The greater chance is that a child born to an HIV positive woman would not be HIV positive. A three out of four chance for a "normal" child may sound like good odds to women who may be poor, minority, and who have probably not been dealt the best hand in life.

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172. See generally Stacey L. Arthur, *The Norplant Prescription: Birth, Women Control or Crime Control?* 40 UCLA L. REV. 1 (1992). See also Roberts, 95 MICH. L. REV. 938 and Catherine E. McCanna, Note, *A Hot Debate in the Summer of 2001: State v. Oakley's Excessive Intrusion on Procreative Rights*, 36 IND. L. REV. 857 (2003). *State v. Oakley* involved David Oakley, a father of nine, who failed to meet his child support obligations. At trial the judge suspended Oakley's 11 year sentence, but imposed a prohibition on Mr. Oakley's right to procreate absent a showing that he could support his children both present and future. On appeal the prohibition was upheld by the Wisconsin Supreme Court. *State v. Oakley*, 629 N.W.2d 200 (Wis. 2001). But cf., Trammell v. State, 751 N.E.2d 283 (Ind. Ct. App. 2001). In this case a trial court included a prohibition on Kristie Trammell's becoming pregnant. She had been convicted of child neglect on two separate occasions and one instance had resulted in her child's death. This provision was struck down by the Indiana Court of Appeals.

173. See Roberts, *supra* note 11, at 94-95 and 304-305.

174. But see Shaw, *supra* note 137.

175. New combinations of drug treatments have been shown to restore immunity and prolong life for infected children and adults. Current treatments have been able to reduce HIV to undetectable levels in the blood and have allowed for recovery of the damaged thymus, which plays a key role in developing the immune system. See <http://www.healthcare.ucla.edu/vital-signs/>. A combination of AZT, 3TC and efavirenz has recently (2004) been shown to be effective in reducing viral loads and increasing CD4 cell counts in patients recently infected with HIV available at <http://www.aidsmap.com/en/docs>.

176. Carole Ulanowsky & Brenda Almond, *HIV and Pregnancy*, in *AIDS—A MORAL ISSUE: THE ETHICAL LEGAL AND SOCIAL ASPECTS* 46 (Brenda Almond ed., 1990).

## PART IV: CONCLUSION AND RECOMMENDATIONS

I agree with Dr. Ronald Bayer that if we are to test pregnant women for HIV, it must be done in a manner that will “empower [them] to make informed choices on their own behalf according to their own private values.”<sup>177</sup> In 1999, 85 percent of HIV positive pregnant women received prenatal care.<sup>178</sup> Of the 90 percent of pregnant women offered AZT prophylaxis, 90 percent were compliant.<sup>179</sup> These numbers would seem to militate against coercive intervention. If the state is to intervene in these cases, over the mother’s objection, the burden for intervening should be extremely high. We are talking of interventions of Constitutional dimensions. The State must show a compelling state interest and the remedy should be narrowly tailored. I would suggest a course of conduct that incorporates the following recommendations:

1. Provide adequate, culturally sensitive treatment for substance dependent pregnant women. This would necessarily entail providing inpatient care where women and their children could be accommodated.
2. Given that outpatient treatment is substantially less expensive, where appropriate, outpatient care should be developed that speaks to the specific needs of women. Outpatient treatment has the added advantage of allowing the mother to maintain relationships with family, friends and external support systems.
3. Identify specific economic, social and emotional barriers to developing these recovery/treatment programs for women.
4. Address the harm caused when the substance dependent pregnant woman is treated using a penal model, rather than a therapeutic model. Addiction has historically been recognized as an illness rather than a crime. The needs of society are not served by incarceration. Moreover, in terms of pure economics, it is much more cost effective to provide treatment for a woman than to imprison her.
5. Provide integrated care for HIV/AIDS and substance dependent pregnant women. Women who use drugs during pregnancy, while small in number, are still the least likely to seek prenatal care. This will only be exacerbated by threats of imprisonment. There must be efforts at all levels (federal, state, local and community) to integrate treatment and prevention services.
6. Develop a system of universal, routine prenatal HIV screening for pregnant women with both notification and counseling provisions. Al-

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177. Ronald Bayer, “Perinatal Transmission of HIV Infection: The Ethics of Prevention,” *in* *AIDS AND THE HEALTH CARE SYSTEM* 63, 68 (Lawrence O. Gostin ed., 1990).

178. See *supra* note 117.

179. *Id.*

though routine screening has traditionally not included a counseling component, given the nature of the disease and the interventions that are available to reduce vertical transmission, counseling would be productive. I would recommend an opt-out approach under which a woman would be tested unless she declined, but she would have the right to decline. Universal screening would allow a woman to learn her HIV status early in her pregnancy (to the extent that we can facilitate early prenatal care). Voluntary screening and counseling would provide a pregnant woman with the information she needs to make informed choices concerning treatment and future child bearing.

7. Identify public and private sector dollars to support treatment and prevention efforts.

8. Be cognizant of the unique challenges presented in developing countries. Even a truncated course of treatment might prove to be cost prohibitive. Relevant drug companies will have to continue with cost reductions and even then the cost may have to be supplemented with funds from more affluent countries. Women identified as HIV positive should be encouraged to bottle feed their infants and adequate breast milk substitutes should be provided.

9. Identify and raise additional funds for research. Much of the progress that has been made in reducing vertical transmission rates has resulted from clinical trials. Current research for a vaccine would be a part of this equation. Ultimately success will not be possible without commitment and dollars.

10. Be honest about recognizing the role that race and class play in this pandemic and our response to it.

Careful routine testing and counseling of pregnant women would be prudent given that half of HIV positive women do not know their status.<sup>180</sup> As indicated above, studies show that the overwhelming majority of women would accept treatment where it is offered and that if they are pregnant they would accept treatment on behalf of their fetus.<sup>181</sup>

Our response should not be paternalistic. Testing should be consistent with the CDC recommendations.<sup>182</sup> Programs that work<sup>183</sup> should be replicated.

Legal recognition of the shared interest of the mother, the community and the potential life is essential. As we develop public policy in

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180. Marla J. Brickman, *HIV Testing is Urged in Every Pregnancy: Early Warning Can Sharply Cut Risk of Transmission to Baby, CDC says Counseling is Critical: Fifty Percent of Infected Women Don't Know it, A Doctor Says*, ATLANTA CONST., July 7, 1995, at A3.

181. See *supra* note 117.

182. See *supra* note 123.

183. See *supra* note 67.

this area, our approach should be wholistic and should cross disciplines. Prevention and thoughtful education are paramount. Other disciplines such as public health and social work must address these issues because neither the law nor medicine can do it alone. Moreover, the legal system is probably the least equipped to address these issues.<sup>184</sup> Care must be taken not to pit mother against child, a choice under which we all lose.

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184. See Cole, *supra* note 52.