

MANDATORY SCREENING OF NEWBORNS FOR HIV: AN IDEA WHOSE TIME HAS NOT YET COME

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An infant may benefit from early detection of his or her risk for HIV. However, the scope of these benefits does not justify state and federal proposals to mandate testing and disclosure of a newborn's HIV test result to the mother. Proponents of mandatory testing tend to 1) overstate the medical benefits of universally testing infants for HIV at birth; 2) minimize the impact of the HIV test for the woman herself, and her legal rights concerning HIV testing; and 3) minimize the importance of the mother's role in facilitating medical care for her infant as well as question her competence as the infant's caretaker. Because the mother's legal rights are substantial, and her cooperation is necessary if the baby is to benefit from an HIV test, these assumptions must be carefully examined before rushing to implement a mandatory testing program.

Mandatory testing proposals by now have taken various forms in New York State and in Congress: New York State Assemblywoman Nettie Mayersohn's bills proposing to "unblind" New York State's seroprevalence survey of HIV in childbearing women,¹ introduced in 1993, 1994,² and 1995;³ New York State Congressional Representative Gary Ackerman's bills introduced in 1994 and 1995, proposing to unblind the seroprevalence survey in every state;⁴ and Representative John Coburn's proposal to phase in mandatory newborn testing in every state, included in the House of Representatives' version of the Ryan White CARE Act reauthoriza-

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¹ Since 1988, 43 states and U.S. territories have tracked HIV in childbearing women by screening blood specimens routinely collected from newborns. The results of the tests are not linked to newborns' or the mothers' identities. Marguerite Pappaioanou et al., *HIV Seroprevalence Surveys of Childbearing Women — Objectives, Methods, and Uses of the Data*, 105 PUB. HEALTH REP., 147, 148 (1990).

² H.R. REP. NO. 1289, 104th Cong., 1st Sess. (1994).

³ A.4413, 1st Sess.(1995).

⁴ H.R. REP. NO. 4507, 103d Cong., 2d Sess. (1994); H.R. REP. NO. 1289, 104th Cong., 1st Sess. (1995).

tion bill.⁵ In New York State, the Association to Benefit Children has brought a lawsuit to require the state government to screen all newborns and children in foster care "below the age of consent" for HIV.⁶ A settlement has been reached between the plaintiffs and state-defendants that would require the Department of Health to propose regulations allowing for testing of newborns without maternal consent based on the presence of at least one enumerated risk factor for HIV.⁷

Although the mother is not tested directly, her legal rights are compromised when an HIV test is performed on her newborn's blood without her consent. All infants born to HIV-infected women have maternal HIV-antibodies at birth; therefore, a newborn screen only definitively identifies HIV infection in the mother. By eighteen months of age, the infant will have replaced the maternal antibodies with her own, and the majority will be HIV-negative as current rates of transmission of HIV from mother to newborn are estimated to be between 15% and 25% in the United States.⁸

Because the newborn's HIV test reveals whether or not the mother is infected, her rights to informed consent and to privacy are at stake. The mother's right to privacy encompasses the right to make personal decisions, including the right to refuse unwanted medical tests and treatment. That right is protected under civil tort law by the informed consent doctrine,⁹ by state statute,¹⁰ and by the federal constitution.¹¹ The right to privacy in medical decision-making¹² and the right to avoid disclosing personal medical

⁵ The Coburn-Waxman amendment calls for phase-in mandatory HIV testing of infants. Within two years all states must know the HIV status of 95% of newborns born in that state. If they cannot demonstrate that information and if mandated screening has become routine care, states must implement mandatory screening in order to receive Ryan White monies.

⁶ Plaintiffs' Complaint at 5, *Baby Girl Doe v. Pataki*, Index No. 10661-95 (1995).

⁷ Stipulation at 5, *Baby Girl Doe v. Pataki*, Index No. 10661-93 (1995).

⁸ See, e.g., Clara Gabiano et al., *Mother-to-Child Transmission of Human Immunodeficiency Virus Type 1: Risk of Infection and Correlates of Transmission*, 90 PEDIATRICS 369 (1992) (18.3%); 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) (25.5% transmission rate in placebo group).

⁹ The doctrine of informed consent is grounded in the right to bodily integrity. In *Schloendorff v. Society of New York Hospital*, the New York Court of Appeals found a tort had been committed in rendering unwanted medical care, declaring that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body." 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914).

