19. **Larry Gostin, A Decade of a Maturing Epidemic : An Assessment and Directions for Future Public Policy, American General of Law and Medicine Vol.XVI, Nos.1- 2, 1-32,1992**

It has been nearly a decade since the first cases of AIDS were reported by the United States Centers for Disease Control (CDC). During that time there have been over 200 statutes enacted in every jurisdiction in the country. Unfortunately, the content of the legislation is highly diverse, even inconsistent, from state to state, and there is very little guiding federal legislation or regulation. The profound social, moral and public policy dilemmas that are magnified by the Human Immunodeficiency Virus [HIV] epidemic are still no closer to resolution. Should testing for HIV infection be voluntary, routiine or compulsory when there is a higher risk of transmission of HIV? Should America return to traditional moral values of abstinence outside of marriage and zero tolerance of drug use, or should we teach safe sex and use of sterile injection equipment? Should health care professionals maintain strict confidentiality or do they have a duty to protect third parties in imminent danger? If there is a duty to protect, to whom does the duty apply and what steps need to be taken to provide protection? Is current anti-discrimination law necessary and sufficient, and should health care professionals have a duty to treat all persons infected with HIV? How much does it cost and who should pay for the care and treatment of persons with HIV disease -- self-pay, private insurers, state or federal government? Should public health officials conduct, or condone, needle distribution programs to protect drug users from the needle-borne spread of HIV? After almost a decade of a maturing epidemic, there are still few innovative statutes to answer these critical public policy questions.

I argue that there has been a fundamental ambivalence in perceptions of the epidemic. For some, AIDS is perceived as a disease, with sympathy for sufferers. When AIDS is viewed as a catastrophic disease, it follows that public policy will be based on science and epidemiology, including health education, research and treatment. For others, AIDS is caused by willful, irresponsible behavior. Persons infected with HIV are seen as morally blameworthy and deserving of punishment. When AIDS is perceived as the result of willful, immoral behavior, public policy at least in part, will be both punitive towards persons carrying the infection [through, for example, criminal penalties and discriminatory treatment], and overly protective of the moral sensibilities of the wider community [through, for example, censorship of explicit public health messages].

This ambivalence in perception of the epidemic is manifested in public opinion and legislation, both of which are critically important for understanding the policies and politics of AIDS. A substantial minority of the public osnsistently shows a callous hostility towards persons with AIDS. Thus, virtually any draconian position on AIDS receives some public support : patients are "offenders getting their rightful due;" "they should be tattooed;" they should be dealt with as "lepers" and sent off to isolated islands. A similar proportion of the public would not work alongside AIDS patients of would exclude infected children from schools, neighborhoods and public housing. A certain percentage of the public even believes that persons with AIDS should not be treated compassionate-ly, which is perhaps the clearest indication of hostgility.

This hostile public opinion has found expression in law and public policy. Statutes have been enacted at both federal and state levels which restrict the dissemination of educational messages because of their morally offensive content. Other statutes seek to control the person infected with HIV through compulsory testing, isolation or criminalization, despite the absence of public health support for such coercive measures.

Public opinion and public policy, then, pull in two opposite directions, with public health and sympathy for the AIDS patient on the one hand, and coercion and moral indignation on the other. The results include a confusing, contradictory educational message and a disjointed, fragmented public policy.

Below, I set out a number of constructive public health policies -- addressed by the Harvard Model AIDS Legislation Project --- which have gained virtually unanimous support in the public health community. These should be the priorities for our public health agenda for the next decade, and not the largely irrelevant moral and punitive concerns which have captured a large segment of media reports, public opinion and legislative enactments.

A Widespread Program of Voluntary Testing and Counseling

The routine testing of persons at high risk for HIV infection has long been recommended by the United States Centers for Disease Control. The CDC recommends pre and post-test counseling as an essential part of any testing program. The objectives of testing coupled with counseling are to help the patient cope with the psychological burdens of contracting a potentially lethal infection, to modify behavior, to reduce the threat of transmission and to provide an opportunity to receive early treatment.

Voluntary testing and counseling, then, are potentially valuable public health programs which encourage reduction in high risk behaviors. However, to some, HIV screening (whether or not associated with counseling) is seen as a panacea to be used quite broadly, even compulsorily.

