

10 Reproduction and Parenting

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Although adult males continue to constitute the majority of people living with HIV disease in the United States, HIV infection among women and children is on the rise. Nationally, women make up 11.5 percent of AIDS cases, and in some areas of the Northeast the figure is closer to 25 percent and growing.¹ Because most women with HIV disease are of childbearing age, as their numbers have grown so has the number of pediatric AIDS cases. Already, HIV infection is among the ten leading causes of death for children between one and four years of age.² Given our relative success in stemming transfusion-related and blood products-related transmission of HIV, the vast majority of pediatric cases, and virtually all new ones, involve transmission from mother to child before or during birth (perinatal transmission).³

As the number of pediatric AIDS cases continues its steep rise (in 1991, an estimated 2,200 HIV-infected babies were born, as compared with 1,500 in 1990),⁴ government officials at all levels have pressed for more effective measures to stem vertical transmission. Often, these measures bear heavily upon the reproductive freedom of HIV-positive women. Although many such women will voluntarily choose to forego pregnancy when fully and sensitively informed about the risks of perinatal transmission, others will not, preferring to take the two-in-three chance that their babies will be born uninfected.⁵ Public health measures designed to dissuade women from freely exercising this option raise serious constitutional issues. Similarly, measures that pressure HIV-positive women to terminate existing pregnancies are constitutionally suspect.

When women with HIV elect to bring pregnancies to term, a host of parenting, child care, and custody issues arise. Who will serve as the child's primary caretaker? If the child is also infected, who will assure that its special needs are met? If the mother is the primary caretaker and questions are raised regarding her capacity to

parent, how should they be resolved? If she becomes too disabled to continue functioning as a parent, who will take over? Who will take over if she dies?

Perinatal HIV transmission highlights the inadequacies of existing mechanisms for assisting families in crisis. Our social service systems have failed to plan for the problems that predictably arise when HIV-positive adults seek to care for small children, much less those that arise when both parents and children are infected. When the primary caregiver is female, poor, and/or non-White, it is almost impossible for the family to remain intact without help. Yet social support services for families are given low priority by government, and agency policies are often hostile to the families that need help the most—single-parent families headed by poor women and women of color. Existing programs provide inadequate options for temporary child care and family support when parents become ill or incapacitated. The emphasis in most cases is on foster care, which disrupts families by removing children from their homes rather than providing in-home support services for sick parents and children.

Many of the reproduction and parenting issues affecting HIV-positive women in America reflect continuing race, sex, and class bias in the delivery and quality of health care and related social services.⁶ For example, the absence of women's unique concerns in scientific and clinical discussions about HIV, until relatively recently, reflects the continuing institutional sexism in medical research. But even when interest is expressed in HIV-positive women, the focus is on their role as transmitters of the disease rather than on the women themselves.⁷ Women have little input into HIV policies, reflecting the tendency of health care providers to adopt paternalistic attitudes toward female patients, discounting their complaints and concerns in the belief that women have no role in determining their own medical treatment. In addition, treatment protocols are geared to the ways in which the disease is manifested in men, and women may therefore be misdiagnosed and may receive inadequate treatment once the disease is diagnosed.⁸

Health policies designed to minimize vertical transmission must take into account the fact that an overwhelmingly disproportionate number of HIV-positive women are Black and Latina and are in their childbearing years,⁹ and that a disproportionate number of them are poor¹⁰ and are drug users or the sexual partners of drug users.¹¹ This is significant, because in this country poor women and women of color have traditionally been discouraged and even coerced by health care and social service agencies to forego pregnancy.¹² Thus, care must be taken lest race, sex, class, and lifestyle biases bear heavily on the reproductive and parenting rights of women with HIV.

REPRODUCTION ISSUES

HIV Testing of Fertile Women

Currently, the Centers for Disease Control (CDC) recommends that all fertile women at risk for HIV infection be routinely tested.¹³ Given the sharp increase in HIV infection among women and the risk of perinatal transmission, it seems likely that future recommendations will advise that all women of childbearing age be tested. Further, there is reason to believe that much of this testing will take place without the women's consent. A survey of 560 randomly selected nongovernment hospitals has shown that many hospitals do not obtain patient consent to HIV antibody tests.¹⁴ In addition, 3 to 4 percent of the hospitals surveyed never or only sometimes informed patients of positive test results.¹⁵

Undoubtedly, voluntary testing of fertile women should be encouraged to minimize the risk of perinatal transmission, and testing is most valuable if it occurs before pregnancy. At that point, an HIV-positive woman can make an informed choice about whether to become pregnant. Such testing, however, raises a troubling issue: what information should be provided to women who test positive? Under the circumstances, counselors should take a "nondirective" approach, providing the client with relevant information in a nonjudgmental manner and taking no position on the issue of childbearing, leaving that decision to the woman.

The push for routine testing of fertile women raises the very real concern that states will use test results to identify women with HIV so they can be counseled not to reproduce. Such "directive counseling" denies women the opportunity to receive an unbiased assessment of their medical situation and make an informed personal decision free of coercive influences. Currently, HIV counseling is not regulated, and many health care professionals quietly advocate that HIV-positive fertile women be counseled to forego pregnancy and, in some cases, to be sterilized.¹⁶

Even when coercion is not intended, directive counseling presents substantial risks. For one thing, such counseling undercuts individual patient autonomy. Health care workers who provide counseling may not know what is best and may sometimes assume, based on sex, race, class, and substance-use history, that the patient is irresponsible. Directive HIV prenatal counseling may be insensitive to the different cultural values about reproduction and group identity held by many of the women counseled. These programs often fail "to be sensitive to the special value of children for Black and Latina women. . . . [Planners must realize that culturally] the ability to reproduce was seen as a powerful tool in the fight for liberation."¹⁷ Much of the

sterilization abuse directed at poor women and women of color during this century was based on similar assumptions.

Directive counseling also raises the possibility that women with HIV may wrongfully believe that compliance with the counselor's recommendation is a necessary condition of continued medical treatment. Since directive counseling in this context may substantially interfere with the reproductive choices of these women, especially where they have limited access to health care, it raises serious right-to-privacy concerns when supported or carried out by government.¹⁸

HIV Testing of Pregnant Women

There are calls for routine HIV testing of pregnant women.¹⁹ But routine testing during pregnancy is even more problematic than screening all fertile women. The goals of prenatal HIV testing are muddled at best. It is said that testing facilitates the counseling of infected women regarding the impact of HIV on pregnancy and the effect of pregnancy on the progression of the disease; the risk of transmission to the fetus; and the risk of transmission to sexual partners and possible infection in older children.²⁰ Another unstated goal of prenatal testing may be preventing HIV-positive mothers from giving birth to healthy children who may soon become wards of the state when their mothers die.

Putting aside the question of whether it is in the interest of an HIV-negative fetus to be born to an HIV-positive mother, the *articulated* benefits of prenatal HIV testing are questionable at best. We simply do not know enough about the impact of HIV on pregnancy, nor about the effect of pregnancy on the progression of the disease, to counsel women on these issues. Although early reports expressed concern that pregnancy accelerated the disease process, there is little evidence to support this theory. In fact, a recent review of the scientific literature on HIV²¹ in women suggests that pregnant women who are infected should be treated no differently than their nonpregnant counterparts, "unless there are documented and compelling fetal concerns that would justify a modification of those standards."²¹ Further, since the effect of abortion on pregnant HIV-positive women is likewise unknown, counseling pregnant women to abort could put them at greater risk than counseling them to continue the pregnancy.

On the other hand, prenatal HIV testing may have some health benefits for women, since prenatal care may be more readily available for women with limited access to care and prenatal clinics are often where women first learn of their infection. Both the length and quality of life for all HIV-infected women can be improved by early diagnosis and treatment. However, pregnant women with HIV

must be treated as individuals, independent of the fetus they carry. This means that they should be fully informed of the risks and benefits of HIV therapies.²² Yet women are being targeted for routine HIV testing because they are pregnant and can transmit the virus perinatally. To date, the primary articulated concern is not with women themselves, but with women as vectors of HIV transmission.