¹⁰ E.g., N.Y. PUB. HEALTH LAW § 2805-d (McKinney 1993) (defining cause of medical malpractice action based on patient's lack of informed consent).

¹¹ In *Cruzan v. Director, Missouri Dep't of Health* 497 U.S. 261 (1990) the Supreme Court recognized the individual's liberty interest in refusing unwanted medical treatment.

¹² See *Whalen v. Roe*, 429 U.S. 589, 598-99 (1977) (recognizing right to informational privacy and right to privacy in medical decision-making); *Carey v. Population Services International*, 431 U.S. 678, 684 (1977) (recognizing that right of personal privacy encom-

matters¹³ further protects the woman's decision whether to undergo HIV-testing. Courts have recognized the special privacy concerns attached to the diagnosis of HIV,¹⁴ noting that "[t]he potential for harm in the event of a nonconsensual disclosure is substantial."¹⁵ A statute or regulation that would impinge on an individual's fundamental rights must use the least drastic means to meet a compelling state interest,¹⁶ and also may violate the constitutional requirement of equal protection under the law, unless its rationale survives strict judicial scrutiny.¹⁷

To date, informed consent and confidentiality laws specifically relating to HIV testing and HIV-related information have been critical in protecting these legal rights, and have served the public health by helping infected persons learn their status, seek health care, and prevent transmission to others.¹⁸ These laws were enacted in response to widespread discrimination against persons infected with HIV.¹⁹ Public health officials have opposed implementing mandatory testing in health services programs, because of the chilling effect that mandatory testing would have on participation in those services, and because testing programs must be voluntary in order to foster cooperation with prevention measures.²⁰

passes the individual's interest in making certain kinds of important decisions free from governmental interference).

¹³ Whalen, *supra* note 12, at 599, 600.

¹⁴ *E.g.*, Doe v. Barrington, 729 F.Supp. 376 (D.N.J. 1990); Doe v. American Red Cross Blood Service, 125 F.R.D. 646 (D.S.C. 1989); Woods v. White, 689 F.Supp. 874 (W.D.Wis. 1988).

¹⁵ Doe v. Barrington, 729 F.Supp. 376, 384 (D.N.J. 1990).

¹⁶ Carey v. Population Services International, 431 U.S. 678, 686 (1977); San Antonio Independent School District v. Rodriguez, 411 U.S. 1, 16-17 (1973).

¹⁷ When the state action impinges on fundamental liberty interests of a particular group of citizens, the State must demonstrate that its scheme has been precisely tailored to serve a compelling governmental interest. Plyler v. Doe, 457 U.S. 202, 216-218 (1982). If mandatory newborn screening is analyzed as gender discrimination that does not impinge on a fundamental liberty interest, the State must show that the classification serves important governmental objectives and that the means employed are substantially related to those objectives. Mississippi University for Women v. Hogan, 458 U.S. 718, 724 (1994).

¹⁸ One study has found that individuals in states with policies protective of individual rights were significantly more likely to be tested than individuals in comparison states. Kathryn A. Phillips, *The Relationship of 1988 State HIV Testing Policies and Planned Voluntary Use of HIV Testing*, 7 J. ACQUIRED IMMUNE DEFICIENCY SYNDROME 403 (1994).

¹⁹ National Academy of Sciences and the Institute of Medicine, *Confronting AIDS: Directions for Public Health, Health Care, and Research* 13-15 (1986). See *e.g.*, Governor's Statement, 1988 N.Y. Laws ch. 584. In 1988, the Presidential Commission on the Human Immunodeficiency Virus Epidemic recognized that as long as discrimination occurs, "individuals who are infected with HIV will be reluctant to come forward for testing, counseling and care." PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC, REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC 119 (1988).

