2003

Legal Issues Concerning Public Health Efforts To Reduce Perinatal HIV Transmission

Zita Lazzarini

Lorilyn Rosales

Follow this and additional works at: https://digitalcommons.law.yale.edu/yjhple

Part of the Health Law and Policy Commons, and the Legal Ethics and Professional Responsibility Commons

Recommended Citation


This Article is brought to you for free and open access by Yale Law School Legal Scholarship Repository. It has been accepted for inclusion in Yale Journal of Health Policy, Law, and Ethics by an authorized editor of Yale Law School Legal Scholarship Repository. For more information, please contact julian.aiken@yale.edu.
Legal Issues Concerning Public Health Efforts To Reduce Perinatal HIV Transmission

Zita Lazzarini, J.D., M.P.H.* and Lorilyn Rosales, J.D.†‡

Since its inception in 1981, the Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome (HIV / AIDS) epidemic has raised challenging legal and ethical questions for public health officials, physicians, policymakers, patients, lawyers, and ethicists. Although HIV / AIDS mostly affects adults in their prime working years, it has also emerged as a pediatric health problem. Current estimates indicate that in the absence of effective maternal treatment, eight hundred thousand children worldwide born to HIV-infected mothers will be infected each year. Yet, one of the most significant advances of the epidemic has been the discovery that antiretroviral medications taken by the mother during pregnancy and delivery, and by the child after birth, can greatly reduce the risk of HIV transmission.¹ As a result, the United States and the rest of the global community have the opportunity to take proactive steps toward the reduction and virtual elimination of perinatal HIV transmission.²

This Article explores the legal issues related to the reduction of perinatal HIV transmission in the United States to demonstrate that proper education, along with voluntary testing and treatment during pregnancy, can significantly reduce such transmission. Part I examines the history of this topic from a medical perspective, focusing on studies of efforts to reduce perinatal transmission. Part II looks at the evolution of recommendations, policies, and laws regarding the testing and treatment

* Zita Lazzarini is the Director of the Division of Medical Humanities, Health Law, and Ethics at the University of Connecticut Health Center.
† Lorilyn Rosales is an associate at Pullman & Comley, L.L.C.
‡ The origin of this project is deeply indebted to the support of Professor Lawrence O. Gostin. The original survey of state laws and policies was supported by Professor Gostin and a cooperative agreement with the Council of State and Territorial Epidemiologists (CSTE) and the Centers for Disease Control (CDC). Extensive additional research and analysis has been conducted by the authors and research assistants. The authors would also like to thank the all the research assistants who worked on the project, particularly Tara von Kohorn.
¹ See infra Part I.
² Perinatal HIV transmission is the transmission of HIV from mother to child during pregnancy or during birth.
of HIV-positive pregnant women. Part III examines existing state laws regarding HIV testing and counseling, while Part IV reviews legal challenges to these and related laws. With the current medical, legal, and policy information in mind, Part V makes recommendations concerning state legal interventions to reduce perinatal HIV transmission. Part VI concludes that a carefully crafted policy of routine testing that incorporates informed consent is the key to a viable strategy to reduce HIV transmission.

I. THE MEDICAL PROBLEM OF PERINATAL HIV TRANSMISSION AND TREATMENT

To comprehend the scope and challenge of the problem of perinatal HIV transmission, it is important to place perinatal transmission in the context of the HIV epidemic among women and men worldwide. In its report on the global HIV / AIDS epidemic, the United Nations Joint Programme on AIDS (UNAIDS) estimated that forty million men, women, and children were living with HIV / AIDS at the end of 2001. In addition, approximately 2.5 million women with HIV / AIDS become pregnant every year. From such pregnancies, an estimated eight hundred thousand infants were infected in 2001.

Since the vast majority of pediatric HIV infections are acquired perinatally, the most effective means of preventing pediatric HIV infection is to prevent infection of women in general. Even for women who are already infected, intervention can substantially reduce HIV transmission from mother to child.

Until the early 1990s, the only known methods to reduce perinatal HIV transmission were to counsel women to avoid pregnancy and to discourage HIV-positive mothers from breastfeeding. In 1994, however, a study by the Pediatric AIDS Clinical Trial Group 076 (PACTG 076) revealed that maternal and neonatal zidovudine (ZDV) treatment reduced perinatal HIV transmission by sixty-six percent. While twenty-five percent

---

4 Id. at 128.
8 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, 1173
of infants of mothers taking placebo were infected, the figure dropped to about eight percent with ZDV-treated mothers.\textsuperscript{9}

Subsequent innovations in the treatment of pregnant women and newborns further reduced rates of perinatal HIV transmission. For instance, highly active combination antiretroviral therapies for the mother, or the combination of maternal ZDV treatment and a caesarean delivery, reduce transmission to less than two percent.\textsuperscript{10} In fact, since adopting combination therapy for pregnant women in 1994 both the United States and Western Europe have witnessed a sharp decline in perinatal HIV transmission.\textsuperscript{11} Specifically, in the United States, the number of reported cases of perinatal HIV transmission has decreased every year since 1992, from 901 new cases in 1992, to approximately 144 newly infected infants in 1999.\textsuperscript{12} Thus, treating HIV-infected pregnant women with certain antiretroviral drugs in a timely fashion can significantly reduce rates of perinatal HIV transmission.

\section*{II. POLICY DEVELOPMENTS REGARDING THE REDUCTION OF PERINATAL HIV TRANSMISSION}

Since the success of the PACTG 076 protocol and other interventions in preventing perinatal transmission, American public health officials and clinicians have recognized the importance of determining the HIV status of pregnant women for early and timely treatment. Accordingly, the policies of government-sponsored agencies and professional organizations regarding perinatal HIV transmission have altered, changing both the way pregnant women are targeted for counseling and HIV testing, and the way

\begin{itemize}
\item [(1994).]
\item \textsuperscript{9} Lynne M. Mofenson, \textit{Perinatal Exposure to Zidovudine B—Benefits and Risks}, 343 N. ENG. J. MED. 803, 803 (2000).
\item \textsuperscript{10} Unfortunately, the rapid decline in perinatal HIV cases in the United States and other developed countries was not matched worldwide. Approximately ninety-five percent of people with HIV / AIDS live in developing countries. U.S. AGENCY FOR INT’L. DEV., GLOBAL HEALTH, HIV / AIDS: FREQUENTLY ASKED QUESTIONS, at http://www.usaid.gov/pop_health/aids/News/aidsfaq.html (last visited Dec. 8, 2002). According to UNAIDS, at the end of 2001, there were three million children living with HIV. JOINT UNITED NATIONS PROGRAMME ON AIDS, supra note 3, at 8. In 2001, the United Nations Children’s Fund (UNICEF) reported that of eight hundred thousand children with HIV, most (ninety percent) were infected during birth or through breastfeeding. UNITED NATIONS CHILDREN’S FUND, MOTHER-TO-CHILD TRANSMISSION OF HIV 2 (2002), available at http://unicef.org/pubsgen/hiv-mothertochild/fact-sheet-mtct-en.pdf. For most HIV-infected women in the world, therapy to reduce the risk of perinatal transmission remains unavailable.
\end{itemize}
HIV tests are explained and administered. While these reforms have made perinatal testing more broadly inclusive, they have also tended to de-emphasize the role of pretest counseling and informed consent.

A. Policy Development by Governmental Agencies, Congress, and the IOM

Although HIV / AIDS appeared on the global scene in the early 1980s, the U.S. moved relatively slowly in developing a policy response. In 1985, the Centers for Disease Control and Prevention (CDC) issued guidelines for HIV counseling and testing that focused on high-risk women, e.g., intravenous drug users and women whose sexual partners were HIV-infected or at risk for infection. Specifically, the CDC recommended testing for women who were pregnant or who might become pregnant if they (1) had evidence of HTLV-III / LAV infection; (2) used drugs intravenously for non-medical purposes; (3) were born in countries where heterosexual transmission is thought to play a major role; (4) engaged in prostitution; or (5) had been sex partners of intravenous drug abusers, bisexual men, men with hemophilia, men born in countries where heterosexual transmission is thought to play a major role, or men who otherwise had evidence of HTLV-III / LAV infection. The CDC recommended that an infected woman be “advised to consider delaying pregnancy . . . [and] be advised against breast-feeding to avoid postnatal transmission to a child who may not yet be infected.” However, the CDC did not advocate routine counseling and testing for women not in the aforementioned groups “due to the low prevalence of infection and concern about interpretation of test results in a low-prevalence population.”

