DENYING ACCESS TO CARE:
Discrimination Against Persons
With HIV-Infection

The Commonwealth of Massachusetts
Massachusetts Senate

Senate Committee
on Post Audit and Oversight

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MASSACHUSETTS SENATE

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DENYING ACCESS TO CARE:
Discrimination Against Persons
With HIV-Infection

Part three of a series on
Acquired Immune Deficiency Syndrome (AIDS) in Massachusetts

A Report of the

SENATE COMMITTEE ON POST AUDIT AND OVERSIGHT

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October 1989
EXECUTIVE SUMMARY

The Acquired Immune Deficiency Syndrome (AIDS) epidemic is one of the most urgent public health problems today. Discrimination against persons infected with the human immunodeficiency virus (HIV) that causes AIDS is both unjust and a significant obstacle to AIDS prevention.

HIV-related discrimination is a difficult problem to document for several reasons:

- Persons with HIV who experience discriminatory treatment are more likely to seek alternative services than to file a discrimination complaint;
- Persons with HIV are often unsure of the remedies available to them for discriminatory treatment;
- Persons with HIV may find that the discrimination complaint resolution process is overly long and not responsive to the unique pressures of coping with a terminal disease.

Nevertheless, the existence of such discrimination has been confirmed by professional studies, legal and AIDS advocates, and persons with HIV.

Professional reluctance to treat persons with HIV is rooted in a variety of concerns:

- Fear of infection with the AIDS virus (HIV);
- Social and professional stigma often associated with treating persons with HIV;
- The financial burden imposed by treating persons with HIV.

An effective antidiscrimination effort needs to consider both the interests of persons with HIV and the concerns of the professionals who treat them.

Currently, the state's HIV-related antidiscrimination efforts are housed in four entities:

- The Massachusetts Commission Against Discrimination (MCAD), as the primary agency for enforcing the state's antidiscrimination laws, extended the legal rights of handicapped persons to persons with HIV infection. However, the MCAD's efforts are weakened by its limited staff for HIV-related work and its confusing and time-consuming complaint resolution process.

- The Attorney General's office (AG), the state's chief law enforcement entity with investigative authority over a wide range of legal issues, has acted effectively in the area of civil rights education and HIV-related discrimination. However, lack of coordination and documentation have limited the effectiveness of the AG in fighting
HIV-related discrimination.

- The Boards of Registration (Boards) license and oversee the conduct of over 600,000 professionals in the state. The Boards recognized the potential for AIDS- and HIV-related problems and produced an impressive set of AIDS guidelines. However, the Boards weakened the impact of these guidelines by not adopting them as regulations and by failing to transmit these guidelines to their licensees.

- The Department of Public Health (DPH) is the state's primary agency for HIV-related services and programs. In addition, the DPH and local boards of health inspect and license facilities such as hospitals, clinics and funeral homes. The DPH has informed and committed personnel for both AIDS and health care quality. However, it lacks the necessary resources and coordination to ensure that licensed facilities--and the people who work in them--are meeting sanitary and infection control standards.

In this report, the Committee makes the following recommendations to increase the effectiveness of current HIV-related antidiscrimination efforts:

A. Remedies for and prevention of professional discriminatory behavior

1. The Attorney General's office should monitor and document incidents of HIV-related discrimination. In addition, the AG's office should ensure inter-agency cooperation for setting consistent responses to HIV-related discrimination complaints.

2. The Boards of Registration should adopt their AIDS Guidelines as official regulations.

3. The Boards of Registration should maintain better communication with state licensees, with a minimum standard of one newsletter every two years. In addition, the Boards should communicate regularly with state professional associations.

4. The Department of Public Health and local boards of health should conduct consistent inspections of facilities within their jurisdictions.

B. Improved outreach to persons with HIV

1. The MCAD should accommodate its complaint resolution process to the unique concerns of persons with HIV.

2. The legislature should consider attaching a limited medical or emergency waiver to the MCAD's six-month statute of limitations.

3. Both the MCAD and Attorney General's office should ensure and publicize that confidentiality is maintained in all cases of HIV-related discrimination.

4. The MCAD should educate potential victims of HIV-related discrimination about their civil rights through informative brochures and other educational means.
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INTRODUCTION

This report by the Senate Committee on Post Audit and Oversight is the third in a series about the Acquired Immune Deficiency Syndrome (AIDS) in Massachusetts. This report addresses the problem of discrimination against persons infected with the human immunodeficiency virus (HIV) that causes AIDS, specifically by medical, dental and funeral professionals. The AIDS epidemic is one of the most urgent public health problems today, and discrimination against persons with HIV represents a significant obstacle to AIDS prevention. The Committee believes that the insights and recommendations in this report will help to reduce the incidence of HIV-related discrimination and thereby improve the effectiveness of AIDS prevention programs.

Since the disease was first reported in 1981, over 100,000 persons in the United States (including 2,396 in Massachusetts alone) have developed AIDS, and over half of these persons have died.¹ The statistics suggest that the AIDS epidemic will get worse. The human immunodeficiency virus (HIV) that causes AIDS is rapidly spreading, especially among blacks, Hispanics and intravenous drug users.² Many, if not most, persons infected with HIV are expected to develop full-blown AIDS.

There is no known cure for AIDS, so prevention is the only viable means of controlling the epidemic. AIDS prevention is severely threatened by the problem of discrimination against persons with HIV. James D. Watkins, head of President Reagan’s Commission on AIDS, called discrimination "the most significant obstacle to progress" against the AIDS epidemic and urged passage of a federal law protecting persons with HIV from discrimination.³ As the Boston Globe asserted, "without such protection, there is little likelihood that the 1.5 million Americans who are infected can be located--to direct them to care, learn where the disease is


² Please see Appendix A for demographic information about the AIDS population.

