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HIV Antibody Screening:

An Ethical Framework for Evaluating Proposed Programs

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Introductory Note

In May 1985, the Food and Drug Administration (FDA) licensed the first test kits to detect antibodies to the human immunodeficiency virus (HIV), then known as HTLV-III. The test kits were developed to screen donated blood in order to detect contaminated units so that they could be discarded. Only a small percentage of AIDS cases had been traced to transfusions; however, federal officials assigned a high priority to developing a method of identifying contaminated blood because of immense public concern about the safety of the blood supply. Moreover, the means of preventing transmission in this way — unlike changes in sexual or needle-sharing behaviors — was amenable to technological intervention.

The introduction of the test kits — formally known as ELISAs, or enzyme-linked immunosorbent assays — for this purpose (still the only FDA-approved one) led almost immediately to a variety of other proposed uses. Some of these appeared to be valid on grounds of public health and ethics; others were suspect on both counts.

Staff at the Hastings Center had begun to consider the ethical ramifications of AIDS as early as 1983, and the result of the first project on AIDS was a set of guidelines on confidentiality in research, published in *IRB: A Review of Human Subjects Research* (November–December 1984). The Hastings Center research group then turned its attention to a range of other problems and quickly agreed that the uses of the HIV antibody test were of paramount concern. The result of a series of meetings involving public health officials, philosophers, lawyers, gay rights advocates, and others was the article printed here — an attempt to lay out an ethical framework for considering proposed uses of the test. Although the authors alone are responsible for the views set forth in it, the article represents the consensus view that had emerged: opposition to widespread mandatory testing and support for expanded voluntary testing, with appropriate counseling and confidentiality and antidiscrimination protections.

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That was the view overwhelmingly endorsed at a conference called by the Centers for Disease Control (CDC) in February 1987. What the CDC had planned as a small, informal discussion turned into a media event attended by over eight hundred public health officials, civil rights advocates, and others. Many criticized the CDC for even the decision to place mandatory testing on the agenda. The conclusions reached at the conference are expressed in a CDC document entitled "Recommended Additional Guidelines for HIV Antibody Counseling and Testing in the Prevention of HIV Infection and AIDS" (dated April 30, 1987). The participants favored "the increased use of voluntary confidential HIV antibody counseling and testing as an adjunct measure in the prevention and control of AIDS." They also concluded that "mandatory testing other than for screening donated blood and plasma was not useful, nor should it be required for the prevention and control of HIV infection and AIDS." Surgeon General C. Everett Koop advocated a similar approach.

At the same time, however, Secretary of Education William J. Bennett took the political lead in calling for increased "routine" testing of individuals in certain age groups and on specific occasions, such as admission to a hospital or application for a marriage license. Rep. William E. Dannemeyer (R-Calif.) promoted the same idea but was more open in calling it "mandatory" testing. At a dinner the night before the opening of the Third International Conference on AIDS in Washington, D.C., President Reagan, speaking out for the first time on AIDS, also called for "routine" testing of several groups. A Gallup Poll taken in July 1987 found that 52 percent of Americans favored testing all Americans, and as many as 90 percent of those polled favored testing of selected groups, such as immigrants.

At the time the original version of the article printed here was published, the Department of Defense was already screening military recruits and rejecting those who were seropositive, and screening active duty personnel and reassigning those who were seropositive. The federal government has moved toward expanding the screening net to include Foreign Service applicants and active personnel; applicants for the Department of Labor's Job Corps; federal prisoners; immigrants; and undocumented aliens seeking to regularize their status under the amnesty program.

States have also moved to institute mandatory screening programs. Two states — Louisiana and Illinois — have mandated premarital screening, although the provisions in each state are somewhat different. Other states are considering a range of settings for screening. Some hospitals have announced policies of screening all admissions; many others are screening selected patients surreptitiously. Insurance companies vigorously defend their right to test applicants for life insurance and even health insurance and to deny coverage to those who are infected. Most employers are not screening job applicants or employees; a few, however, do so.

New concerns have been raised about the accuracy of the current screening tests when applied to populations in which there is a low reservoir of infection — such as marriage license applicants and hospital admissions. A study published in the *Journal of the American Medical Association* (October 2, 1987) concluded that universal premarital screening in the United States "currently would detect fewer than one tenth of 1% of HIV-infected individuals at a cost of substantially more than \$100 million. More than 100 infected individuals would be told that they were probably not infected, and there would likely be more than 350 false-positive results." A report in the *Lancet* (September 12, 1987) warned that the latency period between infection and the development of antibodies might be as long as fourteen months, rather than the six months previously thought to represent

the outer limit. And, as experience with testing accumulates, more reports show that even positive results confirmed by Western blot may occasionally be false positives. Pregnant women, for example, may be in this category because of cross-reactivity to the father's antigens.