In 1988, the Presidential Commission on the Human Immunodeficiency Virus Epidemic issued a report calling for a national plan to help fight the spread of HIV and AIDS. Although the report made a number of broad suggestions to promote research and help protect the

---


14 HTLV-III / LAV, which was the early designation for HIV, stands for human T-lymphotropic virus type III / lymphadenopathy-associated virus.

15 CDC Recommendations, supra note 13, at 724.

16 Id. at 725.

17 Id.

public, it did not address the specific issue of perinatal HIV transmission. The ensuing Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 allocated funding to help states, cities, and hospitals with a disproportionate number of AIDS cases provide treatment and support services for persons with HIV and AIDS. Like the commission report, however, this legislation did not explicitly mention perinatal HIV transmission.

In response to the 1994 PACTG 076 results, the CDC recommended counseling on the risks of HIV and voluntary testing for all pregnant women, as well as counseling on treatment and prevention of perinatal transmission for infected women. The CDC's official 1995 guidelines specifically added that pregnant, HIV-infected women should be offered antiretroviral treatment and that all HIV-exposed newborns should be monitored for early diagnosis and treatment. In these guidelines, the CDC emphasized the benefits of routine, voluntary testing as opposed to mandatory testing, which might deter women from seeking prenatal care. In support of its position, the CDC relied on data from routine HIV counseling and testing programs showing that high levels of testing could be achieved without mandatory testing.

In 1996, Congress reauthorized the Ryan White CARE Act, amending and approving the specific spending priorities and programs originally contained in the legislation. During the reauthorization hearings, Congress struggled with various means to reduce perinatal HIV transmission. The final amendments required all states to adopt the CDC guidelines on HIV counseling and voluntary testing for pregnant women.

---

19 See id. The Commission's suggestions included local and state government promotion of HIV testing and counseling and the enactment of HIV-specific criminal statutes penalizing conduct that created a risk of transmitting HIV. As a result of these recommendations, all fifty states adopted various forms of HIV/AIDS legislation to promote HIV awareness, case reporting, and testing. See Stephen V. Kenney, Comment, Criminalizing HIV Transmission: Lessons from History and a Model for the Future, 8 J. CONTEMP. HEALTH L. & POL'Y 245, 260 (1992).


22 Id. at 10-11.

23 Id. at 6.

24 Id. While the CDC's support of voluntary rather than mandatory testing is well founded, it is crucial for all pregnant women to be properly counseled about the benefits of being tested as well as their options, including their right to refuse testing.

25 42 U.S.C. § 300ff-33(a) (1996). To demonstrate compliance, states had to show a fifty percent reduction in AIDS cases stemming from HIV transmission, a ninety-five percent
In particular, under the final amendments, if a state failed to adopt the CDC guidelines, it risked losing the funding it received under the Ryan White CARE Act of 1990. The amendments also required that each state annually assess its incidence of perinatal HIV transmission and evaluate potential reasons for failure to prevent perinatal transmission. Compliant states could avail themselves of the $10 million set aside for HIV counseling, testing of pregnant women, prenatal care for women with a high risk of infection, and implementation of the CDC guidelines. In addition, compliant states with the highest rates of HIV infection among pregnant women received priority for these funds.

Moreover, in the 1996 amendments to the Ryan White CARE Act, Congress requested that the National Academy of Sciences evaluate state efforts to reduce perinatal HIV transmission. The Institute of Medicine (IOM) initiated the requisite study in 1997 and issued its report in 1999. The report concluded that despite reductions in perinatal HIV transmission, the number of babies born with HIV was higher than attainable levels of prevention. Specifically, prenatal HIV testing had not become universal practice, and consequently many infected women did not receive adequate treatment. Furthermore, the report noted that some health care providers did not offer tests to patients whom they believed were “low risk,” and other providers neglected to do so because they found the pretest counseling requirements burdensome. The IOM concluded that, in light of the advances in antiretroviral therapy and its significant potential to reduce perinatal HIV transmission, “the United States should adopt a national policy of universal HIV testing, with patient notification, as a routine component of prenatal care.” As the executive summary of the IOM report explains:

There are two key elements to the committee’s recommendation. The first is that HIV screening should be routine with notification. This means that the test for HIV would be integrated into the standard battery of prenatal tests and women would be informed that the HIV test is being

HIV testing rate of women with two prenatal visits or more prior to thirty-four weeks gestation, or state legislation or regulations requiring the testing of all newborns whose mothers have not been tested for HIV. Id. § 300ff-34(e) (2).

Id. § 300ff-33(b).

Id. § 300ff-34(a)-(b).

Id. § 300ff-33(c).

Id.


See id. at 107.

Id. at 6 (emphasis added).
conducted and of their right to refuse it. . . . The second key element to the recommendation is that screening should be universal, meaning that it applies to all pregnant women, regardless of their risk factors and of prevalence rates where they live.\textsuperscript{33}

In 2000, Congress again reauthorized the Ryan White CARE Act, providing $30 million to support grants for partner counseling and referral services for individuals who tested positive for HIV.\textsuperscript{34} The 2000 amendments also asked the Secretary of Health and Human Services to contract with the IOM to study the status of perinatal HIV transmission.\textsuperscript{35} Furthermore, provisions pertaining to perinatal transmission were altered to authorize an additional $30 million in grants for the counseling, testing, and treatment of pregnant women.\textsuperscript{36} While existing programs received the first $10 million, a percentage of the remaining funds was reserved for states that could demonstrate a substantial decrease in perinatal transmission and for states that required newborn testing. Thus, states that were most aggressive in their efforts to prevent perinatal HIV transmission received the most funding.

In 2001, the CDC issued long-awaited revisions of its recommendations for HIV counseling and testing of pregnant women.\textsuperscript{37} The revised guidelines differed from the 1995 guidelines insofar as they emphasized HIV testing as a routine part of prenatal care. To achieve the goal of testing all pregnant women for HIV, the CDC recommended that the test process be simplified so that pretest counseling would no longer be a barrier; that various types of informed consent be allowed; that health care providers explore and address a woman's reasons for refusing testing; and that HIV testing and treatment be offered to women who had not received prenatal testing and antiretroviral drugs.\textsuperscript{38} Furthermore, in November of 2002, the CDC issued comprehensive recommendations for the use of antiretroviral drugs during pregnancy that reiterated the importance of

\textsuperscript{33} Id. (emphasis original).
\textsuperscript{35} Id. § 213. The Secretary of Health and Human Services, with the aid of the IOM, was to examine the following: (1) the number of newborns born with HIV where the attending obstetrician was unaware of the mother's HIV status; and (2) barriers existing in states that prevent an obstetrician from routinely testing pregnant women or testing newborns when the HIV status of the mother is unknown. The Secretary was to recommend ways to remove such barriers and reduce transmission. Id.
\textsuperscript{36} Id. § 212.
\textsuperscript{38} Id. at 59.
early testing and treatment of pregnant women to prevent HIV transmission to their fetuses.\(^9\)

In sum, at least two important themes emerged from the CDC’s 2001 revisions and 2002 recommendations. First, the CDC endorsed making HIV testing a routine part of prenatal care (i.e., one that all physicians and midwives should pursue with all pregnant patients). Second, the CDC recommended the simplification of the informed consent requirements for HIV testing. Although the CDC continues to recommend that HIV testing of pregnant women be voluntary, these revisions demonstrate a shift in the CDC’s position toward more routine HIV testing of pregnant women.

**B. Perinatal HIV Transmission Policies of Professional Organizations**

The shift in emphasis toward more routine testing of pregnant women for HIV appears not only in federal legislation and CDC guidelines, but also in the policies of professional organizations closely involved in prenatal care. While some organization policies have closely mirrored those of the IOM, others have retained more emphasis on informed consent and voluntary testing than either the CDC (in its 2001 recommendations) or the IOM. Although not binding on their members or on public or private policy, position statements and recommendations from professional organizations attest to a developing standard of care among providers of prenatal and newborn care. These recommendations also indicate the level of professional support for official policies and laws adopted by legislatures and health agencies. Indeed, these positions can influence the development of the CDC’s recommendations, and Congress often uses adoption of CDC recommendations as a criterion for receiving certain categories of federal funding.\(^0\) Therefore, the policies of professional organizations can potentially impact cash-strapped states and health agencies.