²⁰ See Steven Eisenstat, *An Analysis of the Rationality of Mandatory Testing for the HIV Antibody: Balancing the Governmental Public Health Interests With the Individual's Privacy Interest*, 52

Informed consent laws must continue to protect the rights and health of childbearing women. Stigma and prejudice have persisted for women living with HIV. Women are at risk for discrimination in employment, housing, and social services, and may also face violence²¹ or abandonment by a partner as a result of their positive status. HIV-positive women have faced particular discrimination in health care,²² in large part due to discrimination in obstetrical services.²³ Despite strong confidentiality laws, violations of hospital patients' confidentiality with regard to HIV status are common.²⁴ Surveys of physicians' attitudes suggest that HIV-infected patients may be treated less aggressively than non-infected patients for conditions not related to HIV,²⁵ and surveys of neonatologists raise the possibility that HIV-positive infants may also suffer this discrimination.²⁶ If these surveys of attitudes actually reflect behavior, then infants identified as HIV-positive within the health care system will not receive better care, or even adequate care, that mandatory testing is supposed to guarantee. Further, the burden of discrimination aggravates the problems of access to decent health care that many women and children infected with HIV already face. Most families affected by HIV are poor and depend

U. PITT. L. REV. 327, 342-46 (1991); RONALD BAYER, PRIVATE ACTS, SOCIAL CONSEQUENCES: AIDS AND THE POLITICS OF PUBLIC HEALTH 138-146 (1989) (broad spectrum of U.S. public health officials opposed mandatory screening measures on public health grounds); see also Governor's Statement, *supra* note 19.

²¹ NATIONAL ASSOCIATION OF PEOPLE WITH AIDS, HIV IN AMERICA: A PROFILE OF THE CHALLENGES FACING AMERICANS LIVING WITH HIV 28 (1992) (*hereinafter*, "NAFPA"). Approximately 20% of HIV-positive women surveyed had experienced violence due to their HIV status.

²² In one national survey, 44% of HIV-positive women felt they had experienced discrimination in health care due to their HIV status (compared to 35% of HIV-positive men). NAFPA, *supra* note 21, at 28.

²³ An evaluation of a prenatal HIV counseling and testing program in Brooklyn found that pregnant women who disclosed their positive status to obstetric staff received negative reactions. Susan Holman et al., *Women Infected with Human Immunodeficiency Virus: Counseling and Testing During Pregnancy*, 13 SEMINARS IN PERINATOLOGY 11 (1989). In New York City, a woman who volunteered to be tested for HIV at a prenatal care clinic alleged that she was refused further prenatal services and was told she should have an abortion. Doe v. Jamaica Hospital, 608 N.Y.S.2d 518 (N.Y. App. Div. 1994). At the same time, surveys of abortion providers have found it common for HIV-positive to be refused abortion services. Trilby de Jung et al., *HIV-Related Discrimination in New York City Abortion Clinics, 1988-1992*, New York City Department of Health AIDS Institute & New York City Commission on Human Rights (1992); Stanley K. Henshaw, *The Accessibility of Abortion Services in the United States*, 23 FAM. PLANNING PERSPECTIVES 246, 251 (1991).

²⁴ Philip J. Hilts, *Many Hospitals Found to Ignore Rights of Patients in AIDS Testing*, NEW YORK TIMES, Feb. 16, 1990, at A1.

²⁵ Nancy E. Kass et al., *The Influence of HIV serostatus on Physicians' Clinical Decisions*, 9 AIDS & PUB. POL. J. 93 (1994).

²⁶ Betty Wolder Levin et al., *The Treatment of Non-HIV-Related Conditions in Newborns at Risk for HIV: A Survey of Neonatologists*, 85 AM. J. PUB. HEALTH 1507 (1995); Betty Wolder Levin et al., *Treatment Choice for Infants in the Neonatal Intensive Care Unit at Risk for AIDS*, 265 JAMA 2976 (1991).

upon community health centers and large public inner-city hospitals that face a decline in resources.²⁷

All of these concerns reinforce the need for informed consent regarding HIV testing to include: discussion of the implications of testing for both mother and child; referrals for health care and psychological services; how to redress possible discrimination; issues relating to disclosure of HIV status; as well as the option of anonymous testing.²⁸ Every effort must be made to ensure that the woman understands the meaning and implications of a positive test result. These concerns become no less important when the woman is also the parent of an infant. The woman's knowledge of her HIV-positive status will benefit the child when she is prepared to care for herself and her baby.