The Committee chose to focus on discrimination by practitioners in the medical, dental and funeral professions for several reasons. First, these professionals provide services that are of unrivaled importance to persons with HIV and their families. Second, medical, dental and funeral professionals have often been cited by persons with HIV for their discriminatory treatment. Third, the facilities in which these professionals practice can be considered to be "public accommodations" and are therefore bound by specific antidiscrimination laws.\(^4\) Fourth, these professionals are licensed by the state to practice and must therefore conform to certain standards of behavior.

This report is organized into four chapters:

- **Chapter 1** addresses the problems surrounding documentation of HIV-related discrimination incidents;
- **Chapter 2** discusses the concerns that underlie discrimination against persons with HIV by medical, dental and funeral professionals;
- **Chapter 3** evaluates existing mechanisms in the state that address and remedy incidents of discrimination against persons with HIV, particularly by medical, dental and funeral professionals;
- **Chapter 4** proposes changes or additions to these mechanisms, as necessary, in order to combat more effectively the problem of discrimination against persons with HIV.

The Committee hopes that this report will foster mutual understanding between medical, dental and funeral professionals and potential victims of HIV-related discrimination. At the same time, the Committee urges the state to take remedial and preventive actions to combat the problem of discrimination against persons with HIV.

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\(^5\) The Massachusetts Commission Against Discrimination (MCAD) has indicated its intent to include doctors' and dentists' offices under the definition of public accommodations. However, such a characterization has not been established in case law.
CHAPTER 1:
THE PROBLEM OF DOCUMENTING HIV-RELATED DISCRIMINATION

Public health experts from Massachusetts and across the country contend that discrimination against persons with HIV is a widespread and significant problem, particularly by medical, dental and funeral professionals. Such discrimination not only affects the private lives of persons with HIV, it also threatens the public health. Discrimination against persons with HIV hinders efforts to prevent the spread of the epidemic in three ways: by discouraging people from getting tested for the virus; by making persons with HIV afraid to admit that they have the virus and to seek appropriate treatment; and by preventing individuals and communities from addressing the threat posed by the epidemic.

In this chapter, the Committee looks at documentation of discrimination against persons with HIV, particularly by medical, dental and funeral professionals. The Committee explains why such documentation is important and yet difficult to obtain. While this report is primarily concerned with discrimination within these three professions, the Committee will also touch upon the larger problem of discrimination in places of public accommodation.6

A. Discrimination against persons with HIV: the problem of documentation

Massachusetts’ antidiscrimination, civil rights, and AIDS advocates claim that discrimination against persons with HIV is a problem of potentially explosive proportions, but there is little documentation to prove this claim. As a result, these advocates are caught in a "Catch-22" cycle: because there are so few resources available for locating and remedying

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6 A place of public accommodation, according to Chapter 272, Section 92A of the Massachusetts General Laws, is "any place, whether licensed or unlicensed, which is open to and accepts or solicits the patronage of the general public." Places of public accommodation are prohibited from discriminating against handicapped persons, including persons with AIDS and persons perceived as having AIDS. While the public accommodation statute is the most widely used mechanism for combatting the types of discriminatory treatment addressed in this report, other remedies exist as well. For example, medical, dental and funeral professionals are subject to regulation by Boards of Registration and may be penalized for discriminatory behavior.
HIV-related discrimination, incidents of such discrimination are not being reported or documented; at the same time, additional financial and human resources cannot be justified without empirical data that such discrimination is a problem.

Absent such data, Massachusetts can look to the experience of places such as New York City for proof that HIV-related discrimination exists. One of the hardest-hit and best-organized areas on the AIDS front, New York City has a unit within its Human Rights Commission that is devoted entirely to HIV-related discrimination. This unit has handled over 1,200 cases since its inception in 1983. Public accommodations discrimination cases constitute the largest category (33%) of complaint, and half of these public accommodations cases are related to health care. Despite the heavy caseload, however, Director Keith O'Connor asserts, "If we had 500 people, we couldn't handle all the discrimination that's out there."

The Committee believes that persons with HIV in Massachusetts face the same problems as their counterparts in New York City. However, unlike New York City, Massachusetts does not have an office devoted entirely to HIV-related discrimination. As a result, the state's knowledge of such discrimination is based largely on anecdotal information. During its research for this report, the Committee spoke with numerous AIDS advocates and persons with HIV, all of whom had at least one anecdote of HIV-related discrimination. Alleged incidents of discrimination ranged from neglect by hospital personnel to refusal by an oral surgeon to complete a root-canal operation. Unfortunately, most of these incidents have not been reported to the state.

Denise McWilliams, head of the Gay and Lesbian Advocates and Defenders (GLAD) AIDS Law Project, has heard countless anecdotes of discrimination against persons with HIV. As a well-known advocate for persons with HIV, Ms. McWilliams receives over 100 telephone inquiries per week from HIV-infected persons, persons with AIDS, AIDS advocates and others from Massachusetts and around the country. While she does not keep a tally of discrimination-

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8 Ricklefs, "Victims of Discrimination are Fighting Back."
related inquiries, Ms. McWilliams assured the Committee that HIV-related discrimination is a common complaint. Indeed, Ms. McWilliams has pursued several HIV-related discrimination cases through the Massachusetts Commission Against Discrimination (MCAD) complaint resolution process.

B. Professional acknowledgment of HIV-related discrimination

Persons with HIV and AIDS advocates are not the only sources of anecdotal information about HIV-related discrimination. In interviews with the Committee, medical, dental and funeral professionals have themselves acknowledged that some of their peers may be discriminating against persons with AIDS or persons suspected to have AIDS. These statements are supported by a recent survey of physician attitudes which reports that 66% of the respondents agreed that "people in the health care system seem to be unwilling to treat AIDS patients." According to Surgical Practice News, over 90% of the 1000 surgeons surveyed support a surgeon's policy of refusing to operate on an HIV-infected patient.