Justifications for testing that center on the putative benefits to the fetus are also questionable. We do not know precisely when perinatal transmission occurs, nor by what mechanism. Studies indicate that the rate of maternal-to-fetal transmission in some women may be as high as 45 percent and in others as low as 12.9 percent.²³ Thus, the risk of transmission in any particular case cannot accurately be predicted. In addition, there is at present no approved treatment for fetuses of HIV-positive women.²⁴ Therefore, setting aside the idea of terminating the fetus for its own sake, there is nothing to be gained by prenatal (as against neonatal) testing.

Even if effective treatments were available for the fetus, prenatal HIV testing raises a potential conflict of interest between the pregnant woman and her fetus. In some experiments, still in the early stages, pregnant women are being given AZT in hopes of benefitting the fetus. Initially, at least one of these studies called for the mother's AZT to be discontinued once the child was born, since only the fetus, and not the woman, was the subject under study.²⁵

This study is particularly worrisome. It is a fetus-centered study that treats women as vectors and raises potential conflicts of interest between mother and fetus because AZT may benefit the fetus while harming the mother. In addition, pregnant women may be coerced into continuing their pregnancies because participation in experimental protocols is the only way they can get medical treatment. Whereas pregnant women with HIV should have access to treatment protocols, fetus-centered protocols that treat pregnant women as vectors may not serve their best interests. These protocols should be closely scrutinized before approval to insure that both mother and fetus derive comparable benefits. We need to make sure that women with limited access to health care are not exploited by treatment protocols that seem to offer an opportunity for enhanced care.

Given the current demographics of HIV disease in women, pregnant women may be compelled to be treated once treatment becomes available for fetuses. There are already a few cases, although not involving women with HIV in which courts have ordered forced prenatal invasions. Many of these cases involve poor women of color. A recent study of physician and hospital court-ordered obstetrical intervention found that 81 percent of the women involved were Black, Asian, or Latina. All of them were treated in teaching hospital clinics or were receiving public assistance.²⁶ Forced prenatal invasion of an otherwise legally competent pregnant

woman is always inappropriate, because too often it subordinates the woman's bodily autonomy to the fetus. In addition, judges may not trouble themselves to balance the competing maternal-fetal interests when the women in question are Black or Latina.

These competing maternal-fetal interests are also present when pregnant HIV-infected women are counseled. People who counsel these women may find it difficult to decide whether their primary duty is to the prospective parent, the fetus, or society. This conflict is also reflected in the current scholarly dialogue over fetal rights and the rights of pregnant women to refuse treatment intended to benefit the fetus, or to engage in conduct that may harm the fetus.²⁷ Even when the counselor is clear on where her or his obligation lies, it is not easy for the prospective parent to decide whether to risk her health for that of the fetus, or vice versa. Her choice should be informed and uncoerced, based on all of the available information.

Health care providers who use prenatal HIV testing primarily to identify infected pregnant women so that they can be counseled to abort may well violate federal and (to a lesser extent) state law by interfering with the reproductive choices of women with a protected disability.²⁸ (For more on antidiscrimination law, see chapter 13.) When the health care provider is a government entity, directive counseling to abort may also violate women's constitutional right to privacy.²⁹ It would be truly odd if the Constitution were held, in some circumstances, to protect a woman's right to abort a fetus over the state's objection but not to protect her right to bring it to term. Even if *Roe v. Wade* is overturned, the constitutional argument against coercing HIV-positive pregnant women to abort would be strengthened to the extent that the reversal would be premised on rights inhering in the fetus, or on the protectability of fetal life.

There is no compelling rationale for directive counseling of pregnant women with HIV. Purely financial arguments, such as limiting the cost to society of caring for seriously ill newborns and orphans, cannot be allowed to override the fundamental right to procreate.³⁰ Even if the state asserts an interest in protecting potential life, forced or coerced abortion terminates, rather than protects, that life. In addition, if the state argues that protecting societal health is a compelling governmental interest, there is little evidence that routine or compulsory HIV prenatal testing coupled with directive counseling is sufficiently narrowly tailored to achieve that goal.

Constitutional concerns aside, directive counseling that pressures women to terminate their pregnancies is foolish and cruel in a society that does not make abortions readily available to poor women of color.³¹ Not only are Medicaid funds unavailable in most states for even therapeutic abortions,³² but many clinics refuse to perform abortions on HIV-positive women.³³ Nor is prenatal HIV testing a sensible

means of protecting health care workers from on-the-job exposure. Often there is no time to test for HIV, and even when there is, some infected patients may not have developed detectable antibodies. Thus, the only reliable way for health care workers to avoid infection is to follow the universal precautions recommended by the CDC.

To the extent that support for directive counseling reflects the perception of some health care providers that women generally—and especially poor women, women of color, and drug users—are irresponsible, such counseling is incompatible with the ideal of patient autonomy that is at the heart of the doctrine of informed consent. Directive counseling not only impermissibly interferes with women's procreational choices, but it also denies women the right to participate in treatment decisions affecting their bodies. Any counseling of HIV-positive women that directs them to be sterilized or to seek an abortion if they are pregnant fails to treat them as important participants in health care decisions affecting them.

Finally, prenatal HIV testing is analogous to prenatal testing for genetic diseases. Like HIV, genetic disorders can be transmitted vertically from mother to child, and many genetic disorders are not treatable before birth. Directive counseling is considered inappropriate in these circumstances, and it should be considered similarly inappropriate in prenatal HIV counseling.³⁴

This is not to say that routine HIV prenatal testing, preceded by informed consent and accompanied by *nondirective* counseling, could never be appropriate. Testing would be most useful to women if (1) it provided information that could be used to improve the treatment outcome of women with HIV, and (2) women identified as infected had meaningful access to medical care. Since we do not know enough about the impact of pregnancy on HIV-positive women, the first condition cannot be satisfied. In addition, we have no mechanism for guaranteeing that these women will have access to medical care. In fact, recent studies suggest that many already have less access to medical care than most Americans. For example, in one study only 61 percent of Black women, compared to 79 percent of White women, received prenatal care during the first three months of pregnancy.³⁵ Thus, the practical value of prenatal HIV testing is questionable. We must therefore find other, more appropriate ways of preventing perinatal transmission that do not interfere with women's reproductive freedom.³⁶

HIV Testing of Newborns

From the perspective of newborn children, neonatal testing may well be justified because early detection of possible HIV exposure will determine whether prophylactic

treatment is indicated. It is far from clear whether knowledge of a newborn's HIV status will significantly reduce or delay illness or death.³⁷ Neonatal HIV testing is distinguishable from other neonatal testing in that, even if antibodies are found, there is no truly accurate way of telling whether they are the mother's or the newborn's.³⁸ However, there are relatively benign prophylactic measures for infants who carry their mother's antibodies, and the strong possibility (one in three) of actual infection also has a bearing on medical treatment for other conditions. Recent studies suggest that methods may be available in the near future to detect perinatally acquired HIV infection in infants as young as six months.³⁹ These are very preliminary findings, however, and have yet to be tested on large numbers of infants and in clinical settings.

Even if early detection of HIV becomes possible, neonatal testing raises potential conflicts between mother and infant. The newborn's test results reflect the mother's HIV status. This information will likely be placed in her medical records and will become broadly available to a wide range of health care and social service staff members. Confidentiality within hospitals is notoriously difficult to maintain, and inappropriate disclosure of the mother's infection could subject her to discrimination and render her uninsurable.

Since neonatal HIV testing thus poses real risks for mothers, it should not be performed without their informed consent unless there is a high degree of probability that knowledge of the newborn's status will significantly reduce or delay illness or death. Given the present uncertainty, even though neonatal HIV testing may be appropriate in many circumstances, routine testing without the express consent of the newborns' parents or guardians is not justified.

Finally, an infected woman whose status is disclosed through neonatal testing might be criminally prosecuted if she knew she was HIV-positive before becoming pregnant. Although no such prosecutions have been sought as of this writing, there have been attempts to prosecute pregnant drug users for knowingly transmitting drugs to their children perinatally.⁴⁰ Further, a woman who decides to become pregnant after learning of her HIV status may be characterized as a neglectful or abusive parent because she gives birth to a child who may be HIV-positive.⁴¹ This determination could result in loss of custody. Although it is unlikely that these actions would be successful, the possibility that they might be initiated against women with HIV should not be discounted. Therefore, the privacy interest of the mother should always be considered before unconsented neonatal HIV testing is authorized. (For more on the law of medical confidentiality and informed consent for testing, see chapter 7.)

