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THE MISSOURI AIDS LAW: A PUBLIC HEALTH PERSPECTIVE

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INTRODUCTION

The Missouri AIDS Law1 enacted in 1988 marks a significant advance in the state's effort to contain the AIDS epidemic. This legislation, one of the first and most comprehensive AIDS laws of any state, clearly and objectively addresses AIDS as a public health crisis. The law incorporates legal and social concerns as well as sound public health measures for containing the AIDS epidemic. This Article will discuss those public health measures and begin to assess the impact this law will have in Missouri.

AIDS: THE MAGNITUDE OF THE EPIDEMIC

The potential economic and social impact of this epidemic is enormous. The Centers for Disease Control (CDC) in Atlanta rank AIDS as the eighth greatest cause of the loss of productive life.2 One of the tragedies associated with this epidemic is that AIDS is more prevalent among young adults, typically those responsible for supporting others. In New York City, AIDS is the leading cause of death among young adults.3

Missouri is not immune from the devastation. From 1982 until September 30, 1988, there have been 700 cases of AIDS reported in Missouri; 376 have resulted in death. Based on a Centers for Disease Control (CDC) formula, the Department of Health now estimates that between 15,000 and 30,000 Missourians are infected with HIV, the Human Immunodeficiency Virus causing AIDS. Epidemiologic studies show that 50 percent to 70 percent of those

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Published by University of Missouri School of Law Scholarship Repository, 1988
infected with the virus will advance to AIDS within 10 years. By the year 1992, the Department predicts 3,500 to 5,000 Missourians will be diagnosed with AIDS — 950 to 1,500 of them in that year alone.

MISSOURI'S RESPONSE

The long incubation period of the AIDS virus or Human Immunodeficiency Virus (HIV), coupled with the fact that there is no known cure, compels the Department of Health to use all proven public health measures to prevent further spread of HIV. The public health community has effectively used surveillance, education, counseling and testing, and partner notification in fighting other communicable diseases.

In 1987 Missouri became a leader among states in creating a comprehensive plan to combat AIDS; passage and signing of House Bills 1151 and 1044 were vital to the plan's success. The Eight Point Plan, announced in May 1987, provides for the assurances of confidentiality and protection against discrimination as well as the provision of care for those individuals affected by the AIDS virus. The points of this plan include 1) surveillance through named reporting of HIV seropositive individuals, 2) partner notification, 3) confidentiality and anti-discrimination safeguards, 4) expansion of counseling and testing, 5) public education, 6) provision of care, 7) management of non-compliant individuals and 8) restrictions against establishments implicated in the spread of HIV infection.

Missouri is fortunate that its 84th General Assembly and governor endorsed this aggressive and comprehensive plan. The Missouri AIDS Law directly addresses the legal and social ramifications of the AIDS epidemic. It endorses the state's comprehensive plan for AIDS and provides the basis for a public health response to this epidemic.

The public health response to any epidemic is first to characterize the disease and the persons who become ill, then to identify risk factors for becoming ill, and finally to develop and implement control measures to prevent further illness. While such a response seems simple and direct, nothing about the AIDS epidemic is simple. The fact that AIDS may be caused by socially unacceptable activities—either actual or perceived, the fact that it is a deadly disease for which there is no known cure and the fact that this disease has so many social ramifications make this standard response much more difficult to implement.

Public health focuses upon the community as a whole and strives to pro-


5. Centers for Disease Control, U.S. Dep't of Health & Human Services, 37 MORBIDITY & MORTALITY WKLY. REP., July 1, 1988, at 393-402; see also AMERICAN PUBLIC HEALTH ASS'N, TUBERCULOSIS (Vital and Health Statistic Monographs 1969).
mote and protect its health. At times individual’s rights must be carefully weighed against community rights so as to prevent further illness while assuring confidentiality. Such is the case in implementing a public health response to AIDS.

