

Understanding the Debate: HIV Counseling and Testing in Pregnancy

New clinical advances that can prevent HIV transmission from mother to child have sparked a compelling public policy debate about HIV counseling and testing in pregnancy. Pregnant women who know they are HIV positive can avail themselves of therapies that dramatically reduce the chances that their newborns will be HIV infected. This means that there is a profound advantage to knowing one's HIV status in pregnancy and knowing about the new therapies. At stake in the policy debate are the legal and medical rights of pregnant women and the opportunity to almost eliminate perinatal transmission of HIV infection.

Since our founding in 1994, AIDS Alliance for Children, Youth & Families (originally AIDS Policy Center for Children, Youth & Families) has explored these complex issues, creating a forum to listen to women's voices and bringing diverse stakeholders together to seek common ground. AIDS Alliance's goal in this sometimes contentious debate is to support and promote the health and well-being of HIV-positive and at-risk pregnant women and their newborns and families. At the center of our research, policy development, and advocacy on this issue is giving voice to the concerns and experiences of women affected by federal and state law and policies related to HIV counseling and testing in pregnancy. It is essential that policy makers who formulate HIV testing policy for pregnant women and newborns hear from women living with HIV/AIDS, as well as women living in high-risk circumstances.

The professional and public debate on HIV testing in pregnancy has been strongly influenced in recent months by a report from the Institute of Medicine (IOM) that recommended universal HIV testing for pregnant women, with notification, as a routine component of prenatal care. Many have embraced this recommendation as the best way to ensure that pregnant women know their HIV status. Many others, including the majority of AIDS Alliance members, are concerned that "notification" of an HIV test with a right to refuse is a poor substitute for the legal

and ethical imperatives of informed consent.

After listening to women, reviewing the professional literature and state and federal law and policy, participating in the IOM study, and surveying and consulting with our clinician and researcher members, AIDS Alliance for Children, Youth & Families makes the following core recommendation about HIV testing in pregnancy:

Universal HIV counseling and voluntary HIV testing, with explicit informed consent, should be routine components of prenatal care for all pregnant women.

Understanding the Debate: HIV Counseling and Testing in Pregnancy reviews the public policy context for the debate surrounding this issue -- including AIDS Alliance's advocacy -- and expands on this core recommendation. AIDS Alliance gratefully acknowledges the generous support of the Children Affected by AIDS Foundation for this document.

The Public Policy Context

Since the early days of the epidemic, advocates have sought to protect people living with HIV from discrimination, abuse, and ostracization by guaranteeing their civil rights and civil liberties in a variety of areas, including HIV testing. Acknowledging the stigma associated with HIV/AIDS and the life-altering nature of an HIV diagnosis, state laws and federal and state policies and regulations have laid out conditions that govern various aspects of HIV testing, including the privacy of medical information and the necessity for informed consent.

With very few exceptions, such as accused rapists in many states, Americans cannot be tested for HIV against their will and must provide their fully informed consent to be tested. "Informed consent" is both a legal and ethical concept, defined in federal and state law and regulation, as well in clinical practice and research guidelines articulated within a variety of medical and health professions. Key to this concept has been the provision of adequate information to enable an informed choice and the free right of refusal, without fear of coercion or imposition of adverse consequences, such as care being contingent upon consent.

But biology has confounded the issue somewhat for pregnant women: the presence of HIV antibodies in a newborn's blood does not necessarily mean that the infant is HIV infected, but it does always mean that the mother is. Therefore, testing

a newborn for HIV and informing the mother when HIV antibodies are present is, in essence, testing the mother for HIV as well. From the moment that perinatal HIV infection was identified, there have been those who advocate for testing newborns and informing parents. The potential benefits of treatment for the infant were held by proponents of newborn testing to outweigh the mother's right not to be diagnosed without her consent. In recent years, however, some have advocated for mandatory testing of the pregnant woman herself, also argued as an avenue for reaching her child with treatment, including, with the advent of clinical trial results in 1994, treatment in utero that can prevent HIV transmission from mother to child.