FAMILY ISSUES

Impact of the Changing Demographics of HIV

Most early HIV-related family law cases involved disputes between parents over child custody or visitation rights when the father was gay.⁴² Much more common these days, however, are disputes between parents and the state. Problems typically arise when the custodial parent—usually a woman—is HIV-positive, and the state questions and impedes her attempt to make temporary or permanent custody arrangements for her children or questions her ability to care for her child, who may also be infected. (Although some HIV-positive fathers are custodial parents, and many of the problems described would apply to them, this section focuses on mothers with HIV who are single parents.)

Much of family law relating to child care operates on the assumption that most children live in two-parent homes. Thus, when one parent is sick or dies, the remaining parent continues to care for and have custody of the children. As a result, both the legal and social systems governing child custody are geared to the problems most commonly faced by financially stable, middle-income, two-parent families. Unfortunately, this is not the environment in which most HIV-positive parents live, and their parenting needs are often not adequately addressed.

The Typical HIV-Positive Parent

According to the statistics, many custodial parents with HIV are women with young dependent children. A New York study of HIV-positive mothers found that they were more likely than HIV-positive fathers to be the custodial parent of children under ten years of age.⁴³ When these women are involved in a steady relationship, their partners are usually also infected and may be dying as well. So some women with HIV are the primary caretakers for adult partners as well as for dependent children.

Unfortunately, most social policies aimed at seropositive women fail to consider the special needs of these caretakers: the policies focus narrowly on preventing pregnancy and fail to provide adequate health care and social services to keep families healthy and together. For example, Medicaid and private insurance reimbursement schemes either do not cover or do not adequately reimburse for home care for HIV-positive mothers or their children. These gaps in critical services undermine the capacity of women with HIV to seek care for themselves, and thus impair their ability to care for their children and adult partners.

Even when infected women have access to health care, their children may still

suffer because existing support services suppose that there are two potential caregivers in the home. For example, a mother with HIV may not be sick enough to require a visiting home health-care attendant for herself but may be too sick to care adequately for a child who also has HIV. No support is provided because of the underlying assumption that a second parent is available to care for the children. When a home health-care attendant is provided, the attendant's job does not include child care, again on the assumption that someone else is available. Thus children of dying mothers may be neglected in the process.

Poor single-parent mothers with HIV face other problems more directly related to their gender and income. For example, health care providers have a tendency to override the traditional right of parents to make decisions regarding their children's care when the parent is poor, female, and HIV-positive. In one Maryland case a mother was reported for medical neglect when she threatened to remove her HIV-infected child from the hospital after a disagreement with the attending physician over treatment. The mother felt that treatment should not proceed because the hospital had not instituted adequate measures to insure that the child's medical records would remain confidential.⁴⁴ Similarly, a mother's refusal to let her child take AZT because of concerns about its toxicity might also be construed as medical neglect. In such circumstances, the health care provider's reluctance to defer to parental authority and readiness to report the mother to a child protection agency might well reflect the fact that the patient is a woman, is poor, is probably Black or Latina, and is most likely a drug user or the sexual partner of one. Given those attributes, the provider might unconsciously assume that the mother is not competent to make health care decisions for her child and might be outraged that she has had the temerity to challenge the provider.

Similarly, medical authorities are often blind to the fact that failure to keep a doctor's appointment may say more about a city's public transportation system than it does about a parent's commitment to her children. Thus, a mother who fails to bring her fifteen-month-old HIV-negative child into the hospital for follow-up testing might be unfairly charged with medical neglect. This overeagerness to seek state intervention when parenting falls below some ideal level that bears little relationship to reality, especially for poor parents, must be reassessed. Too often intervention by the state means removing children from their homes.

Temporary Disability or Death

Ultimately, every custodial mother with HIV will have recurrent instances of hospitalization. In these circumstances she may have to relinquish custody either tem-

porarily or permanently. However, family members who volunteer to care for her dependent children receive little or no financial support for temporary care. If the cooperating family member is on public assistance, extensive documentation is required before Aid to Families with Dependent Children (AFDC) funds can be obtained and the children put on the family member's budget.⁴⁵ In addition, foster care funds usually are not available where the family member is employed, and informal child care arrangements are not effective when the mother is so disabled that she will never be able to care for her dependent children.

Most important, it is often difficult for a seriously ill mother to retain custodial rights when her dependent children must be cared for outside of the home. To avoid loss of custody, some lawyers recommend that HIV-positive mothers use a letter or other written notarized document to grant a power of attorney to a family member, giving that person some authority to care for the children and make necessary decisions for their well-being. In this instance, the power of attorney operates as an informal temporary guardianship. This mechanism is favored by poor single parents because it is much faster than formal guardianship and does not involve going to court. In some states a power of attorney can be used to grant another unrelated person temporary custody.⁴⁶ This device may be useful when the mother is estranged from her family but has family-like contacts with unrelated people.

However, a power of attorney is sometimes not recognized as legally valid by schools, health care providers, or courts, and is thus not fully effective in fulfilling the mother's intentions. Even when legally recognized, a power of attorney will not be effective in permanent or long-term custody situations or in situations where the parent is mentally incapacitated.⁴⁷ A power of attorney is good only for a limited period of time and requires periodic renewal. It is thus inappropriate for an HIV-infected parent who has periodic physical or mental lapses, because it cannot spring into action when the parent is incapacitated and then lapse when the parent is well enough to continue her parenting duties.

To avoid the legal uncertainties of a power of attorney, a mother with HIV might want a temporary or permanent guardian appointed for her children. A guardian stands in the shoes of the parent, is legally responsible for the children's well-being, can receive benefits for the children, and can make medical and other decisions for their benefit. There are, however, some disadvantages to guardianship. For example, in some states the appointment of a guardian means that the parent permanently relinquishes all parental rights and loses all control over fundamental decisions affecting her children. In other states the parent retains some, but not all, parental rights and can make decisions about the children's care with the consent of the guardian. In these states, when the parent and the guardian disagree over

fundamental decisions, there is an element of uncertainty about the extent of the parent's rights.

Even when the parent is willing to relinquish custody temporarily or permanently, the guardianship option may be particularly difficult for a poor HIV-positive mother because she will usually need legal assistance in petitioning the court to appoint a guardian, and the process can take several months. In the meantime, she may be too sick to care for her children and may be forced to make informal, legally ineffective child care arrangements or place her children in foster care.

In situations where family members are willing to care for the children but need financial assistance, some lawyers suggest that the mother voluntarily surrender her children to foster care on a temporary basis and request that they be placed with relatives, in what is commonly called "kinship foster care." This arrangement has certain advantages. Relatives, who otherwise may be financially unable to provide for the children, are given the same monthly allowances as nonrelated foster parents, and the children, emotionally upset about the illness of their custodial parent, remain with family members. However, all foster care homes must be reviewed and approved by the appropriate agency. This process takes time, and in the interim the children, now wards of the state, may remain in state custody or be placed with strangers. Further, while the relatives may want to care for the children, they may be unwilling to undergo the government scrutiny and monitoring of their lives required by the foster care system, and the children may remain with strangers. Perhaps even more important to the mother, surrendering her children to foster care means relinquishing custody.

There are other disadvantages to foster care. The state controls the parent-child relationship and can dictate many things, including the time and frequency of parental visits. As a result, it may be difficult for the HIV-positive parent to regain custody of her children, or even to visit them regularly, once her circumstances have improved. This is especially true when the children are receiving certain benefits such as AFDC, Medicaid, and Social Security Disability.

Once the parent surrenders control of her children, either to the foster care system or to a legal guardian, any benefits the children receive are transferred to the foster parents or guardian, thus reducing the parent's income, often substantially. The parent may not be able to maintain the current home and may lose some of her health care benefits as well. Only through more informal, but less legally effective, child care arrangements can she both retain legal custody and avoid losing public benefits provided for the children. Thus, the legal and social structures often work against the HIV-infected mother who is eager to play a major role in raising her children although she is ill.