Similarly, the Journal of Public Health Dentistry asserts that, "many dentists are reluctant to care for patients with AIDS, and incidents of dentists 'dumping' AIDS patients have been reported." A recent survey of over 500 dentists reveals that 63% of the respondents do not want to treat persons considered to be at risk for AIDS, such as homosexual males, intravenous drug users and hemophiliacs. Moreover, 74% of the respondents indicated that they would rather refer people with AIDS or at risk for AIDS to other dentists. In Massachusetts, notices were placed in two state dental society newsletters--with a combined

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9 Jean J. Richardson, Thomas Lochner et al., "Physician Attitudes and Experience Regarding the Care of Patients with Acquired Immunodeficiency Syndrome (AIDS) and Related Disorders (ARC)," Medical Care 25, No.8 (1987): p.678.


circulation of 4,000 practitioners--to locate dentists willing to treat persons with AIDS. According to Myron Allukian, director of Boston's Community Dental Programs, only two dentists responded affirmatively to the notices.¹³

Practitioners in the funeral industry have also exhibited reluctance regarding the treatment of persons with HIV. Recently, a damage suit was filed by the mother of a deceased person with AIDS after it was revealed that the funeral director--fearing transmission of HIV from the corpse--had conducted services with an empty casket.¹⁴ While no such cases have been reported in Massachusetts, some funeral directors interviewed by the Committee admitted that they offer a narrower range of funeral services to families of deceased AIDS patients than they do to other clients. For example, some funeral directors refuse to embalm an HIV-infected corpse, while others insist on conducting a closed-casket service. Moreover, some funeral directors charge higher prices for embalming and burial of an AIDS patient.

The American Medical Association, American Dental Association and National Funeral Directors Association have all issued AIDS policy statements.¹⁵ In anticipation of--or perhaps in response to--allegations of discriminatory practices by their members, all of these associations include "duty to treat" as part of their AIDS policy statements. The Massachusetts Medical Society, Massachusetts Dental Society and Massachusetts Funeral Directors Association have adopted the policies of their national counterparts and have informed their respective members of their duty to treat persons with HIV.

¹³ Dan Hickey, "Some AIDS patients lie to get dental work, official says," Boston Globe (July 9, 1986).


"AIDS Policy of the National Funeral Directors Association of the United States, Inc.," (July 23, 1985).
C. Reasons for the lack of documentation

Documentation of HIV-related discrimination has been difficult to obtain nation-wide, not just in Massachusetts. While part of this difficulty arises from the lack of available resources for fighting HIV-related discrimination, the primary obstacle is the hesitancy among persons with HIV to notify the state of discriminatory treatment. The Committee believes several factors contribute to this hesitancy: the relative impact of discrimination on the lives of persons with HIV; skepticism about the state's ability or willingness to remedy discrimination; and lack of understanding about the legal process and civil rights. The state needs to understand these factors if it is to be more responsive and effective in addressing the problem of discrimination against persons with HIV.

1. The relative impact of discrimination

Discrimination is seldom the most urgent problem faced by person with HIV. The death of friends or loved ones, personal illness, financial worries, and fear for one's own life often overshadow the problem of discrimination. Persons with HIV who are turned away by a particular doctor or dentist may prefer to seek services at a different facility rather than engage in a drawn-out discrimination battle. The personal and financial resources required to file a discrimination complaint are generally in precious supply among persons with HIV and may be better spent on other things.

Families of deceased persons with HIV are even less likely to file or continue a discrimination complaint. While most discrimination complaints can survive the death of the complainant, the families of persons with HIV have little reason to proceed with a complaint once the victim has died. Similarly, families who are turned away or charged higher fees by a funeral home often choose to pay the additional cost or to go to another facility. These families are understandably hesitant to endure the publicity, legal fees and time demands of filing a discrimination complaint. The costs—emotional, financial and otherwise—of filing a discrimination complaint often exceed the potential benefits.
2. The public's perception of the state and antidiscrimination

Some persons with HIV are skeptical of the state's ability or willingness to remedy discrimination. This skepticism is perhaps strongest among persons engaging in illicit activities, such as intravenous drug users and prostitutes. The state, and particularly the Attorney General's office, is often seen by these persons as an adversary to be avoided, not as an ally or advocate.

Moreover, many persons with HIV belong to social groups that have historically suffered from discrimination, such as homosexuals, persons of color and the homeless. For these persons, HIV-infection may merely worsen an already difficult situation. As a result of their prior experiences with discrimination, some persons with HIV may feel powerless or forgotten. This sense of disempowerment is exacerbated by the fact that the discriminating party often holds significant power and prestige in the community. Doctors, dentists and funeral directors may be perceived to have more credibility than persons with HIV, and this perception may discourage the victims of HIV-related discrimination from taking legal action against them.

3. The lack of civil rights information and legal assistance

Many persons are unaware of their civil rights or confused about the legal process. The people most likely to suffer discrimination--persons of color, the poor, the disabled, persons with HIV--are also the least likely to know about their rights. There is a critical need for civil rights education, especially among persons with HIV. Up to now, AIDS organizations have focused on AIDS-prevention education rather than civil rights education, and understandably so. As more and more persons become infected with HIV, however, education about the rights of persons with HIV will become increasingly important for persons with HIV and the general public alike.

Besides civil rights education, persons with HIV need better access to low-cost legal services. Persons with HIV often face complex legal problems: estate-planning, applying for Medicaid and other benefits, breaches in HIV-test confidentiality, and HIV-related
discrimination. The procedures for remedying these problems are often complicated, and many persons with HIV lack the financial resources to hire a lawyer for legal assistance. At the same time, legal services agencies that cater to low-income persons are rarely able to handle discrimination complaints, choosing instead to use their limited resources for life-and-death issues such as advocacy for public benefits or eviction prevention.

