

November 30, 2000

Technical Information and Communications Branch
Mailstop E-49
Division of HIV/AIDS Prevention
National Center for HIV, STD, and TB Prevention
Centers for Disease Control and Prevention (CDC)
1600 Clifton Rd., N.E.
Atlanta, GA 30333

Re: U.S. Public Health Service (USPHS) Recommendations for HIV Screening of
Pregnant Women."

To Whom It May Concern:

The undersigned organizations commend the CDC for including in its draft Recommendations for HIV Screening of Pregnant Women such important provisions as upholding the right to voluntary testing, the right to refuse HIV testing, and warnings against coercing women into testing under any circumstances. We also appreciate the intent to make HIV testing available for all pregnant women.

However, we remain very concerned that the draft guidelines you are considering also generally undermine earlier CDC messages about the importance of HIV counseling and a woman's right to fully informed, written consent to HIV testing. Although we strongly support efforts to encourage the provision of HIV testing for all pregnant women, testing should always be done with a fully informed, written consent and should include culturally and linguistically appropriate HIV pre- and post-test counseling and assistance accessing medical care. We believe that HIV testing, in and of itself, is a very poor substitute for prevention education, counseling, and accessible medical care. We believe that the changes you are proposing may unnecessarily weaken a woman's right to a written, informed consent and lead to a decrease in effective prevention education and HIV counseling—a cornerstone of our HIV prevention efforts in the United States. This could have particularly negative consequences for pregnant women who are not currently HIV-positive, but who are at high-risk of becoming infected.

In general, we are concerned about the modifications you are proposing that "simplify" the testing process and make the process of informed consent more "flexible." In particular, we object to changes that accept the provision of educational materials as sufficient substitutes for face-to-face HIV counseling and allow the provider to determine whether written informed consent is a barrier to HIV testing. In addition, we take objection to the framework you have accepted, in which the HIV counseling guidelines—and not provider failure to effectively counsel pregnant clients—are treated as the barrier to HIV testing that must be

modified and overcome. Since the CDC first published and disseminated HIV guidelines in 1986, there has been a dramatic decrease in the rate of vertical HIV transmission in the United States. But as you know, many cases of pediatric AIDS continue to result from births to women whose HIV status was not established during their pregnancy. That HIV-positive pregnant women continue to reach full term without being tested for HIV or receiving appropriate medical care is largely the result of two problems. First, many women—especially those at high risk for HIV—do not receive adequate prenatal care. Second, many providers fail to encourage—or even raise the issue of—HIV testing for their pregnant clients. According to the 1998 Institute of Medicine study referred to in your letter of October 31, 2000, this failure stems from provider belief that they know who "ought" to be tested and general discomfort with the counseling process itself. Therefore, some providers are willing to forgo the HIV counseling necessary to obtain a woman's fully informed consent for some of their pregnant clients. While modifications to CDC guidelines are unlikely to increase access to health care for disenfranchised social groups, they can be expected to have a very real impact on the standards of care employed by providers. To respond to the current failure of providers to do thorough HIV counseling by relaxing CDC guidelines for counseling and written informed consent only confirms the devaluation of HIV counseling and informed consent to testing that some providers have been expressing through their failure to provide it to all pregnant women. In other words, those providers who have dismissed HIV counseling as too time-consuming or uncomfortable have been exhibiting a failure to understand the nature and problem of HIV, and failing to appreciate the proven interest women have in being educated about and tested for HIV. The modifications currently proposed fail to encourage members of the medical community to become better educated on HIV. They also fail to fully support the same counseling and written informed consent standards for pregnant women that are enjoyed by most people at risk for HIV. Finally, they do not encourage standards of care that treat pregnant women as partners in their own health care.