There are even more problems when the custodial parent dies. When no guardian has been appointed, the children may be placed with strangers in foster care until they can be adopted. When guardianship proceedings have been initiated before the parent's death, the court may appoint a temporary unrelated guardian to make necessary decisions for the children pending final resolution of the guardianship petition. This shifting of environments can be particularly upsetting for young children who have just lost their mother.

By law, in most states, the surviving noncustodial parent has the right to custody of any children. This parent is preferred over other family members, even when the parent had little or no prior involvement with the children. However, some custodial parents may object to the surviving parent's obtaining custody. In this instance, a terminally ill HIV-positive custodial parent needs to resolve the care issue before she dies, since she may have evidence of the surviving parent's unfitness that might help other family members obtain custody. To do this, the custodial parent must not only arrange for the appointment of a guardian for her children, but must also be prepared, in some states, to initiate action to terminate the soon-to-be surviving parent's rights. The process may take many months, draining the limited energies of the terminally ill parent.

Some of the child care problems created when the parent is temporarily ill could be alleviated if there were sufficient in-home support services so that the child could remain at home and the parent and child could be cared for together. Studies of the cost of in-home (as opposed to hospital) care for HIV-positive people indicate that home care is much cheaper and seems to have a more positive psychological effect on the patients. In addition, both mothers and children benefit when they are kept together.⁴⁸ Considering the most likely alternative—long-term foster care in numerous foster homes—and the likely consequence of such arrangements—severe emotional disturbance—it may be far preferable for dependent children to remain with a sick parent as long as possible.⁴⁹ It may also benefit the mother's health if her children are present and her family is intact. There is anecdotal evidence that maintenance of family structure and continued interaction with family members can prolong the life of terminally ill people.

Some of these concerns led in 1980 to the enactment of the federal Adoption Assistance and Child Welfare Act. Congress wanted to encourage states to adopt reforms that would protect children at home, thus reducing the number of children in foster care, and provide family-focused rehabilitative services in situations where children had been removed from their homes.⁵⁰ Under the Act, state foster care systems that receive federal funds must make "reasonable efforts" to prevent removing children from their homes.⁵¹ Reasonable efforts could include family ad-

vocacy measures such as homemaking services, transportation to and from health care providers, crisis counseling, drug and alcohol abuse counseling where necessary, and provision of temporary child care.

The extent of a state's obligation to affirmatively take preventive steps to avoid removing children from their homes is unclear.⁵² Although the secretary of the Department of Health and Human Services can hold states accountable for failing to take appropriate steps to keep families intact, the rights created by the Act are not enforceable in lawsuits brought by private citizens under federal civil rights law.⁵³ In addition, social workers who wrongfully remove children from their homes are immune from suit.⁵⁴

When Parenting Abilities Are Questioned

Our legal system usually assumes that parents, especially mothers of young children, are the most caring and knowledgeable custodians of their children. In fact, most HIV-positive mothers are not only ready and able to take care of their children, but also go to extraordinary lengths to do so, often neglecting their own health in the process. By contrast, there are some mothers with HIV whose lives are so disorganized—due to illness, drug use, financial problems, and so forth—that they have little interest in caring for their children. Then too, there are women whose lives are in a shambles at the time of their children's birth, leading them to give up custody, who later regain some control and want their children back.

Unfortunately, government agencies seldom draw distinctions between HIV-positive mothers when making child custody decisions. Instead, state-initiated custody disputes often reflect the perception of many decisionmakers that HIV-infected mothers are bad and that their infected children are "innocent victims."⁵⁵ The "bad mother" label attaches in part because the mother's biological responsibility for the child's status is converted into a kind of moral responsibility. (Tellingly, this type of conversion does not usually occur with mothers of infants who have serious genetic defects.)

Black women are especially stigmatized, because the inseparable combination of their race and gender results in their devaluation as mothers.⁵⁶ Economically needy parents are also perceived this way. Thus, when a mother is HIV-positive, Black, and poor, the cumulative biases cannot help but influence how health care and social service workers judge her conduct as a parent. True, when the mother is also a drug user, the "bad mother" label may have more validity, although not invariably. Yet this labeling, whether accurate or not, influences attitudes about the mother and her parenting skills that can result in the wrongful removal of children from her home.

Similarly, mothers with HIV may be more likely to be accused of neglect by social service agencies and to have their children removed by the state. This is especially true for the large number of HIV-infected women identified as drug users. Drug-using mothers may lose custody because their drug status alone is seen as evidence of child neglect. Further, child neglect proceedings are often instituted when neonatal testing discloses illicit drug use by the mother.⁵⁷ The child-neglect label attaches even though the mother may have tried unsuccessfully to enter a drug treatment facility. Yet health and social services workers, when assessing the existence of neglect, may act to punish the mother because she has not obtained treatment for her drug problem.

The absence of drug treatment facilities for female drug users, especially pregnant women, makes rehabilitation exceedingly difficult to pursue. Even when a drug-using woman is not pregnant, few of the treatment programs that admit women allow mothers to reside on the premises with their children.⁵⁸ Thus drug-using mothers who are also HIV-positive have few support mechanisms to help them handle their addiction while keeping their families together; yet government agencies may be quick to sever family bonds and take children from loving parents because of their drug status.

Drug users die faster after HIV diagnosis than non-users, yet it has not been determined whether drug users' infection advances more rapidly to AIDS and death. One possible explanation may be that drug users generally are in poorer health because they do not take good care of themselves and get inadequate nutrition.⁵⁹ Consequently, they may be less able to attend to the basic needs of their children. Unless local social service agencies are pressured to provide support services to keep their families intact, active drug users may be even more likely than other HIV-positive parents to lose custody of their children because of poor health. Social support services, as well as medical care, are necessary components of adequate care for HIV-infected parents.

Whether or not the mother's own poor health justifies removal of her children, physically abusing them and neglecting their medical needs are certainly appropriate grounds for state intervention. However, charges of medical neglect should be viewed with caution since they often reflect the racial, class, and lifestyle assumptions of the person who lodged them. Thus, Black children tend to be significantly over-represented in child abuse and neglect reportings. Further, the parents most often reported for child neglect are young single women who are on public assistance.⁶⁰ Many of the parents and children whose lives are affected by HIV fit these profiles.

Since abuse and neglect charges often stem from the perception that poor and non-White mothers are incapable of being good parents, we should look closely at

what agencies characterize as medical neglect. All too often the neglect charged is simply the parent's inability to provide adequate health care due to lack of transportation, failure to maintain Medicaid benefits or provide proof of eligibility, or the existence of more pressing family problems that need to be addressed. Home-based support services could substantially reduce this alleged neglect. Here again, social service policies are not designed to assist poor HIV-positive mothers in handling their family-related problems and keeping their families intact.

An HIV-infected parent also may be reported for medical neglect for reasons related to, but distinct from, her HIV status. For example, several mothers who gave birth to babies with narcotic toxicity have lost custody of their children on grounds of neglect.⁶¹ Most of these mothers were Black, and many were also HIV-positive. Although one court has concluded that removing newborns with narcotic toxicity from their mothers is an unconstitutional restriction on the integrity of the pregnant woman, most states continue this practice.⁶²

Many child advocates oppose removing children from their homes solely on account of medical neglect, in light of the myriad inadequacies of foster care.⁶³ Whether or not one adopts that position, efforts to remove children based only on allegations of child neglect should be closely scrutinized, especially in light of the state's obligations under the Adoption Assistance and Child Welfare Act. Unfortunately, Black and Latino parents are less likely to receive the support services encouraged by the Act, and their children are therefore overrepresented in foster care.⁶⁴

The State as Substitute Parent

There is a growing number of HIV-positive children whose care has been entrusted to state social services agencies.⁶⁵ It is estimated that in New York City alone, 50,000 to 100,000 children will lose at least one parent to AIDS in this generation, and of this number 20,000 will lose one parent by 1995. Many of these children will become wards of the state. As noted previously, many "chemically dependent HIV-positive women may be unable or unwilling to care for their children" and may make no arrangements for transferring custody.⁶⁶ Since appropriate care settings within the children's extended family may be impossible, the next-best placement is often in foster or small group homes. According to one study, approximately 26 percent of all HIV-infected children who do not live with their parents live in foster care.⁶⁷

HIV Testing and Confidentiality. State social service agencies often face difficult problems when acting as substitute parents. One problem concerns the right of

infected children to confidentiality regarding their HIV status when they are placed in foster care. Two questions often arise in this situation: whether the state agency may test children in foster care for HIV antibodies and whether it may include information about their HIV status in their files.