Framing the Debate:

Mandatory Testing of Pregnant Women and Newborns

Proponents of mandatory testing of pregnant women and/or newborns define the debate in terms of saving the lives of infants, either by preventing transmission from mother to child or by providing early treatment to infected newborns. They argue that society has an obligation to aggressively intervene with pregnant women to reduce risk of perinatal transmission, no matter the wishes of or consequences to the mother. Essentially unaddressed are concerns that mandatory or coercive testing may prevent women in high-risk circumstances from seeking or participating in prenatal care, including the choice to take drug therapies to prevent perinatal transmission.

One strategy put forth by mandatory testing proponents was the unblinding of an anonymous CDC seroprevalence survey used to track the epidemic and allocate resources. Debate on unblinding the survey became a lightning rod that intensified debate on mandatory versus voluntary HIV testing policy in state legislatures and Congress. Public health experts arguing for keeping the survey anonymous were accused of deliberately keeping new mothers in the dark about their infants' health status, and newspaper op-ed pieces compared the anonymous survey to the infamous Tuskegee experiment. After a bill was introduced in Congress to unblind the survey, CDC halted the survey entirely.

Opponents of mandatory testing, including most clinicians and advocates, have presented compelling information suggesting that mandatory testing alienates women from the health care system, thereby defeating the stated purpose of testing. Those who oppose mandatory testing argue for universal HIV counseling and voluntary testing provided as part of a comprehensive continuum of health care and support for pregnant women and their newborn children.

076 and a New Urgency

Current federal law and policy has been shaped primarily in response to the groundbreaking results of the AIDS Clinical Trial Group (ACTG) 076 study, which demonstrated that the incidence of HIV transmission from mother to child could be dramatically reduced with the prenatal, interpartum, and postpartum use of zidovudine (ZDV), also known as AZT. In response to this finding, the Public Health Service (PHS), in August 1994, issued new guidelines for HIV testing of pregnant women and newborns recommending the universal offering of HIV counseling and voluntary HIV testing, with informed consent, to all pregnant women in the United States.

The 076 finding and the PHS guidelines generated a highly emotional and visible debate among policy makers, politicians, clinicians, and advocates about the best way to prevent perinatal HIV transmission, a debate in which AIDS Alliance gave voice to the concerns and experiences of women who will be affected by the outcome of the debate. Legislative efforts aimed at determining HIV status of pregnant women and newborns intensified after 076 and resulted in new provisions in the Ryan White CARE Act Amendments of 1996.

The testing debate held up that reauthorization of the CARE Act for over a year, until compromise statutory language was added. The compromise language requires that the Secretary of Health and Human Services make a determination about routine practice related to mandatory HIV testing for pregnant women and newborns. The Secretary, as part of the determination process, was to contract with the Institute of Medicine to evaluate the extent to which states have been effective in reducing perinatal HIV transmission and to analyze existing barriers to further reducing such transmission.

The CARE Act directed the Secretary to report IOM study findings to Congress, along with any recommendations made by the Institute. The Secretary also was directed to make a determination of routine practice concerning voluntary or mandatory HIV testing of newborns, using information from the IOM study and from other experts. In January 2000, the Secretary determined that it has not become routine practice to require testing of newborn infant for HIV infection in the United States. Had she determined otherwise, then states would have been required to meet certain additional criteria, including a large reduction in the rate of perinatal HIV transmission, or lose federal AIDS funds provided through the CARE Act.

It was in this context that AIDS Alliance, with support from the Ford Foundation, undertook a research project to identify the perspectives of women who are HIV infected or living in high-risk circumstances. These perspectives must inform HIV testing policy and practice, as a simple matter of justice and sound public health policy.

Listening to Women's Voices

As part of our Ford Foundation research, AIDS Alliance assessed the knowledge, attitudes, and behaviors associated with HIV testing of pregnant women and newborns using eight focus groups of women of childbearing age in high-risk circumstances in five cities: Houston, Chicago, Fort Lauderdale, Miami, and New York. In order to get the views of a diverse group of women at risk for or infected with HIV, focus groups were designed to include women alienated from mainstream systems of either health care or human and social services because of their drug use, occupational status, or other personal or social characteristics.