Among professional organizations, the American College of Obstetricians and Gynecologists (ACOG) took one of the more aggressive positions by launching a campaign for universal HIV screening of all pregnant women.\(^1\) The ACOG is motivated by scientific advances made in


\(^0\) See, for example, the 1996 Amendments to the Ryan White CARE Act, described *supra* in Part IIA.

\(^1\) Press Release, American College of Obstetricians and Gynecologists, *HIV Tests Urged for*
the “prevention of perinatal transmission of HIV, testing for HIV, and the treatment of HIV-infected women.” The ACOG recommends that all pregnant women in the U.S. be tested for HIV as a routine part of prenatal care. Although the ACOG does not advocate mandatory testing, its goal is to implement universal testing with notification and the right to refuse.

Other professional organizations also endorse routine HIV counseling and testing for pregnant women, but insist that testing be of the opt-in variety rather than of the opt-out variety advocated by the ACOG and the IOM. For example, while the American College of Nurse Midwives (ACNM) recognizes the importance of preventing perinatal HIV transmission, it opposes mandatory testing as a condition of prenatal care. Instead, the ACNM recommends that “all women should be counseled on HIV risk behaviors and risk reduction strategies. Following counseling, all women should be offered HIV testing with informed consent.”

Reiterating the importance of identifying HIV-positive pregnant women, the American Academy of Pediatrics (AAP) recommends “documented, routine HIV education, and routine testing with consent, for all pregnant women in the United States” as well as “utilization of consent procedures that facilitate rapid incorporation of HIV education and testing into the routine medical care setting.”

The American Public Health Association (APHA) also opposes mandatory HIV testing of pregnant women. Its 1995 policy statement, entitled “Opposition to Mandatory HIV Testing of Pregnant Women,” explicitly urged the federal government to prohibit mandatory testing of pregnant women. As an alternative, the APHA recommends that the Department of Health and Human Services educate health care providers on HIV counseling and voluntary testing for pregnant women, and that health care providers “routinely recommend counseling and voluntary


testing with informed consent to women, especially pregnant women.”

Similarly, the American Medical Association (AMA) endorsed the CDC's 1995 recommendations with regard to HIV counseling and voluntary testing for pregnant women. In 1998, the AMA issued a recommendation for routine voluntary testing, stating that, “a system for offering HIV tests in the intrapartum period, using a good faith effort to ensure an informed process of consent, is reasonable.”

In short, the consensus among many professional organizations involved in the delivery of care for pregnant women favors routine testing with consent—as opposed to mandatory testing—to prevent perinatal HIV transmission. In particular, while the ACOG recommends that women be given the right to refuse testing, the ACNM, the AAP, the AMA, and the APHA have been more protective of women's rights, recommending that pregnant women be counseled and given an opportunity to consent prior to testing. Thus, although the public health justification for HIV testing of pregnant women is very strong, it appears most professionals would not override a pregnant woman's right to participate in the testing decision.

III. EVALUATING EXISTING STATE LAWS ON HIV TESTING AND COUNSELING

Since 1981, every state has adopted HIV-specific laws. While thirty-seven states have general HIV testing statutes, only seventeen have prenatal testing statutes, and only four have newborn testing statutes. To understand the legal measures in place to reduce perinatal HIV transmission, it is important to examine the structure of HIV testing and counseling laws in each state.

A. General HIV Testing Statutes

General HIV testing statutes establish each state's overall approach to HIV testing, pretest counseling, and the role of informed consent in the testing process. In states and territories with no specific statute covering HIV testing of pregnant women, general HIV testing statutes govern how pregnant women may be tested. Three types of informed consent policies are found in many of these statutes: (1) voluntary testing with written

49 Id.
50 See CDC 1995 Recommendations, supra note 21.
52 Arkansas, California, Connecticut, Delaware, Florida, Indiana, Iowa, Maryland, Michigan, New Jersey, Pennsylvania, Rhode Island, Tennessee, Texas, Virginia, Washington, and West Virginia have prenatal testing statutes.
53 Connecticut, Indiana, New York, and Rhode Island have newborn testing statutes.
informed consent; (2) voluntary testing with informed consent (which may be written or oral, or not specified in the statute); and (3) testing based on general consent to medical testing and treatment.

1. Voluntary Testing with Written Informed Consent

Fifteen states have statutes classified as voluntary testing with written informed consent.\(^5^4\) The statutes require documentation via a general consent form for medical or surgical treatment that specifically includes consent for HIV antibody or antigen testing,\(^5^5\) a form that contains specific information about the risks and benefits of HIV testing and counseling,\(^5^6\) or a form that simply contains a written statement signed by the patient indicating that she consents to HIV testing, without delineating the risks and benefits of testing.\(^5^7\) Of the fifteen states that require voluntary testing with written informed consent, twelve also require health care providers to include pretest counseling as part of HIV testing.\(^5^8\) Among these twelve states, nine specify what pretest counseling entails.\(^5^9\) Maine's statute is typical:

"Pre-test counseling" must include [f]ace-to-face counseling that includes, at a minimum, a discussion of: (1) the nature and reliability of the test being proposed; (2) the person to whom the results of the test may be disclosed; (3) the purpose for which the test results may be used; (4) any reasonably foreseeable risks and benefits resulting from the test; and (5) information on good HIV preventative practices and HIV risk reduction plans; and [a] written memorandum summarizing the

---

\(^5^4\) Alabama, Arizona, California, Hawaii, Illinois, Maine, Maryland, Massachusetts, Michigan, Nebraska, New York, North Dakota, Pennsylvania, Rhode Island, and Wisconsin have such statutes.

\(^5^5\) See, \textit{e.g.}, \textsc{ala. code} § 22-11A-51(b) (2002) ("A general consent form should be signed for medical or surgical treatment which specifies the testing for HIV infection by any antibody tests or other means and may be considered as meeting the standard of informed consent. . . .").

\(^5^6\) See, \textit{e.g.}, \textsc{conn. gen. stat.} § 19a-582(b) (2002) (requiring that informed consent include a statement that the health care provider explained to the patient a variety of matters related to HIV testing).

\(^5^7\) See, \textit{e.g.}, \textsc{cal. health & safety code} § 120990(a) (Deering 2002) ("The person giving the test shall have a written statement signed by the subject or conservator or other person . . . confirming that he or she obtained the consent from the subject.").

\(^5^8\) Arizona, Hawaii, Illinois, Maine, Maryland, Massachusetts, Michigan, Nebraska, New York, North Dakota, Pennsylvania, and Rhode Island have such requirements.

\(^5^9\) Arizona, Illinois, Maine, Maryland, Michigan, Nebraska, New York, North Dakota, and Pennsylvania have such provisions.
In contrast, three states, Hawaii, Massachusetts, and Rhode Island, prescribe pretest counseling in more general terms, thereby leaving more discretion to the health care provider. For example, Massachusetts defines pretest counseling as simply "a face-to-face meeting . . . between the member [of the community] and a physician, physician assistant, nurse practitioner, registered nurse, or counselor . . . for the purpose of providing counseling before HIV testing.”

2. Voluntary Testing with Informed Consent (Non-Specific)

The second category of statutes requires informed consent but does not insist on written consent. For example, Indiana’s statute provides:

[A] person may not perform a screening or confirmatory test for the antibody or antigen to the human immunodeficiency virus (HIV) without the consent of the individual to be tested or a representative. . . . A physician ordering the test or the physician’s authorized representative shall document whether or not the individual has consented.

Sixteen states follow this pattern, with eleven requiring pretest counseling.

3. General Medical Consent

While the majority of states require informed consent specifically for HIV testing, several states do not require such specific consent. In particular, Texas and Kentucky permit HIV testing based on general consent to medical treatment.

In Texas, the relevant statute provides that “[a] person who has signed a general consent form for the performance of medical tests or procedures

60 ME. REV. STAT. ANN. tit 5, § 19204-A (West 2002).
62 IND. CODE § 16-41-6-1 (2002).
64 The eleven states are Connecticut, Delaware, Florida, Louisiana, Missouri, Montana, New Mexico, Ohio, Virginia, Washington, and West Virginia.
66 KY. REV. STAT. ANN. § 214.181(2)–(3) (Banks-Baldwin 2002).
67 In addition to these two states, Arkansas, Georgia, Illinois, and Mississippi allow testing based on general consent when specific circumstances pertain, as described in Subsection 4 infra.
is not required to also sign or be presented with a specific intent form relating to medical tests or procedures to determine HIV infection." In addition, the statute allows oral consent if there is evidence that the HIV test has been explained to the individual and consent was obtained.