Public health officials are caught between the public pressures to test and professional concerns about the wisdom and cost-effectiveness of widespread testing of populations unlikely to be infected. The New Jersey Department of Health's policy on testing, issued in September 1987, is as much a refutation of mandatory testing as it is a proposal for expanded voluntary and routine testing (with informed consent) in state-funded clinics for prenatal care, family planning, and sexually transmitted diseases.

Without a vaccine, without a cure, and with only the beginnings of effective treatment, AIDS will continue to present a challenge to those who make public policy. Faced with a new and lethal disease, the public demands action, any kind of action. The HIV antibody test is a valuable tool, but not a solution. The principles outlined in the following article, I believe, still constitute an ethical approach to the use of the test, but they may not withstand the political pressures.

— Carol Levine

The acquired immunodeficiency syndrome (AIDS) poses a compelling ethical challenge to medicine, science, public health, the legal system, and our political democracy. This report focuses on one aspect of that challenge: the use of blood tests to identify individuals who have been infected with the retrovirus human immunodeficiency virus (HIV). In this article, we follow the terminology recently proposed by the International Committee on the Taxonomy of Viruses; that is, we use the term *human immunodeficiency virus*. This replaces the more cumbersome dual terminology of human T-cell lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV).

The issue is urgent: the tests are already in use and plans to implement them much more broadly are being proposed.¹ The issue is also complex: at stake is a potential conflict between the community's interests in stopping the spread of a devastating disease and in preserving important values of individual liberty and equal rights.

Screening may seem to be a minor intrusion in the face of a deadly disease; yet even such an ostensibly limited intervention can have dramatic and deleterious consequences for individuals. Such intrusions must, therefore, be warranted by the potential public health benefits.

It is important to reaffirm our society's commitment to promoting the health of its citizens, but public health efforts undertaken with a beneficent intent have sometimes had the opposite effect. An example is mandatory screening for sickle cell trait among blacks in the 1970s, which resulted in misinformation, stigmatization, and discrimination.²

This report is addressed to all those considering the introduction of screening and testing programs, including employers, public health officials, legislators, health care providers, and insurers, as well as those who would be screened and whose interests would be affected. We have adopted prevailing usage and define *screening* as the application of the HIV antibody tests to populations and *testing* as the application of that procedure to individuals on a case-by-case basis.³ Using this distinction, blood donations tested for HIV antibodies are screened; people who go to an alternative test site for the same procedure are tested.

We believe that in each situation in which screening is considered, the proposed program should be subjected to ethical analysis. This report provides a framework for that task. Ethical evaluation is necessary but not sufficient for decision making; it should be performed in conjunction with other types of evaluation, such as legal and economic analyses, before screening is instituted.⁴ In addition, those who consider screening should consult with members of affected populations, since these individuals are best able to identify the potential hazards of proposed programs.

This document argues at various points in favor of moral obligations without advocating legal coercion. In a society that recognizes individual privacy and liberty, law and ethics are often distinct spheres. Not all moral obligations should be translated into law.

Screening for HIV Antibodies

The test now being used to detect the presence of antibodies elicited by HIV viral antigens is an enzyme-linked immunosorbent assay — the ELISA (or EIA) test. Because the ELISA test was developed to protect the blood supply, the cutoff between reactive and nonreactive values was set very low to capture all true positives. The price of such sensitivity is a loss of specificity. In high-risk populations, there will be comparatively few false positives. In low-risk populations, however, as many as 90 percent of the small number of initially reactive results will be false positives. To distinguish true positives, it is necessary to repeat the ELISA and to use an independent, supplemental test such as the Western blot.⁵

In addition to the false positives, there may be false negatives; that is, the tests may fail to detect antibodies, or there may be none even though the person is infected. The problem of false negatives is only partly a characteristic of the test; it also reflects the latency period (on rare occasions as long as six months) between infection with HIV and the development of antibodies.