Focus group participants in some ways reflected the same push/pull as other stakeholders in the mandatory vs. voluntary HIV testing debate. But, as those whose lives are actually likely to be affected by the government's actions, they were much more concerned than others about the intrusion of government into their private lives and private medical decisions. In general, participants strongly wanted to protect babies from HIV infection. Further, they believed that a subgroup of women, particularly those actively addicted to drugs, might make bad decisions during pregnancy and need external limits to ensure the baby's health and welfare. Mandatory testing was seen by some as a useful intervention for that group. No one believed it was a necessary intervention for all women. Further, it was viewed as both a threat to personal freedom and potentially stigmatizing.

Mandatory testing was clearly recognized as government intervention into personal lives. The government was personified as unable to keep a secret ("You can't call it confidential if the government knows because the government's going to run around and tell everybody."), unable to be trusted (betrayal in Tuskegee), and already too powerful. There was little enthusiasm for the extension of new powers to this untrustworthy entity.

In general, participants were opposed to mandatory testing and the extension of government powers. However, when confronted with the problem that some

people were thoughtless, reckless, or undisciplined, mandatory testing seemed an appropriate option. Mandatory testing was always something to be used with others. No one wanted such a coercive strategy applied to herself. Indicating support for mandatory testing was voiced as "They should be mandated," but hesitance was often expressed in the first person, as in "What else will you mandatory me to do?"

It's interesting to note that the most nuanced views about mandatory testing are those expressed by the people most likely to be affected by such policies. Although the IOM recommendations neither call for nor endorse mandatory testing, they do represent an erosion of a pregnant woman's right to make fully informed decisions about her care, just the kind of creeping government intrusion that many women fear.

The IOM Recommendations

The IOM's central recommendation -- the imposition of universal HIV testing of pregnant women, with notification -- is an unprecedented inroad into the standards of informed consent. Rather than being asked to consent to an HIV test, pregnant women would be told they were being tested and be allowed to refuse, a remarkable change that does not reflect the privacy and other concerns of women in high-risk circumstances and many of their care providers. Instead, the IOM focuses on pretest counseling as an "onerous" burden on health care providers that prevents them from offering HIV testing to all pregnant women.

The IOM's recommendations continue to be discussed by professional groups, think tanks, and advocacy organizations. AIDS Alliance agrees with many of the IOM's adjunct recommendations and applauds their emphasis on access to care as a priority for reducing perinatal transmission of HIV infection, while disagreeing strongly with the central recommendation.

As part of our continuing response to the IOM report and recommendations, AIDS Alliance sponsored a debate on the recommendations at our annual conference. The debate was one more in a series of activities contributing to the development of AIDS Alliance's recommendations for HIV counseling and testing in pregnancy.

Voices '99: Who Decides?

"Voices," AIDS Alliance's annual meeting, brings together HIV/AIDS care

providers and consumers from across the country to discuss cutting-edge policy issues, as well as the state of the art in care and prevention. HIV counseling and testing in pregnancy has been a central concern each year. At our first meeting in 1995, AIDS Alliance took the then-unusual step of putting passionate opponents on this issue in one room and handing them microphones. Among the participants were a state assemblywoman and a Congressman, outspoken advocates of mandatory testing, who debated clinicians and advocates on the other side. Five years later, HIV counseling and testing in pregnancy remains a hot-button issue, but the 076 results and the opportunities they present to reduce perinatal HIV transmission demand new and better efforts at seeking common ground among stakeholders.

This year, at Voices 99, AIDS Alliance again sponsored a debate on HIV counseling and testing in pregnancy. This time our format was less adversarial and more interactive, billed as a "Talk Show," the debate was titled "Who Decides?: Patient Choices in Health Care." Who Decides? was a lively and informative debate, which quickly focused on the IOM's core recommendation and the issue of informed consent. Because the debate neatly captured the key concerns of both sides, a summary is presented below.

