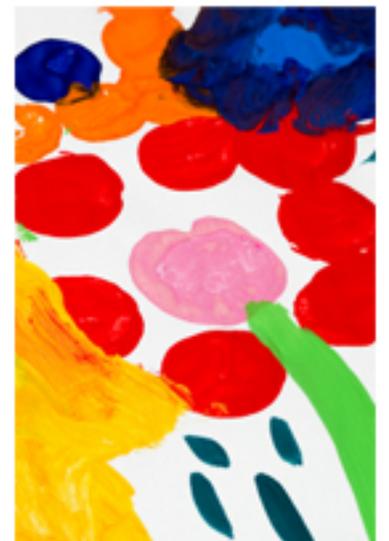
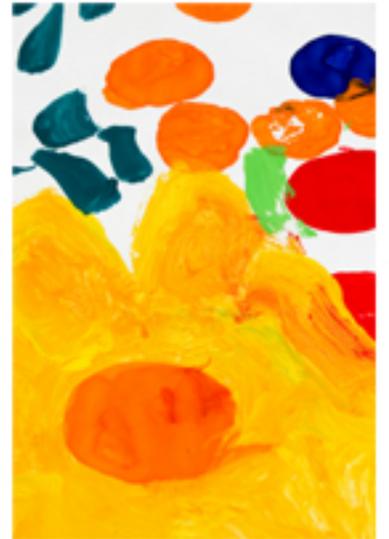


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HIV TESTING: Pregnant Women and Newborns



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HIV Law Project believes that all people deserve the same rights, including the right to live with dignity and respect, the right to be treated as equal members of society, and the right to have their basic human needs fulfilled.

These fundamental rights are elusive for many people living with HIV/AIDS. Through innovative legal services and advocacy programs, HIV Law Project fights for the rights of the most underserved people living with HIV/AIDS.



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I. Overview

HIV testing is public policy territory over which public health advocates and privacy rights advocates have often disagreed. The principles involved are put into sharp relief in the context of HIV testing of pregnant women and newborn babies, where the rights of a pregnant woman and the rights of a mother are also implicated. Nonetheless, advocates on both sides of the debate share common goals: decreasing rates of HIV, increasing numbers of people who know their HIV status, and, more specifically, decreasing rates of mother-to-child transmission (MTCT).

Perinatal HIV transmission is at an all-time low. States now have an opportunity to commit to positive health outcomes for mothers and children while respecting basic principles of consent for HIV testing by expanding comprehensive women's health care, universally counseling pregnant women about HIV, and encouraging all women to be tested.

At the heart of any consideration of HIV testing of pregnant women and newborns are the clear interests in detecting HIV during pregnancy and preventing mother-to-child transmission. Increasing testing rates will allow more women to learn their status. In turn, those who test positive will have the opportunity to focus their health care appropriately. The strategy for preventing mother-to-child transmission, however, cannot focus solely on testing and treatment of pregnant women and newborns.

As defined by the World Health Organization, and agreed upon by the United Nations, the MTCT prevention strategy has four elements:

- Prevention of HIV infection among young people and pregnant women;
- Prevention of unintended pregnancies among HIV-positive women;
- Prevention of HIV transmission from HIV-positive women to their infants;
- Provision of treatment, care and support to HIV-infected women and their families.

A narrow focus on testing and treatment in the context of the third prong ignores the full spectrum of women's health care needs, and privileges the health and the rights of the infant over the mother.¹

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II. What We Know: Medical Background

Infants born to an HIV-positive mother carry their mother's antibodies and will always test positive for HIV antibodies at birth. However, those infants have a 75 percent chance of sero-converting and testing HIV-negative by approximately eighteen months of age.² In other words, with no medical intervention the transmission rate of HIV from mother-to-child is approximately 25 percent. The results of a newborn's HIV antibody test therefore reflect the mother's HIV status more accurately than the baby's.

Medical treatment during pregnancy, labor, and immediately after birth has been shown to dramatically decrease MTCT. In 1994, the National Institutes of Health (NIH) sponsored Pediatric AIDS Clinic Trials Group Protocol 076 (PACTG076), which demonstrated that perinatal HIV transmission rates were reduced by two-thirds (from approximately 22 percent to approximately 8 percent) with the use of antiretroviral therapy in a three-part regime during the antenatal, intrapartum and newborn periods.³ Transmission rates are reduced to 2 percent as a result of antiretroviral treatment in combination with the use of elective cesarean delivery when appropriate.⁴ Largely as a result of this medical protocol, the number of perinatal AIDS cases in the U.S. dropped 67 percent from 1992 to 1997.⁵

Medical intervention is still possible in those cases where the newborn's exposure to HIV is first detected after birth (i.e., where the mother's status was not known during pregnancy or delivery), but with reduced rates of success. When treatment was begun within the first 48 hours of life, the transmission rate was approximately 9 percent, and when begun on day 3 of life or later, the transmission rate was approximately 18 percent.⁶

III. Legislative Schemas

With the knowledge that medical intervention during and immediately after pregnancy can affect the health outcomes of newborns, numerous states, medical agencies, and associations have adopted policies aimed at increasing the number of women and babies tested for HIV. Three schemas: opt-in, opt-out, and mandatory newborn testing, differently reconcile the balance between public health concerns and the privacy and liberty concerns at stake.