Mandatory screening programs may seem intuitively obvious, because no public health strategy can be effective unless cases of HIV can be identified. Case-finding, it is argued, is the first line of defense in curbing the epidemic. While compulsory screening may seem attractive, if examined logically it would be ineffective and possibly counter-productive.

First, a person can be expected to make more rational dicisions about behavior change if informed about his or her serological status. This is an assumption that has yet to be demonstrated. There is still insufficient behavioral research to prove whether nowledge of seropositiveity influences behavior and in what direction. Knowledge of seropositivity, therefore, may be helpful to some in modifying their behavior. To others, however, education and conseling will be the critical factor, regardless of test results.

Even if it could be demonstrated that knowledge of a positive test result does influence behavior significantly, it does not necessarily follow that compelling a person to take an antibody test will produce voluntary changes in behavior. Introduction of compulsory screening may have the reverse effect of causing persons vulnerable to HIV to avoid coming forward for testing counseling and treatment. If the public health strategy is to encourage as many people as possible to receive education and counseling, then the use of measures that may be regarded as controlling or punitive might be counterproductive.

A second argument in support of mandatory screening is that it serves as an early indicator of disease status so that the person can come in for prompt treatment. Knowledge of seropositivity cannot be used to alleviate an infectious condition, because there is currently no cure or vaccine for the prevention of HIV infection. HIV is not like venereal disease, where the chain of infection can be broken by simple antibiotic treatment. Thus, even with early knowledge of a person's serological status, medicine cannot alter the cycle of infenction.

Consent to an HIV test is particularly critical because of the contemporary personal and social significan e of HIV infection. There is a real risk of severe emotional consequences, even suicide, when a patient learns of an HIV positive test result. In addition, serious social consequences can accompany a positive HIV test. Unauthorized disclosure may result in ostracism by family and friends, as well as loss of a job, home, place in school, insurance or other benefits.

A third argument in support of mandatory screening is that it will assist public health officials in gaining a truer epidemiologic picture of the spread of HIV.

There are other more effective and less intrusive methods of obtaining a better epidemiologic understanding of infection patterns. The testing of blood samples collected for other purposes as in, for example, hospitals or maternity clinics. The samples are not identified by name, but only by demographic characteristics. Using a scientific sampling theory is much more likely to produce an accurate epidemiologic understanding than ad hoc testing and reporting requirements.

Prevention : A Comprehensive and Well-Resourced Program of Education

Congress and the states have mandated AIDS education focusing on four populations.

(i) The General Public -- Legislatures have sponsored AIDS education campaigns (including non-Englishj campaigns). These include mailings to every household, the designation of "AIDS Awareness" months and the creation of an "AIDS hotline." Some legislation emphasizes specific areas of education such as the safety of donating blood or the encouragement of testing.

(ii) High Risk Groups -- Some states authorize the distribution of graphic gay literature, education about the use of condoms and the sterlization of drug paraphernalia, and outreach programs for drug dependent populations. Other states, however, have enacted conten- based restrictions which specifically prohibit graphic literature or vernacular language.

(iii)Health Care and Other Professionals -- Several states require educational programs for all health care workers. Physicians, dentists and emergency workers are required to receive training in blood and body fluid precautions. Florida has enacted a comprehensive package requiring mandatory training for health care workers law enforcement officers, teachers and state employees. A physician's failure to comply will result in the revocation of his or her medical license.

(iv) Schools -- AIDS education is required in several states at a primary, secondary or college level. Some municipalities such as San Francisco have developed a comprehensive HIV education curriculum. Compulsory school attendance at AIDS education classes has become a contentious issue.

Public health officials and legislators, of course, can frustrate as well as facilitate educational objectives. Some officials at federal and state levels have been decidedly squemish about explicit sex education. Religious and moral beliefs have interfered with critical efforts to disseminate accurate and clear public health information.

Educational restrictions impede the ability of public officials to disseminate effective AIDS prevention materials. "Efforts to stifle candid materials that discuss safer sexual practices and that are targeted at appropriate audiences may take a toll in human lives." To be effective, educational efforts must be accurate and consistent, understandable and credible; they must be targeted at specific populations and be culturally specific. Sex education materials must be graphic and appropriate for the target audience. Accordingly, they should be clear in warning that fellation and unprotected vaginal and anal sex with an infected person have a real probability of transmitting the virus. Information given to drug-dependent people must be similarly frank in describing the risk of transmission from sharing contaminated needles.

