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REPRODUCTIVE HEALTH CARE, AIDS AND PUBLIC POLICY IN MISSOURI

Erika Schwenn Fox*

Reproductive health care providers and educators are an extremely important line of defense against the spread of Acquired Immune Deficiency Syndrome (AIDS) through heterosexual and perinatal transmission. These agencies prevent the spread of the human immunodeficiency virus (HIV) through a number of services. Such services include: risk assessment; HIV testing, counseling and referrals; pregnancy prevention and counseling; diagnosis and treatment of sexually transmitted diseases (STDs); and community and patient education about AIDS risk reduction and infection prevention. Unfortunately, current Missouri law and resource allocation relating to AIDS and other reproductive health matters hamper the ability of the reproductive health community to play this key role.

EXPANDED ROLE OF REPRODUCTIVE HEALTH PROVIDERS

Reproductive health care providers' critical role in the prevention of AIDS flows from the fact that the three major modes of HIV transmission today are: 1) through sexual contact involving the exchange of semen or vaginal secretions; 2) from mother to fetus in utero, during birth or through breastfeeding; and 3) between intravenous (IV) drug users who share unsterilized needles and syringes. Accordingly, among those groups classified by the Center for Disease Control (CDC) as being at high or increased risk of HIV infection are: homosexual and bisexual men, IV drug users, hemophiliacs, sexual partners of those in the first two groups, babies born to HIV-infected mothers, and heterosexuals who have had multiple sexual partners or a history of STDs.

Family planning clinics, which nationwide serve five million sexually active women a year (primarily those who are young and low income), are in an ideal position to slow this epidemic. This is bolstered by the fact that eighty

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percent of the women currently diagnosed with AIDS are of reproductive age.\textsuperscript{8} In recognition of this, the Office of Population Affairs, U.S. Department of Health and Human Services, the federal agency which administers the Title X national family planning program,\textsuperscript{4} issued the following directive for program participants:

All Title X clinics must offer, at a minimum, education on HIV infection and AIDS, counseling on risks and infection prevention, and referral services. Other services such as risk assessment, counseling about testing and administering tests may also be provided. If other resources are unavailable, Title X funds may be used to support these services. Of particular importance is the role of Title X projects in offering effective methods of family planning to sexually active HIV-infected women who run a high risk of perinatal transmission in pregnancy and who run a significant risk of transmitting HIV to other sexual partners.\textsuperscript{5}

Despite the increased educational and counseling requirements imposed by this Title X program instruction on AIDS, federal Title X family planning funds did not increase commensurately for Missouri's twenty-six participating agencies serving 80,000 women annually. Nor was there a significant increase from state-controlled revenues for such educational activities beyond funds for training of reproductive health care workers. In fact, $100,000 of the state's $1.2 million AIDS education and prevention budget was recently shifted to pay operating expenses for a Kansas City AIDS hospice.\textsuperscript{6}

Missouri's general failure to provide for prevention programs in the area of reproductive health is reflected in the state legislature's failure to appropriate any general revenue funds to family planning programs except where required for federal program match.\textsuperscript{7}

Statistics compiled by the Missouri Department of Health from 1982 through October 14, 1988, indicate that 25 women in Missouri have been reported as having AIDS. While only one child is reported to have contracted AIDS through perinatal transmission,\textsuperscript{8} the number of women and children infected with HIV who have not developed the disease is not known. Missouri

\textsuperscript{4} 42 U.S.C. § 300a-d (1982).
\textsuperscript{5} Dep't of Health & Human Services, Memorandum from Nabers Cabiness, Office of Population Affairs Program Instruction Series OPA-87-4: AIDS Education, Counseling and Testing in Title X (Dec. 8, 1987).
\textsuperscript{8} Telephone interview with Jim McDonald, Missouri Dep't of Health, AIDS Prevention Bureau (Oct. 1988). These numbers represent 3.4% and 0.1% respectively of the 730 total AIDS cases reported through October 14, 1988.
now participates in a nationwide, federally funded CDC survey to determine how common HIV infection is in women giving birth. This anonymous testing of approximately 62,000 of the babies born annually in Missouri will provide that information. Using these test results, both heterosexual and perinatal transmission rates in Missouri can be estimated.9