In 2006 the CDC recommended opt-out testing of all pregnant women⁷, and numerous states have adopted this approach.⁸ In opt-out jurisdictions, medical providers perform an HIV test after notifying the patient that the test will be performed and that the patient may elect to decline or defer testing. The patient's consent to the test is inferred unless the patient explicitly declines testing. Other states have adopted an opt-in approach in which patients are offered an HIV test, provided with HIV counseling before the test, and must consent to the test either orally or in writing. Further, ten states currently have legislated some form of mandatory newborn HIV testing.⁹ In these states, every newborn whose mother's HIV status is unknown at the time of delivery is tested for HIV. This approach attempts to identify, presumably for purposes of treatment, any infant whose exposure to HIV was not known or learned during pregnancy.

IV. Claims of Success in Opt-Out Testing Are Misleading

In 2002, the CDC published a report touting the increased rates of HIV testing of pregnant women in U.S. and Canadian jurisdictions that required opt-out testing during pregnancy, as well as (oddly) those jurisdictions with mandatory newborn testing.¹⁰ In tune with this data, state public health departments and the media have looked to opt-out testing of pregnant women and mandatory newborn testing as sure steps on the path to eradicating mother-to-child transmission. Yet, a closer examination reveals that these mandated testing regimes are not the reason for the gains in testing rates.

The CDC report itself acknowledges that the "increases in prenatal HIV-testing rates... were

probably associated with a greater likelihood that (women) were offered HIV testing during prenatal care."¹¹ In fact, the vast majority of pregnant women who are offered an HIV test accept testing. One study found that when offered an HIV test, more than 86 percent of women agreed to be tested. Of those who declined testing, the reasons most frequently given for doing so were: no perceived risk, administrative and scheduling difficulties, prior testing, and lack of endorsement of testing by provider.¹² These results indicate that with the systematic removal of institutional barriers to testing, implementation of systems to streamline and facilitate testing, and universal offer and endorsement of testing by health care providers, regardless of perceived risk, we could achieve truly voluntary HIV testing rates of nearly 100 percent among pregnant women. In other words, nearly perfect testing rates during pregnancy can be achieved with an opt-in approach.

Formula for Real Success

We could achieve voluntary opt-in HIV testing rates of nearly 100 percent among pregnant women by removing institutional barriers to testing, by implementing systems to streamline and facilitate testing, and by mandating that health care providers universally offer and endorse HIV testing for pregnant women, regardless of perceived risk.

V. Mandatory Testing Violates Individual Rights

A woman's right to make informed decisions about her own health and the health of her child is a principle that should guide HIV policy development at every phase in which testing and treatment is considered. States have wisely refrained from legislating forced treatment of babies born to positive mothers. This restraint reflects the legislatures' appreciation of the complex, and case-specific nature of medical advice. The debate over testing should similarly recognize that the personal stories of pregnant women and women who have just given birth are too diverse, and the passion and fear associated with HIV are still too intense, to rely on compulsory testing as a successful solution.

Mandatory testing of pregnant women and newborns is premised upon the notion that a positive HIV test will necessarily trigger medical and possibly surgical intervention to prevent mother-to-child transmission. The decision to decline treatment, however, can be reasonable. The prescribed anti-retroviral treatment may be highly toxic with numerous potential side effects, or may induce drug-resistance.¹³ Additionally, the long-term effects of this treatment on an infant are not fully known. When this uncertainty is coupled with the strong odds favoring a healthy baby without medical intervention, a woman might reasonably decide against treatment. The validity of this decision is emphasized in the Public Health Service Task Force's recently revised guidelines, which clearly state:

“ The benefits of antiretroviral therapy for a pregnant woman must be weighed against the risk of adverse events to the woman, fetus, and newborn.... After counseling and discussion, a pregnant woman's informed choice on whether to take anti-retroviral drugs either for her treatment or for prevention of mother-to-child transmission or to follow other medical recommendations intended to reduce perinatal HIV transmission should be respected. Coercive and punitive policies are potentially counterproductive in that they may undermine provider-patient trust and could discourage women from seeking prenatal care and adopting health care behaviors that optimize fetal and neonatal well-being. ”