Proponents of mandatory testing, on the other hand, implicitly view the mother and child as opponents, maintaining that the medical benefits of antibody testing of the child outweigh the woman's rights to privacy and informed consent. The Association to Benefit Children argues that prophylactic and anti-retroviral treatments must occur as soon after birth as possible — even before the newborn's diagnosis can be established — in order to be effective in preventing the opportunistic infections symptomatic of HIV.²⁹ Proponents argue that protection of the mother's privacy has prevented doctors from administering medications to HIV-infected infants that could ward off fatal illness.³⁰

These arguments do not appear to be supported when one carefully examines the benefits to be gained by the intrusion of mandatory testing. Public health experts do not agree that mandatory screening for HIV in newborns is presently justified.³¹ A treatment or intervention that is curative or controls the diagnosed condition must be available before a disease may be in-

²⁷ Margaret C. Heagarty, *Pediatric Acquired Immunodeficiency Syndrome, Poverty, and National Priorities*, 145 AM. J. DISEASE & CHILDREN 27 (1991).

²⁸ For a discussion of pre-test counseling, See NEW YORK STATE DEPARTMENT OF HEALTH, A GUIDE TO HIV COUNSELING AND TESTING (1993). Cf. Neil A. Holtzman et al., *Effect of Informed Parental Consent on Mothers' Knowledge Of Newborn Screening*, 72 PEDIATRICS 807, 811 (1983) (informing parents of newborn screening procedures prepares parents for possible consequences, lessens anxiety, and can improve care they give their infants).

²⁹ Plaintiffs' Complaint at 11, *Baby Girl Doe v. Pataki*, Index No. 10661-95 (1995).

³⁰ E.g., Gretchen Buchenholz, *HIV Babies Have Rights, Too*, NEW YORK DAILY NEWS, Jan. 18, 1994, at 32.

³¹ National organizations that have offered statements opposing recent mandatory testing proposals include the American Academy of Pediatrics, the American College of Obstetricians & Gynecologists, the Association of State and Territorial Health Officials, and the March of Dimes Birth Defects Foundation.

cluded in the neonatal screening panel.³² Lynne Mofenson and Jack Moye, physicians at the National Institute of Child Health and Development, have stated, "Pediatric HIV infection, even given recent advances in diagnosis and treatment, does not fit neatly into [the] traditional framework for screening."³³ Unlike syphilis, for example, that can be treated safely and effectively shortly after birth, there are few proven treatments and methods that can be sure to prolong an infant's lifespan.³⁴ Even if some infections can be prevented, the infant's lifespan that follows will be of uncertain quality and duration.³⁵

For example, proponents argue that mandatory screening is required at birth in order to prevent pneumocystis carinii pneumonia ("PCP"), an opportunistic infection that can be fatal during the first year of life. According to the New York City Department of Health thirty-eight percent of pediatric AIDS cases have been diagnosed with PCP.³⁶ In order to prevent PCP, many pediatricians recommend that parents administer the antibiotic bactrim, particularly if the infant's immune system is functioning below a normal level.³⁷ There are also potentially serious side effects from bactrim, such as rash, fever, blood toxicities,³⁸ and possible liver damage if the infant is premature.³⁹

Other therapies are intended to lower the level of virus in the system. These therapies, including AZT, are far less efficacious,

³² Lynne Mofenson & Jack Moye, *AIDS Experts Examine HIV-intervention Pros, Cons*, AM. ACAD. PEDIATRIC NEWS, September 1993, at 14. See also Eisenstat, *supra* note 20, at 340-41 (proposing criteria for assessing governmental interests in mandatory screening); Gostin, Curran & Clark, *The Case Against Compulsory Casefinding in Controlling AIDS-Testing, Screening, and Reporting*, 12 AM J. L. & MED. 7, 21-4 (1987).

³³ *Id.*

³⁴ *HIV Testing of Pregnant Women and Newborns, 1995: Hearings Before the Subcommittee on Health and Environment*, 104th Cong., 1st Sess. 21 (1995) (statement of Dr. Helen Gayle, Acting Director for the Centers for Disease Control).

³⁵ Howard Minkoff and Anne Willoughby, *Pediatric HIV Disease, Zidovudine in Pregnancy, Screening and Unblinding Heelstick Surveys: Reframing the Debate on Prenatal HIV Testing*, 274 JAMA 1165, 1167 (1995).

³⁶ OFFICE OF AIDS SUREVEILLANCE, NEW YORK CITY DEPARTMENT OF HEALTH, AIDS SUREVEILLANCE UPDATE (July 1995).