Despite these problems, the ELISA test has satisfactorily served its initial purpose — screening blood donations. The antibody test also enables clinicians to monitor the infection status of their patients. It may be useful in establishing risk to the patient when immunosuppressive therapy is contemplated. It may provide epidemiologists with baseline data for the conduct of longitudinal studies of the natural history of AIDS. Finally, it may provide many individuals with data that are useful in supporting their voluntary modification of sexual, drug-using, and reproductive behavior.

The current screening method (a repeated ELISA plus a supplemental test) compares favorably, in terms of accuracy, to other screening methods used in medical practice, all of which have some limitations. Concern about the possible misuses of test results must not be confused with challenges to the accuracy of the tests.

Principles and Prerequisites for Evaluating a Screening Program

To evaluate the ethical acceptability of a proposed screening program, we recommend an analysis that is based on seven prerequisites. The prerequisites are based on the principle of respect for persons and the principles of harm, beneficence, and justice. These four widely accepted ethical principles are derived from secular, religious, and constitutional traditions and are commonly applied to medicine, research, and public health.^{6, 7} A brief discussion of each of the four principles follows:

1. *Respect for persons* requires that individuals be treated as autonomous agents who have the right to control their own destinies. It requires that persons be given the opportunity to decide what will or will not happen to them. The right to privacy and the requirement of informed consent flow from this principle. A corollary — requiring that persons with diminished autonomy be given special protections — may also apply to some populations, such as children and prisoners.

2. *The harm principle* permits limitations to be placed on an individual's liberty to pursue personal goals and choices when others would be harmed by those activities.

3. *Beneficence* requires that we act on behalf of the interests and welfare of others. The obligations of beneficence apply to actions affecting both individuals and the community. Potential risks must be weighed against potential benefits, followed by adoption of the actions with the most favorable risk-to-benefit ratio. The justification for public-health authority derives from both the harm principle and the beneficence principle.

4. *Justice* requires that the benefits and burdens of particular actions be distributed fairly. It also prohibits invidious discrimination.

These ethical principles may sometimes conflict. For example, the principle of beneficence and the harm principle may outweigh the need to obtain consent in some situations, but they never outweigh the obligation to treat persons with respect for their intrinsic worth and dignity.

The following seven prerequisites are based on the preceding principles. These prerequisites constitute the threshold requirements for ethical acceptability, but they do not cover all the ethical problems that may arise, as we will see later.

1. *The purpose of the screening must be ethically acceptable.* There is at present one acceptable purpose for screening: to stop the spread of AIDS. This purpose draws on the principle of beneficence — the duty to protect the welfare of those who might become infected with HIV. The use of medical tests and of the public health power of the state is justifiable to protect the health of the community. However, use of these resources merely to express social disapproval of sexual orientation or of drug use violates the principles of justice and respect for persons. If a therapy or vaccine becomes available, screening may be justified to benefit those at risk.

2. *The means to be used in the screening program and the intended use of the information must be appropriate for accomplishing the purpose.* If a screening program is intended to stop the spread of HIV infection but is designed in a way that precludes achieving that end, it is unjustifiable, since it would involve an invasion of privacy without any public health benefit. For example, screening all food handlers is not justifiable, since there is no evidence that the disease is spread through food.

3. *High-quality laboratory services must be used.* Given the importance of interpreting not just one but a series of tests to arrive at a confirmed positive result, the availability of highly qualified technicians and laboratory services is essential. Beneficence requires that persons not be subjected to any risk — whether social, psychological, or medical — if the information about them to be generated in screening does not meet the current standard levels of accuracy. The need for confirmatory testing applies both to low- and high-risk populations.

4. *Individuals must be notified that screening will take place.* Respect for persons requires that individuals be notified that they are or may be the subjects of screening. In some cases, individuals may choose not to participate in the activity for which screening is required (for example, they may choose not to donate blood or semen). In other cases, they may not have that option, but they should, nevertheless, be notified to protect their

autonomy; they should also be made aware that highly sensitive data about them will be generated, with the associated psychological burdens and risks of breaches of confidentiality. Physicians who contemplate testing an individual on the basis of membership in a risk group should notify the person and should seek consent. This prerequisite does not preclude the use, without notification, of blood or other samples unlinked to personal identifiers in research approved by institutional review boards (IRBs).

5. *Individuals who are screened have a right to be informed about the results.* There is no ethical justification for withholding test results. Certainly that information may be profoundly disturbing — not just to the individual but to the health care provider who has to convey it — but the principles of respect for persons and beneficence support notification.