Kentucky's law also affords substantial opportunity for HIV testing without informed consent. In particular, testing without informed consent is permissible (1) when an individual "has signed a general consent form for the performance of general medical procedures and tests" or (2) "[i]n any emergency situation where informed consent of the patient cannot reasonably be obtained before providing health-care services." The Kentucky General Assembly clearly wanted to encourage widespread testing, as evidenced in the statute's description of the legislative intent. In fact, under Kentucky's scheme, it is difficult to imagine a clinical setting in which HIV testing of patients without their consent would be prohibited.

4. Exceptions to General Informed Consent Requirements

Even states that generally require consent for HIV testing may have exceptions that permit testing without consent under specific circumstances. For example, New York normally requires written informed consent, but a party "is to submit to a physical, mental or blood examination by a designated physician after the commencement of an action in which the mental or physical condition . . . of a party is in controversy, upon notice by the other party." The Supreme Court of New York has held that, where a party voluntarily informs the opposing party of his or her HIV or AIDS status, an HIV test may be administered without the informing party's consent. Meanwhile, Missouri allows the Department of Health and Senior Services to obtain a court order to test certain individuals after reasonable efforts have been made to obtain informed consent if "there are reasonable grounds to believe that an individual is infected with HIV and there is clear and convincing evidence of a serious and present threat to others posed by the individual if

68 TEX. HEALTH & SAFETY CODE ANN. § 81.106 (Vernon 2002).
69 Id. § 81.105.
70 KY. REV. STAT. ANN. § 214.181(2)-(3) (Banks-Baldwin 2002).
71 Cf. KY. REV. STAT. ANN. § 214.635 (Banks-Baldwin 2002) (requiring the state to estimate the potential impact of HIV infection on state expenditures).
73 553 N.Y.S.2d at 947.
infected.”74 Likewise, Georgia allows testing to protect the public only after obtaining the subject’s consent or upon successful petition for a court order.75 A court must find “clear and convincing evidence that the person is reasonably likely to be infected with HIV and that there is a compelling need to protect the public health.”76 Such statutory language establishes a relatively high threshold both for evidence that an individual is infected, and for evidence that the individual poses a threat to the community. Moreover, in Missouri and Georgia, court adjudication of these issues provides due process protections.

While Georgia, Missouri, and New York thus permit HIV testing without consent in relatively limited circumstances, at least three other states, Arkansas, Illinois, and Mississippi, carve out potentially broad exceptions to consent.

Arkansas permits HIV testing without full informed consent when (1) a physician determines that the testing is necessary for appropriate diagnosis and treatment of a patient, and the patient has provided general consent to the physician for medical treatment;77 or (2) a health care provider risks becoming infected with HIV after he or she has come in direct contact with the blood or bodily fluids of an individual.78 The second exception affords only a modicum of discretion as long as “exposure” is clearly defined. However, the first exception could cover virtually any situation where a physician thinks a patient is infected and the patient has sought any kind of medical care. Similarly, Mississippi allows testing without consent “if the hospital or physician determines that the test is necessary for diagnostic purposes to provide appropriate care or treatment to the person to be tested, or . . . to protect the health and safety of other patients or persons providing care and treatment to the person to be tested.”79 Such unfettered discretion could lead to abuse by individual physicians or by institutions. To reduce the likelihood of abuse, states

74 MO. ANN. STAT. § 191.674(1) (West 2002).
76 GA. CODE ANN. § 31-17A-3 (2002).
77 ARK. CODE ANN. § 20-15-905(c)(1) (Michie 2002) (“Informed consent, information, and counseling are not required for the performance of an HIV test when, in the judgment of the physician, such testing is medically indicated to provide an appropriate diagnosis and treatment to the subject of the test provided that the subject of the test has otherwise provided his or her consent to such physician for medical treatment.”).
78 ARK. CODE ANN. § 20-15-905(b)(1) (Michie 2002) (“Consent is not required for a health care provider or health facility to perform a test when a health care provider or employee of a health facility is involved in a direct skin or mucous membrane contact with the blood or bodily fluids of an individual which is of a nature that may transmit HIV, as determined by a physician in his medical judgment.”).
could either promulgate clear criteria for applying exceptions to informed consent or require an impartial decision-maker to determine in each instance whether an exception applies.

A different ambiguity—that of potential conflict between HIV testing provisions—plagues Illinois law. While one statute demands written consent,80 another allows HIV testing based only on general consent to treatment if a physician determines testing is medically necessary.81 Specifically, the latter statute states:

[W]ritten informed consent, information and counseling are not required for the performance of an HIV test . . . when in the judgment of the physician, such testing is medically indicated to provide appropriate diagnosis and treatment to the subject of the test, provided that the subject of the test has otherwise provided his or her consent to such physician for medical treatment.82

Absent clear legislative intent to the contrary, such exceptions should be narrowly interpreted in light of the general consensus favoring informed consent and voluntary testing.

B. Prenatal HIV Testing Statutes

Of the fifty states and the District of Columbia, only seventeen have specific prenatal HIV testing statutes.83 In states without such statutes, the general HIV testing laws apply, and most such states have policies and programs addressing perinatal HIV transmission.84 These policies and initiatives most commonly emphasize education, counseling, and providing testing for all pregnant women.85 The seventeen states that have prenatal testing statutes generally feature two types of statutes: (1) routine offer of and informed consent required for prenatal HIV testing; or (2) routine prenatal HIV testing with an implicit or explicit “opt-out” provision.

1. Routine Offer of and Informed Consent Required for Prenatal HIV Testing

Eleven states routinely offer HIV counseling and testing to pregnant women and make testing itself voluntary, based explicitly on informed consent or an implicit consent to testing.86

81 410 ILL. COMP. STAT. 305 / 8 (2002).
82 Id. (emphasis added).
83 See supra note 52.
85 Id.
consent, pursuant to a specific prenatal testing provision. California’s statute exemplifies this scheme:

The prenatal care provider primarily responsible for providing prenatal care to a pregnant patient shall offer human immunodeficiency virus (HIV) information and counseling to every pregnant patient. The prenatal care provider primarily responsible for providing prenatal care to a pregnant patient shall offer an HIV test . . . to every pregnant patient. . . . If the pregnant woman voluntarily consents to testing, the provider shall arrange for HIV testing directly or by referral. . .

The only significant difference between such specific statutory regimes and those predicated on general HIV testing statutes requiring informed consent is that the former specifically require physicians to offer all pregnant women HIV testing one or more times during pregnancy.

2. Routine Prenatal HIV Testing with an Explicit or Implicit Opt-Out Provision

Six states routinely conduct prenatal HIV testing pursuant to a specific statute. Routine testing means that the HIV test is incorporated into the battery of tests that pregnant women normally receive. Usually, women are informed of the general nature of the battery of tests, but the tests will be performed unless the woman actively objects or refuses ("opts out"). Florida’s statute exemplifies this opt-out scheme:

The prevailing professional standard of care in this state requires each health care provider and midwife who attends a pregnant woman to counsel the woman to be tested for human immunodeficiency virus. . . . If a pregnant woman objects to HIV testing, reasonable steps shall be taken to obtain a written statement of such objection.

Ideally, under an opt-out system, pregnant women would receive sufficient information about individual tests to provide them with notice of testing and a meaningful opportunity to accept or refuse. One concern of patient advocates, however, is that routine testing may mean that a patient will not receive any real notice or that she will not realize she can refuse or delay the HIV test. The language in some prenatal HIV testing statutes

---

86 These states are California, Connecticut (which has both voluntary and routine testing provisions), Delaware, Indiana, Iowa, Maryland, New Jersey, Tennessee, Virginia, Washington, and West Virginia.
87 CAL. HEALTH & SAFETY CODE § 125107(b)–(d) (West 2002).
88 These states are Arkansas, Florida, Illinois, Michigan, Rhode Island, and Texas.
89 FLA. STAT. ANN. § 384.31(2) (West 2002).
90 Ruth R. Faden et al., Warrants for Screening Programs: Public Health, Legal, and Ethical
bears out this concern. For example, Michigan’s statute provides:

A physician or an individual otherwise authorized by law to provide medical treatment to a pregnant woman shall take or cause to be taken, at the time of the woman’s initial examination, test specimens of the woman’s . . . [for] HIV or an antibody to HIV. . . . This subsection does not apply if, in the professional opinion of the physician or other person, the tests are medically inadvisable or the woman does not consent to be tested.\textsuperscript{91}

Although the language clearly indicates that testing, while routine, should be voluntary (based on consent), the law could also permit routine testing without real notice or right to opt out. This statute does not include a clear mechanism for notification, counseling, or refusal.