In the meantime, similar studies indicate that in New York City, where IV drug use is prevalent, 1.64 percent of all babies are born to infected mothers. That study estimated that 1,000 infected infants would be born in New York state in 1988.10 Others estimate that, although San Francisco and New York City accounted for 40 percent of all AIDS cases in 1986, they will account for less than 20 percent of the nationwide total by 1991, as patterns of transmission established there are replicated across the country.11 Most ominously, during the past two years, the largest growth in new AIDS cases has been in heterosexual partners of infected individuals and in children whose mothers abuse drugs or are sexual partners of high risk men.12

State officials should consider these studies and projections a signal that it is time to spend money on education and prevention services available through the 100 family planning clinic sites in Missouri. G. Stephen Bowen, deputy director of the CDC's AIDS program, warns "not to be complacent about the overall low level of infection in the general population," but to learn how to take advantage of the opportunity that such clinics have to slow the spread of infection among homosexuals before it explodes.13 This service network needs additional funding to carry out its expanded public health responsibilities. Additional state appropriations would also allow such agencies to reach more women in need of reproductive health care, including AIDS prevention services.

HIV TESTING: MANDATORY NAME REPORTING

The AIDS statute passed by the General Assembly during the 1988 session focusses upon HIV testing.14 Excellent legislative leadership and a determination by most members of the Assembly to address important public health issues in a responsible way resulted in an approach which rejects large-scale, expensive mandatory screening of low risk populations. Implicit in this approach is an emphasis on encouraging voluntary testing to allow higher risk

11. INSTITUTE OF MEDICINE, supra note 1, at 52.
12. Id. at 51.
13. Donovan, supra note 2, at 138 (citing an address by G. Steven Bowen at the Planned Parenthood AIDS Working Meeting (June 8, 1987)).
persons to obtain the information and assistance they need to make important decisions about healthier behaviors.¹⁵

The necessary encouragement for voluntary testing can be provided through several mechanisms. These include: 1) provision of free testing; 2) assurance of absolute confidentiality; and 3) public education and laws which make it clear that the state will not tolerate discrimination against persons with AIDS or HIV infection.

With the help of the federal government, the Missouri Department of Health is making free HIV testing and counseling available on a voluntary basis in a variety of settings around the state.¹⁶ The General Assembly has also wisely included provisions of its AIDS law¹⁷ which extend the anti-discrimination protections of the state human rights law¹⁸ to those with HIV infection and AIDS. Unfortunately, the panic created in the wake of an AIDS epidemic, may make such protections insufficient to deter discrimination and the loss of important support systems for those affected by this disease.

Until non-discrimination becomes the rule, all involved in testing, counseling and reporting must guard the confidentiality of those testing positive for the virus. Without such confidentiality, many who need and want to be tested will fail to do so.¹⁹ Missouri's new law requires that health care facilities conducting testing “shall report to the department of health the identity of any individual confirmed to be infected with HIV.”²⁰ There is evidence that this requirement deters high-risk individuals from testing.²¹ For reproductive health care clients, the decisions and activities dealt with in AIDS education, testing and counseling process are intimate. They include discussions and decisions about sexual contacts and practices, personal relationships and marriage, contraception, childbearing, abortion and STD prevention. They also may involve discussion of illegal drug use.²² To effectively participate in such discussions with a health care professional, clients must deeply trust that

¹⁵. Institute of Medicine, supra note 1, at 69-70.
¹⁶. Bureau of AIDS Prevention, Missouri Dep't of Health, Fiscal Year 1989 Budget (1988). This document shows that nearly one million dollars will be spent on HIV counseling and testing sites.
²⁰. H.B. Nos. 1151 & 1044, § 2(3).
professional. The trust must be grounded in an assurance of strictest confidentiality.\textsuperscript{23}

Under our present law, if a reproductive health clinic wishes to offer its clients on-site testing — and still maintain a relationship of trust — it must clearly warn in pre-test counseling of its obligation to report the client’s name and address to the State if the test results are positive. It must also warn of the consequences which could flow from such a revelation. This warning will either deter the client from taking the test or greatly increase her apprehension if she — or he — agrees to proceed. If, instead, the client chooses referral to an anonymous test site in Kansas City, St. Louis or Springfield,\textsuperscript{24} she may fail to show up for testing. Even if she does proceed with anonymous testing, she will lose the benefits of continuous reproductive health care (and the established relationship of trust) which is possible only if testing and services are available at the same site.