REGULATION OF LABORATORIES AND TESTING

The social, psychological, and medical implications of a positive HIV antibody blood test cannot be overstated. For that reason, laboratory testing must be accurate and of high quality. A positive test means that the person is infected. While one may or may not have AIDS when tested, he or she is probably infectious. Missouri’s statutory provision that regulates anti-HIV testing — both serological6 testing in the laboratory and counseling of the client — protects as well as educates the client. It is compatible with national policy.7 The new AIDS law offers safeguards to Missourians through the regulation of anti-HIV serological testing at all laboratories other than those in hospitals currently regulated under chapter 197 of the Missouri Revised Statutes. The Department of Health is expanding this laboratory program to encompass other laboratories that wish to perform serologic testing for HIV. The Department’s rule will regulate existing laboratory testing yet be flexible enough to accommodate new technological developments.

In addition to hospital laboratories licensed under chapter 197 of the Revised Statutes of Missouri, statutes empower the state to regulate laboratories that perform serologic testing for syphilis under the prenatal testing law,8 testing for metabolic diseases under the metabolic testing law,9 and all laboratories with Medicare certification.

Anti-HIV testing first became available in March 1985, with the development of a relatively simple and inexpensive enzyme linked immunosorbent assay test (ELISA).10 This test was designed to protect the nation’s blood supply. Thus, when in error, it is more likely to report the result as positive than negative. Such errors, known as false positives, are acceptable when the primary concern is protecting the blood supply by excluding potentially infected blood. But, they cannot be tolerated in testing individuals. The false positivity rate will vary according to the actual prevalence of infection in the population tested; the smaller the number of persons truly infected, the greater the potential number of false positives.

6. Serologic testing is the application of laboratory procedures to serum, a component of the blood. In HIV testing, the procedures attempt to establish the absence of presence of antibodies against HIV. The presence of such antibodies indicate that the person has been exposed to HIV.
10. See Centers for Disease Control, U.S. Dep’t of Health & Human Services, 34 MORTALITY & MORBIDITY WKLY. REP., Jan. 11, 1985, at 1-5.
The Western Blot analysis, a specialized research laboratory test, improved the accuracy of anti-HIV testing. It is more specific for antibodies to HIV than the ELISA test but requires subjective interpretation of the results. Therefore, only well-trained, proficient technicians should perform this test.

All Missourians should be assured high-quality, accurate laboratory testing. Such testing for HIV antibodies requires the combined application of these tests performed by only qualified technicians. The State Public Health Laboratory performs sequential testing using ELISA technology followed by supplementary Western Blot testing before confirming positive results. This sequential and supplemental testing reduces the risk of false positive results to 1 in 100,000 tests performed.

To assure confidentiality, the State Public Health Laboratory uses a numbering code for processing HIV antibody tests. It receives and processes blood samples using coded identification only. The health care professional at the testing site — whether a physician’s office, private clinic, or public health clinic — is responsible for matching the test results with the client’s name. Private laboratories must also adopt similar systems to assure confidentiality.

**REGULATION OF TESTING, COUNSELING, AND REPORTING BY NAME**

The Missouri AIDS Law recognizes counseling as a vital part of the anti-HIV testing process. The goal of counseling and testing is to reduce the spread of HIV by informing persons how to prevent transmission or infection and providing assistance and motivation to attain this goal. The pre-test counseling session is a frank, intensive discussion of how the virus is transmitted and is structured so clients can determine which behaviors put them at risk of infection.

During the post-test counseling session, counselors encourage clients to modify high-risk behaviors. If test results are negative, they advise how to avoid acquiring the infection in the future. If test results are positive, they advise how to avoid spreading the virus to others. The post-test counseling session begins the partner notification process, further reducing the spread of HIV. Also in the post-test counseling session, the counselor assists the infected client to obtain necessary social and mental health support and appropriate medical evaluation or care.

Case identification and subsequent counseling of infected individuals are sound, effective measures public health has used for years to control communicable diseases such as tuberculosis, syphilis, and gonorrhea.12

In managing those illnesses, counseling also served to gather important epidemiologic information. Using only the number of reported AIDS cases to

11. The Western Blot test analysis is a serologic test that establishes the presence or absence of antibodies to specific components of HIV.
12. A. BRANDT, NO MAGIC BULLET: A SOCIAL HISTORY OF VENEREAL DISEASE IN THE UNITED STATES SINCE 1880 (1985); see supra note 4.
judge the extent of the epidemic is inadequate. To control the epidemic, it is important that the Missouri AIDS Law provides for reporting confirmed seropositive\textsuperscript{13} individuals by name to the Department of Health. Epidemiologic\textsuperscript{14} information allows the Department to plan to meet the needs of infected populations and allows for accurate follow-up to assure that the Department provides individual education. Follow-up is essential to change at-risk persons' behavior, thereby reducing the spread of the virus. It also assures that individuals are aware of and have access to care and support.