At least one state, Connecticut, requires routine offer and testing with informed consent during pregnancy, as well as routine testing with an opt-out provision at delivery. Specifically, a physician providing prenatal care is required to inform the patient that HIV testing is “routine” and offer her HIV testing at two different times during pregnancy (usually in the first and third trimesters).\textsuperscript{92} On these occasions, the patient can opt in by giving her informed consent to be tested. At delivery, however, a woman who has no evidence of prior testing in her records, or no records at all, will be tested routinely unless she objects in writing.\textsuperscript{93}

Routine HIV testing is motivated by the desire to provide all pregnant women with counseling and testing. Yet, existing laws may needlessly de-emphasize consent, since their goal could arguably be achieved by mandating counseling and offering voluntary testing (with informed consent) at multiple stages of pregnancy. By subjecting pregnant women to


\textsuperscript{91} MICH. COMP. LAWS ANN. § 333.5123 (West 2002).

\textsuperscript{92} CONN. GEN. STAT. ANN. § 19a-593(a) (West 2002) (“Each health care provider giving prenatal care to pregnant women in this state shall inform her, or ascertain from the woman’s medical record that such information has already been provided to her, that HIV testing is a part of routine prenatal care and shall inform her of the health benefits to herself and her newborn of being tested for HIV infection.”).

\textsuperscript{93} CONN. GEN. STAT. ANN. § 19a-593(b) (West 2002) (“If, during the current pregnancy, an HIV-related test has not been documented in the patient’s medical record at admission for delivery of the baby, then the health care provider responsible for the patient’s care shall inform the pregnant woman as required under subsection (a) of this section and shall also inform her of the health benefits to herself and her newborn of being tested for HIV infection either before delivery or within twenty-four hours after delivery and, in the absence of specific written objection, shall cause such test to be administered.”).
different standards for HIV testing, the routine testing laws that are currently in place undermine women’s autonomy and decrease incentive for health care professionals to educate pregnant women about HIV. During pregnancy, women are more likely to accept HIV testing and modify risky behaviors if they understand the potential benefits both to themselves and their fetuses. Therefore, any provision that makes it less likely that physicians will take time to educate pregnant women about the relevant risks and benefits should be avoided.

In short, the most important element of any HIV testing law is whether it affords a substantive right to choose supported by truly informed consent. As illustrated by the routine testing laws, the notion that testing is voluntary may be illusory when women are not told that they can refuse. For example, unless the law requires that a pregnant woman be notified of her right to refuse, either she or her physician may assume that she cannot refuse, or that refusal could result in penalties for the patient or for the physician. Under such circumstances, only careful scrutiny of the actual practices of health care professionals can determine whether patients have a realistic opportunity to make an informed choice about HIV testing.

C. Newborn HIV Testing Statutes

Of the fifty states and the District of Columbia, only four states have specific newborn HIV testing provisions.94

Connecticut requires testing of all newborns for whom there is no record of maternal testing during pregnancy or delivery.95 The relevant statute states that “[t]he administrative officer or other person in charge of each institution caring for newborn infants shall cause to have administered to every such infant in its care an HIV-related test . . . as soon after birth as is medically appropriate.”96 The provision is intended as a final backstop for determining the need for intervention. Nonetheless, it provides one exception—an infant will not be tested if the parents object on religious grounds.97

Indiana permits but does not require physicians to test newborns

94 Because HIV antibody testing of newborns immediately after birth measures exposure to HIV rather than actual infection, newborn testing reveals the mother’s true infection status, not the baby’s. Thus, most infants who initially test “positive” for HIV antibodies will revert to “negative” over time. Detecting exposure in a newborn is still useful, however, to determine whether treatment with antiretrovirals to reduce the risk of infection is appropriate.


96 Id.

without parental consent if the mother had not been tested and a physician believes testing is medically necessary.\textsuperscript{98} If such testing occurs, the mother must receive notification and counseling.\textsuperscript{99} As in Connecticut, parents may prevail on religious grounds, but they must submit such objections in writing.\textsuperscript{100}

Rhode Island generally requires informed consent\textsuperscript{101} but allows several exceptions. One such exception is when "the person to be tested is under one year of age."\textsuperscript{102}

Finally, New York regulations illustrate the state's goal of universal prenatal HIV counseling and testing:

[H]ospital maternity staff are to approach all women in labor who do not have an HIV test result from prenatal care and offer them expedited HIV testing with preliminary results available as soon as possible, but no later than 48 hours. . . . For those women without prenatal HIV test results who decline HIV testing during delivery, hospitals are required to conduct expedited HIV testing of all newborns with preliminary results available in the same time frame.\textsuperscript{103}

The state Department of Health explicitly warns that "[w]omen should be aware that their newborn will be tested even if they choose not to be [sic] and that it is better to be tested for HIV during pregnancy than to wait until delivery."\textsuperscript{104}

IV. CHALLENGES TO STATE HIV TESTING LAWS

State newborn testing provisions, exceptions to general informed consent, and opt-out regimes reflect the federal trend toward routine HIV testing at the cost of women's autonomy. Accordingly, much commentary has been devoted to the constitutionality, public health justifications, and ethical issues surrounding general,\textsuperscript{105} prenatal,\textsuperscript{106} and newborn HIV

\textsuperscript{98} IND. CODE § 16-41-6-4(a) (2002).
\textsuperscript{99} IND. CODE § 16-41-6-4(b) (2002).
\textsuperscript{100} IND. CODE § 16-41-6-4(e) (2002).
\textsuperscript{101} R.I. GEN. LAWS § 23-6-12 (2002).
\textsuperscript{102} R.I. GEN. LAWS § 23-6-14(1) (2002).
\textsuperscript{104} Id.
testing.\footnote{107}

\section*{A. Ethical Issues}

While conflicts between the principles of autonomy and beneficence in health care are now usually resolved in favor of patient autonomy, concerns over fetal welfare complicate matters in the perinatal context.\footnote{108} With perinatal HIV testing in particular, public health officials and clinicians must weigh the burdens on a woman's autonomy against the potential benefits of early diagnosis and treatment to both the woman and her fetus. Earlier in the HIV / AIDS epidemic, neither mandatory nor routine testing provided much benefit to pregnant women. However, since 1995, advances in antiretroviral treatment and success in reducing perinatal transmission provided a strong public health justification for


testing. Accordingly, the debate has shifted significantly in favor of increased testing.

B. Legal Challenges to General Testing Laws

Despite the prevalence of general HIV testing statutes, these provisions have sparked scant litigation. The most recent case, *Sierakowski v. Ryan*, arose over the Illinois AIDS Confidentiality Act, which affords physicians discretion to test without patient consent. In *Sierakowski*, although the plaintiff refused an HIV test during a routine hospital visit, he was tested nonetheless and notified of the results at his next appointment. Sierakowski alleged that the Illinois statute violated his rights under the Fourth and Fourteenth Amendments. The District Court for the Northern District of Illinois dismissed the suit, and the Seventh Circuit affirmed. According to the circuit court, Sierakowski did not have Article III standing because his test results were negative. The court found that not only were his alleged injuries abstract and conjectural, but also "[t]here [was] nothing in the proposed amended complaint or the record below to suggest that future injury [was] likely and that Sierakowski face[d]

109 Some commentators have argued that various anonymous HIV testing programs, including the Survey of Child-Bearing Women (SCBW), unethically withhold information from pregnant women, similar to the withholding of information from subjects in the infamous Tuskegee study of syphilis. See Ronald Bayer, *Rethinking the Testing of Babies and Pregnant Women for HIV Infection*, 7 J. CLINICAL ETHICS 77 (1996); William Raspberry, *Shades of Tuskegee*, WASH. POST, Sept. 22, 1997, at A19. This claim turns the principle of autonomy on its head by arguing that it is the withholding of information obtained from non-consensual testing that offends or violates a pregnant woman's autonomy. *Cf.* Amy L. Fairchild & Ronald Bayer, *Uses and Abuses of Tuskegee*, 284 SCIENCE 919 (1999) (highlighting the withholding of treatment, not information); Gershon B. Grunfeld, *Dissimilarities Between Tuskegee Study and HIV / AIDS Programs Emphasized*, 82 AM. J. PUB. HEALTH 1176 (1992) (same). The SCBW was a "screening project in which all newborns were screened for HIV . . . to try to get some idea of what HIV infection prevalence was among their mothers and from there to generalize on HIV infection in the United States." Linda Valleroy, Address at the 70th Meeting of the Blood Products Advisory Committee, Department of Health and Human Services, Food and Drug Administration (Dec. 14, 2001) (transcript available at http://www.fda.gov/ohrms/dockets/ac/01/transcripts/3817t2.htm). The survey found a 0.2- to 0.3-percent prevalence of HIV in the general population of the United States. *Id.* Those asserting that withholding information from pregnant women is unethical successfully lobbied to end Public Health Service support for the SCBW.