The public health considerations encouraging voluntary testing and facilitating continuity of care should be sufficient arguments against Missouri’s mandatory name reporting provision. However, more ominous possibilities counsel that it should be repealed.

Despite assurances of strict confidentiality contained in the law itself,\textsuperscript{25} as well as in information about the law’s operation distributed by the Missouri Department of Health, reports of breached confidentiality involving similar government lists cast doubt upon the ability to safeguard the information. Some lists have been lost or stolen.\textsuperscript{26} In other incidents, names of persons with AIDS have been improperly revealed.\textsuperscript{27}

Beyond these unfortunate incidents is the spectre of possible future legislative action permitting additional disclosures or mandating repressive measures such as isolation of those on the State’s list. Comments by public figures about tattooing and quarantine are reminiscent of the medieval treatment of bubonic plague and leprosy. As with AIDS, both diseases were deemed by many to be divine judgment for sinful behavior. Victims were stigmatized and scapegoats were found. In both cases, the public health response was to isolate the afflicted.\textsuperscript{28} Nor has more recent public health response to epidemics been

\begin{footnotes}
\item[23] Francis & Chinn, \textit{supra} note 1, at 1364.
\item[24] These three anonymous test sites were provided for in H.B. Nos. 1151 \& 1044, § 13(1), after much opposition to mandatory name reporting surfaced during consideration of the House Bills.
\item[25] H.B. Nos. 1151 \& 1044, § 3(1).
\item[28] \textit{Comment, supra} note 27, at 193-96.
\end{footnotes}
devoid of such stigma, scapegoating and punishment. There is a striking simi-
larity between the reaction to AIDS and the reaction to venereal disease out-
breaks in the early twentieth century. Then, suspected carriers were detained
and isolated. Their rights were ignored.\(^{29}\)

Some legal commentators seem to conclude, however, that name reporting
in itself may withstand a constitutional challenge so long as the information
sought is reasonably related to a valid public health purpose and as long as
statutory confidentiality protections are provided.\(^{30}\) Others argue that develop-
ments in the law, particularly in the area of privacy rights, may offer relief
from disclosure requirements.\(^{31}\) Perhaps the keys to the analysis of this ques-
tion are considerations of the public health interests served by reporting re-
quirements and whether those interests can be served without jeopardizing in-
dividual rights.

During consideration of Missouri's present AIDS Law (H.B. Nos. 1151
and 1044), Missouri Department of Health lobbyists insisted that mandatory
name reporting of HIV infection was needed for the adoption of a contact
tracing system. Such a system allows notification of sexual or IV paraphenalia
partners of infected individuals. A Health Department memorandum reiter-
ates this reason and adds that names are also necessary to assure that duplica-
tate reports do not occur.\(^{32}\)

But, name reporting to the State is not necessary to accomplish partner
notification. Once the index person (first person tested in a chain) gives his or
her partners' names to the post-test counselor for notification purposes — or
agrees to notify contacts him or herself, there is no need to send the index case
name into a registry in Jefferson City. Notification occurs at the local level
and does not reveal the name of the original patient.\(^{33}\) That such notification
can occur under anonymous testing conditions is clear from section 13(4) of
the AIDS statute. That section requires anonymous testing site personnel to
initiate contact notification when discussing positive test results with the in-
fected person. Similarly, test sites can use a unique, coded patient identifier to
report AIDS cases to the State, allowing interception of duplicate test results
while still providing demographic and risk factor information. This would be
more reliable that the pseudonyms now often given by test takers and which
may change from test to test.\(^{34}\)

An analysis of these procedures casts doubt on the State's claims that

\(^{29}\) Brandt, *A Historical Perspective*, in AIDS AND THE LAW 37-43 (H. Dalton
& S. Burris eds. 1987).