Summary

As the problem of HIV-infection continues to grow, so does the potential for discrimination against persons with HIV. The need for documentation of such discrimination, along with the need for civil rights education and low-cost legal services, is becoming increasingly apparent. While state agencies, AIDS advocacy groups and pro-bono attorneys are meeting part of this need, their efforts are characterized by an insufficiency of resources and a lack of coordination. The state must therefore look into more effective methods of locating and documenting HIV-related discrimination while integrating civil rights education and legal assistance into already existing AIDS programs.
CHAPTER 2:
THE PROFESSIONAL'S PERSPECTIVE ON SERVING PERSONS WITH HIV

Thus far in this report, the Committee has shown that discrimination is a problem for persons with HIV in Massachusetts. In doing so, the Committee looked at the problem from the perspective of persons with HIV, their families, AIDS advocates and community leaders. The Committee believes, however, that it is also important to explore the motivations and concerns of medical, dental and funeral professionals. Only through understanding of the dynamics behind discrimination can the state begin to shape appropriate and effective remedies for such discrimination.

In this chapter, the Committee looks at some of the concerns that medical, dental and funeral professionals have expressed about serving persons with HIV. During the course of its research for this report, the Committee spoke with many professionals, persons with HIV and AIDS advocates. The Committee was impressed by the overall quality of care provided by the state's professionals. Many persons with HIV and AIDS advocates confirmed that professionals have generally been sensitive and fair in their treatment of persons with HIV.

However, the threat of HIV can be overwhelming to even the most dedicated of professionals. There are three key concerns that affect the willingness of professionals to serve persons with HIV: the fear of infection, the desire not to be labelled an "AIDS specialist," and the financial burden of AIDS work. The state needs to address these concerns in order to ensure that professionals respond to the threat of HIV with understanding and caution, not fear and discrimination.

A. "I am afraid to get infected"

Fear is perhaps the most common explanation for discrimination against persons with HIV. AIDS is an infectious and incurable disease. Medical, dental and funeral professionals interviewed by the Committee were oftentimes more concerned about infecting their families than they were about being infected themselves. These professionals felt torn between the
responsibility to serve their clients and the desire to protect themselves and their loved ones from disease.

Recent data from the federal Centers for Disease Control (CDC) reveal that health care workers are no more likely to develop AIDS than employees in any other field. Nonetheless, health care workers, along with dental and funeral workers, do have legitimate cause to worry about exposure to the AIDS virus. The very nature of their professions requires them to perform intrusive procedures on a variety of clients. These workers routinely come in contact with their clients' bodily fluids and often employ sharp instruments such as scalpels and syringes. It is not uncommon for these workers to suffer occupational injuries such as cuts and "needlesticks," thereby creating potential routes for HIV-transmission.

Consistent use of proper infection control procedures can help to minimize, if not eliminate, the possibility of exposure to the AIDS virus. As an AIDS prevention measure, infection control is much more effective than discrimination. Most HIV-infected persons are currently unidentified, both to themselves and to the public. According to a recent article in the Wall Street Journal:

> With so many healthy carriers of the virus—the CDC estimates 1.5 million in the U.S. alone—Dr. [David] Busch [infectious-disease consultant in San Francisco] says: "You don't always know who is a carrier. You need to assume everybody's blood is a risk item.... You don't want to become a blood brother with anybody."  

AIDS experts predict that it will take an average of ten years for currently infected persons to develop full-blown AIDS. In the meantime, these outwardly healthy-looking people may unknowingly infect others with the AIDS virus. As a result, discrimination against known or perceived persons with AIDS is a poor method of avoiding HIV-infection. Discrimination may give the professional a false sense of security and ironically increase the risk of infection.

The AIDS tragedy has promoted an increased awareness of the need for infection

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18 Chase, "Medical Personnel Scramble."
control procedures not only from HIV, but also from other infectious viruses such as hepatitis B. Speaking at the Third National Forum on AIDS and Hepatitis B, health experts from the National Institutes of Health, the Centers for Disease Control, and university hospitals agreed that:

The risk of contracting hepatitis B is substantially higher [than the risk of contracting HIV] despite the availability of a vaccine against [hepatitis B]. Each year, about 12,000 to 18,000 U.S. health care workers contract hepatitis B, and about 300 die from the disease. In comparison, only about 22 health care workers world-wide have contracted AIDS.¹⁹

These statistics reveal that hepatitis B is a much greater occupational hazard than HIV, yet some professionals unwisely continue to rely on discrimination rather than proper infection control procedures to protect themselves. The Committee understands the fear of HIV-infection but believes that this offers neither a scientific nor an ethical basis for discrimination against persons with HIV.

B. "I don't want to be known as an AIDS specialist"

Some professionals discriminate against persons with HIV out of fear that they will gain a reputation as an "AIDS specialist." Such a reputation has negative social and professional ramifications. In a recent Hastings Center Report, John D. Arras describes the stigma associated with AIDS work:

[AIDS] is perceived primarily as a problem for gays and inner-city minorities. Many people are not likely to interpret widespread refusals to treat as a threat to themselves. Unfortunately, they are equally unlikely to praise physicians for steadfastly treating the victims of AIDS and HIV infection. Indeed, for many people such behavior only serves to identify treating physicians with stigmatized social groups. Numerous physicians have confided to me that in many social circles being an "AIDS doctor" carries a highly pejorative connotation.²⁰

According to interviews conducted by the Committee, the pressure of such stigmatization


affects dental and funeral professionals as well.

The stigma associated with being an "AIDS specialist" is disturbing for a variety of reasons. On a broad level, this stigma reveals that the general public is still not aware of the epidemic's magnitude. The attitudes described by Dr. Arras reflect both a false sense of security about the disease and deep-rooted prejudices based on race, economic status, addiction and sexual orientation. While these problems are not within the scope of this report, the Committee believes it is important to be aware of their influence on HIV-related discrimination.