110 Currently, there are thirty-seven states with general HIV testing statutes on the books. See supra Part III.

111 223 F.3d 440 (7th Cir. 2000).

112 410 ILL. COMP. STAT. 305 / 8 (2002).


114 *Id.* at 441.

115 *Id.* at 443.
an immediate threat of harm."\textsuperscript{116} By deciding the case on the narrowest possible grounds (applying the findings only to Sierakowski), the court overlooked the possibility that other patients could be harmed and provided no guidance to other health care providers and patients on when non-consensual testing is permitted.\textsuperscript{117}

\textbf{Sierakowski} remains the only case that directly challenged the legitimacy of a general HIV testing statute. Other cases arose over statutory application. In \textit{Doe v. High Tech Institute, Inc.},\textsuperscript{118} for example, although the Colorado statute allows testing without consent under certain circumstances, the plaintiff’s situation did not fall within statutory exceptions. The plaintiff was told that his blood sample was obtained only for rubella testing. There was no other demonstrable reason for taking the plaintiff’s blood, and there was no legitimate reason for testing the sample for HIV. The court held that “a person has a privacy interest in his or her blood sample and in the medical information that may be obtained from it,” and that “an additional, unauthorized test . . . can be sufficient to state a claim for relief for intrusion upon seclusion.”\textsuperscript{119} In other words, it is illegal to obtain a blood sample for non-HIV testing purposes and then subject the sample to HIV testing without medical justification.

In suits challenging the propriety of an HIV test conducted without consent, state courts often stress the defendant’s intent. For example, in \textit{Doe v. Ohio State University Hospital & Clinics}, the court ruled that a plaintiff must demonstrate that the defendant “knew” he or she did not have the patient’s consent.\textsuperscript{120} Mere knowledge that consent is legally required does not establish that, on the occasion when the defendant performed the test in dispute, the defendant knew he or she was violating the statute.\textsuperscript{121}

\textsuperscript{116} \textit{Id.}

\textsuperscript{117} Future plaintiffs challenging the Illinois provision might consider an alternative argument. Rather than seeking injunctive relief, which would prohibit future incidents, they might seek damages for the non-consensual testing to which they have already been subjected by claiming that the testing violated their rights under the Fourth and Fourteenth Amendments. An action for damages rather than injunctive relief would avoid the problem of standing presented in \textit{Sierakowski} because a plaintiff in a case for damages would only have to show that an injury had occurred, not that the injury was likely to occur again. The threat of a viable legal action would help prevent physicians from overstepping their bounds, thus reducing invasions of privacy like that in \textit{Sierakowski}.

\textsuperscript{118} 972 P.2d 1060 (Colo. Ct. App. 1998).

\textsuperscript{119} \textit{Id.} at 1068. “Intrusion upon seclusion” is a variant of invasion of privacy.

\textsuperscript{120} 663 N.E.2d 1369, 1373 (Ohio Ct. App. 1995).

\textsuperscript{121} \textit{Id.}
C. Legal Challenges to Perinatal Testing Laws

As of 2002, thirty-seven states require prenatal syphilis testing.122 Other states mandate testing for disorders such as hepatitis B, phenylketonuria (PKU), and sickle cell disorder.123 Research in both state and federal databases yields a paucity of cases challenging statutes requiring prenatal or newborn testing for diseases such as PKU and syphilis,124 and commentators have noted the absence of legal challenges to other prenatal testing programs.125 Based on the lack of litigation over perinatal screening in general, it is not surprising that perinatal HIV testing statutes have not been widely challenged.

Moreover, where perinatal testing laws have spawned legal protest, plaintiffs generally have not prevailed. In one such case, the Connecticut Hospital Association filed a complaint against Connecticut Governor John Rowland, seeking pre-enforcement injunctive relief from the state’s newborn HIV testing statute.126 The Association claimed that the provision, which requires the screening of newborns whose mothers refused testing or for whom test results were not available, violates the Fourth and Fourteenth Amendment rights of pregnant women and newborns. The district court denied immediate injunctive relief, and hospitals soon became accustomed to the changes. Hence, the Connecticut Hospital

122 Three other states (Louisiana, Maine, and Missouri) require the patient’s consent for testing. New Hampshire repealed its statutory mandate in 1986. Minnesota requires that midwives recommend testing. The remaining eight states (Florida, Iowa, Michigan, Mississippi, North Carolina, Oregon, Virginia, and Wisconsin) have no testing requirement.
123 Eden, supra note 106, at 669.
124 Research was conducted using Westlaw. Searches were performed both in the federal cases database and in the all-states database. A separate search was conducted in both databases for sickle cell testing. This yielded only eighteen cases, none of which involved legal challenges specifically aimed at sickle cell testing. Rather, the cases dealt with medical malpractice in diagnosis or treatment.
125 See, e.g., R. Curtis McNeil, Prenatal HIV Testing Under Ohio Revised Code Section 3701.242: The Doctors’ [sic] Dilemma and the State’s Shame, 22 DAYTON L. REV. 301, 309 (1997) (“No recorded cases have challenged the ability of the State of Ohio to require gonorrhea testing. . . . Although prenatal syphilis testing has been the law throughout the United States for over 50 years, research has not uncovered a single reported case, in any state or federal jurisdiction, where the authority of the state to require these tests has even been questioned.”). The only successful challenges to non-HIV, mandatory prenatal testing programs appear to have come against testing for sickle cell disease. These challenges were accompanied by growing public awareness that sickle cell screening clearly discriminated against African-Americans. The public outcry, more than individual litigation, led to a change in federal law that required voluntary testing aimed at preventing, diagnosing, and treating the disease while maintaining confidentiality. Kristin M. Raffone, The Human Genome Project: Genetic Screening and the Fundamental Right of Privacy, 26 HOFSTRA L. REV. 503, 521 (1997).

Some commentators perceive the lack of legal challenges to prenatal and newborn testing in general as evidence of tacit moral acceptance of these practices. According to one observer, “[w]hen a woman seeks prenatal treatment, she is consenting to be tested for what is mandated by the state in which she is seeking treatment. She submits to testing and treatment.” This characterization of prenatal testing casts the decision to seek prenatal care as a privilege. From this perspective, the prospect of testing is no more objectionable than the drug test that a prospective employee implicitly consents to when she applies for a job. Yet, this characterization overlooks the coercive nature of attaching conditions to a decision to seek prenatal care. A pregnant woman is virtually bound to seek medical care at some stage of pregnancy unless she is willing to risk her own life and that of her fetus by giving birth without the assistance of medically trained personnel. Thus, pregnant women are faced with a starkly limited range of alternatives: they can avail themselves of medical assistance, which may involve unwanted testing, or receive no care at all. For public health and policy reasons, it seems unsound to so constrain women’s choices. This unfortunate outcome can be avoided by giving women a real choice as to prenatal testing.