\(^{30}\) See, e.g., Gostin, *Traditional Public Health Strategies*, in AIDS AND THE


\(^{32}\) Missouri Department of Health, Confidentiality From the Clinical and De-
partment of Health Perspectives (undated memorandum).

16, 1988, at B-1, col. 1.

\(^{34}\) *AIDS Victims Shun Name Requirement*, supra note 21.

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name reporting is necessary. When the detrimental public health effects of such reporting requirements are taken into account, it appears that whether or not the requirement passes constitutional muster, it does not make good policy sense. As already discussed, testing disincentives created by this reporting requirement result in fewer high-risk individuals being tested. As a consequence, the public health community does not receive the needed statistical surveillance information, it loses a powerful mechanism for education, prevention and behavioral change, and fails to notify unsuspecting partners. The chief public health officer for the United States, Surgeon General C. Everett Koop, opposes mandatory name reporting.\(^\text{35}\)

Thus, in balancing public health considerations alone — even disregarding threats to individual rights — those formulating this year’s AIDS bill should work to repeal the name reporting requirement. Instead of name reporting, they should devise a system which gives the state the statistical surveillance information it needs to track transmission patterns and plan for health needs, but which makes individual health provider testing sites the sole guardians of their confidential records — a responsibility for which they are best prepared.

Under such a system, reproductive health care providers would be more eager to provide on-site HIV testing and counseling services. They would be secure in the knowledge that their confidential relationship with clients will remain intact and continuity of medical care and education will be promoted.

**Pregnant Women Who Test Positive for AIDS: Their Options**

Reproductive health care facilities provide more than just general information about the transmission and prevention of AIDS. In many cases, such facilities may be a high-risk woman’s only contact with the health care system. In any medical facility where women at risk are encountered, health care providers must be able to initiate conversations about sexual practices and partners, as well as about protection from both HIV infection and unplanned pregnancy. If a risk assessment indicates that a woman is or has been at risk of infection, on-site HIV testing and counseling can give her information as to her own status. It can also teach her how to prevent sexual or perinatal transmission to others, if she is already infected.\(^\text{36}\)

In an ideal situation, reproductive health care facilities could reach all women before they are infected. However, in reality many are now infected. Thus, the public health community must educate such infected women, about the risks to their own health and that of children they might bear if they were to become pregnant. Access to effective birth control is doubly important for

\(^{35}\) See Surgeon General’s Report on Acquired Immune Deficiency Syndrome 30 (Oct. 22, 1986) [hereinafter Surgeon General’s Report]. A similar recommendation is contained in Institute of Medicine, supra note 1, at 82.

\(^{36}\) See Am. Ob./Gyn., supra note 22, at 3; Donovan, supra note 2, at 112-13.
these women. Studies suggest that the probability of HIV transmission from mother to infant is in the range of 30 to 50 percent and may be higher if the mother shows symptoms of infection during pregnancy.\(^3\) Newborns have the highest progression rate from HIV infection to AIDS.\(^3\) Most become ill during the first one to two years of life.\(^3\) Further, some limited evidence indicates that pregnancy may speed the progression rate for infected women due to immune system changes during pregnancy.\(^4\) Finally, 80 percent of perinatally-infected children come from families where drug abuse is a serious problem. This and progressive maternal illness may interfere with their ability to care for their newborn. Hospitals sometimes become the "home of last resort" for these children.\(^4\)

Health care and reproductive service providers should review these risks with an HIV-infected woman who becomes pregnant. They should apprise her of the option to terminate the pregnancy.\(^4\) Unfortunately, such options counseling in pregnancy is threatened in Missouri by the 1986 Missouri act regulating abortions.\(^4\) Three provisions of that act\(^4\) prohibit expenditure of public funds, action of public employees and use of public facilities "for the purpose of encouraging or counseling a woman to have an abortion not necessary to save her life." A United States district court permanently enjoined the State from enforcing these provisions, holding them unconstitutional. While that ruling was upheld in \textit{Reproductive Health Services v. Webster},\(^4\) Missouri’s Attorney General has appealed the case to the United States Supreme Court. Should the prohibition against the use of public funds for such counseling again become effective, discussions between HIV-infected pregnant women and their health care providers about pregnancy termination would be severely limited — particularly where state-controlled funds are used to do AIDS counseling.