The converse — that individuals have a “right not to know” — is in dispute. We believe that persons who are screened and whose seropositivity is confirmed have a moral obligation to learn that information; that is, we reject the right not to know in this case.⁸

The most important potential benefit of the knowledge of a positive test result is the motivation for an individual to change behavior that puts others at risk. A person at low risk (for example, a blood donor who has no knowledge of a sexual partner’s drug use) has no reason to suspect that he or she is infected and, therefore, has no reason to change behavior. To protect others, that person must know the fact of potential infectiousness.

This conclusion is generally accepted; the major controversy concerns the right of individuals at high risk not to know. The claim is made that as long as such an individual acts as though he or she were seropositive and avoids high-risk behavior, there is no need for knowledge of seropositivity. Moreover, the argument continues, such information may be so psychologically devastating that the individual will suffer greatly without any benefits to himself or herself or additional benefits to others.

We acknowledge the potential burden of such information. We also recognize that there is insufficient evidence to determine whether notification will in fact motivate behavioral change or whether it will lead to enormous distress with no compensating benefits. However, there are two problems with the arguments in favor of a right not to know. First, they underestimate the power of denial and the difficulty of sustaining behavioral change in the absence of specific information. Second, there is no way to discern in advance which of the infected people will modify their behavior without notification and which will not, much less which ones will be consistent in these changes.

Therefore, we conclude that given the disastrous consequences of HIV infection and the imperative of the harm principle, those who are infected have an obligation to know their antibody status, to inform their sexual partners, and to modify their behavior. We urge immediate research into both the positive and negative consequences of notification.

6. *Sensitive and supportive counseling programs must be available before and after screening to interpret the results, whether they are positive or negative.* Individuals should be counseled about the test before screening; should be told the significance of both positive and negative results; and should be informed about the availability of future counseling. A confirmed positive test result should not be conveyed by letter. It should be provided by personal contact in the context of, or with referral to, competent counseling services. Referral to a person’s private physician may not be adequate, since many physicians in general practice, particularly those in low-incidence areas, have little experience with interpreting HIV antibody test results.

7. *The confidentiality of screened individuals must be protected.* Respect for the privacy of those who undergo therapeutic and diagnostic procedures demands that the results of such procedures be kept confidential. In the case of HIV antibody testing, where the

inadvertent or unwarranted disclosure of positive test results could have disastrous social consequences for individuals, preserving confidentiality is especially critical.

However, there are a few circumstances in which public health reasons could provide a justification for the breach of confidentiality. For example, if it were known that a sero-positive individual had recently donated blood, notifying the blood collection agency would be appropriate on grounds of benefiting blood recipients. However, that agency would then have the obligation to protect the confidentiality of the information received.

Appropriate legislation or administrative regulations should be designed to protect the confidentiality of antibody test results. Whenever disclosure is to occur, individuals must be informed that a breach of confidentiality will take place and must be told why it is necessary. Under no circumstances should test results be used in ways that bear no relationship to legitimate public health concerns.

Mass Screening and Screening in Special Settings: Applying the Ethical Prerequisites

Using the framework we have established in the previous sections, we will now discuss the specific application of the principles and prerequisites to the current policy debates.

Should Universal Mandatory Screening Be Undertaken?

Universal mandatory screening can be justified on the basis of beneficence when a therapeutic intervention is available or when an infectious state puts others at risk merely through casual contact. However, neither is the case with AIDS. Thus, there is no demonstrable public health benefit that justifies universal mandatory screening, given the invasion of privacy involved.

Representing the extreme position, advocates of universal mandatory screening suggest it be a prelude to isolation.⁹ This would entail a sweeping deprivation of civil and human rights — the segregation of a million or more people for life on the assumption that they will behave in ways that spread disease. Such a drastic measure cannot be justified, particularly when less intrusive measures are available. Isolation would probably increase the incidence of disease, because those who were segregated would become a closed community, with the prospect of repeated reinfection.

Others justify mandatory screening less drastically. They see it as a way of making each individual learn his or her antibody status, hoping that this will prompt behavioral change. However, long-term behavioral modification is a complex process that is less likely to be achieved under circumstances of coercion, where long-term follow-up and support are nearly impossible to provide on a mass scale. Even in this case, universal mandatory screening would require the creation of an immense and costly apparatus. Since screening would have to be repeated periodically, it would be necessary to trace each individual's whereabouts to preclude avoidance of the test. Even were such screening feasible, it would require an extraordinary and repeated intrusion into the privacy of all Americans, with little probable benefit. Therefore, on grounds of beneficence, it would be unacceptable.