The stigma of being an "AIDS specialist" is disturbing for yet another reason: it reflects the false belief that discrimination against persons with HIV is an effective substitute for infection control. As previously mentioned, employees in medical, dental and funeral facilities should be aware of all the occupational risks of their professions, not just HIV, and the precautions necessary to minimize these risks. The importance of universal infection control cannot be stressed enough, and all professionals who may potentially come in contact with infected bodily fluids should be aware of this crucial issue.

C. "I can't afford to serve persons with HIV"

In addition to the social and professional stigma of being an "AIDS specialist," some professionals discriminate against persons with HIV because of the financial burdens of serving these clients. Such burdens include:

- the cost of additional infection control equipment, such as sterilizers, masks, robes, gloves;
- increased employee (dental hygienists, medical technicians, embalming apprentices) turnover due to concerns about occupational injury;
- loss of business among non-infected clients who fear infection or stigmatization from seeing an "AIDS specialist";
- increased business insurance and personal life insurance rates;
- increased business among persons with HIV, accompanied by increased paperwork, non-payments and risk to personal health.

Once again, some of these financial concerns are rooted in a false sense of security
about HIV. Infection control equipment is costly, but such equipment should be used by all professionals, not just "AIDS specialists," and in all cases, not merely for clients who are known to be HIV-infected. If proper infection control is followed, employees and clients of an "AIDS specialist" have no greater chance of contracting HIV than those of a practitioner who discriminates against persons with HIV. Indeed, because an "AIDS specialist" is more likely to follow proper infection control procedures, the chance of contracting HIV or another virus may actually be less with an "AIDS specialist" than with a practitioner who discriminates against persons with HIV.

At the same time, some of the financial concerns expressed by medical, dental and funeral professionals are valid. AIDS has brought about changes in the way that medical, dental and funeral professionals have to conduct their business. For example, about 40% of all persons with AIDS are dependent on Medicaid to meet their health care costs.21 As a result, medical and dental professionals who serve persons with AIDS or HIV may have to do additional paperwork and wait several months for reimbursement for their services. Moreover, Medicaid may not reimburse for some HIV-related services, such as experimental drug treatment, thereby forcing some professionals to make difficult financial and ethical decisions.

Similarly, funeral professionals contend that Medicaid reimbursement for funeral and burial expenses is not sufficient for the services they provide to persons with HIV. Some funeral professionals make up for this by charging significantly higher prices—up to four times the normal fee—for persons with AIDS or HIV who are not on Medicaid. Others have a policy of offering "limited" services to persons with HIV, such as closed-casket funerals or burial without embalming, to minimize both cost and risk. While such policies are legally suspect, funeral professionals contend that they are legitimate business practices.

Summary

During its interviews with medical, dental and funeral professionals throughout the state, the Committee noticed a wide variety of attitudes about serving persons with HIV and an equally wide range of knowledge about AIDS, HIV-transmission and infection control procedures. Not surprisingly, the Committee found that the professionals most knowledgeable about HIV also have the most sympathetic policies about serving persons with HIV.

All of the professionals interviewed by the Committee expressed concern about the threat of occupational injury and HIV-infection, but most also acknowledged that discrimination against persons with HIV is both illegal and unethical. These professionals differed significantly, however, in how they drew the line between illegal discrimination and legitimate business practice. Considering these inconsistencies, the Committee believes that the state needs to provide greater guidance and oversight of its licensed professionals regarding HIV education and policies.
CHAPTER 3:
STATE AGENCIES AND THEIR ANTIDISCRIMINATION EFFORTS

Discrimination against persons with HIV, particularly by medical, dental and funeral professionals, is a problem of unknown proportions, and documentation of such discrimination has been difficult to obtain. As a result, Massachusetts has had little incentive to increase the state's human and financial resources for combatting discrimination against persons with HIV.

The Committee believes that the lack of formal documentation of such discrimination belies the substantial anecdotal evidence and experiences of persons with HIV. Given the ramifications of discrimination against persons with HIV on personal lives and public health, the state must move forward and take action against this problem. The state needs to have a coordinated plan for locating, remedying and preventing discrimination against persons with HIV.

In this chapter, the Committee reviews the state's laws, agencies and activities that deal with discrimination against persons with HIV, particularly by medical, dental and funeral professionals. The purpose of this review is twofold: to give the reader an understanding of the existing mechanisms for locating, remedying and preventing such discrimination; and to create a foundation for the Committee's recommendations. The agencies reviewed in this chapter are as follows: the Massachusetts Commission Against Discrimination, the Attorney General's office, the Boards of Registration, and the Department of Public Health.

A. Massachusetts Commission Against Discrimination

The Massachusetts Commission Against Discrimination (MCAD), established under Chapter 6, Section 56 of the General Laws, is responsible for overseeing the state's antidiscrimination laws and policies. According to Chapter 151B, Section 3 of the General Laws, the MCAD is authorized "to receive, investigate, and pass upon complaints of unlawful practices...alleging discrimination because of race, color, religious creed, national origin, sex,
age, ancestry or handicap."

In January of 1986, the MCAD issued the following AIDS policy statement, extending the rights of the handicapped to persons with AIDS and persons perceived to be at risk of having AIDS:

Massachusetts law prohibits discrimination in employment and public accommodations against persons with a physical or mental handicap or who are perceived to have a physical or mental handicap (Massachusetts General Laws Chapter 151B, et seq., and Chapter 272, Section 98.)

The MCAD interprets these laws to prohibit discrimination against persons with Acquired Immune Deficiency Syndrome (AIDS) or who are perceived to be at risk of having AIDS. The following practices are illegal pursuant to these laws:

- to refuse to hire or advance in employment or otherwise discriminate against a qualified person with AIDS or who is perceived to be at risk of having AIDS;
- to make a preemployment inquiry as to whether the applicant has AIDS or is at risk of having AIDS;
- to make any distinction, discrimination or restriction relative to the admission of any person to, or his treatment in, any place of public accommodation because the person has AIDS or is perceived to be at risk of having AIDS.