"Talk Show: Who Decides? Patient Choice in Health Care." Dorothy Mann of The Family Planning Council of Southeastern Pennsylvania moderated. Panelists included the following:

- Maria Isabel Fernandez (Isa), PhD, University of Miami School of Medicine, Miami, Florida.
- Stella Gusby, Outreach Educator, Southside Help Center, Chicago, Illinois.
- Zita Lazzarini, JD, MPH, University of Connecticut Health Center, Farmington, Connecticut.
- Howard Minkoff, MD, Maimonides Medical Center, Brooklyn, New York.
- Mike Stoto, PhD, Study Director, Institute of Medicine, Washington, D.C.

Dr. Stoto, the first person to speak, summarized the IOM recommendations, which he presented within the context of the PACTG study 076, existing PHS guidelines, and state laws and policies supporting voluntary counseling and testing for HIV, all of which resulted in a 43% reduction in pediatric AIDS in a 4-year

period. Dr. Stoto described the IOM recommendations as an attempt to answer the question "What can be done now?" to achieve the following goal: All pregnant women be tested for HIV as early in pregnancy as possible to receive optimal care and remain in care for both themselves and their children.

The IOM's answer to "what can be done now?" is the following core recommendation: A policy of universal HIV testing with patient notification as a routine component of prenatal care. Dr. Stoto identified and described the two components of this recommendation: "routine with notification" and "universal."

Routine with notification was described as being part of the standard battery of tests in pregnancy, as doing "one more lab test." Women would be informed that the test is taking place and have the right to refuse. Dr. Stoto stated that the amount of pre-test counseling can be less than in other situations, although he acknowledged that some women would need more, not less, pre-test counseling and women who test positive will need post-test counseling about how to get care. Universal was described as testing all pregnant women, which Dr. Stoto stated would reduce stigma, be cost-effective, and ensure that cases not be missed in geographic areas where rates are low now but may be increasing.

Following Dr. Stoto's opening statements, Dorothy Mann responded that the problem was not with the IOM's goal, but with one aspect of IOM's recommendation on how to get to that goal -- "with notification." Notification represents a fundamental change from how things are currently being done, replacing explicit informed consent to be tested with an ability to opt-out of an HIV test. Rather than agreeing to be tested, a pregnant woman would have to say that she does not want to be tested. One debate panelist in favor of the IOM's recommendation called this "implied" informed consent.

Zita Lazzarini emphasized that this approach oversimplifies informed consent, which she described as a process of a health care provider educating a patient about the risks and benefits of a test or treatment and gaining consent or disapproval. Education, understanding, and agreement equals informed consent.

Dorothy Mann and, later others in the audience, identified a contradiction within the IOM study and recommendation. The IOM is concerned that pregnant women are not getting HIV tests because physicians and staff don't have enough time, are not trained in HIV testing, and are not comfortable providing counseling according to current standards. Yet, the solution offered by the IOM is not training

providers and ensuring that they have enough time to provide adequate counseling. Instead, its solution was to cut short the accepted counseling process for this one group of people only -- pregnant women -- and to shift from explicit informed consent to be tested to an ability to refuse testing, with permission otherwise assumed.

Dr. Howard Minkoff commented that there used to be an overwhelming burden to being tested, with relatively trivial benefits. Now an HIV test and treatments -- AZT and cesarean section -- can result in 98% prevention. This possibility means that there is a different balance now, which Dr. Minkoff stated was why public health is best served by the IOM recommendations.

Later in the debate, the moderator and several audience members raised a provocative question related to this point: Since there are now considerable benefits to every individual in knowing one's status, in terms of early treatment, should all HIV testing be done this way? Should all routine physician visits include an HIV test, with notification? If not, why is it okay to make this change just for pregnant women? Behind these questions was an expressed fear that a pregnant woman is still viewed by some as a vector of disease rather than as a person who is learning her HIV status at that moment and as a mother who wants the best for the child she is carrying. Dorothy Mann also voiced her concern that by removing explicit informed consent the IOM recommendation creates a slippery slope toward mandatory testing.