**PROTECTION OF CONFIDENTIALITY**

With name reporting comes the issue of confidentiality. Missouri's AIDS Law is consistent with the long standing Department of Health policy that confidentiality is paramount. It provides legal safeguards for infected individuals, and rightfully extends the burden to protect confidentiality to society as a whole.

The Department always has demanded confidentiality in its activities. In more than sixty years the Department has never been responsible for a breach of confidentiality. In fact, there has been no substantiated breach of confidentiality by any public health agency involving AIDS.\textsuperscript{15}

Because of the potential conflict between the need to protect the community’s health and the individuals’ rights, protection of confidentiality has been a theme running throughout all public health actions. The public health response to this epidemic is similar to that used in containing other communicable diseases, and this approach continues to protect individual rights.

The AIDS epidemic has prompted the strengthening of state statutes and departmental policies so as to enhance the Department’s ability to keep information confidential. In addition, the Department’s post-test counseling not only assists individuals in coping with the knowledge of their infection, but teaches them to exercise discretion in sharing that information with others.

Disclosures permitted under this section of the Missouri Aids Law are consistent with the major mission of public health in containing this epidemic: to prevent the further spread of the virus and to ensure that those already infected receive adequate care. Disclosure may be necessary in planning to provide care (physical, social, or medical) to an individual such as a child in foster care. The need-to-know clause is a problematic aspect of permitted disclosure.\textsuperscript{16} Clear, situation-specific definitions of this need-to-know must be developed, reviewed, and applied when the section is invoked. This will insure the

\textsuperscript{13} H.B. 1151 & 1044, § 3.2(1)(a).

\textsuperscript{14} Epidemiology is a science that identifies the pattern of disease in a population, characterizes the risk factors for getting the disease and makes recommendations, based on this information, for controlling the disease.

\textsuperscript{15} Testimony by W. Cates, Jr. before the Presidential Commission on the Human Immunodeficiency Virus Epidemic (Mar. 18, 1988).

\textsuperscript{16} H.B. 1151 & 1044, § 3.1(1)(a)(b).
best interests and rights of the infected person are respected.

Hospitals medical files are confidential records. Law bars disclosure of the information in a patient's records. Missouri's AIDS Law extends protection to those infected by allowing test results to be included in a medical file only if the file will be afforded the same confidentiality of other medical records. To maintain test results in a separate portion of the file marked confidential would probably call attention to its presence. Further, medical care professionals obtain medical histories on which they base decisions. To provide incomplete information would not only be a disservice to the patient but as well could lead to devastating results if a misdiagnosis is made or inappropriate care is provided.

The Missouri AIDS Law contains a "common-sense" clause which requires infected people to inform health care professionals of their positive test results before receiving medical care. This both protects the patient and provides necessary information to health care professionals so that appropriate medical care will be given. Further, prudent practice and the Department encourage health care professionals to take universal precautions with all patients to protect themselves from becoming infected. Professionals need not modify these standard universal precautions to treat an HIV infected person.

In addition, the permitted disclosure to emergency personnel could not prevent infection of the worker since this disclosure would only occur after exposure but could prevent secondary spread, i.e., from the exposed worker to spouse. For this to be effective, exposures under this section must be qualified and must be reported to the employer on a routine basis.

Disclosure to mortuary personnel is already required by state rule but, as is the case with health care professionals, mortuary personnel should take universal precautions to prevent infection whether or not they have been informed.

A portion of the law that may need further review is the section that exempts physicians conducting research approved by an institutional review board from having to report the identities of participating individuals to the Department of Health. Aside from the loss of epidemiologic information, this exemption is questionable in that it may deny research subjects access to pretest and post-test counseling, care coordination, and partner notification. Institutional review boards must be willing to offer alternative support services to the research subjects.