MCAD will receive, investigate and resolve by conciliation or adjudication complaints of AIDS-related discrimination which are filed with the agency within six-months of the alleged discriminatory practice.

This statement by the MCAD forms the cornerstone of discrimination protection for persons with HIV in Massachusetts. It also provides a good starting point for assessing the strengths and weaknesses of the state's strategy against HIV-related discrimination.

The MCAD's policy extending the rights of handicapped persons to persons with AIDS and persons perceived to be at risk of having AIDS marked a major step forward in the area of disability law. In fact, this precedent-setting decision was echoed two years later at the federal level in School Board of Nassau County, Florida v. Gene H. Arline (107 S. Ct. 1123 (1987)). Moreover, the U.S. Senate recently approved federal legislation granting

\[22\] In Arline, the federal court held that a school teacher with tuberculosis was a "handicapped individual" within the meaning of Section 504 of the Federal Rehabilitation Act (29 USC §794). While the Arline decision did not directly address persons with AIDS or persons perceived to be at risk of having AIDS, mention was made in a footnote of the possible
antidiscrimination protection to disabled persons, including persons with AIDS or perceived to be at risk of having AIDS. Known as the "Americans with Disabilities Act," this law would grant on a federal level many of the protections already enjoyed by handicapped persons in Massachusetts. The MCAD's staff members, particularly those who worked on the AIDS policy statement, should be commended for their foresight, leadership and sensitivity regarding the rights and problems of persons with AIDS and HIV.

Since receiving its first HIV-related discrimination complaint in 1985, the MCAD has handled a total of forty such complaints. Thirty of these complaints have been about employment discrimination. The remaining ten complaints, of which eight remain open, have been about public accommodations discrimination. As this report concentrates on the area of public accommodations discrimination, the Committee recommends its previous report, AIDS in Massachusetts: Workplace Issues, Rights and Responses (November, 1987), to readers interested in employment discrimination.

The MCAD's primary weakness in the area of HIV-related discrimination is one shared by many state agencies: a shortage of financial and human resources. The MCAD currently has one attorney and one investigator assigned to handle HIV-related discrimination complaints. Both the attorney and the investigator have other caseload assignments besides their HIV-related work, and when time allows, they also do public speaking about antidiscrimination law. While HIV-related discussion sessions are convened on an ad-hoc basis, the MCAD itself does not have a formal agenda for HIV-related discrimination. Indeed, the MCAD seems to have its hands full dealing with its current caseload of HIV-related and non-HIV-related complaints.

The MCAD is further weakened by systemic barriers that separate the agency from its potential clients. The regulations that govern how the MCAD responds to, investigates and makes rulings on discrimination complaints are time-consuming, complicated and demanding.\(^{23}\) implications of this decision on these persons. Arline is regarded as the case which opened the door to handicapped protections for persons with AIDS and persons perceived to be at risk of having AIDS.

\(^{23}\) Please see M.G.L. c.151 B, §5, and 804 Code of Massachusetts Regulations 1.01 et seq.
Some HIV-related discrimination complaints have been at the MCAD for over two years and have yet to be decided. The slowness of the MCAD process is particularly problematic for HIV-related complaints, as most persons with AIDS die within a year of their diagnosis with the disease.\textsuperscript{24}

Furthermore, filing a discrimination complaint requires significant initiative, perseverance and money from the complainant. Few persons with HIV have the personal or financial resources to devote to such a demanding process. At the same time, the MCAD offers little reward for a successful discrimination complaint. According to the public accommodations discrimination statute, anyone found guilty of such discrimination is liable for the complainant's damages, but damages are often difficult, if not impossible, to measure.\textsuperscript{25} As a result, the successful complainant often receives little compensation for his or her suffering and effort.

Another source of difficulty is the MCAD's six-month statute of limitations for filing discrimination complaints. Civil rights advocates have long contended that six months is an unrealistic deadline for filing a discrimination complaint. AIDS presents special problems that may make it even more difficult for a complainant to meet the six-month deadline. For example, it is not uncommon for a person with AIDS or HIV to suffer a severe illness, such as pneumonia, only to recover after a few months of treatment and care. Several persons told the Committee that they did not file a discrimination complaint at the MCAD because they had been ill at the time, and were later unable to pursue a complaint because more than six months had elapsed since the discrimination incident.

The MCAD's AIDS policy statement and dedicated staff are two of the state's greatest assets in the fight against HIV-related discrimination. At the same time, it is clear that

\textsuperscript{24} According to a survival study of persons with AIDS, the median conditional probability of survival from date of diagnosis with AIDS is 347 days. The cumulative probability of survival at one year after date of diagnosis is 48.8%; and at five years, 15.2%.


\textsuperscript{25} M.G.L. c.272, §92A.
persons with HIV continue to suffer widespread discrimination and that the MCAD may need to reconsider its strategy against such discrimination. The MCAD cannot realistically combat HIV-related discrimination singlehandedly. Other agencies, such as the Attorney General's office, Boards of Registration, and Department of Public Health, have powers that may aid the MCAD in locating, remedying and preventing such discrimination. The state needs to devise and carry out a cooperative and innovative approach to HIV-related discrimination in order to succeed in reducing such discrimination and preventing the spread of the epidemic.

B. Attorney General's Office

Chapter 12 of the state's General Laws establishes the office of the Attorney General (AG). Unlike the MCAD, which is empowered to oversee a specific area of law, the Attorney General's office has jurisdiction over a broad range of issues, giving it significant power and flexibility in setting a legal agenda. Among the AG's various powers is the authority to enforce civil rights and consumer protection laws.

In the area of civil rights, the Attorney General is authorized to bring "civil action for injunctive or other appropriate equitable relief in order to protect the peaceable exercise or enjoyment of the right or rights secured [in state and federal laws]." 26 One of the rights secured by state law is "the right to the full and equal accommodations, advantages, facilities and privileges of any place of public accommodation." 27 As previously mentioned, MCAD considers medical, dental and funeral facilities to be places of public accommodation.