As the Public Health Service Task Force warns, compelling HIV testing runs the risk of alienating patients from their medical care provider, and in turn driving them from care. Meanwhile, the vast majority of women will accept HIV testing, especially if encouraged to test by their doctors. Even more women would test if institutional barriers to testing were lifted, and if health care providers universally offered and endorsed HIV testing.¹⁴ Nonetheless a small minority of women will likely decline testing for fear of the results.¹⁵ Their fears may be grounded in eminently practical considerations. A woman experiencing intimate

partner violence, for instance, might well fear that an HIV diagnosis would trigger an escalation of violence. Another woman may reasonably fear that her job will be in peril if she learns that she has HIV. Others may fear that estrangement from family and community would flow from an HIV diagnosis, and might choose ignorance over isolation.

For these women, coercion is neither an appropriate nor effective basis upon which to build a provider-patient relationship, or to begin the process of long-term care and treatment. It is precisely in those cases where women fear testing that mandatory or coerced HIV testing drives a wedge between patient and health care provider. By contrast, a system which strives for universal testing, but allows for patient autonomy and freedom, rightly puts the responsibility on health care providers to recognize and address the distinct needs of individual patients. Opt-in schemas, which are the only true form of voluntary HIV testing, require well-trained, readily available counselors to work intensively with that minority of women who may be initially resistant to an HIV test.

While this prescription may seem to place unreasonable demands on health care providers, it is the only way to ensure that women who test positive do not abandon the health care system. If in our haste to boost testing rates we sacrifice the pregnant woman's or the new mother's trust in her provider, and ignore the importance of her buy-in and participation in her own care, we risk alienating her from the health care system. If this happens, then we are no closer to our goal of reducing MTCT.

VI. Opt-Out Schemas Are Inherently Problematic

Universal testing for HIV is a realistic goal. It is time that we move beyond risk-based testing, and toward a preventative health care model that incorporates the universal offer and endorsement of an HIV test. Under such a model, every sixteen year old, as well as every sixty year old, should be routinely offered an HIV test by a medical provider who genuinely endorses the test.

But HIV testing must be truly voluntary. Though an opt-out schema, in theory, promotes voluntary testing, in actuality the possibilities for confusion,

missed communication, or coercion are great. Patients of limited English proficiency might easily not understand when their provider hastily informs them that they will be given an HIV test. Rushed providers are likely to de-emphasize the HIV test, perhaps mentioning it amidst a steady stream of information which the patient may not fully absorb. In the worst case scenario, a patient who shows reluctance to test will be coerced by the provider, leaving the patient feeling helpless, resentful, and mistrusting. If instead the provider affirmatively offers the test and obtains the patient's consent to testing, an opportunity is presented for the provider to recommend HIV testing as part of routine prenatal care generally, and to respond to specific fears or concerns on the part of the individual patient. This way the provider encourages patient trust, an element essential to the future care and treatment of the woman and her baby – and to the successful prevention of mother-to-child transmission.

VII. Recommendations

If we are to eliminate perinatal HIV transmission entirely, we need to shift our concentration away from coercive testing during pregnancy or mandatory newborn testing and refocus our efforts on providing women with comprehensive health care. States should provide all women, as well as their sexual partners, with HIV/AIDS education around issues of infection, transmission and prevention. As is recommended by numerous states (including California, Delaware, Louisiana, and Minnesota), physicians should offer and strongly encourage pregnant women to test for HIV periodically and provide the appropriate

follow-up to their HIV test results. A 2004 survey from 28 states illustrates that the number of women who knew their HIV status before giving birth or at the time of birth increased from 81 percent in 1996 to 93 percent in 2004.¹⁶ In order to achieve HIV testing of all pregnant women, we need to ensure health care providers universally offer HIV tests and provide pre-test counseling to their patients.

With eliminating perinatal HIV transmission, while respecting the rights of women and mothers, as our goal, we recommend the following:

- Increase voluntary (opt-in) HIV testing rates among pregnant women by implementing mandatory HIV counseling and universal offering of voluntary HIV testing during both the first trimester and the third trimester regardless of perceived risk;
- Provide services through a comprehensive women's health care model that includes universal offering of voluntary HIV testing with informed, written consent as part of standard gynecological visits (opt-in, not opt-out); and
- Expand access to prenatal care for all women and replicate successful prenatal and HIV outreach and prevention programs.

It is time to refocus our energy and resources, and to tackle more ambitious policy initiatives aimed at decreasing HIV infection among all women. The end of perinatal HIV transmission is in sight; we cannot stop now.

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