Should Mandatory Screening Be Implemented in Special Settings?

In certain limited circumstances, mandatory screening is appropriate — only where it can be shown, under stringent standards of scientific evidence, to reduce certain dangers. The mandatory screening of all blood donations has aroused virtually no opposition, because

everyone has an interest in a blood supply that is free of HIV. For similar reasons, there should be routine screening of semen donors for artificial insemination and of organ donations for transplant purposes, both under conditions consistent with our ethical prerequisites.¹⁰ With respect to donations of blood, semen, or live organs, individuals can avoid screening by avoiding the activity; these activities may be desired but are not central to a person's life plans.

Screening all applicants for marriage licenses presents quite a different situation. Marriage, unlike the act of donating blood, is central to an individual's freedoms. The likelihood of detecting a significant number of true positives, a goal that might be defended on grounds of beneficence, is exceedingly small in relation to the economic costs and ethical dangers of invasions of privacy and potential curbs on individual liberties in instituting a screening program. Those at risk for contracting AIDS are not likely to be the ones applying for marriage licenses. Moreover, neither sex nor childbearing is dependent on marriage in our society.

The state has an interest in stopping the spread of AIDS, but any bar to marriage for a seropositive individual would pose serious legal and ethical problems. Seropositive heterosexuals, like gay men in long-term relationships, can practice safer sex and take their antibody status into account in making childbearing plans. Individuals who are at high risk or who are concerned about their own or their partner's antibody status may voluntarily take the test before marriage, with appropriate counseling.

General screening in the workplace is unjustifiable under our ethical prerequisites, because the usefulness of such screening for the protection of others is unsupported by epidemiological or clinical evidence.¹¹ In some cases, although the protection of the public health is the stated purpose for workplace screening, the underlying reason is the desire to avoid the economic burden of providing health care benefits for people who might become ill with AIDS. The economic costs of AIDS are a matter of serious concern and ought to be addressed directly, so that equitable mechanisms for sharing the burden can be developed. However, to disguise these concerns as matters of public health serves neither purpose well.

But are there circumstances that fall between the extremes of blood screening and general employment screening where mandatory screening might be ethically acceptable? A range of settings must be considered.

Employment settings. Since casual contact is not a route of transmission of HIV, the only employment settings in which mandatory screening might be justified are, first, health care involving the open wounds of others and, second, prostitution. Careful investigation of the potential of HIV transmission from infected workers and professionals to patients indicates no evidence of such transmission when standard infection control precautions are taken.¹² Since the risks are, therefore, only theoretical, no grounds currently exist for instituting routine screening of health care workers, including dentists. Prudence, however, dictates that health care personnel who are themselves at high risk for AIDS, whether or not they know their antibody status, take all precautions when they enter a situation in which contact might pose a hazard to others.

A strong public health argument can be made for screening prostitutes. First, male and female prostitutes may have significant rates of seropositivity, either because of drug use; because of a greater risk of infection, owing to their large numbers of sexual contacts; or because of high-risk sexual practices in which they may engage. Second, seropositive prostitutes can potentially infect large numbers of people. Because the great majority of infected persons in this country are male, and because male-to-male transmission of HIV

is most common, it is likely that male prostitutes constitute a greater threat to their clients than do female prostitutes at this time. Finally, prostitutes' motivation to practice safer sex or to stop prostitution may be questionable; even if they are so motivated, the pressures to maintain their current behavioral patterns are probably considerable.

As a practical matter, however, only where prostitutes are licensed and subject to periodic health examinations could such screening, when used in conjunction with license revocation, interrupt the transmission of HIV without creating huge problems. Nevada has recently introduced such screening.¹³ Where prostitution is illegal, screening can occur only as an adjunct to arrest. Those prostitutes who are seropositive would have to be threatened with rearrest and perhaps with isolation if they continued to engage in prostitution. Effective and consistent enforcement would raise difficult logistic and legal questions.

These practical difficulties, and the moral issues raised by singling out one group for a regimen of screening, arrest, and isolation, warrant immediate attention. Although moving incrementally is morally permissible, targeting a specific population requires particular justification to prevent invidious discrimination. There is an urgent need for educating prostitutes and their clients. It is also important to examine possible ways to reduce the spread of HIV which take into account the social realities of prostitution.