³⁷ SAMUEL GRUBMAN ET AL., CENTERS FOR DISEASE CONTROL, 1995 REVISED GUIDELINES FOR PROPHYLAXIS AGAINST PNEUMOCYSTIS CARINII PNEUMONIA FOR CHILDREN INFECTED WITH OR PERINATALLY EXPOSED TO HUMAN IMMUNODEFICIENCY VIRUS (1995). Dr. Alan Fleischman Remarks at the Center for Reproductive Law and Policy (June 1995) (The infant's weakened immune system also makes the infant vulnerable to other potentially fatal infections, which may prove life threatening despite the administration of bactrim.).

³⁸ Walter T. Hughes, *Pneumocystis Carinii Pneumonia: New Approaches to Diagnosis, Treatment and Prevention*, 10 PEDIATRIC INFECTIOUS DISEASE J. 391, 395-96 (1991). See also Deborah Sanders-Laufer et al., *Pneumocystis Carinii Infections in HIV-Infected Children*, 38 PEDIATRIC CLINICS OF NORTH AMERICA 69, 73 (1991).

³⁹ Affidavits of Dr. Denise Sutherland and Dr. Mabelle Allen, Defendant-Intervenor's Motion to Vacate Settlement at —, *Baby Girl Doe v. Pataki*, Index No. 106661-95 (1995).

can produce severe side effects, and their long-term effects are still unknown.⁴⁰ Treatment decisions are especially difficult because diagnosis of HIV in the newborn remains uncertain.⁴¹ If these therapies are administered to all newborns testing positive for HIV from their mothers' antibodies, at least 75% of those infants will have been exposed to the medications unnecessarily.⁴²

Treatment decisions are especially difficult because diagnosis of HIV in the newborn remains uncertain.⁴³ Parents retain the right to make medical decisions on behalf of their children, so long as the refused treatment is not curative of a serious illness.⁴⁴ Courts have ordered medical treatment over a parent's objection only when necessary to avoid serious impairment of a child's health.⁴⁵ An antibody test of a newborn, even when the mother is

⁴⁰ NATIONAL INS. OF ALLERGY AND INFECTIOUS DISEASE, QUESTIONS AND ANSWERS ABOUT ACTG PROTOCOL 152 (1995) (In a recent trial studying the efficacy of various antiviral drugs in young children, the arm of the trial in which AZT was administered alone was stopped because AZT was found to be ineffective and possibly contributed to serious complications); See also Ross E. McKinney, *Antiviral Therapy for Human Immunodeficiency Virus Infection in Children*, 38 PEDIATRIC CLINICS OF NORTH AMERICA 133 (1991).

⁴¹ The polymerase chain reaction test (PCR), which detects HIV-specific DNA, is currently available in New York state for diagnosis of HIV in infants who have tested positive using the standard HIV antibody screen. The sensitivity of the test is still limited before ages three to four months.

⁴² Clara Gabiano et al., *Mother-to-Child Transmission of Human Immunodeficiency Virus Type 1: Risk of Infection and Correlates of Transmission*, 90 PEDIATRICS 369 (1992); 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).

⁴³ A woman who knows that she is HIV-positive would also be advised to avoid breastfeeding and the immunizations for her newborn may be altered. E.g., NEW YORK STATE DEPT. OF HEALTH, POLICY ON BREASTFEEDING AND HIV (1991). However, the risk from immunization with live vaccines is still only theoretical — live vaccines have in fact been administered to hundreds of HIV-infected mothers and infants without incident. John Modlin and Alfred Shah, *Public Health and Clinical Aspects of HIV Infection and Disease in Women and Children in the United States*, in AIDS, WOMEN AND THE NEXT GENERATION 47-48 (Ruth R. Faden et al. eds., 1991).

An aggregation of studies on transmission of HIV by breastfeeding places the risk of transmission of HIV by breastmilk at approximately 14%. The period of greatest risk of transmission by breastmilk, in addition to the later stages of AIDS disease, is between the period of initial infection and the development of antibodies. During this period a woman would not test positive for the HIV antibody. NEW YORK STATE DEPT. OF HEALTH, POLICY ON BREASTFEEDING AND HIV (1991). Thus, these benefits are reasons to encourage voluntary testing, they are not so compelling as to justify mandatory testing.

⁴⁴ Matter of Sampson, 328 N.Y.2d 686 (1972); Matter of Hofbauer, 419 N.Y.2d 937 (1979).