Some states may attempt testing without parental consent when placing children in foster care. The CDC recommends that agencies routinely screen children thought to be at risk before placing them in foster or adoptive homes.⁶⁸ However, federal regulations suggest that, in the absence of parental consent, a child advocate be appointed before testing occurs.⁶⁹ The argument in favor of testing is that infected children should be identified so that they can receive appropriate medical care, including access to AZT and experimental treatment protocols. This argument is stronger today, since HIV-positive children are no longer denied access to experimental drugs. However, "the treatment arsenal is meager."⁷⁰ At least one commentator appropriately suggests that testing should occur only if "uncertainty concerning [the] child's HIV status is hampering foster placement and if it is clearly demonstrable that testing will be beneficial to the child, even if the child is seropositive."⁷¹

Many public agencies do not follow the CDC guidelines, some fearing that disclosure of a child's HIV status will jeopardize foster care placements. On the other hand, some child advocates argue that prospective foster or adoptive parents have a right to know that a child in their care is infected. These advocates also argue that agencies need this information to assess the fitness of parents to handle HIV-positive children and determine eligibility for special financial subsidies.⁷²

The right to know may be more important for prospective adoptive parents. Otherwise, adoptive parents may attempt to return HIV-infected children to the state, claiming that they were misled or not fully informed at the time of adoption. Some states already allow abrogation of adoptions, despite opposition by many courts and the drafters of the Uniform Adoption Act.⁷³

However, there are several arguments against disclosure under these circumstances. First, reporting children's HIV status almost inevitably discloses the parents' status or at least the mother's, if she is still living. Once more there is the question of who should balance the competing interests here, and how they should be balanced. It may be difficult for the mother to decide whether her interest or her children's is paramount, and the law provides little guidance in this area. Second, departments of social services may not be able to maintain adequate confidentiality and deal appropriately with this information. The very difficult question is whether the benefits of disclosing children's antibody status outweigh the detriments. Given the continued public hysteria toward people with HIV, it may be best for infected

children to be adopted by people who are fully aware of their status. This reasoning may not apply to foster parents, however, since placement is temporary and the virus is not transmitted through casual contact. Even then, disclosure may be warranted where there is some showing of a clear danger to the foster parents or their immediate family; where special monthly allowances are given to foster parents of HIV-positive children; or where the foster children are eligible for special medical benefits because of their HIV status. (For a detailed discussion of privacy law, see chapter 7.)

Treatment. The state has an affirmative obligation to insure the safety and general welfare of children in its custody.⁷⁴ Children in foster care also have a right to treatment or medical care.⁷⁵ In fact, federal law provides children with a private right of action against state foster care agencies for failure to provide adequate health care⁷⁶ or adequate services. Of course, having a right does not always ensure that it will be respected, and better monitoring of state foster care agencies is needed.

When HIV-infected children are in foster care, serious medical treatment issues may arise, such as whether they should be given AZT. Since infants and young children are not legally competent to consent to medical treatment, in the absence of parental involvement the state must petition the court for authority to consent to even routine medical treatment.⁷⁷

Much HIV treatment, especially for infants and young children, is experimental, and special procedures are warranted. Clinical drug trials are now more widely available to children, but some children in foster care may be denied access to these opportunities. For example, some states refuse to allow children in foster care to participate in AZT protocols when there is no active parental involvement, because they do not want to be responsible for giving consent. Other states may claim that some AIDS-related protocols, because they are experimental, do not constitute medical treatment, and may deny access on that basis. In New Jersey, a local child-protection agency refused on those grounds to let infants under its care participate in then-experimental AZT treatment clinical trials.⁷⁸ States may also refuse to let HIV-positive children in their custody enroll in clinical drug trials using a placebo control,⁷⁹ but there are stronger arguments for this position since the children receiving the placebo obtain no possible benefit from their participation. In some instances court-appointed special advocates will review and monitor special treatment for the children,⁸⁰ but to date there is no uniform policy for handling treatment issues.

At present, seven states have policies specifying the conditions under which the state may consent to experimental treatment for children in foster care.⁸¹ Four

states do not allow foster children to enroll in clinical trials without parental consent, the consent of some designated committee, or a court order if the natural parent is unavailable.⁸² Other states have created central boards that review treatment protocols and make decisions on a case-by-case basis.⁸³ Although approximately 26 percent of HIV-positive children are in foster care, a 1989 study found that only 16 percent of children participating in NIH-funded clinical trials were in foster care. The researchers speculated that many other children in foster care are denied access because proper consent cannot be obtained.⁸⁴

When parental rights have not been terminated, it is often difficult to determine who has the authority to consent to experimental treatment of children in foster care. It also is important to remember that children's health may not necessarily require that they participate in research, and their use in experimental HIV clinical trials is still controversial. In addition, because a disproportionate number of infected children are Black and Latino, there are potential racial overtones to either decision, allowing or denying participation.

It is difficult to adopt a single approach to the participation of children in foster care in clinical trials. Admission to these trials may be the only means by which they can obtain free medical care. Therefore, no children who can benefit from experimental treatment should be denied access simply because they are in foster care. Nevertheless, no children in foster care should be enrolled in an experimental treatment protocol without the informed consent of their biological parents. When the biological parent is unavailable, there must be some review and monitoring of the treatment protocols, coupled with a determination that the child can benefit from participation. This determination should be made by either a neutral multidisciplinary committee (which includes an ethicist, pediatrician, social worker, and community member or parent of an HIV-infected child), or a court of law.

These precautions may not be sufficient to prevent abuse of HIV-positive children in clinical trials. Meaningful constraints on human experimentation by medical researchers are fairly recent, and they were influenced by the history of abuses directed at various groups including people of color, poor people, and children. There are sound reasons for excluding children from some clinical trials, and when the children most likely to be participating are members of economic, racial, or ethnic groups who historically have been exploited by medical researchers, there is even more reason for concern.

Increased participation of children in clinical trials, justified by the fact that participation may be the only way these children can receive medical care, is a harsh indictment of the United States' health care system. It is hoped that public outrage at these shortcomings will stimulate action to restructure the entire health

care system or, at the very least, make health care more readily available for women and children.

CONCLUSION

The AIDS pandemic could provide the United States with the opportunity to seriously reassess both its health care and its social support systems for families, especially poor women, women of color, and their children. Since any strategy directed toward HIV-positive women carries with it the legacies of sexism and racism in medicine coupled with class biases, models must be developed for planning effective health care strategies that take all of these factors into account. We must be more willing to draw distinctions between individuals, rather than allowing our biases about the parenting abilities of poor HIV-infected mothers to control our decisions about their children.

It is also important that our legal and social services systems be able to provide for hospital "boarder babies" and children who are abandoned; to attend to the needs of dysfunctional mothers and give them a second chance once their lives are stabilized; to acknowledge and support mothers and other family members or close friends who are eager to serve as full-time caregivers; and to make allowances for, and provide support to ease, any temporary periods when HIV-positive mothers are disabled. Our health care policies for women and their children will remain ineffective so long as race, sex, and class biases influence who gets care and the quality of that care.

NOTES

1 *Update: Acquired Immunodeficiency Syndrome—United States, 1981–1990*, 265 J.A.M.A. 3226, 3226 (1991). In 1981 women made up only 3 percent of the total cases reported to the CDC. Weissman, *Working with Pregnant Women at High Risk for HIV Infection: Outreach and Intervention*, 67 Bull. N.Y. Acad. Med. 291, 292 (1991). Today, AIDS is fifth in the leading causes of death among women of childbearing age. Gayle, Selik & Chu, *Surveillance for AIDS & HIV Infection among Black & Hispanic*

Women of Childbearing Age, 1981–1989, 39 MMWR 23, 24 (1990).