Drs. Stoto and Minkoff maintained that the enormous and unique benefits to an HIV test in pregnancy make pregnancy a special case in terms of the benefit vs. burden calculation. Dr. Minkoff, however, agreed that a slippery slope is possible if consent withers away and "with notification" becomes a fig leaf for mandatory testing.

Dr. Maria Isabel Fernandez voiced support for universal testing, but expressed concern about merely informing a woman that she will be tested and has a right to refuse. She stressed that preventing perinatal transmission requires that a woman who is diagnosed as HIV positive accept treatment and take it faithfully. Her own research indicates that if a woman understands why her provider wants her to get tested and if she believes that the test is doing something good for herself and her baby, then she is most likely to accept testing. Dr. Fernandez recommended that pregnant women be offered an HIV test with a simple, targeted message that tells them what they need to know as pregnant women.

Stella Gusby, who does street outreach with sex workers, injecting drug users, and youth involved in gangs, among others, strongly supported the need to engage in education as part of the HIV testing process. Spending the extra time to engage pregnant women in a conversation about HIV is a great opportunity to help them stay negative if they test negative and help get them into care if they test positive. This last point was supported by audience comments throughout the debate, as was her later call for health care providers to be educated about this opportunity. Ms. Gusby described a program in Chicago where consumers and peer advocates trained physicians in ways to condense pre- and post-test counseling and still get the message across. The training, which included a mock counseling session, is proving popular with local hospitals.

Dr. Minkoff stated that the problem rests more with the health care system in general than it does with physicians. He stressed the need to balance the health needs within a particular community; for example, in a low-prevalence area where smoking kills many more women than AIDS, HIV counseling competes with counseling about smoking. Flexibility is necessary; a cookie cutter approach will not work.

Ms. Lazzarini addressed implications of the IOM recommendations at the state level, where laws on HIV testing originate. Between 1987 and 1998, the majority of states relied on counseling and voluntary testing with informed consent as a general approach to HIV testing, not just testing in pregnancy. Therefore, laws in many states conflict with the IOM recommendations. At least 35 states have laws requiring informed consent and voluntary testing; five more have that policy. Twenty-one states require pre-test counseling beyond notification, and such counseling requirements are sometimes quite detailed.

Implementing the IOM recommendation for testing with notification and right of refusal would be difficult in many states, requiring going to the legislature to change HIV testing law or going through a state agency to change regulations. Doing this carries a risk of its own: once the process is opened to changes, new laws could be better, but they could also be worse and more burdensome. Shaping new laws carefully will be a challenge.

One audience member raised the issue of the relevance of the IOM recommendations in light of new rapid testing technologies and AZT treatment at birth. Panelists and audience members agreed that not all women will be reached

through prenatal care, and new testing approaches will be helpful for these women and their babies.

Dr. Stoto reiterated that the barriers to HIV testing are not the women themselves, who generally will make decisions that are best for their children. The problem is with prenatal care providers in low-prevalence areas who say that they don't have time to counsel women. The IOM recommendation is an attempt not to let counseling get in the way of pregnant women being offered HIV tests, because testing when a woman is in prenatal care is an opportunity we can't afford to lose.

Dorothy Mann expressed concern about the right to refuse an HIV test. What happens when a woman refuses the test? Can she truly say no? Saying no means something; there is a reason when a woman refuses an HIV test, and her physician needs to take time to explore what that reason is.

Dr. Fernandez agreed that when women are offered the test, they generally accept. She stressed that women can make informed decisions when given the right information; the message does not need to be long or complex. A pregnant woman needs to know that if she tests positive for HIV, there are things that can be done for her and for her baby.

