

Olds Plaza Building, 10th Floor Lansing, Michigan 48909 Phone: 517/373-6466

HIV TESTING OF PREGNANT WOMEN, NEW MOTHERS

House Bill 4558 as enrolled Second Analysis (7-18-94)

Sponsor: Rep. John Jamian House Committee: Public Health Senate Committee: Health Policy

THE APPARENT PROBLEM:

Michigan has participated since 1988 in a federal study designed to develop a data base on the spread of HIV (human immunodeficiency virus) infection. The state receives \$1.4 million per year in federal grants for HIV/AIDS surveillance seroprevalence activities, of which about \$535,000 goes for the anonymous HIV testing of all newborn babies. Since newborn babies carry their mothers' antibodies, when a newborn tests positive for HIV this positive test result indicates only that the baby's mother is HIV-infected. That is, a newborn who tests positive for HIV may or may not be infected himself or herself -- reportedly only 30 percent of newborns who test positive for HIV are themselves infected. Roughly seven out of every 10,000 babies born to HIV-infected mothers will themselves be HIV-infected, which means that of the roughly 140,000 babies born in Michigan every year, 25 will be HIV-infected.

Under federal grant requirements, the testing must be done anonymously, which means that when a test shows a positive result, there is no way to know which baby has tested positive for HIV. Because of this requirement for anonymity, parents of newborns who test positive for HIV have not been notified of positive test results, unlike what happens when newborns are tested for seven treatable but otherwise handicapping metabolic conditions. (These seven tests are required by the Public Health Code, which further requires that positive test results be reported to the babies' parents.) Legislation has been introduced to address this problem.

THE CONTENT OF THE BILL:

Currently, under the Public Health Code, when a pregnant woman is examined medically for the first time, her medical caregiver is required to test her for venereal disease, HIV (or an antibody to HIV),

and for hepatitis B. There are two exceptions to this required testing: (a) if the woman refuses to be tested or (b) if the caregiver decides that the tests are medically inadvisable. The health code also prohibits testing for HIV without (a) first obtaining the patient's written, informed consent and (b) preand post-test counseling. (Currently, only criminals convicted of certain sex-related crimes can be ordered tested for HIV without their written, informed consent.)

The bill would require that pregnant women who went to a health care facility to give birth or for care immediately after having given birth outside of a health care facility be tested for venereal diseases, HIV, and hepatitis B if the caregiver had no record of results of these tests for that patient.

In addition, the bill would remove language referring to "acquired immunodeficiency syndrome related complex" (ARC) from several sections of the health code.

MCL 333.5101 et al.

BACKGROUND INFORMATION:

Federal "blinded maternal [HIV] antibody study." Michigan is one of 44 states participating in a national survey monitoring the prevalence of HIV infection among women giving birth (maternal HIV seroprevalence) since July 1988. This survey is one part of a number of seroprevalence surveys funded by the U.S. Public Health Service to help monitor the extent and progression of the epidemic of HIV infection in the United States. The purpose of these surveys is to help public health authorities at all levels to develop, target, and evaluate programs to track and prevent HIV infection and AIDS. The maternal antibody seroprevalence survey is designed to monitor the prevalence of HIV infection among

all women giving birth in Michigan, and is particularly important because it cuts across geographic, socioeconomic, ethnic, and age groups. The survey is conducted according to federal protocols, which include a requirement that the survey be done anonymously, and uses blood specimens routinely collected according to Michigan law for metabolic testing of newborn babies. The blood from newborns is used because all newborns have their mothers' antibodies at birth, so that it is possible to find out the HIV status of the mothers from the blood of their newborn babies.

Since July 1988, when the survey began, roughly 7 per 10,000 mothers in Michigan have tested positive The rates vary within the state: in southeastern Michigan 11 to 13 mothers per 10,000 will test positive for HIV; outstate, 2 to 3 mothers per 10,000 will test positive. Roughly 80 percent of the infected mothers are infected through illegal IV drug use. The rate of infection is fairly evenly distributed across the range of age groups, and no consistent upward or downward trend is apparent. In general, the study is showing that each year about 100 HIV-infected women are giving birth in Michigan. Since studies of babies born to mothers who are HIV-antibody-positive suggest that 30 percent of the babies born to these women are HIV-infected (as opposed to merely being HIVpositive), about 30 HIV-infected babies are born each year in the state.