D. Beyond Testing Statutes

Even if all, or nearly all, pregnant women accept HIV testing, reduction of perinatal HIV transmission requires additional steps. At present, the best medical advice for an HIV-infected woman is that she receive antiretroviral treatment according to current guidelines (usually combination therapy), adhere to the medication schedule through delivery, give her baby antiretrovirals as prescribed, and not breastfeed. Based on existing data, it may also be advisable for some women to deliver via caesarean section. Such measures come into play after testing and are, currently, fully voluntary. Nevertheless, as evidence mounts on the efficacy of these interventions in reducing mother-to-child transmission, pressure to comply with these treatments and procedures will increase. Therefore, it is relevant to consider whether, and under what circumstances, a woman’s

---

127 Eden, supra note 106, at 670.
128 See generally CDC Recommendations, supra note 13.
129 The American College of Obstetrics and Gynecology, supra note 41, recommends that “HIV-positive pregnant women with high viral loads ... be counseled by physicians about both the benefits and risks of elective caesarean delivery to help reduce the rate of perinatal transmission.”
physician can force her to undergo medical interventions for the benefit of her fetus rather than herself. While there does not appear to be any cases in which health officials or prosecutors sought to force a pregnant woman with HIV to accept treatment, the issue of forced intervention in a pregnancy has arisen in other contexts that bear reviewing.

1. Court-Ordered Cesarean Deliveries

During the past several decades, courts have issued a series of opinions concerning physicians who sought court orders to perform caesarean sections on women who, for religious or other reasons, refused the surgery. The seminal case is that of Angela C. in 1990.\textsuperscript{130} Angela C. was diagnosed with a recurrence of cancer late in her pregnancy and faced death before her due date. Before falling into a coma, she refused the request of one of her doctors to perform a caesarean section to try and save her premature fetus. The District of Columbia Court of Appeals concluded that the lower court had erred in granting the order for surgery over the mother’s objections, upholding the right of a mother to refuse interventions that pose a risk to her merely for the benefit of her fetus.\textsuperscript{131}

The case of Angela C. provides strong support for a pregnant woman’s right to make choices about medical treatment during pregnancy, even when those decisions are contrary to medical advice and may have serious consequences for herself or her fetus.\textsuperscript{132} According to Angela C., a pregnant woman with HIV should retain the right to accept or refuse antiretroviral therapy or a caesarean section regardless of the potential benefit to the fetus because both pose some risk to her.

\begin{itemize}
\item[\textsuperscript{130}] In re A.C., 573 A.2d 1235 (D.C. 1990).
\item[\textsuperscript{131}] Id. at 1243. Neither Angela nor her baby survived despite the surgery.
\item[\textsuperscript{132}] State courts have followed the holding in Angela C. even when the fetus is much closer to full term (and thus clearly “viable”). For example, in In re Baby Boy Doe, 632 N.E.2d 326 (Ill. App. Ct. 1994), the court found that a mother may refuse a caesarean section immediately before delivery even though physicians predicted serious harm to the infant without intervention. However, the case of Angela C. did not fully resolve the issue of maternal surgery, as local and state courts have both granted and denied orders requested by physicians. See Robin M. Trindel, Fetal Interests v. Maternal Rights: Is the State Going Too Far?, 24 AKRON L. REV. 743 (1991). Compare Pemberton v. Tallahassee Mem. Reg’l Med. Ctr., 66 F. Supp. 2d 1247 (N.D. Fla. 1999) (holding that forced caesarean section performed in the interests of an unborn baby does not violate the mother’s constitutional rights), and Jefferson v. Griffin Spalding County Hosp. Auth., 274 S.E.2d 457 (Ga. 1981) (upholding a forced caesarean order), with In re Baby Boy Doe, 632 N.E.2d 326, 333 (Ill. App. Ct. 1994) (finding that a forced caesarean section, undertaken for the benefit for the fetus, cannot pass constitutional muster).
\end{itemize}
2. Court-Ordered Medical Care

Other recent cases, however, suggest possible limitations on women’s autonomy during pregnancy. In 2000, a Massachusetts prosecutor obtained an order to confine a pregnant woman until delivery where the woman and her husband refused to seek any prenatal care or medical assistance for birth, and where an earlier child was believed to have died from lack of medical care.\(^\text{13}\) After birth, the healthy child was placed in state custody. The parents were detained on contempt charges for refusing to provide information on the fate of a third child, who the couple maintained died as a result of a miscarriage.\(^\text{14}\)

Although this case has not been appealed or published, and thus provides little legal precedent, it illustrates a prosecutor’s discretion to characterize a pregnant woman’s choices as dangerous to her fetus. An aggressive prosecutor in this or another jurisdiction could attempt to intercede in the pregnancy of an HIV-positive woman to force either treatment with antiretrovirals or other interventions at delivery.

3. Drug Use During Pregnancy

A separate series of cases involves criminal charges against women for actions during pregnancy that could harm their fetuses. In many cases, prosecutors jailed women and removed their children from custody for “delivery” of drugs to the fetus during pregnancy or birth.\(^\text{15}\) Appellate courts have largely upheld these decisions. In addition, some states automatically seek custody of children suffering from withdrawal symptoms due to maternal drug use during pregnancy.\(^\text{16}\)

In 2001, the U.S. Supreme Court decided Ferguson v. City of Charleston,\(^\text{17}\) which involved a South Carolina hospital’s practice of testing

---

\(^{13}\) See Paul E. Parker, Thrust into the Spotlight—Judge Takes the High Road, PROVIDENCE J.-BULL., Feb. 4, 2002, at B01; David Wedge, Judge Confines Cult Mom to Secure Hospital, Judge’s Ruling Locks Up Defiant Pregnant Cult Mom, BOSTON HERALD, Sept. 1, 2000, at 001; Editorial, Woman Imprisoned over Prenatal Care, L.A. TIMES, Sept. 12, 2000, at B8.


\(^{16}\) Practice Commentaries, N.Y. Fam. Ct. § 1012 (2002). Thus, for almost two decades, it has been well-settled law in some states that “[a] newborn baby having withdrawal symptoms is prima facie a neglected baby.” In re Vanessa F., 351 N.Y.S.2d 337, 940 (Surr. Ct. N.Y. 1974); cf. In re "Male" R., 422 N.Y.S.2d 819 (N.Y. Fam. Ct. 1979).

\(^{17}\) 532 U.S. 67 (2001).
pregnant women for drugs and providing the results directly to law enforcement officials for prosecution purposes. The Court held that such a practice violated a woman’s constitutional rights under the Fourth Amendment. The Court ruled that if health officials intend to collect information for criminal prosecution, they must ensure that women are aware of their constitutional rights. Thus, Ferguson suggests that some prenatal testing regimes may violate the Fourth Amendment prohibition against unreasonable search and seizure. However, the case also acknowledges public health claims related to prenatal testing. Therefore, if a prenatal HIV testing statute does not set criminal penalties and includes provision of notice to women that testing would be performed, a court following Ferguson might uphold the law regardless of consent.


HIV-related cases that have invoked state child welfare or protection powers have mainly been concerned with medical care of a child after birth. For example, in an Oregon child custody case, an HIV-infected woman refused ZDV treatment for her newborn and wanted to breastfeed against medical advice. A family court intervened and granted legal custody of the child to the state. The mother and father retained physical custody on the following conditions: they were not to breastfeed the child, and they had to submit to monitoring by social services to ensure compliance with the order.

Another case involved a woman in Maine who did not want to give her HIV-infected toddler antiretrovirals. The woman had already suffered through the illness and death of another child from AIDS and “expressed her distrust of the drug therapy and declined to permit her son to participate (in experimental treatment studies) at that time.” Health officials sought an order that would require the woman to give ZDV to her child or else grant the state custody of her child. The court denied the request, reasoning that a woman who had already cared for and lost one

138 Id. at 85.
141 Id. at 563.
142 Id.
child to AIDS could weigh the potential side effects and benefits of treatment and determine what was best for her child.

Both the Oregon and Maine courts struggled to determine what would be best for the child in question. The key difference may have been that the Oregon child was uninfected, and all the testimony in the case suggested that avoiding breastfeeding could prevent infection. The child in Maine, on the other hand, was infected and already quite ill. Thus, it seems the Oregon court ruled against parental autonomy because intervention could protect a healthy child from a deadly infection, while the Maine court preserved parental decision-making where child medications are difficult to take, have significant side effects, and will not effect a cure.

Indeed, the Oregon and Maine cases address the medical care of a child after birth, not choices that women make during pregnancy. Parental decisions regarding children’s care are governed by a set of rules and case law that differs significantly from those governing the decisions of pregnant women. For instance, child protection authorities have much greater latitude to act in “the best interests of the child” after birth. 143 Nonetheless, child welfare cases may be relevant to the issue of perinatal testing and treatment because they illustrate the powerful pressures that can come into play when public health authorities believe a parent is endangering a child (or future child).