Public health departments must be realistic in understanding that behaviors of an intimate or addicting nature are difficult to alter. Many young men and women will not abstain from sex, prostitution or drug abuse. They need unambiguous instruction about how to engage in gay or hetertosexual relations in a reasonably safe manner. Drug-dependent people require clear information about the use of sterile needles, where they can be obtained or, at the very least, how they can be sterlized. Thus, the information must be explicity, understandable, and directly relevant to the target audience. Public health officials cannot overly concern themselves with morality or even the fact that the behavior is unlawful.

Confidentiality and Discrimination

Early on in the AIDS epidemic, the CDC embraced a strong position favouring confidentiality and the need for state and federal legislation to protect HIV records.

Conservative forces in Congress in 1988 were able to resist the clamor for a federal AIDS confidentiality state. The problem invoved the line that had to be drawn between confidentiality and public health. In particular, the question was whether there should ab absolute requirement to maintain confidentiality if there is an unsuspecting sexual or needle-sharing partner in immediate danger of contracting HIV. Some would extend that line beyond sexual or needle-sharing partners to a broader "right to know" the serological status of infected persons. This "right tgo know" has been asserted by various groups ranging from health care professionals, "first responders" (for example, ambulance workers and law enforcers), funeral workers and others who fear occupational exposure to body fluids.

Proliferation of state statues purporting to protect the confidentiality of HIV-related information. These states have sought to clarify professional responsibilities. Many of the states have given physicians a power, not a duty, to warn specified groups at risk for HIV. These groups include spouses, emergency workers, health care professionals, funeral workers, sexual assault victims, lab workers and school administrators.

These laws often create more problems than they solve. For example, under these sttutes, a spouse at risk for HIV could be warned, whereas equally vulnerable sexual and needle-sharing partners could not. At the same time, the statutes yield to wider claims for a "right to know" as they give a power to breach confidentiality in order to warn a person whose risk is very low.

Anti-Discrimination Statutes

There is, however, a critical difference between discrimination based on race or gender and discrimination based on disease status. An infection is potentially transmissible and can affect a person's abilities to perform certain tasks. A decision to exclude an HIV- infected person from certain actitivites because of a real risk of transmission or because of performance criteria would be understandable and would not breach anti-discrimination principles. But denying such persons rights, benefits or privileges where health risks are only theoretical or very low and when performance is adequate is morally unacceptable. Because the risk of HIV transmission in most settings is remote, and because persons with HIV infection may function normally when not experiencing serious symptoms, there are no morally acceptable grounds for discrimination in those settings.

Not only is discrimination against the HIV-infected morally wrong, it can also be counterproductive from a public health perspectve.

Fears of a breach of confidentiality and subsequent discrimination discourage individuals from cooperating with vital public health programs and treatment for sexually transmitted diseases and drug dependency. These fears also mobilize opposition to routine voluntary testing and counseling for people with high risk behaviors. Such resistance to testing might melt away of individuals believed that they were strongly protected by the law.

The Americans with Disabilities Act, the government comprehensively will extend anti-discrimination protection for people with disabilities, including HIV infection, to the private sector in employment, public accommodations, transportation and public services.

The fifty states and the District of Columbia have handicap statutes similar to the federal Rehabilitation Act. In all jurisdictions except five, handicap statutes prohibit discrimination against employees in both private and public sectors. In thirty-four states, the courts, human rights commissions or attorneys general have declared, either formally or informally, that handicap laws apply to AIDS or HIV infection.

To those who have doubted the adequacy of such statutes and for those whom the explicit defense of the rights HIV-infected persons is perceived as socially and politically crucial, specific AIDS-related enactments have had a special allure. Thus, as Professors Edgar and Sandomire show, many states and municipalities have enacted AIDS- specific statutes or ordinances that target specific areas such as employment, housing or insurance. Local ordinances, as in San Francisco and Los Angeles, are more comprehensive in prohibiting discrimination in business establishments, public accommodations, educational institutions and municipal facilities or services.