The debate was lively and well-informed throughout and could have continued to engage the panelists and the audience for the remainder of the day. However, mindful of time constraints, the moderator called for final statements. Dr. Stoto reminded the audience that nothing in the IOM recommendations says mandatory testing. Rather, the goal is to make sure that women are offered HIV tests. He concluded that the study did not view women as vectors for disease. Ms. Lazzarini described the dilemma as how to make women's choices informed without creating a situation in which doctors don't offer an HIV test because of the counseling requirements. Ms. Gusby asserted the need for women's voices to be heard on these issues. Dr. Fernandez called for streamlining the counseling process so that women can be told what is relevant to them and can decide accordingly. Finally, Dr. Minkoff cautioned that we not let the perfect be the enemy of the good.

Both sides of this debate -- at Voices '99 and in the larger debate among policy makers, care providers, and advocates -- share a common goal. Everyone is seeking to promote the health and well-being of pregnant women and their children. The disagreement, and it is considerable, centers on how to bring about the shared goal. Following are the AIDS Alliance recommendations, in response to the Institute

of Medicine report.

AIDS Alliance Recommends

The culmination of AIDS Alliance's research, collaboration, and debate are recommendations for sound public health policy on HIV testing that will save lives, guarantee informed decision making, and minimize medical, social, and legal risks for women and families.

AIDS Alliance for Children, Youth & Families recommends:

Universal HIV counseling and voluntary HIV testing should be routine components of prenatal care for all pregnant women.

Recommendations for Health Care Providers

- Prenatal care providers should counsel every pregnant woman about the benefits of knowing her HIV status so that she can make informed decisions about being tested as part of prenatal care.

Many HIV-positive women not only do not know their HIV status, but also are unaware that they were ever at risk for contracting HIV infection. This became increasingly true when the primary risk factor for women in the U.S. became the sexual and drug-using behavior of their partners. Therefore, many HIV-positive women who become pregnant may not know that there is any reason to be tested for HIV as part of prenatal care. In order for a pregnant woman to make an informed decision about being tested for HIV, she must be provided with information about the benefits to herself and her baby of knowing her HIV status, including the availability of therapies that can dramatically reduce perinatal HIV transmission.

- Prenatal care providers should offer HIV testing to every pregnant woman as part of prenatal care. A woman who refuses testing should be given multiple and continuing opportunities to be tested for HIV throughout the course of her pregnancy.

Pregnancy is a window of opportunity for a woman to learn her HIV status and to take steps to care for her own health and that of her unborn child. Therefore, all pregnant women should be offered HIV testing following counseling about the benefits of knowing their HIV status. A pregnant woman who refuses IV testing

should continue to be counseled throughout her pregnancy about the benefits of HIV testing to herself and her baby.

- Prenatal care providers should provide every pregnant woman who is tested and found to be HIV-positive with counseling and support that includes complete and unbiased information about the benefits of ZDV and other therapies in reducing the chances that her baby will be HIV infected and about any risks associated with the therapy.

HIV counseling and testing alone will not prevent a single case of perinatal HIV transmission. An HIV-positive pregnant woman must know the potential benefits, as well as any risks, of ZDV therapy or other therapies to herself and her unborn child before she is able to make an informed decision about these therapies. Because an HIV diagnosis is often a life-altering event, post-test counseling also must address the psychosocial needs of newly diagnosed women. Health care providers and organizations offering HIV testing to pregnant women should provide or arrange for such support when HIV-positive test results are delivered.

- Prenatal care providers should provide every pregnant HIV-positive woman who chooses ZDV or other therapies with the care and support necessary to help her complete the regimen.

Optimal care for HIV-positive pregnant women and their infants is complex and specialized. ZDV and other therapies to reduce perinatal transmission require adherence to a treatment regimen that can be difficult. Women choosing these therapies must be offered comprehensive, coordinated care and support for adherence.

- Women who are found to be HIV positive must be referred immediately to health care providers and organizations qualified to provide HIV specialty care to pregnant women, such as Ryan White CARE Act Title IV programs and other community-based providers.