In fact, the current modifications, by suggesting that testing itself is more important than a fully informed, written consent and effective HIV counseling, increase the likelihood that providers will postpone any substantive HIV counseling efforts until they have obtained a positive HIV test result for their patient. If this happens, it will mean that women may agree to an HIV test without a full understanding of the implications to their own health and their pregnancy. Additionally, HIV-negative women—the vast majority of all pregnant women—will obtain no meaningful HIV prevention information during their prenatal care.

Following a positive HIV test result with appropriate medical care and prevention education will allow the medical establishment to continue to positively impact the rate of vertical transmission of HIV. But it is only by providing all women with appropriate HIV counseling and the right to a fully informed consent to HIV testing that the medical community can hope to have a more far reaching preventative impact, affecting the rate at which women become HIV-positive. To effectively fight HIV/AIDS and to eradicate pediatric HIV/AIDS, the medical community must prioritize the prevention of HIV in women. Therefore, it must

remain committed to communicating—and communicating effectively and respectfully—with women on the subject of HIV.

In addition to the potential weakening of the standards of written informed consent and appropriate pre-test counseling, we are concerned about the encouragement of the use of rapid HIV testing during labor and delivery for women whose HIV status is unknown at the time of delivery. We recognize that testing during labor and delivery may be an opportunity for a woman who was previously unaware of her status to prevent the transmission of HIV to her newborn. We also appreciate the language that addresses the difficulty and sensitivity of obtaining an informed consent during labor. However, the guidelines do little to address clinical practice or offer best-practice guidance. The question of how informed consent might be ensured and how anti-retroviral treatment should be approached for women who test HIV-positive is extremely important in the context of labor and delivery. Every effort should be made to allow a pregnant woman both the right to a fully informed consent and the opportunity to consider both the risks and the benefits of anti-retroviral treatment—should she test HIV-positive—for both herself and her newborn, whenever her first HIV test occurs. We encourage the CDC to draw on the expertise of researchers, clinicians who regularly treat HIV-positive pregnant women, women living with and at risk for HIV—particularly those who have been pregnant or given birth—and their advocates to determine guidance for the use of rapid testing and the consideration of anti-retroviral treatment during labor and delivery. We believe this group should be consulted before finalizing the emphasis on rapid testing in the context of labor and delivery in the guidelines.

As members of organizations that are ultimately and continuously accountable to men and women living with HIV, we were dismayed to note that the list of expert panelists and authors relied upon in the development of the proposed new guidelines included many fewer women than men. Additionally, and perhaps most important, the experts apparently did not include any women identified as living with or at-risk for HIV—particularly women who have experienced a pregnancy or birth. On a related note, we also think it is worth pointing out that the fundamental critique we are offering of the proposed guidelines has an unfortunately long heritage in the medical community. Specifically, these proposed guidelines give a higher priority to the convenience of medical providers than to the experience of women in the development of recommendations for a medical issue that is centered in women's lives.

We believe that the most effective strategies for meeting the needs of pregnant women with and at risk for HIV must include efforts to increase the number of pregnant women offered counseling and voluntary HIV testing, creation of coordinated systems of care to link greater numbers of pregnant HIV-positive women to prenatal care services, and outreach services to reach women at high risk for infection with prevention and care services. Given these priority activities and given our concerns with the draft guidelines, we are of the opinion that the CDC should withdraw its draft Recommendations for HIV Screening of Pregnant Women and maintain and actively promote the current USPHS Recommendations for HIV Counseling and Voluntary Testing for Pregnant Women. In addition, we recommend that that CDC lead an exploratory process—with meaningful participation by HIV-positive women, women at risk for infection, and their

Page Four

November 30, 2000

Comments: Recommendations for HIV Screening of Pregnant Women

advocates—to identify ways to increase training, knowledge, and acceptance among medical providers for offering all women, including pregnant women, HIV testing with pre- and post-test counseling and informed written consent. In addition, the CDC should explore and identify (with broad community input) recommendations for increasing access to prenatal care for all pregnant women, and in particular, for HIV-positive pregnant women.

Thank you for your consideration.

Sincerely,

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