The Department of Health is working to assure that every clinic in Missouri offers routine risk assessment and voluntary testing for HIV antibodies. The goal of this testing is to reduce the spread of HIV by teaching people how

18. H.B. 1151 & 1044, § 3.5.
19. Id. § 3.8.
to prevent transmission and to provide assistance and motivation in attaining this goal. Mandatory testing as required by the statute is warranted only for certain groups in which high risk behaviors are likely to be common (e.g., prisoners and intravenous drug abusers) and for other groups where there are specific, documented reasons to suspect infection and transmission but testing is refused.22

ANTI-DISCRIMINATION PROVISIONS

The Missouri AIDS statute’s anti-discrimination provisions are necessary to protect the rights of individuals infected or perceived to be infected with HIV. Counseling and testing, care coordination, partner notification, and requiring HIV infected persons to inform their health care professionals can only be accomplished in a climate which will protect persons from discriminatory treatment and loss of care. Epidemiologic information about HIV transmission continues to support initial findings that HIV is not transmitted through casual contact.23 Normal interaction with HIV infected individuals in the workplace, in housing units and households, in stores, and in schools will not transmit the AIDS virus. Certain health care professionals, emergency personnel, and other care providers are at increased risk of exposure when caring for infected individuals. However, this risk is lessened by implementing precautionary techniques, information on which has been widely disseminated to these groups.24 Despite such knowledge about casual contact, a genuine but unfounded fear has led to discrimination.

Educational campaigns can alleviate fear but cannot replace swift implementation of legal safeguards. Unwarranted discrimination must be stopped if the epidemic is to be stopped. While Missouri’s AIDS Law begins to provide protection, the anti-discrimination provision must be broadened.25 Only qualified health authorities should determine when an individual poses a direct threat to the health and safety of others. That determination can still protect against discrimination if it is based on scientific fact, not fear.

EDUCATION PLANS AND PROGRAMS

The most effective, available means of reducing the spread of infection is frank, intensive education about the nature of HIV infection, how it is transmitted, and the precautionary choices available. The Missouri AIDS Law mandates comprehensive age, group-specific, educational and public awareness

22. H.B. 1151 & 1044, § 4 (prisoners), § 5.1 (IV drug abusers and “other groups”), § 9 (“other groups”).
programs. The Department, clinics, schools, and other groups and institutions must use all possible means to convey the truth about the modes of transmission and to teach infection prevention at a level that can be understood by the targeted population. The Department of Health emphasizes avoiding, or at the very least, modifying high-risk behaviors.

Education at all levels is necessary to dispel misconceptions that lead to unfounded fear, that fuel discrimination, and that allow people to continue to practice risky behavior. General awareness campaigns also combat the misconceptions about AIDS and are necessary. However, such education must go beyond merely communicating facts about AIDS; education must motivate individuals as well to avoid or change certain behaviors. But the success of such education depends not only on disseminating education; it also is founded upon an understanding of the concepts of human behavior. Families, children, adolescents, minorities, and persons who practice high risk behaviors; as well as health care professionals must receive targeted education.

**AIDS and Insurance**

The insurance industry has always practiced a form of discrimination in issuing policies. Good fiscal management requires that companies assess a population before assuming the risks associated with its members. For this reason, AIDS legislation must somehow assess acceptable and unacceptable discrimination as the state's insurance industry deals with anti-HIV testing and HIV infected individuals. Providing health care to this group is necessary to contain the epidemic. The prohibition of insurance industry discrimination against HIV infected or at-risk people promotes testing.

In striving toward this prohibition, the Missouri AIDS Law provides that continued coverage of insured persons who become infected with HIV cannot be denied or altered solely because of HIV infection. However, safeguards must be established to ensure that only consistent, uniform criteria are used to deny, cancel, or alter insurance coverage.

The Missouri AIDS Law addresses the issue of assuring the quality and accuracy of insurance company laboratory testing. Laboratories that perform anti-HIV testing for any Missouri insurance company must comply with the standards of national organizations referred to in the law. These standards will be as strict as state serologic testing requirements.

Under authority granted in the Missouri AIDS Law, the Division of Insurance is establishing rules for anti-HIV testing. These standards should assure that adequate post-test counseling is provided when an applicant receives positive test results.