Since the only ethical justification for workplace screening is derived from beneficence — reducing the risk of infection to others — the Department of Defense's routine screening of all recruits and active duty personnel is troubling. Communal living does not result in the transmission of HIV. The Department of Defense publicly justifies its policy with the claim that each member of the armed services is a potential blood donor and that in a battlefield emergency there would be no time to screen blood.¹⁴ However, it is not at all clear that soldier-to-soldier battlefield transfusions are standard practice today. Moreover, the rejection of seropositive recruits cannot be justified on such grounds if seropositive active duty personnel are not also being discharged. Even if all seropositive individuals were discharged, one-time screening would not suffice to protect the military donor pool over time. Given the social costs associated with repeated screening, it would be more appropriate to ensure alternatives to battlefield soldier-to-soldier transfusion.

More plausible is the justification that screening identifies those whose compromised immune system might lead to adverse reactions to live-virus vaccines routinely given to recruits. But even this paternalistic justification is weak. The HIV tests are not the only way to identify these individuals.

As in general-employment screening, other factors may be concealed under the guise of public health: the military's policies against homosexuality and drug use; relations with foreign governments that are concerned about the exportation of AIDS by U.S. servicemen; and the desire to avoid the economic burden of AIDS. Here, too, we urge that these concerns be discussed directly, not masked as purported public health issues.

Clinical and residential settings. Because hepatitis B is far more infectious than HIV, it is widely accepted that those institutional precautions which are currently in place to prevent infection by hepatitis B are sufficient to protect against infection by HIV (see note 15). Since the routine screening of hospital admissions for hepatitis B is not deemed necessary, neither is the routine mandatory screening of all hospital admissions for HIV infection.

Dialysis centers are the only clinical setting in which routine hepatitis B screening occurs. Yet here the CDC has argued against routine antibody screening for HIV because of the potential breaches of confidentiality, although it does not object to dialysis on separate

machines for those with clinically diagnosed AIDS.¹⁵ Epidemiological evidence has provided no evidence thus far of transmission of HIV infection in dialysis centers. However, given the frequent occurrence of blood spills in such centers, we believe that the routine screening of dialysis patients for HIV and the adoption of especially careful precautions for those who are seropositive require further consideration. Such screening, however, should never be used to deny dialysis.

In other settings, such as mental hospitals and residential homes for retarded people, routine screening might be considered because of the possibility of sexual contacts among residents or patients. Especially in those settings where sexual segregation is practiced, homosexual contact — voluntary and involuntary — is known to occur. Given the reduced competence and diminished autonomy that characterize residents of mental hospitals and homes for retarded people, it might be appropriate to consider screening residents and patients in such settings as a way of protecting those who are uninfected from possible HIV infection. However, the need to provide extra supervision for those who are seropositive does not warrant isolation, stigmatization, or the deprivation of services.

The screening of infants born to mothers at high risk, prior to foster care or adoption placement, raises unique issues.¹⁶ The purpose of antibody testing under these circumstances would not be to stop the spread of AIDS or to benefit the child, but to provide potential foster and adoptive parents with information that would undoubtedly play a role in their decision to care for the child. But for that purpose, the test results may be inconclusive. Some babies born to seropositive mothers may be seropositive at birth but not viremic and may lose the antibodies in the first year of life.¹⁷

A seropositive child may be difficult, if not impossible, to place in a foster or an adoptive home, even though the child may never develop illness. Isolation and stigmatization would almost inevitably follow. The tension is between the potential harm to such children and the interests of the prospective foster and adoptive parents in obtaining this information. These issues require further study.¹⁸

Finally, screening in prisons has been discussed. Since there are substantial numbers of intravenous drug users in prisons, and since homosexual activity, including instances of homosexual rape, is known to occur, proponents of screening argue that it is the obligation of the state to protect inmates from possible infection. Those who oppose such screening point out that the identification of seropositive prisoners might well place them in imminent danger of violence from other inmates. To prevent such violence, and to protect other inmates from infection, isolation has been suggested by proponents of prison screening. The logical consequence of such a proposal would be the creation of a separate prison system. The problems of logistics posed by such an effort would be staggering. Furthermore, segregating those who are seropositive without measures to educate and protect them from repeated infection would only increase the likelihood of disease.

In prison and in clinical and residential settings, a question ought to be asked of all proposals for mandatory screening: Are there alternative measures less intrusive than screening which could provide the necessary protections? If so, then screening cannot be justified.