Obstetric AZT therapy. The clinical trials of AZT drug therapy in pregnancy began in April 1991, with 748 HIV-infected women in their 14th to 34th week of pregnancy. Treatment lasted from one to 29 weeks, based on the time of the women's enrollment in the study, and within 24 hours of birth, infants were started on the same treatment as their mothers. (During pregnancy, the women on AZT received a standard adult dose of the drug, and during labor, a continuous intravenous dose. Infants received the drug in a syrup form four times a day.) An interim review of study findings revealed an HIV transmission rate of 8.3 percent after the women and their babies received AZT, compared with 25.5 percent for those receiving a placebo. Nationally, about 25 percent of infants born to HIVinfected women also are infected with HIV. HIV infection is the fifth leading cause of death of U.S. children younger than 15, with transmission from the mother during pregnancy accounting for the overwhelming majority of cases. As of September 30, 1992, for example, the federal Centers for Disease Control had received reports of 4,906 AIDS cases in children under age 13. Of those, 4,328 had a mother who was infected or at risk of infection. Every year, about 7,000 HIV-infected women give birth in the U.S.; in Michigan, reportedly about 100 HIV-infected women give birth.

FISCAL IMPLICATIONS:

The Department of Public Health reports that the bill would have indeterminate costs since the number of new tests captured under the bill is unknown. (7-18-94)

ARGUMENTS:

For:

Michigan's Public Health Code requires that pregnant women be tested for HIV at their initial prenatal examination. This testing is accompanied by pre-test counseling and requires the woman's informed consent. A woman who turns out to be HIV-infected receives counseling to deal with the test result and its implications, receives the care she needs before her baby is born, and is taught how to take precautions to protect herself and her baby.

The bill would extend these current health code provisions regarding prenatal testing for HIV, VD, and hepatitis B to include two groups of women who currently may not receive HIV testing and counseling prenatally: women whose first "prenatal visit" occurs when they come to the hospital to give birth and women who give birth outside of a hospital and who come to the hospital for immediate postpartum care.

Against:

The bill does nothing to address the identified problem, namely, that currently, under the federally-funded anonymous HIV testing of newborn babies, there are babies that test positive for HIV infection but their mothers aren't being told because nobody knows exactly who these babies are (because the testing is being done anonymously).

It is appalling and outrageous -- even, some would charge, a form of child abuse and neglect -- that the state would test all newborn babies for HIV without informing parents of positive test results. Newborns who are HIV-infected need to be identified as soon as possible and given appropriate care to prolong their lives and to maximize the quality of their lives. Moreover, it is important to educate the mothers of

babies who test positive for HIV, since there is the possibility that the infection can be transmitted to their babies through breastfeeding, to their sexual partners, and to future children through future pregnancies.

All babies should be tested for HIV infection and their identities be recorded so that if their test results were positive their mothers could be notified and appropriately counseled.

Response:

That approach would jeopardize the federal money the state currently is receiving for doing anonymous testing for HIV. If parents had to be told of positive HIV test results, and the identity of the newborn being tested were kept on record, the test would no longer be anonymous and the state would lose the approximately \$500,000 it receives each year to do anonymous HIV testing.

Besides, according to testimony before the House Public Health Committee, virtually all HIV-infected babies are being identified despite the anonymous testing, so there is no need to jeopardize the current anonymous testing program in order to get appropriate medical treatment for HIV-infected newborns.

Against:

If the state would lose too much federal money by abandoning its anonymous HIV testing of newborns, then all pregnant women (and new mothers who hadn't been tested prenatally) should be required to be tested for HIV, without the option of refusing the test. Given that the primary way that babies are infected with HIV is through "vertical" transmission from their HIV-infected mothers, and that the number of babies infected perinatally is increasing rapidly, it is imperative that the HIV status of all pregnant women be established as early as possible in their pregnancies. Reportedly, the number of perinatally-acquired AIDS cases increased 17 percent in 1989, and 21 percent in 1990 (rates for heterosexual transmission increased 27 percent in 1989 and 40 percent in 1990). But identifying HIVinfected pregnant women would make it possible to apply the results of a recent interim review of a study which indicates that it is possible to reduce -by as much as two-thirds -- the risk of transmission of HIV infection from a pregnant woman to her fetus if the pregnant woman (and, subsequently, the newborn baby) receive the drug AZT (zidovudine). By mandating universal HIV testing of pregnant women the number of babies at risk because of their mothers' prenatal HIV status could be greatly reduced, babies who were born HIV-infected could get appropriate early treatment, and babies who initially tested positive but who turned out not to be infected could be protected from future possible infection from their mothers through breastfeeding (since, if a woman knew she was HIV-positive, she could refrain from breastfeeding).

With the rapid growth in heterosexual transmission of HIV, every means available should be used to determine the HIV infection status of pregnant women in order to institute early care of infected mothers and to prevent or reduce further spread of the infection, both from mother to infant and by further heterosexual transmission to partners.