Under New York law, failure to provide adequate medical care can be grounds for neglect if the child's physical condition has been impaired or is in imminent danger of becoming impaired. N.Y. Family Ct. Act § 1092(f)(i)(A) (McKinney 1995). A court may authorize a physician or hospital to provide emergency medical or surgical procedures if such procedures are necessary to safeguard the child's life or health. N.Y. Family Ct. Act § 1027.

⁴⁵ N.Y. Family Ct. Act § 1092(f)(i)(A) (McKinney 1995). An antibody test of a newborn even when the mother is known to be at risk for HIV, would not meet the legal criterion that requires establishing a threat of imminent harm to the child because the risk of the infant being infected is relatively small, and because the medical benefit to the newborn is

known to be at risk for HIV, would not meet the legal criteria that requires establishing a threat of imminent harm to the child.⁴⁶ This is because because the risk of the infant being infected is relatively small.⁴⁷

At the same time, the complexity of decisionmaking and monitoring require the cooperation and continuing involvement of the parents. Treatments must be administered over a period of time, some at least daily, and the infant must be monitored for side effects. This cooperation is best promoted through the informed consent process. Dr. Helen Gayle, testifying for the Centers for Disease Control before the Congressional Subcommittee on Health and Environment last May, stated that the HIV testing "is likely to be most successful if it begins with an informed patient and a trusted provider. Voluntary testing accomplishes this; mandatory testing. . . may actually reduce the chance that a woman and her baby will receive needed therapies if they are alienated from the health care system."⁴⁸ Many women at risk for HIV will be especially sensitive to the punitive message of forced testing.⁴⁹ Any benefit of testing depends on continued voluntary cooperation of the woman, who trusts that health care is available both for herself

uncertain. Parents would have the right to refuse preventive as well as antiviral treatment on a newborn because the actual quality and length of life that could be prolonged is unclear, and because of justifiable concerns over toxicity. See *Matter of Hofbauer*, *supra* note 44, at 941 (parents' choice of nutritional therapies over chemotherapy and radiation treatment for child with Hodgkins' disease did not constitute neglect).

⁴⁶ See SAMUEL GRUBMAN ET AL., CENTERS FOR DISEASE CONTROL, 1995 REVISED GUIDELINES FOR PROPHYLAXIS AGAINST PNEUMOCYSTIS CARNI PNEUMONIA FOR CHILDREN INFECTED WITH OR PERINATALLY EXPOSED TO HUMAN IMMUNODEFICIENCY VIRUS (1995) (describing diagnosis of HIV infection among children. In New York State a positive antibody test on a newborn must be followed by a PCR test, which is given three times before a positive diagnosis can be confirmed).

⁴⁷ *Id.* Recommended drug regimens for bactrim are two doses daily three times per week on consecutive days. *Id.*

⁴⁸ *HIV Testing of Pregnant Women and Newborns, 1995: Hearings Before the Subcommittee on Health and Environment*, 104th Cong., 1st Sess. 21 (1995) (statement of Dr. Helen Gayle, Acting Director for the Centers for Disease Control).

⁴⁹ The women most affected by HIV in the United States are poor African-Americans and Latinas. Seventy-seven percent of cases among women have occurred among African-Americans and Hispanics. CENTERS FOR DISEASE CONTROL, *Update: AIDS Among Women — United States, 1994*, 44 MORBIDITY & MORTALITY WEEKLY REPORT 82 (1995).

Forty-one percent of women with AIDS reported injecting drug use. *Id.* Current and recovering drug addicts have the greatest difficulty accessing regular medical care. GLORIA WEISSMAN ET AL., HEALTH RESOURCES AND SERVICES ADMINISTRATION, *WOMEN LIVING WITH SUBSTANCE ABUSE AND HIV DISEASE: MEDICAL CARE ACCESS ISSUES* (1995).

Women of color have a history of being subjected to coercion in reproductive decision-making and are currently at greatest risk for mandated reporting for substance abuse at delivery. See Dorothy Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality and the Right of Privacy*, 104 HARV. L. REV. 1419 (1991) (recounting history of coercion among African-American women); Chasnoff, Landress & Barrett, *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 (1990).

and for her child, and who wants to continue to participate in a system that will respond to her family's needs. To best meet the health needs of women and children infected with HIV, the public health system should build upon the best aspects of successful voluntary counseling and testing programs that do exist. Retaining the informed consent process as a part of these programs will safeguard the woman's legal rights, build trust with her health care providers, and ensure that the woman is knowledgeable about health care choices for herself and for her child.