In fact, alternatives to screening in prisons do exist. The state could reduce the risk of forcible spread of HIV infection by seeking to reduce the incidence of prison rape. The spread of HIV infection in prison would also be reduced by providing condoms and education regarding the risks of drug use and high-risk sexual behaviors.

Screening and insurance. Both health insurance and life insurance are at issue here. First, with respect to health insurance, we have determined as a society that, with the

exception of the very poor and the elderly, it will be available through the private sector, largely through the workplace. The acquired immunodeficiency syndrome has provided the occasion to reexamine elements of that system, including exclusions for preexisting conditions and reliance on experience rather than community rating.¹⁹

The sole purpose for which screening would be instituted by health insurance carriers would be either to deny coverage or to increase sharply premiums for those who are seropositive.²⁰ Persons who apply for insurance as individuals, rather than as members of groups, are particularly vulnerable, but dangers exist as well for persons covered by group plans. Employers who are self-insured may seek to dismiss employees, penalize them, or refuse to hire applicants who could increase the costs of health care coverage. In any case, given the proportion of the population which would be involved, screening for group health insurance would be, in essence, universal mandatory screening, and the arguments presented against that policy apply here as well.

Although we recognize that this view is controversial, we believe that state regulatory agencies should not permit those who provide group or individual health insurance coverage to exclude persons who are at increased risk for any illness, including AIDS. A denial of health insurance would ultimately create overwhelming burdens for the public and private hospitals that would be forced to provide uncompensated care to the uninsured. From a societal perspective, the central issue is whether the cost of health care for AIDS patients and others at high risk for illness will be broadly distributed or borne by those who become sick, and by their friends and families, reducing them to dependency on the welfare system. The moral issue is one of justice.

The moral problems posed by life insurance are more difficult to evaluate, since it is not as basic a need as health insurance. The social purpose of life insurance is to provide protection for dependents in the event of death, although individuals may purchase life insurance for other purposes as well. Those who are at increased risk for a broad range of medical conditions face barriers to life insurance either through formal exclusion or prohibitive premium rates, especially when insurance is purchased individually rather than through a group.

Insurance carriers fear that those who know they are at risk for AIDS will seek large amounts of life insurance coverage, thus potentially endangering a company's solvency and its ability to pay other claims. Consequently, insurers seek to protect the interests of their other policyholders and stockholders by screening applicants in high-risk categories for HIV antibodies.

Despite such fears, there is no solid information yet on the potential impact of AIDS on insurance companies' solvency or on future premium rates. Moreover, there is a substantial risk to individuals who are screened; the information produced may be accessible to employers and others with no legitimate public health interest. Those who are denied life insurance coverage may also be denied loans, mortgages, and other forms of credit.

In determining public policy, state regulatory agencies must entertain the full range of issues beyond narrow actuarial considerations. If screening is ultimately permitted by state regulatory agencies for life insurance, these agencies should also explore innovative arrangements to provide appropriate coverage to seropositive individuals, and should mandate strict confidentiality requirements as well.

Alternatives to Screening: The Promise of Voluntarism

We believe that those who are at high risk for developing AIDS have a moral obligation to

take all possible steps to prevent harm to others, including taking the antibody test. This moral obligation should not, however, be translated into legal coercion. Mandating universal screening, as we have explained, would violate norms of beneficence and respect for persons and might drive the HIV infection underground, thus subverting public health goals.

Where voluntary testing programs are instituted, they should follow the relevant ethical prerequisites set out earlier: that is, high-quality laboratory and data services must be used; individuals who are tested must be informed about the results; sensitive and supportive counseling programs must be available before and after testing to interpret the results, whether positive or negative; and the confidentiality of tested individuals must be protected. In addition, voluntary testing should involve full disclosure of risks and benefits as well as informed consent.

Some have rejected the moral obligation to take the test, arguing that all members of high-risk groups should simply act as if they were antibody-positive. These persons cite dramatic changes in sexual behavior (as measured by a reduction in sexually transmitted diseases in homosexual men in San Francisco and New York) in populations that include men who have not taken the test.

If such advice were sufficient to motivate radical alterations in sexual conduct and in childbearing plans among the diverse populations involved, it might not be necessary to encourage the use of the antibody test. No conclusive evidence exists on either side, but there is reason to doubt that advice alone provides sufficient motivation.²¹ Given the risks associated with AIDS and the uncertainty about what will in fact modify high-risk behavior, there is a strong community interest in encouraging voluntary testing. Public health authorities and clinicians should encourage the use of such tests, to be taken anonymously or with strict confidentiality protections.