Another Missouri statute\(^4\) also limits the options of women in this situation. This law denies Medicaid coverage for abortions unless the life of the mother would be endangered if the fetus were carried to term. In view of the uncertain evidence about the effect of pregnancy on the progression of AIDS,

\begin{itemize}
  \item 38. \textit{Institute of Medicine}, \textit{supra} note 1, at 36.
  \item 39. \textit{Am. Ob./Gyn.}, \textit{supra} note 22, at 4.
  \item 41. \textit{Institute of Medicine}, \textit{supra} note 1, at 95-96.
  \item 42. \textit{Am. Ob./Gyn.}, \textit{supra} note 22, at 4.
  \item 44. \textit{Id.}
  \item 45. 851 F.2d 1071 (8th Cir. 1988). The court held that the words "counsel" or "encourage" are "void for vagueness" and that the prohibition interferes with a woman's privacy right to consult her physician about abortion. \textit{Id.} at 1077.
\end{itemize}
few physicians might risk certification of life endangerment. Yet denial of funding in cases such as these is usually tantamount to denial of the option to terminate the pregnancy altogether.47

Thus, the current AIDS crisis and the problems of HIV-infected pregnant women calls for the General Assembly to abandon its "kneejerk" reaction to abortion-related legislation and give serious consideration to situations like these where fatal fetal conditions, and other tragic circumstances, dictate a more compassionate approach — both to funding of, and discussions between a woman and her physician concerning pregnancy termination.

EDUCATION: BEST HOPE FOR THE FUTURE

In its 1988 AIDS update, the National Academy of Sciences reiterated its view of the importance of education in the fight against AIDS: "Educational efforts to foster and sustain behavioral change remain the only presently available means to stem the spread of HIV infection."48 Thus, the most striking omission in the Missouri legislature's bills in the 1988 session was that, as originally introduced, they made no provision whatsoever for public education about AIDS. The education provisions which eventually became section 7 of the AIDS statute were proposed as an amendment by representatives of reproductive health organizations who knew the importance of education in changing attitudes and high-risk behaviors.

Given the paramount importance of AIDS education, most reproductive health care agencies offer community education programs in addition to patient education. A large percentage of recent community programming requests have been for sessions on AIDS. In order to extend this service further into the community, a natural source of funds would be state revenue earmarked for AIDS education.

Remembering Missouri's usual reluctance to fund preventive efforts, it is no surprise that the FY89 budget for the Bureau of AIDS Prevention showed that only one-sixth of its composite state-federal dollars ($530,238) was devoted to primarily prevention activities.49 One of the challenges of AIDS policy in the coming year should be to increase the amount and percentage of funds devoted to education and other AIDS prevention efforts.

In addition to the lack of funds, state funded educational efforts may be restricted by language in the AIDS statute. This language prohibits the preparation or provision of materials and programs which "promote" behavior that is made criminal by laws relating to homosexuality, illegal drugs, incest or

47. Mo. Rev. Stat. § 188.205 (1986) also prohibits the expense of any public funds for the purpose of performing or assisting an abortion. That portion of the Act has not been held to be unconstitutional.
48. INSTITUTE OF MEDICINE, supra note 1, at 64.
49. $530,238 out of the $3,278,904 total is designated for health education and risk reduction. Of the state monies totaling $1,366,786, just over 10% of it falls in the prevention category.
prostitution. This prohibition conflicts with the requirement in a preceding subsection that risk reduction programs be prepared "for specific populations at high risk of HIV infection." This prohibition should be modified or eliminated. It would be irresponsible and callous to prohibit the presentation of materials which would be most effective in changing the behavior of those most at risk for HIV infection: homosexuals and bisexuals, IV drug users and women with multiple partners.