26. *Id.* § 7.
27. *Id.* § 8.2.
28. *Id.* § 8.4.
29. *Id.* § 8.1.
The law’s confidentiality safeguards must be strengthened. 30 In the proposed rule, test results disclosure clearly requires the applicant’s written permission. However, applicants must be given the added protection against discrimination through misuse of test results. The current law holds the company accountable for maintaining confidentiality. This responsibility, and the penalties for breach of confidentiality, must be extended to include each employee of the insurance company.

NONCOMPLIANT INDIVIDUALS

Only when every available public health measure has failed to modify behavior in an infected individual must legal action be taken to protect others. There are occasions when people infected with HIV resist modifying their behavior. This occurs, for instance, when destitute individuals return to prostitution or try to obtain money by selling blood; or when one without adequate support services to cope with their illness strikes out by deliberately infecting others. There may be times when a person may not be aware of their actions because of impaired judgement caused by the illness. Whatever the reason, law enforcement and public health officials must take action to stop the spread of infection and to provide appropriately for such people.

The Missouri AIDS Law provides for the management of noncompliant people, 31 but enforcement officials need accurate and complete information before they take action. This includes documentation of infection and counseling for behavior modification, documentation that the person’s behavior constitutes a scientifically recognized mode of transmission, and documentation that all other attempts to change their behavior have failed. The Department of Health will assist prosecuting attorneys in collecting this information and evaluating these conditions.

THE REPORT OF AIDS IN MISSOURI TO THE GENERAL ASSEMBLY

The Department of Health’s regular report to the General Assembly, mandated by the Missouri AIDS Law, 32 will keep members informed of the status of the epidemic and the public health measures taken to control it. Governmental bodies are responsible for the welfare of the people and must have accurate and timely information with which to make their decisions.

PREMARITAL TESTING

Missouri AIDS Law gives the Department of Health authority to promulgate a rule for testing individuals applying for marriage licenses when

30. *Id.* § 8.
31. *Id.* § 10.
32. *Id.* § 11.
scientific evidence indicates the need for such testing.33

Premarital testing for AIDS is considered largely because it was previously effective in controlling syphilis. Missouri instituted premarital screening in 1943 and abandoned it in 1980 because it was no longer useful in finding syphilis cases. Other public health methods of syphilis control — screening of high risk groups, prenatal screening, name reporting and partner notification — were found much more effective.34

The Department currently recommends voluntary premarital testing and provides information about HIV infection to all applicants for marriage licenses. If the Centers for Disease Control determine premarital screening for HIV to be an effective public health measure, the Department has the authority to implement such a rule.

ANONYMOUS AIDS TESTING

The Missouri AIDS Law calls for three anonymous testing sites in St. Louis, Kansas City and Springfield.35 These sites were established on September 6, 1988.

The role of anonymous testing in containing the AIDS epidemic remains unclear. Some fear that names of individuals testing positive for HIV will not be held in confidence by public health agencies. They argue that this fear discourages testing.

While the Missouri General Assembly debated the issue of anonymous testing, data from Colorado indicated that the implementation of named reporting did not seem to reduce the number or type of persons being tested.36 Missouri experienced a 300 percent increase in testing despite the implementation of named reporting in October 1987.37 Only one study indicates that offering anonymous testing encourages persons with certain risk behaviors to present themselves for testing.38 As stated before, named reporting and partner notification have been effective in controlling other sexually transmitted diseases.

The State of Missouri offers confidential and anonymous testing and performs partner notification for HIV-infected persons. The Missouri AIDS Law and analysis of state-funded AIDS activities will provide the answer to whether anonymous testing is more effective in preventing the spread of AIDS

33. Id. § 12.
than named reporting including partner notification.

PARTNER NOTIFICATION

The Missouri Law mandates partner notification for those who test positive at the anonymous test sites. As stated above, the Department of Health has initiated a program of partner notification for those who test positive. It has always been public health officials’, medical care providers’, and other health care delivery personnel’s duty to assure that accurate information and proper care is available to the public. In many cases, more than only treatment was necessary. Information was delivered directly to individuals, such as those exposed to tuberculosis, typhoid, smallpox, syphilis, hepatitis and other serious diseases. This system of notification and information provision is a basic function and duty of public health. No matter how limited the intervention, it should be provided. The duty to warn is implicit, in fact central, to the philosophy of public health.

