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MANDATORY HIV TESTING OF PREGNANT WOMEN

House Bill 4558 (Substitute H-2) First Analysis (4-12-94)

Sponsor: Rep. John Jamian Committee: Public Health

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.) In order to address this problem without losing existing federal money, legislation has been introduced that would require pregnant women to be tested for HIV.

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 amend the health code to remove a pregnant woman's right to refuse testing for venereal diseases, HIV, or hepatitis B, and would exempt HIV testing of pregnant women from the code's requirement that written, informed consent be given prior to HIV testing. (The bill would keep the other current exemption to otherwise required prenatal testing: that is, physicians or other caregivers still could decide not to test their pregnant patients for VD, HIV, and hepatitis B if, in their professional opinion, the tests were medically inadvisable.)

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

Finally, 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 for HIV. 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:

According to the Department of Public Health, the state gets about \$500,000 a year in federal money for newborn HIV testing. If the state didn't meet the federal requirements for participation in this study (namely, anonymous testing), the state would stand to lose the annual \$500,000. (4-5-94)

ARGUMENTS:

For:

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.

To know that certain babies test positive for HIV and yet not tell the parents is morally reprehensible, and yet the state could lose valuable federal dollars if it dropped its anonymous testing program. The bill would solve the problem of how to identify

newborns at risk for HIV infection without losing any of the federal dollars that the state currently is receiving to conduct "blind" testing for the prevalence of HIV. What is more, by identifying HIV-infected pregnant women, the bill also 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).

Thus, the number of babies at risk because of their mothers' prenatal HIV status could be greatly reduced, while 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. If a woman knew she was HIV-positive, she could refrain from breastfeeding, thereby protecting her newborn. She also could protect her other children, if any, as well as her sexual partners.

Against:

It seems ironic that while "informed consent" is now statutorily required of pregnant women in Michigan before they can obtain an abortion, this bill would take away women's existing statutory right to informed consent with regard to prenatal testing. In fact, the bill would make pregnant women the only class of people, other than convicted sex offenders, who would be deprived of their right to prior written informed consent to, and of their right to refuse, HIV testing. Surely if it is important to have women sign written informed consent forms before an abortion it is equally important to preserve their existing right to written, informed consent prior to HIV testing, and their right to refuse such testing.

Against:

While physicians should be able to perform HIV testing as indicated to appropriately manage their patients medically and without fear of liability, nevertheless, to target only pregnant women for mandatory HIV testing will harm rather than enhance the physician-patient relationship, possibly to the detriment of the health of the pregnant woman and her fetus.

The American Academy of Pediatrics, 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 American Academy of Pediatrics (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. However, pregnant women who do test positive for HIV still will need to voluntarily participate in recommended therapies, and, as Dr. Fleischman points out, 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.

Against:

The bill isn't necessary, since Michigan already has a law (Public Act 491 of 1988, enrolled Senate Bill 1041) which requires the HIV testing of all pregnant women at their initial prenatal examination. This testing is accompanied by pre-test counseling and requires the woman's informed consent. Women who turn out to be HIV-infected receive counseling to deal with the test results and their implications, receive the care they need before the baby is born, and are taught how to take precautions to protect themselves and their babies. Women who don't receive prenatal care could get HIV counseling and testing at the time of delivery or shortly after the baby was born. As written testimony from the state medical society indicates, women can refuse to have the test done, but rarely do so.

Response:

Given that the primary way 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 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). 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. informed consent is important, the public health concerns in this instance surely outweigh women's rights to bodily privacy. And while refusal of tests currently recommended for pregnant women is rare, even those refusals should not be permitted. What is more, 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. Finally, 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.

Against:

The bill doesn't go far enough. If the point of the bill is basically to let mothers know when they give birth to HIV infected babies, then it should do so. That is, if a newborn was tested for HIV, the baby's identity should be recorded so that if the test results were positive the mother 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. The bill would achieve virtually the same results without jeopardizing this federal grant money.

Against:

The bill would constitute an unwarranted invasion of a woman's right to bodily integrity. Given the social stigma still associated with AIDS, moreover, mandatory HIV testing of pregnant women could result in them avoiding future medical care, including medical care during their pregnancies. Requiring mandatory HIV testing assumes that women are incapable of making the right decisions for themselves and their offspring, and relegates to "big brother" decision making powers that rightly belong with the individual. Rather than treat women like convicted criminals -- and rather than begin the obstetric care relationship in an atmosphere of coercion rather than trust -- women

should be given the information and support they need to make decisions about themselves and their offspring. Women should not have their fundamental right to self-determination diminished in this way.

Response:

Unlike convicted HIV-infected sex criminals, who can infect others only through further criminal actions, HIV-infected women can and do infect others -- their offspring -- who have no say in the maternal-fetal relationship. What is more, 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. In addition, not all pregnant women are competent to make these kinds of decisions, whether because of youth or for other reasons. Finally, as a number of people pointed out, 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.

Reply:

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.

Secondly, with regard to the so-called right to refuse treatment: this "right" appears nowhere in the Public Health Code. A right that doesn't exist in statute and of which an individual is unaware 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.

POSITIONS:

The Department of Public Health supports the bill. (3-25-94)

The Michigan State Medical Society supports HIV testing during pregnancy but has concerns about the targeting of pregnant patients for mandatory HIV testing, believing that physicians should be able to perform HIV testing on patients as indicated for appropriate medical care. (3-24-94)

The National Organization for Women - Michigan Conference has not yet taken an official position on the bill, but has concerns about it. (4-8-94)