The National Academy warns that those concerned about the immorality of straightforward public health programs are inhibiting educational efforts:

The Committee believes that government at all levels, as well as private sources, should continue to fund effective, factual educational programs designed to foster behavioral change. This may mean supporting AIDS education efforts that contain explicit, practical, and perhaps graphic advice targeted at specific audiences about safer sexual practices and how to avoid the dangers of shared needles and syringes.

Those who have difficulty with such recommendations are the same people who have stood in the way of meaningful sexuality education programs for Missouri's schools. They believe that by recognizing and attempting to modify a behavior, such as the sharing of IV drug paraphernalia, one is condoning the use of illegal drugs. Similarly, with a rigid "Just Say No" attitude toward sexuality, they have blocked the development of effective teen pregnancy prevention programs. Unfortunately, with AIDS the stakes are even higher.

With these sorts of problems in mind, the Surgeon General recommended: Education concerning AIDS must start at the lowest grade possible as part of any health and hygiene program. The appearance of AIDS could bring together diverse groups of parents and educators with opposing views on inclusion of sex education in the curricula. There is now no doubt that we need sex education in schools and that it must include information on heterosexual and homosexual relationships. The threat of AIDS should be sufficient to permit a sex education curriculum with a heavy emphasis on prevention of AIDS and other sexually transmitted diseases.

The AIDS statute requires the Department of Elementary and Secondary Education to "prepare educational programs for public schools, regarding means of transmission and prevention and treatment of the HIV virus," to include, without limitation, "[m]edically correct, age specific, transmission and prevention programs for use at the discretion of the public schools beginning with students at the sixth grade level. The educational programs shall stress moral responsibility in and restraint from sexual activity and avoidance of controlled substance use whereby HIV can be transmitted.

51. Id. § 7.1(2).
52. INSTITUTE OF MEDICINE, supra note 1, at 65.
53. SURGEON GENERAL'S REPORT, supra note 35, at 31.
55. Id. § 7.1(1).
This is merely a beginning. It is far from a state mandate to offer AIDS education in every public school in Missouri. Twenty states and the District of Columbia had such a mandate as of April 11, 1988. In some of these states, it has come in the form of newly mandated comprehensive health education for all grades. Other states, where the health and education departments have worked for years for comprehensive health education, find “increased support for the idea.”

States like Missouri, with no current requirement for a health education program in every school, are finding it more difficult to provide AIDS education as promptly as is needed, and there is doubt that AIDS information makes sense to children without the broader context. The Presidential Commission on the Human Immunodeficiency Virus Epidemic addresses the issue:

The Commission strongly believes that the introduction of an age-appropriate comprehensive health education curriculum that encompasses grades K through 12 is long overdue. Providing our nation’s school children with education about HIV transmission, as recommended in the near-term response section, is a significant step. However, it represents only a stop-gap measure to correct a larger problem. The expert witnesses who testified before the Commission clearly demonstrated that the problems that are afflicting youth today — such as sexually transmitted diseases including HIV infection, drug abuse, school-aged pregnancy, and decisions to drop-out or run away — are all inseparably intertwined. The HIV epidemic provides a unique impetus to address these problems in total rather than continue the piecemeal, fractured, and largely ineffective approach that is being undertaken today.

Hopefully this impetus will serve such a purpose in Missouri. As a result of a statute passed in 1987, the “Coordinating Council for Health Education of Missouri’s Children and Adolescents” has been charged with developing models for comprehensive health education and otherwise making recommendations relating to health education for Missouri’s children. Their report is due December 31, 1989.

If they do their work well, public health policy in Missouri will benefit in both the short and long run, and the State will be ready to face its next health crisis with greater understanding, tolerance and commitment to a preventive approach.

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57. Id. § 2.
58. Id.