2 *Update: Acquired Immunodeficiency Syndrome—United States, 1981–1990*, note 1 above at 3226; Gayle, Selik & Chu, note 1 at 24.

3 Zylke, *Another Consequence of Uncontrolled Spread of HIV among Adults: Vertical Transmission*, 265 J.A.M.A. 1798, 1798 (1991).

4 *HIV Prevalence Estimates and AIDS Case Projections for the United States*, 39 13

(1990); Zylke, note 3 above at 1798 (1,800 to 2,000).

5 Pizzo & Butler, *In the Vertical Transmission of HIV, Timing May Be Everything*, 325 *New Eng. J. Med.* 652, (1991) (noting maternal-fetal transmission average of about 25 to 30 percent).

6 As Antonia C. Novello, the Surgeon General of the United States, said recently: "The issue of infected women and AIDS is much broader than the actual numbers of infected women. It goes to the heart of how we as women are going to live our lives. Too many women take care of their families and not themselves. We must do both." Novello, *Women and HIV Infection*, 265 *J.A.M.A.* 1805, 1805 (1991).

7 Amaro, *Women's Reproductive Rights in the Age of AIDS: New Threats to Informed Choice*, 5 *The Genetic Resource* 39, 40 (1990); accord Weissman, note 1 above, at 293.

8 See Anastos & Marte, *Women—Missing Persons in the AIDS Epidemic* in *The AIDS Reader: Social, Political, Ethical Issues* 190 (N. McKenzie ed. 1991). A recent study by Georgetown University Hospital found that 75 percent of urban women had T-cell counts under 500 at the time they discovered their seropositive status. Pfeiffer, *Highlights from the National Conference on Women and HIV Infection, Part One: Early Care and Policy Issues*, 5 *AIDS Patient Care* 67, 68 (1991); see also White, *Highlights from the National Conference on Women and HIV Infection, Part Two: Case Definition and Clinical Trials*, 5 *AIDS Patient Care* 70, 72 (1991) (women are sicker at the time of diagnosis and die sooner after diagnosis than men).

9 Gwinn, *et al.*, *Prevalence of HIV Infection in Childbearing Women in the United States*, 265 *J.A.M.A.* 1704, (1991); CDC, *Characteristics of and HIV Infection among Women Served by Publicly Funded HIV Counseling and Testing Services—United States, 1989–1990*, 265 *J.A.M.A.* 2051 (1991). Black and Latino women also comprise a disproportion-

ate percentage of the women who die from AIDS. CDC, *AIDS in Women—United States*, 265 *J.A.M.A.* 23, 23 (1991) (Black and Hispanic women, only 19 percent of all U.S. women, comprise 72 percent of all U.S. women diagnosed with AIDS).

I capitalize "Black" because I use the term as proper noun to refer to a specific cultural group rather than merely skin color. I use "Latina" rather than "Hispanic" to emphasize that most of the Hispanic HIV-positive women are from the Americas. When referring to both groups of women and other non-White women in America (Asians and Native Americans), I use the term "women of color." The term "people of color" refers to the collective non-White communities in America.

10 House Committee On Government Operations, 101st Cong. 2d Sess., *AIDS Treatment and Care: Who Cares?* 36–41 (1990) (noting the disproportionate impact of AIDS on poor residents of the larger urban inner cities).

11 Gwinn, *et al.*, note 9 above at 1706; CDC *Characteristics of and HIV Infection among Women Served by Publicly Funded HIV Counseling and Testing Services*, note 9 above, at 2051.

12 See, e.g., Nsiah-Jefferson, *Reproductive Laws, Women of Color, and Low-Income Women*, 11 *Women's Rts. L. Rep.* 15, 20–23, 30–32 (1989); Asaro, *The Judicial Portrayal of the Physician in Abortion and Sterilization Decisions: The Use and Abuse of Medical Discretion*, 6 *Harv. Women's L. J.* 51, 93–101 (1983); Grosboll, *Sterilization Abuse: Current State of the Law and Remedies for Abuse*, 10 *Golden Gate L. Rev.* 1147, 1153–56 (1980).

13 See Minkoff, *Care of Pregnant Women Infected with Human Immunodeficiency Virus*, 258 *J.A.M.A.* 2714, 2714 (1987). The CDC is currently revising this guideline.

14 Hilts, *Many Hospitals Found to Ignore Rights of Patients in AIDS Testing*, *N.Y. Times*, Feb. 17, 1990, at A1; see also Henry, Willenbring & Crossley, *Human Immunodeficiency*

ciency Virus: Analysis of the Use of HIV Antibody Testing, 295 J.A.M.A. 1819, 1820 (1988) (34 percent of 183 United States hospitals that conduct infectious disease training and 57 percent of 103 Minnesota hospitals rarely obtained patient consent to HIV antibody tests).

15 Hilts, note 14 above.

16 See, e.g., *Doe v. Jamaica Hospital*, N.Y. L. J., May 16, 1991 at 21; Angell, *AIDS Babies Remain a Puzzle*, Gannet News Service, May 21, 1991 (LEXIS) ("The prevalent recommendation is that [HIV] infected women should consider postponing pregnancy and should have an abortion if they do become pregnant."); Flannery, *Whose Rights Come First—Victim or Her Endangered Baby?*, Chicago Tribune, Nov. 18, 1990, at C3 (HIV-infected women are told to be sterilized).

17 Mays & Cochran, *Issues in the Perception of AIDS Risk and Risk Reduction Activities by Black and Hispanic/Latina Women*, 43 Am. Psychologist 949, 953 (1988).

18 For a more detailed discussion of these issues, see Banks, *Women and AIDS—Racism, Sexism, and Classism*, 17 Rev. L. & Soc. Change 351 (1989–1990).

19 Angell, *A Dual Approach to the AIDS Epidemic*, 324 New Eng. J. Med. 1498, 1499 (1991); see Zylke, note 3 above, at 1798. Two states appear to require prenatal HIV tests: Del. Code Ann. Rev. tit. 16, § 708 (1988); Tenn. Code Ann. §§ 68–5–102, 68–5–602 (1987). Florida requires prenatal screening for all sexually transmitted diseases, including HIV. 14A Fla. Stat. Ann. §§ 384.31, 384.23(3) (defining sexually transmissible disease). However, it is reported that Florida is applying the HIV prenatal screening requirement only to "high-risk" women. I AIDS: A Public Health Challenge 2–28 (M. Rowe & C. Ryan eds. 1987).

20 Minkoff, note 13 above, at 2714–15.

21 Compare Allen & Curran, *Prevention of AIDS and HIV Infections: Needs and Priorities for Epidemiologic Research*, 78 Am J.

Pub. Health 381, 383 (1988) with Minkoff & DeHovitz, *Care of Women Infected With the Human Immunodeficiency Virus*, 266 J.A.M.A. 2253, 2256 (1991).

22 Minkoff & DeHovitz, note 21 above, at 2257.

23 Pizzo & Butler, note 5 above, at 652.

24 Zylke, note 3 above, at 1798.

25 The protocol was subsequently modified so that HIV-positive mothers would continue receiving AZT after their child's birth. But even under the modified protocol, the trial is focused on preventing transmission to the fetus, and the mother is viewed simply as the vector who is, at best, a secondary beneficiary.

26 Kolder, Gallagher & Parsons, *Court-Ordered Obstetrical Interventions*, 316 New Eng. J. Med. 1192 (1987); see Gallagher, *Prenatal Invasions & Interventions: What's Wrong with Fetal Rights*, 10 Harv. Women's L. J. 9, 48 n.203 (1987).

27 See, e.g., Goldberg, *Medical Choices during Pregnancy: Whose Decision Is It Anyway*, 41 Rutgers L. Rev. 591 (1989); Johnsen, *From Driving to Drugs: Government Regulation of Pregnant Women's Lives After Webster*, 138 U. Pa. L. Rev. 179 (1989); Johnsen, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy, and Equal Protection*, 95 Yale L. J. 599 (1986); Lichtenberg, *Gestational Substance Abuse: A Call for a Thoughtful Legislative Response*, 65 Wash. L. Rev. 377 (1990).