The civil rights division of the Attorney General's office, created under Chapter 652 of the Acts of 1962, has great potential for remedying HIV-related legal problems. For example, the division recently intervened to have a local school committee withdraw an employee policy that violated the civil rights of persons with HIV. However, while the civil rights division is eager to remedy discrimination against persons with HIV, it has received very few civil rights complaints. According to an attorney in the division, the paucity of

26 M.G.L. c.12, §11H.
27 M.G.L. c.272, §92A.
complaints received by the division indicates that persons with HIV may not feel comfortable asking the Attorney General for civil rights protection. Furthermore, because the AG's office generally effects change through injunctions rather than damage awards, persons with HIV have less incentive to pursue complaints through the AG than through the MCAD.

The civil rights division is working with the AG's community outreach division to establish a better relationship with persons with HIV and other potential victims of HIV-related discrimination. These two divisions have worked closely in the past to increase the AG's visibility in local communities and to encourage reporting of civil rights violations. The AG's civil rights and community outreach divisions recently produced and distributed a brochure entitled, "Your Civil Rights Under Massachusetts Law," containing information about civil rights, practical examples of unlawful treatment, and telephone numbers of local Attorney General offices across the state. The brochure was in turn translated into Chinese, Spanish, Laotian, Cambodian, French Creole, Vietnamese and Portuguese, and distributed in these communities. This brochure should serve as a model for future outreach efforts by the AG's office, especially those aimed at reaching the growing population of persons with HIV.

Besides its authority in the area of civil rights, the Attorney General's office is empowered by the Consumer Protection Act, Chapter 93A of the General Laws, to make rules and regulations regarding unfair or deceptive practices in trade or commerce, and to enforce these rules and regulations through civil action. Because of this authority, the AG's consumer protection division can be a powerful agent against discriminatory treatment of persons with HIV, particularly in places of "trade or commerce," such as medical, dental and funeral facilities. According to a representative from the AG's consumer protection division, the Attorney General has used his consumer protection authority to intervene in two cases against local hospitals and in several cases against HIV-testing laboratories.

The consumer protection division maintains community-level contact through twenty-eight local consumer advocacy groups funded by the Attorney General's office. These groups do intake, referral and advocacy work for consumer complaints, and all have been alerted by the AG to take special notice of concerns about AIDS, nursing homes and condominium
conversions. In addition, these consumer groups write "trend memos" to the Attorney General to inform him of problematic issues or businesses in their particular communities. The Attorney General also has a consumer protection hotline and an extensive referral network with organizations such as the Gay and Lesbian Advocates and Defenders, AIDS Action Committee and the Disability Law Center. The consumer protection division's varied approach to community outreach accounts in great part for its success in locating and remediing illegal activities within its jurisdiction.

The Attorney General's office, with its broad scope of power, its established ties with the community and its dedicated staff, is potentially one of the state's most valuable agents in the fight against HIV-related discrimination. Over the past few years, the AG's office has proven itself to be an effective and responsive advocate for persons with HIV. However, while both the MCAD and the AG's office have been successful in "putting out fires," neither agency has a long-term plan for combatting HIV-related discrimination. The Committee believes that the state should capitalize on the complementary strengths of the MCAD and Attorney General's office, and encourage both agencies to work on a cooperative plan for locating and remediing the problem of discrimination against persons with HIV.

C. Boards of Registration

The fight against the AIDS epidemic has three major components: identifying those who are infected, treating those who are ill, and preventing the further spread of the disease. Similarly, the fight against HIV-related discrimination is made up of three parts: locating incidents of discrimination, remediing those incidents, and preventing further incidents from occurring. While the MCAD and Attorney General's office are the state's chief agents for locating and remediing HIV-related discrimination, the Committee believes the greatest potential for preventing such discrimination lies with the state's Boards of Registration.

The state examines and licenses practitioners in a variety of professions--such as medicine, dentistry, and funeral and embalming services--and each of these professions has its own Board of Registration and set of regulations. All of the Boards of Registration, with
one exception, fall under the jurisdiction of the Division of Registration, a unit of the state's Executive Office of Consumer Affairs and Business Regulation. The sole exception is the Board of Registration in Medicine, which exists as an independent entity directly under the Executive Office.

A state license carries with it certain obligations as well as privileges. In exchange for the privilege of being able to practice in the state, a license obligates the practitioner to obey the regulations for the particular profession and the general laws of the state. The regulations for each profession include specific educational requirements for initial licensure, and many professions also have continuing education requirements for subsequent license renewal.

Just as public education about HIV is currently the best available method for preventing the spread of the disease, professional education about HIV is potentially the most effective way to prevent HIV-related discrimination in public accommodations. Such professional HIV education should include information about HIV-transmission, infection control procedures, the civil rights of persons with HIV, and the duties of professionals in public accommodations.

In early 1988, Paula W. Gold, then Secretary of Consumer Affairs and Business Regulation, convened the Inter-Agency Taskforce on AIDS Issues. The Taskforce, which included members from eighteen Boards of Registration, was formed with the purpose of anticipating and discussing the problems posed by HIV to the state's licensed professionals. In March of 1988, the Taskforce developed a set of guidelines that addressed the issues of professional duty to care, antidiscrimination and confidentiality standards, AIDS education and infection control.