Health care providers must spread this confidence in the duty to warn to HIV seropositive clients. Everyone exposed to HIV must have the opportunity to understand their risk of infection and alter their behavior accordingly. To this end, the American Medical Association recently endorsed physician’s responsibility for warning either personally or through public health agencies.

Physicians and other health care providers must recognize their obligation to the community as well as to their individual patients. While physicians may focus exclusively upon their patients and overlook that each patient is part of a community, no infectious disease can be treated as a single case. Physicians must cooperate with public health more than ever to protect the community as a whole. The medical delivery system needs to work as a team with public health to provide care and prevention to all.

CARE COORDINATION

Because of the magnitude of the epidemic and the expected toll in human suffering, consideration must be given to the spectrum of care that will be necessary. Although those with AIDS do not require inpatient medical care for the majority of their illness, they require a variety of alternative services. These include outpatient services, home care by skilled nurses, homemaker/chore worker services, and hospice services. Persons who receive adequate health care and support are more capable of maintaining a risk-free lifestyle, which is an important component in controlling the epidemic.

Care coordination, or health care planning, is responsible for locating, coordinating and monitoring services to promote effective and efficient access.

For HIV infection, health plans must address persons at three levels: those infected but asymptomatic, those with evidence of disease but not diagnosed with AIDS, and those diagnosed with AIDS. The Department of Health's efforts to develop a care coordination system will be included in its report to the General Assembly.

Health care professionals must be willing to provide this care. Educational and fiscal considerations also must be addressed. By dispelling myths, health care provider training can assure that persons with AIDS receive appropriate medical care and can enhance the availability of alternative care methods. Often less skilled, therefore less expensive, care is appropriate. Many AIDS patients' lack of financial resources and the restrictions on Medicaid reimbursements are potential problems in care provision.

THE SPREAD OF AIDS THROUGH ESTABLISHMENTS

Some establishments, such as bathhouses that facilitate or promote high-risk behavior, have been implicated in the spread of HIV infection.41 The Law authorizes restrictive measures when there is evidence for such implication.42 Here, as in cases of noncompliant individuals, the rights of an individual or business must be weighed against the need to protect the community. Only with the cooperation of local health and law enforcement officials can proper control over such establishments be achieved.

AIDS AND SCHOOLS

Missouri has an unblemished record in providing education to HIV infected students. The Department of Health has assisted a number of school districts in developing policies related to chronic communicable diseases including HIV infection. In each situation, one thing remained clear: school-aged HIV infected children can remain in school and enjoy confidentiality, privacy, and access to medical care. These students can receive an education in a safe, normal school environment. The Missouri AIDS Law assures that this will continue.

Before the Department of Health or the parents must disclose the identity of an infected student to school authorities, the school must adopt a policy consistent with the recommendation of the Centers for Disease Control (CDC).43 This assures that the infected child's rights will be protected and the child's physical condition and behavior will be considered before making a decision regarding school admission.

The CDC recommend that a team of the child's physician, public health personnel, the child's parent or guardian, and school personnel decide which

41. Peterman, Drotman, & Curran, Epidemiology of the Acquired Immunodeficiency Syndrome (AIDS), 7 Epidemiologic Revs. 1, 9-10 (1985).
42. H.B. 1151 & 1044, § 14.
43. Id. § 15.
setting is appropriate. They give consideration to the risks and benefits of the child as well as of other children in the school. The CDC policy also addresses the need for educational programs for students, staff, and parents, including procedures for cleaning spills of bodily fluids.

Members of this team would most likely be informed of the child’s health status. But, serious consideration should be given to including penalties in school policies for any breach of confidentiality.

**Sunset Clause**

The present statute contains a sunset clause under which it expires on December 31, 1989. This expiration, combined with the report requirement, shows that legislators wish to review the law and ensure that it continues to meet the needs of Missourians.

While much is known about the spread of AIDS in this country, the epidemic’s first few years were marked by confusion and fear that linger today. Thus, the Missouri General Assembly addressed a difficult and controversial issue in its last session.

**Conclusion**

Considerable attention is now focused on implementation of Missouri’s new AIDS statute. Significant federal and state funding, over $4 million for fiscal year 1989, is dedicated to the state AIDS program. Now attention is being directed to long term care for AIDS victims and better financing of medical care.

AIDS clearly will be a challenging issue well into the 1990s.

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