28 See, e.g., Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982 & Supp. V 1987); Civil Rights Restoration Act of 1987, Pub. L. No. 100–259, 102 Stat. 31 (codified at 29 U.S.C. § 706 (Supp. V. 1987); Americans with Disabilities Act of 1990, Pub. L. 101–336, 104 Stat. 327 (1990); see also, N.Y. Exec. Law, §§ 291 *et seq.* (McKinney 1992).

29 But see *Rust v. Sullivan*, 111 S. Ct. 1759 (1991) (prohibition of abortion counseling by

recipients of federal family planning funds does not violate the Constitution).

30 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Screening and Counseling For Genetic Conditions: A Report on the Ethical, Social and Legal Implications of Genetic Screening, Counseling and Education Programs* 47-52 (1983).

31 Selwyn, *et al.*, *Knowledge of HIV Antibody Status and Decisions to Continue or Terminate Pregnancy among Intravenous Drug Users*, 261 J.A.M.A. 3567, 3568 (1989).

32 Twenty-nine states have legislated the equivalent of the Hyde Amendment and restrict Medicaid funds to women in life-threatening situations. Ten states pay for abortion in which rape and incest are involved; twelve states, including Washington, New York, and California, still fund all abortions. Carlson, *Abortion's Hardest Cases*, Time. July 9, 1990, at 22.

33 Donovan, *AIDS and Family Planning Clinics: Confronting the Crisis*, 19 Fam. Plan. Persp. 111, 113 (1987). A more recent study of abortion clinics in New York City found that two-thirds refuse to treat HIV-positive women. Zarembka & Franke, *Women in the AIDS Epidemic: A Portrait of Unmet Needs*, 9 St. Louis U. Pub. L. Rev. 519, 525 (1990).

34 See Elias & Annas, *Reproductive Genetics and the Law* 43, 243 (1987).

35 *Health Data Show Wide Gap between Whites & Blacks*, N.Y. Times, Mar. 23, 1990, at A17. In addition, the number of pregnant women who received either no prenatal care or care late in their pregnancy increased dramatically. *Infant Deaths*, Wash. Post, Mar. 13, 1990, at A24 (editorial); Council on Ethical & Judicial Affairs, Am. Med. Ass'n, *Black-White Disparities in Health Care*, 263 J.A.M.A. 2344 (1990) (noting persistent and often substantial differences in health between Blacks and Whites

and citing obstetrics as one of the areas studied). For a discussion of the general lack of access to health care for Blacks and Latinos, see Blendon, Aiken, Freeman & Corey, *Access to Medical Care for Black and White Americans: A Matter of Continuing Concern*, 261 J.A.M.A. 278 (1989); Munoz, *Care for the Hispanic Poor: A Growing Segment of American Society*, 260 J.A.M.A. 2711 (1988).

36 See, e.g., Working Group on HIV Testing of Pregnant Women and Newborns, *HIV Infection, Pregnant Women, and Newborns*, 264 J.A.M.A. 2416 (1990) (setting out a ten-point program for pregnant women and newborns).

37 For a more detailed discussion of this point, see Nolan, *Ethical Issues in Caring for Pregnant Women and Newborns at Risk for Human Immunodeficiency Virus Infection*, 13 Seminars in Perinatology 55, 56-57 (1989).

38 Levine & Bayer, *The Ethics of Screening for Early Intervention in HIV Disease*, 79 Am. J. Pub. Health 1661, 1662 (1989).

39 Connor, *Advances in Early Diagnosis of Perinatal HIV Infection*, 266 J.A.M.A. 3474, 3475 (1991); Quinn, *Early Diagnosis of Perinatal HIV Infection by Detection of Viral-Specific IgA Antibodies*, 266 J.A.M.A. 3439 (1991); Lindsman, *Clinical Utility of HIV-IgA Immunoblot Assay in the Early Diagnosis of Perinatal HIV Infection*, 266 J.A.M.A. 3443 (1991).

40 In *State v. Johnson*, No. 89-890-CFA (Fla. Cir. Ct. 1989) a woman was criminally prosecuted for delivering drugs to her newborn through the umbilical cord moments after birth.

41 In *re Baby X*, 293 N.W.2d 736 (Mich. App. 1980), a state court allowed evidence of a mother's drug use during pregnancy to be used a proof of neglect or abuse in a state-initiated proceeding to deprive the woman of her newborn child.

42 *Stewart v. Stewart*, 521 N.E.2d 956 (Ind. App. 1988); *Doe v. Roe*, 139 Misc. 2d 209

(N.Y. Sup. Ct. 1988); *In re Marriage of Lena Roe v. Leslie Roe*, Chicago Daily L. Bull., May 16, 1988, at 3 (Cir. Ct. Ill.); *Jane W. v. John W.*, 519 N.Y.S.2d 603 (Sup. Ct. 1987); *In re Marriage of Grein*, 491 N.E.2d 1382 (Ill. App. 1984). See generally, Note, *Public Hysteria, Private Conflict: Child Custody and Visitation Disputes Involving an HIV Infected Parent*, 63 N.Y.U. L. Rev. 1092 (1988).

43 Drucker, *Drug Users with AIDS in the City of New York: A Study of Dependent Children, Housing, and Drug Addiction Treatment* in *The AIDS Reader: Social, Political, Ethical Issues*, note 8 above, at 147.

44 V. B. v. Department of Social Services (on file at Maryland AIDS Law Clinic).

45 Drucker, note 43 above, at 154.

46 See, e.g., Mo. Rev. Stat. § 475.024 (1986); *In re Marriage of Criqui*, 798 P.2d 69 (Kan. Ct. App. 1990).

47 For a discussion of the inadequacy of law in this area, see Zarembka & Franke, note 33 above, at 539-41.

48 See Greene, *D.C. Children in Crisis, New Report Declares*, Wash. Post, Sept. 1, 1991, at A1, (citing \$3,000 annual cost per child of intensive family preservation programs compared to \$10,000 annual cost per child for foster care). For an example of a support program geared to HIV-infected women, see Rierden, *Yale Center Helps Families Learn to Live with AIDS*, N.Y. Times, Sept. 29, 1991, § 12CN, at 1.

49 More than half of children in foster care remain in that status for six years or more, and long-term foster care often results in severe emotional and behavioral problems. Besharov, *The Misuse of Foster Care: When the Desire to Help Children Outruns the Ability to Improve Parental Functioning*, 22 Family L. Q. 213, 220 (1986).

50 D. Duquette, *Advocating for the Child in Protection Proceedings* 95 (1990).

51 42 U.S.C. §§ 620, 671(a)(15) (1988). Recently the Foster Care Review Board in

Maryland issued a report recommending increased expenditures for its model Intensive Family Services program which is designed to prevent foster care placements. The Board concluded that early preventive action with troubled families not only reduces the number of children placed in foster care, but also reduces costs to the extent of \$30,000 for every child not placed into foster care. Maryland Department of Human Resources, Foster Care Review Board, 1990 Annual Report 5-7 (1991).

52 See *Grant v. Cuomo*, 509 N.Y.S.2d 685 (N.Y. Sup. Ct. 1986), modified, 518 N.Y.S.2d 105 (App. Div. 1987). For example, a recent study by the Children's Legal Defense Fund found that virtually nothing was spent on intensive family preservation programs in the District of Columbia, and as a result, the number of children (overwhelmingly Black) in foster care is almost twice the national average. Greene, note 48 above, at A8.

53 See *Suter v. Artist M.*, 112 S.Ct. 1360 (1992).

54 See e.g., *Vosburg v. Department of Social Services*, 884 F.2d 133 (4th Cir. 1989); *Jenkins v. County of Orange*, 260 Cal. Rptr. 645 (Cal. Ct. App. 1989); *Myers v. Contra Costa County Department of Social Services*, 812 F.2d 1154 (9th Cir.), cert. denied, 484 U.S. 829 (1984); *Kurzawa v. Miller*, 732 F.2d 1456 (6th Cir. 1984).