Response:

There are a number of objections to mandatory testing of all pregnant women. In the first place, according to written testimony from the state medical society, few pregnant women refuse to have an HIV test done even though they are allowed to do so under the health code. What is more, the American Academy of Pediatrics (AAP), the national organization representing physicians who provide care to infants and children, has already issued a set of recommendations strongly urging all pregnant women to be tested for HIV, but at this time opposes mandatory, involuntary HIV testing of pregnant women and newborn babies. Speaking on behalf of the AAP, Dr. Alan Fleischman, director of neonatology and professor of pediatrics at Albert Einstein College of Medicine, predicts that HIV testing will become a routine part of obstetric care. He says it will become standard for all women of childbearing age to know their HIV status, and for all women who enter into prenatal care to be offered HIV testing and have it explained why such testing is so important. Finally, as Dr. Fleischman points out, pregnant women who do test positive for HIV still will need to voluntarily participate in recommended therapies, and it's important for physicians to be able to engage their pregnant patients in a professional discussion in an atmosphere of trust, rather than one of coercion. Targeting only pregnant women (rather than, say, the general population) for mandatory HIV testing would harm rather than enhance the physicianpatient relationship, possibly to the detriment of the health of the pregnant woman and her fetus. Given the social stigma still associated with AIDS, mandatory HIV testing of pregnant women could

result in them avoiding future medical care, including medical care during their pregnancies.

Secondly, mandating HIV testing for pregnant women would remove the current requirement that written informed consent be given before an HIV test is performed. Women should not have their fundamental right to self-determination diminished Mandatory HIV testing would in this way. constitute an unwarranted governmental invasion of a woman's right to bodily integrity. Ironically, this also would remove women's statutorily protected right to prior written informed consent to prenatal HIV testing even as "informed consent" recently was statutorily required of pregnant women in Michigan before they can obtain an abortion. At the same time, mandatory HIV testing of pregnant women would make them the only class of people, other than convicted sex offenders, who would be deprived of their right to prior written informed consent to -- and their right to refuse -- HIV testing.

The intersection of HIV infection and pregnancy clearly has significant public health implications. However, the fact that only women are affected and the fact that the increase in HIV infection among heterosexuals is rising most rapidly in so-called nonwhite populations means that an already socially vulnerable population -- poor women of color -- is likely to bear the brunt of yet more government intervention into their lives. Significantly, nearly 80 percent of the women in the study of the obstetric use of AZT were either African American (reportedly half of the study participants) or Hispanic (29 percent). If the population of this study is typical of the population that would be most affected by mandatory HIV testing during pregnancy, then at the very least, there should be some guarantees that this mandatory intervention will benefit them and not just society at large.

Even though a number of people pointed out that, under the common law right to refuse treatment, pregnant women who didn't wish to be tested for HIV could simply refuse to allow any of their blood to be drawn for tests, this "right" appears nowhere in the Public Health Code. And a right that doesn't exist in statute -- and which people don't know exists in common law -- isn't likely to be asserted. How many pregnant women would know -- without being told -- that they could refuse to be tested for HIV by refusing to have their blood drawn for (unspecified) prenatal tests? And how many

people, whether pregnant women or not, would understand that drawing blood for tests is considered "treatment" which can be refused? At the very least, this common law right to refuse treatment -- and explicit notification to the woman prior to blood being drawn -- should be codified and made explicit in statute.

Finally, requiring mandatory prenatal HIV testing assumes that women are incapable of making the right decisions for themselves and their offspring, and relegates to the state decision making powers that rightly belong with the individual.

Reply:

Though informed consent is important, the public health concerns in this instance surely outweigh women's rights to bodily privacy. Even if the newborn infant of an HIV-infected mother isn't born HIV-infected, if the baby is breastfed and the mother doesn't know that she's HIV-infected, the baby still can wind up with this deadly infection. Given, moreover, that many HIV-infected babies wind up as wards of the state, whose care is paid for by all taxpayers, the state has a legitimate interest in ensuring that the number of preventable HIV-infections is minimized.

Even if refusal of tests currently recommended for pregnant women is rare, those refusals should not be permitted because of their possible public health repercussions. In addition, not all pregnant women are competent to make these kinds of decisions, whether because of youth or for other reasons. And finally, many of the women most at risk for HIV infection may well have the least access to medical care, so mandatory testing would benefit not only their babies and society at large but the individual women themselves.

HIV infection has for too long been treated not like an infectious disease but like a civil rights issue. It is long past time to recognize that this infection is a public health issue, and to stop treating it as though it is a moral failing.