5. Criminal Exposure and Transmission Laws

Some commentators worry that women who refuse testing, treatment, or interventions at delivery could be prosecuted under state laws that specifically criminalize knowing exposure to, or transmission of, HIV, or even under criminal laws such as assault, attempted murder, or reckless endangerment. 144 In fact, of the twenty-four states that have HIV-specific laws criminalizing exposure or transmission, 145 only Oklahoma’s law

---

143 E.g., CONN. GEN. STAT. § 17a-103b(a) (2002).
currently exempts in utero exposure.\textsuperscript{146} However, a query of all fifty state health departments on the possible use of criminal provisions against pregnant women revealed that no department had knowledge of any attempts or intentions on the part of health officials to use criminal law in this manner.\textsuperscript{147} Officials in only one state, Washington, had specifically examined their criminal HIV transmission law for applicability to pregnancy and concluded that the statute would only apply if, a woman intended to infect her infant.\textsuperscript{148}

Given the apparent lack of interest in prosecuting perinatal HIV transmission, it seems unlikely that a woman who complies with public health recommendations for HIV testing and treatment during pregnancy would be charged with knowing exposure or transmission, even if her child became infected. A more likely scenario for possible criminal charges would involve women who refuse treatment, do not comply with treatment regimens, insist on breastfeeding, or avoid prenatal care altogether. Such choices would clearly run against the weight of public health and clinical recommendations.

In sum, based on the lessons of Angela C. and related cases, a pregnant woman with HIV who refuses her physician's advice to have a caesarean delivery or take antiretrovirals would not likely be compelled to undergo surgery or accept treatment. Nonetheless, prosecutors might pursue criminal charges in spite of health department policies to the contrary. It remains unclear, moreover, whether health officials or physicians might use the threat of criminal prosecution or child custody actions to coerce women into accepting antiretroviral treatment or other medical interventions during pregnancy or birth.

V. RECOMMENDATIONS FOR REDUCING PERINATAL HIV TRANSMISSION

In its report, Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States, the IOM recommended universal testing with patient notification as a routine component of prenatal care.\textsuperscript{149} The IOM stated that implementing such a policy would require numerous other steps,

\textsuperscript{146} OKLA. STAT. tit. 21 § 1192.1 (2002) ("It shall be unlawful for any person knowing that he or she has Acquired Immune Deficiency Syndrome (AIDS) or is a carrier of the human immunodeficiency virus (HIV) and with intent to infect another, to engage in conduct reasonably likely to result in the transfer of the person's own blood, bodily fluids containing visible blood, semen, or vaginal secretions into the bloodstream of another, or through the skin or other membranes of another person except during in utero transmission of blood or bodily fluids.") (emphasis added).

\textsuperscript{147} Lazzarini et al., supra note 84.

\textsuperscript{148} Id. at 4410.

\textsuperscript{149} INST. OF MED., supra note 30, at 6.
including (1) educating prenatal care providers; (2) improving provider practices and bringing the clinical practice guidelines of professional organizations in line with enumerated best practices; (3) contractually imposing success in universal testing as a performance measure; (4) improving coordination of care and access to high-quality HIV treatment so that all women who are tested can take advantage of the most successful intervention strategies currently available; and (5) addressing underlying reasons that drive some HIV-infected women to refuse testing or treatment.

The IOM also noted that substantial federal and state funds are needed for a coordinated effort to meet these specific objectives and to achieve the overarching goal of reducing perinatal HIV transmission. Specifically, the IOM noted that certain groups of women are most likely to "fall through the cracks" of the current counseling, testing, and treatment systems and urged the government to take extra steps to reach these women. Such women include those in correctional settings, women without access to prenatal care, and women who do not intend to become pregnant. In addition, the IOM urged efforts that would reduce primary infection in women since such efforts can contribute markedly to reducing perinatal HIV transmission.

Overall, the IOM recommendations address a broad range of issues and would improve prenatal care for all women as well as reduce HIV infection. Unfortunately, much of the attention at the state level has focused on laws related to testing and on the manner of testing (e.g., voluntary, mandatory, or routine). Some legislators appear to have followed the IOM's assumption that the consent process must be changed or eliminated to increase levels of testing among pregnant women. Yet there is little empirical evidence to support that this is the only way, or the best way, to increase testing rates and reduce HIV transmission.

A comprehensive perinatal HIV transmission policy ought to include mechanisms directed at changing the behavior of health care professionals, such as (1) training health care workers to provide effective HIV education and counseling to pregnant patients, (2) incorporating education, counseling, and testing of pregnant women as performance measures; and 3) reimbursing physicians, nurses, and midwives who spend time educating and counseling pregnant women. A comprehensive program should also address the needs of pregnant women more directly. Public education campaigns in many states have already raised awareness of the benefits of HIV testing during pregnancy without reducing women's

control over their bodies. In addition, as the IOM noted, it is critical to reach women least likely to receive prenatal care, encouraging them to seek care as early in pregnancy as possible and to make health-promoting changes while pregnant.

Finally, where states have moved to routine testing, officials need to examine how routine testing is actually implemented to ensure that “routine” does not amount to “compulsory.” While, in theory, routine testing with the option to opt-out confers a greater degree of autonomy than mandatory testing, in practice, this may not be the case. Adoption of the rhetoric of “routine” testing may subject women to testing with little or no meaningful information about the test or their right to refuse and still receive medical care. Under such circumstances, not only do women lose the opportunity to make an autonomous choice about medical care, but also—and more importantly—health care providers lose the opportunity to educate them, either because women opt not to receive any care at all, or because the testing process involves no real dialogue about HIV testing and treatment.

Indeed, given the problems that may arise from routine testing with an opportunity to opt out, an opt-in method may be more effective and prudent. In other words, a pregnant woman should have to give her express permission for an HIV test to be performed. Once provided with the necessary counseling, the majority of pregnant women might choose to opt in, thus furthering the goal of testing all pregnant women.\(^{151}\) At the same time, the express-permission requirement would assure that some discussion of the test takes place and promote use of the opportunity to educate.

**VI. Conclusion**

Although most states (1) emphasize the importance of informed consent for HIV testing, both prenatally and generally, and (2) recognize the privacy and constitutional interests accompanying a person’s medical information, many jurisdictions allow HIV testing without full informed consent in certain circumstances. With general testing provisions, common exceptions to informed consent include protecting health care providers and the public, as well as enhancing the ability of health care providers to diagnose and treat patients effectively. The majority of the seventeen states that have statutes specifically addressing prenatal testing also require informed consent for testing. However, since the IOM issued its report in

---

\(^{151}\) See CDC Revised Guidelines, *supra* note 37, at 68.
some have modified their laws to require “routine” testing at some point in pregnancy, and two states have instituted mandatory newborn testing programs. Similarly, professional organizations have developed a substantial consensus on the value of routine (universal), voluntary HIV testing during pregnancy, though they differ subtly on the meaning of routine testing, the role of informed consent, and the extent of health care providers’ duties to educate pregnant women on the risks of HIV as part of the testing process. The push to achieve routine testing risks eliminating any real opportunity both to educate women and to provide women with a real choice to accept or refuse testing. Focus on legal reform may also obscure another important issue—whether HIV-infected women can be persuaded to accept treatment, and if so, whether they can be persuaded to adhere to prenatal and postnatal medication regimens.

Yet, the efficacy of prenatal treatments in preventing HIV transmission provides a strong public health justification for ensuring that all women know their HIV status and have the opportunity to receive antiretroviral therapy, for themselves and for their children. Widespread adoption of prenatal counseling and testing and acceptance of treatment by HIV-infected women have already significantly reduced the annual incidence of HIV transmission to newborns. With one hundred or fewer cases per year since 2000, the U.S. has achieved remarkable success. Nevertheless, some preventable transmission continues to occur. Thus, the challenge of how best to reduce or eliminate new cases without sacrificing important values and compromising women’s role in their own health care remains. An effective way to balance a woman’s autonomy with the welfare of her fetus would be to adopt comprehensive HIV prevention measures that focus on changing the behavior of health care providers, educating pregnant women, making testing “routine” in the sense that the test is available to all women at every stage of pregnancy, ensuring that all pregnant women know they should be tested, and providing adequate prenatal care for all women before changing or eliminating the requirement of informed consent. Such a strategy would provide women a real choice to delay or refuse testing and treatment while still educating them about HIV.

See INST. OF MED., supra note 30.