55 Weissman, note 1 above at 293; see also Henderson, *Care: What's in It for Her?* in *AIDS: Responses, Interventions and Care* 266 (P. Aggleton, G. Hart & P. Davies eds. 1991) (study of women in Britain, Ireland and Italy).

56 For a discussion of this point in the context of drug-addicted Black mothers, see Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy*, 104 Harv. L. Rev. 1419, 1423-4, 1436-1444 (1991).

57 *Id.*

- 58 *Id.* at 1448.
- 59 Karan, *AIDS Prevention and Chemical Dependence Treatment Needs of Women and Their Children*, 21 *J. Psychoactive Drugs* 395, 396 (1989).
- 60 Hogan & Sui, *Minority Children and the Child Welfare System: An Historical Perspective*, 33 *Social Work* 493 (1988).
- 61 See, e.g., *In re Danielle Smith*, 128 Misc.2d 976 (Fam. Ct. N.Y. 1985); *In re Gloria C. & William C.*, 124 Misc.2d 313 (Fam. Ct. N.Y. 1984). Recently a New York State appeals court upheld a New York City policy of seeking neglect hearings whenever a hospital informs it that a child has been born with cocaine in her/his system. Three-fourths of the newborns reported are taken from their mothers and one-half enter foster homes. Baquet, *Hearings on Neglect Upheld in Newborn Cocaine Cases*, *N. Y. Times*, May 30, 1990, at B3.
- 62 *In re Sharon Fletcher & Lisa Flynn*, 141 Misc.2d 333 (Fam. Ct. N.Y. 1988).
- 63 Black children are more likely to be in foster homes and stay in those homes, longer than White children. They are also less likely to be adopted if their parents die or parental rights are terminated. Jenkins, *et al.*, *Ethnic Differences in Foster Care Placements*, 19 *Social Work Research & Abstracts* 41 (1983). A recent American Civil Liberties Union (ACLU) study of the foster care system in Washington, D.C., found numerous violations of regulations adopted under the Federal Adoption Assistance and Child Welfare Act of 1980. Similar violations were found in seven of the twenty-three state foster care systems studies. Barden, *A.C.L.U. Says Violations Pervading Foster Care System in Capital*, *N.Y. Times*, Oct. 28, 1990, at A22. Subsequently, the ACLU filed suit in New York City, the District of Columbia, Philadelphia, Kansas City, Missouri, and against the states of Connecticut, Kansas, Louisiana, New Mexico, and Pennsylvania, challenging the adequacy of existing foster care systems. In December 1990 Connecticut settled its suit by agreeing to have an outside panel direct its child welfare system. In April 1991 a federal district judge ruled that the District of Columbia's foster care system violated the constitutional rights of children in the system and violated federal laws by not regularly reviewing foster care placements. Barden, *Washington Cedes Control of Foster Care System to Private Agency*, *N.Y. Times*, July 14, 1991 at A11.
- 64 Hogan & Sui, note 60 above, at 493.
- 65 For example, Dr. James Oleske, who works with HIV infected children at Children's Hospital in Newark, New Jersey, reported that approximately 40 percent of his patients are wards of child protective services departments. Staff of the Select Committee On Children, Youth, And Families, 100th Cong., 2d sess., *Continuing Jeopardy: Children and AIDS*, 7 (1988).
- 66 Lambert, *AIDS Abandoning Growing Generation of Needy Orphans*, *N.Y. Times*, July 17, 1989, at A1. (citing M. Boland, *Management of the Child With HIV Infection: Implications for Service Delivery*, Report of the Surgeon General's Workshop on Children with HIV Infection and their Families (1987)); Shaw & Paleo, *Women and AIDS*, in *What to Do about AIDS* (L. McKusick ed. 1986).
- 67 Weimer, *Beyond Parens Patriae: Assuring Timely, Informed, Compassionate Decision Making for HIV-Positive Children in Foster Care*, 46 *U. Miami L. Rev.* 379 (1991).
- 68 *Education and Foster Care of Children Infected with Human T-Lymphotropic Virus—Type III—Lymphadenopathy Associated Virus*, 34 *MMWR* 517 (1985).
- 69 *Research Involving Greater than Minimal Risk and No Prospect of Direct Benefit to Individual Subjects, but Likely to Yield General Knowledge about the Subject; Disorder of Condition* 45 C.F.R. §§ 46.406-.409 (1989).
- 70 Hankins, *Issues Involving Women, Children, and AIDS Primarily in the Developed World*, 3 *J. AIDS* 443, 446 (1990).

- 71 Field, *Testing for AIDS: Uses and Abuses*, 16 Am. J. L. & Med. 33, 100 (1990).
- 72 The Abandoned Infants Act of 1988, 42 U.S.C. § 670 (1988), provides funds for demonstration grants for the care of HIV-infected infants in foster families, as well as their own families; *see also* the Federal Adoption Assistance & Child Welfare Act, 42 U.S.C. §§ 602–628 (1988).
- 73 Uniform Adoption Act, § 15 9 U.L.A. 11, 477 (1979); *see, e.g.*, Cal. Civil Code § 227b (1982); *Allen v. Allen*, 330 P.2d 151 (Or. 1958). *See generally* Annot., *Annulment or Vacation of Adoption Decree by Adopting Parent or Natural Parent Consenting to Adoption*, 2 A.L.R.2d 887 (1948); Annot. *Action for Wrongful Adoption Based on Misrepresentation of Child's Mental or Physical Condition or Parentage and Uniform Adoption Act*, 56 A.L.R.4th 375 (1987).
- 74 *See Escamilla v. City of Santa Ana*, 796 F.2d 266, 269–70 (9th Cir. 1986) (state has an affirmative duty to protect when there is a custodial relationship with an individual); *Taylor ex rel. Walker v. Ledbetter*, 818 F.2d 791, 797–98 (11th Cir. 1987) (1983 action will lie where foster child was beaten in home due to special relation between child and the state); *L. J. ex rel. Darr v. Massinga*, 838 F.2d 118, 122 (4th Cir. 1988) (civil rights action permitted for physical and medical abuse in foster home because of state's special relation to foster child), *cert denied*, 488 U.S. 1018 (1989).
- 75 *Doe v. N.Y. City Department of Social Services*, 709 F.2d 782 (2nd Cir. 1983); *Lynch v. Dukakis*, 719 F.2d 504 (1st Cir. 1983).
- 76 *Massinga*, 838 F.2d 118; *G. L. v. Zumwalt*, 564 F. Supp. 1030 (W.D. Mo. 1983); *Lynch v. King*, 550 F. Supp. 325 (D. Mass. 1982), *aff'd sub nom*, *Lynch v. Dukakis*, 719 F.2d 504 (1st Cir. 1983).
- 77 Martin & Sacks, *Do HIV-Infected Children in Foster Care Have Access to Clinical Trials of New Treatments?* 5 AIDS & Pub. Pol'y J., Winter 1990, at 3 (citing four methods of obtaining consent, including parental consent and court order).
- 78 Staff of the Select Committee on Children, Youth and Families, note 65 above, at 8 (testimony of Dr. Oleske about the Division of Youth and Family Services in New Jersey). This policy is currently under review and is expected to change shortly. Martin & Sacks, note 77 above, at 3.
- 79 Prentice, *et al.*, *Can Children Be Enrolled in a Placebo Controlled Randomized Clinical Trial of Synthetic Growth Hormone?* IRB: A Review of Human Subject Research, Jan.-Feb. 1989 at 6.
- 80 45 C.F.R. § 46.409.
- 81 Martin & Sacks, note 77 above, at 3 (Connecticut, Georgia, Illinois, Massachusetts, New Jersey, Texas & Wyoming).
- 82 *Id.* (Illinois, New York, Pennsylvania & Wyoming).
- 83 *Id.* (New York City, Georgia & Massachusetts). Although Martin & Sacks include Maryland among the states that grants foster parents a medical guardianship which enables them to consent for the child, lawyers in that state question this interpretation of the law. *Id.* (citing Md. Est. & Trust Code Ann. 13–708(b)(8) (1990)).
- 84 Martin & Sacks, note 77 above, at 4.