In addition, antibody-positive individuals have a moral obligation to notify their partners, especially when their partners have no reason to suspect that they have had contact with an individual at risk for HIV infection. Counselors have a professional duty to encourage such notification.

We recognize that sexual contact tracing by public health officials might be considered the next logical step, since some individuals may refuse to notify their sexual partners directly. This issue requires further discussion, to consider both whether this is an appropriate strategy at this time and what kinds of protection would be needed. Sexual contact tracing might be justified in low-risk and low-incidence areas, for example, but not in other settings.²²

Women who are at high risk should be encouraged to undergo testing as they consider the prospect of childbearing.²³ In the case of positive results, pregnant women should be fully informed about the risks to themselves and their fetuses (the risks are high but not necessarily determinative) so that they can make informed decisions about whether to terminate the pregnancy. However, encouragement to undergo testing should be just that, not coercion.

Because of the uncertainty and anxiety that surround the issue of confidentiality, antibody testing has been undertaken under conditions of anonymity in many cities at alternative test sites. In these settings, individuals do not provide their names; are counseled about the test; and, if they decide to take the test, are given a number. It is up to the tested individual to request the results and to obtain further counseling. Anonymous testing thus offers the greatest protection for the confidentiality of test results. As a result, testing under such circumstances has been recommended as the single most effective way of

encouraging the voluntary use of the test. However, drawbacks to such testing do exist. It may preclude appropriate counseling and follow-up and may make long-term epidemiological studies in the tested populations either difficult or impossible. In the short run, anonymous testing may be the only effective strategy for both privacy and public health reasons. Ultimately, if it were possible to construct stringent confidentiality protections, anonymous testing with its obvious limitations might be replaced.

The most serious threat to the widespread use of voluntary testing comes from proposals or already enacted regulations that require reporting to state public health officials the names of those who are antibody-positive. The arguments for such reporting resemble those which are used to justify the mandatory reporting of AIDS itself — now universally required in the United States — as well as other venereal diseases and infectious conditions. It has been asserted that epidemiological study, sexual contact tracing, and future therapeutic interventions all require mandatory reporting by private physicians and by all health care facilities.

In fact, mandatory reporting by name instead of code may deter rather than encourage voluntary testing. The knowledge that names will be given to public health authorities, even when those authorities affirm their commitment to confidentiality, is not conducive to voluntary testing. Some have even suggested that mandatory reporting may encourage anonymous sexual activity, so that individuals could not be named as sexual partners if contact tracing were implemented.

For voluntary testing to be effective, it would have to be widely available, not only in alternative test sites, but also in clinics established for the treatment of sexually transmitted diseases, in drug treatment facilities, and in prenatal clinics. Information in these settings should describe the services available in alternative test sites under conditions of anonymity as well.

Moreover, under the principle of justice, voluntary testing should be publicly funded. Many individuals at high risk, especially those who are intravenous drug users, do not have the resources to pay the cost of testing. The cost of widely available testing programs will be substantial, especially when the requisite services of counselors are considered. But to the extent that significant public health benefits might be achieved, these costs should not be a barrier to the creation of testing centers throughout the United States. Furthermore, since the primary purpose of testing is the protection of other individuals, including potential offspring, the burden of paying for testing ought to be borne by the public.

Summary

In conclusion, we believe that the greatest hope for stopping the spread of HIV infection lies in the voluntary cooperation of those at higher risk — their willingness to undergo testing and to alter their personal behavior and goals in the interests of the community. But we can expect this voluntary cooperation only if the legitimate interests of these groups and individuals in being protected from discrimination are heeded by legislators, professionals, and the public. Yet voluntary testing is not enough. We must proceed with vigorous research and educational efforts to eliminate both the scourge of AIDS and the social havoc that has accompanied it. 🍷

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Notes

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"This is a great disease to be a drama queen with. I mean, it's really easy to fall into that 'victim role' trap and have everybody running around getting you glasses of water and doing all sorts of stuff for you. But I made a decision that first day, or possibly the second day — I was crying too much that first day — to choose life, and I've never looked back. I assume responsibility for my own life. I don't blame people. I assume responsibility for my own life. I refuse to play the victim role. I feel that I have control over my life. I have the right to lead a rich and full, rewarding life. I still play softball. I refuse to let this disease dictate my life. **"**