HIV-positive pregnant women require continuing medical care and support from health care providers with HIV experience. Medical research continues to demonstrate significantly better outcomes for patients treated by physicians and other health care providers with a high level of HIV expertise and experience. Prenatal care providers without such experience should work with more experienced providers and should refer HIV-positive women to Title IV and other community-

based programs where they can be offered care and support tailored to their needs and circumstances. Choosing not to participate in ZDV or other therapies to prevent perinatal HIV transmission must not interfere with a woman's access to continuing prenatal care and HIV specialty care.

- Hospitals, clinics, managed care plans, and other prenatal care providers should develop, implement, and evaluate policies and clinical practice guidelines that facilitate universal HIV counseling and voluntary testing for pregnant women.

Health care professionals and organizations that provide HIV counseling and testing to pregnant women should follow clinical practice guidelines that reflect state-of-the-art opportunities to reduce perinatal HIV transmission, while at the same time guaranteeing that pregnant women are tested for HIV infection only with their fully informed consent and with adequate pre- and post-test counseling. New models and approaches to counseling pregnant women about the benefits of HIV testing, such as expedited counseling, are appropriate if they ensure fully informed consent. Rapidly changing treatment options mean that clinical practice guidelines for HIV counseling and testing must be periodically evaluated and revised as needed.

Recommendations for Providers of Preservice and Continuing Education

- Training programs for professionals caring for pregnant women and their newborns should highlight the vital role of universal HIV counseling and testing in preventing perinatal transmission of HIV infection.

Health care providers who work with pregnant women and their newborns are on the front-line in the fight to reduce perinatal transmission of HIV infection. It is imperative that preservice and continuing education for these professionals include the latest information about advances in preventing perinatal HIV transmission, including the role of HIV counseling and testing in pregnancy. The range of complex ethical and legal issues surrounding informed consent should be addressed at both the preservice and continuing education levels.

- Professional training programs and organizations whose members care for pregnant women and their newborns should offer training to community-based organizations serving women about the vital role of HIV counseling

and testing in preventing perinatal HIV transmission.

Community-based organizations that are traditional providers of care to women living in high-risk circumstances, such as those in communities with a high prevalence of HIV infection, can be key resources for reaching pregnant women and informing them about the benefits of HIV testing in pregnancy. Many of these organizations already participate in local networks of HIV care for women, including Title IV programs and other programs funded through the Ryan White CARE Act. Professional training programs and organizations whose members care for pregnant women and newborns should offer training and technical assistance to community-based organizations and providers in their localities who are not part of local HIV care networks and may be unaware of the role they can play in helping pregnant women in high-risk circumstances learn about the importance of an HIV test during pregnancy.

Recommendations for Policy Makers and Advocates

- Federal and state policy makers should avoid interfering with a pregnant woman's right to make decisions about her own medical care, including her right to provide informed consent for HIV testing and treatment.

Pregnancy does not invalidate a woman's legal and ethical right to medical autonomy and control of decision making. Testing pregnant women for HIV without their informed consent violates accepted standards of ethical practice, as well as their Constitutionally protected privacy rights. Voluntary, non-coercive measures to encourage and promote HIV counseling and testing during pregnancy are proving successful and must be strengthened and continued.

- The minimum components of informed consent for HIV testing in pregnancy should be identified and promoted as the standard of care for universal HIV counseling and voluntary testing of pregnant women.

In the urgent push to ensure that all pregnant women know their HIV status, there is a real danger women will not be provided with the necessary counseling to ensure their fully informed consent to be tested. To protect the privacy and autonomy of pregnant women while at the same time facilitating HIV testing during pregnancy, the minimum components of counseling to ensure fully informed consent for HIV testing in pregnancy must be identified.

AIDS Alliance proposes a blue-ribbon panel of clinicians, ethicists, researchers, and women in high-risk circumstances and their advocates be convened to develop a consensus on these minimum necessary components of informed consent. We view this final recommendation as a necessary next step forward to promote universal, voluntary HIV testing of pregnant women, with fully informed consent.