The Taskforce members subsequently discussed, revised and adopted these guidelines

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28 M.G.L. c.6A, §9 et seq.; M.G.L. c.13, §§8-9B, 10-11, 19-21, and 29-31. In addition to its responsibilities over the Boards of Registration, the Executive Office of Consumer Affairs and Business Regulation also oversees the Division of Insurance. Unlike places of public accommodation, insurance companies are allowed to discriminate on the basis of AIDS or HIV-infection. However, under the leadership of former Secretary Paula Gold and current Secretary Mary Ann Walsh, the Executive Office has been committed to protecting the rights of persons with AIDS and HIV. Recently, the Division of Insurance amended its regulations to require insurance companies to obtain informed consent for HIV-testing and to maintain standards of confidentiality regarding the results of such tests.
with the other members of their respective Boards. The Board of Registration in Medicine was one of the first to take action on these guidelines, making minor revisions to the original text and formally adopting the revised guidelines as an advisory policy in June of 1988. The Medical Board’s version has subsequently been used and adopted by most of the other professional Boards. The Medical Board’s guidelines are included as Appendix B of this report.

The Committee applauds the foresight and initiative of former Secretary Gold and the participating Boards of Registration. The AIDS guidelines produced by the Taskforce are thorough, helpful and sensitive to the concerns of both professionals and persons with HIV. The timely and conscientious actions of the Board of Registration in Medicine are particularly praise-worthy, especially given the Medical Board’s uniquely independent status. At the same time, the Committee believes that the Boards of Registration are the most under-utilized resource for preventing discrimination against persons with HIV. Recommendations for increasing the Boards’ participation in such prevention efforts are described later in this report.

D. Department of Public Health

In addition to regulating the behavior of licensed professionals, the state can prevent discrimination against persons with HIV by regulating the facilities in which these professionals practice. Chapter 17 of the General Laws enumerates the various powers and duties of the Department of Public Health, including the power to license and inspect medical facilities such as hospitals and clinics. The Department is responsible for ensuring that these facilities have proper infection control equipment and that the practitioners in the facilities adhere to certain sanitary standards. Other facilities, including funeral homes, are licensed and inspected by local boards of health.

Through vigilant enforcement of the state’s sanitary code, the Department and local boards can help to reduce significantly both the possibility of HIV-infection and the fear of

29 Please see M.G.L. c.111, §§51-56; M.G.L. c.222, §127 A et seq.; and 105 C.M.R. 130 et seq., 140 et seq., 310 et seq., and 400 et seq.
such infection among medical, dental and funeral professionals. Once the fear of infection is addressed, discrimination against persons with HIV should be reduced significantly.

According to Department officials, licenses for medical facilities are renewed every two years. However, due to an insufficiency of resources, the Department often extends licenses without conducting the mandatory inspections. Both the survey operations unit, which conducts these inspections, and the division of community sanitation, which oversees sanitary regulations, have recently experienced cutbacks. The Committee believes that such cutbacks pose substantial risk to the public health.

As the state's primary agent for AIDS treatment and prevention, the Department also has a unique opportunity to interact with, educate and receive feedback from the state's HIV and intravenous drug user populations. The Committee believes that the state can improve its antidiscrimination efforts by taking advantage of the Department's contacts in these populations. Civil rights and antidiscrimination information should become part of the message delivered by the Department during its education and outreach work. The Department would also be of invaluable assistance to the Attorney General and the MCAD in doing outreach to the victims and potential victims of HIV-related discrimination.

Summary

The problem of discrimination against persons with HIV, particularly by medical, dental and funeral professionals, poses a major threat to AIDS prevention and treatment. Massachusetts is fortunate to have many assets for combating such discrimination: precedent-setting legal protections for persons with HIV, hard-working attorneys at the MCAD and Attorney General's office, progressive policy-makers within the professional Boards of Registration and Department of Public Health, and responsive advocates at various AIDS and community organizations.

At the same time, the state is sorely lacking a united front against HIV-related discrimination. While many of the state's agencies have programs or policies to fight such discrimination, there is little coordination of activity among agencies. As a result, persons
with HIV suffer from gaps in services, and licensed professionals are confused by conflicting signals from the state. Massachusetts needs to coordinate, clarify and intensify its HIV-related antidiscrimination activities. With the current shortages in the state's human and financial resources, it is more crucial than ever to explore creative, cooperative ways of maximizing the effectiveness of state programs.
CHAPTER 4:
RECOMMENDATIONS

The Committee acknowledges that there are no easy solutions to the problems raised in this report. Education about AIDS, HIV-transmission and infection control appears to be the best long-term solution to these problems, but the state needs to pursue some short-term remedies as well. In this chapter, the Committee examines potential solutions, both long- and short-term, to the problem of discrimination against persons with HIV. In order to maximize effectiveness and minimize cost, these solutions build upon already existing state programs, policies and activities mentioned previously in this report. The Committee's recommendations fall into two basic categories: those aimed at remedying and preventing discriminatory behavior by medical, dental and funeral professionals, and those intended to improve outreach to persons with HIV and other potential victims of HIV-related discrimination.

A. Remedies for and prevention of professional discriminatory behavior

1. The Attorney General's office should monitor and document incidents of HIV-related discrimination. In addition, the AG's office should ensure inter-agency cooperation for setting consistent responses to HIV-related discrimination complaints.

Without documentation of HIV-related discrimination incidents, it is difficult not only to justify additional financial and human resources for antidiscrimination programs, but also to identify where such programs should be targeted. While it may be impossible to document the full extent of HIV-related discrimination, it is clear that current mechanisms for monitoring and documenting such discrimination are insufficient.

The Committee therefore recommends that the Attorney General's office be responsible for monitoring and documenting HIV-related discrimination incidents in Massachusetts. The Attorney General's office is the best agency to undertake this responsibility because of its broad legal authority, acknowledged concern for AIDS issues, and ability to initiate investigations. The AG's office could fulfill this responsibility internally or could subcontract
the responsibilities to another entity, such as the AIDS Action Committee or GLAD.

The Attorney General's office or its subcontractor should monitor and document formal complaints of HIV-related discrimination lodged at the MCAD and Boards of Registration, as well as official action taken by the AG's office itself against such discrimination. Currently, there is no comprehensive documentation of formal HIV-related discrimination incidents, as each of these agencies maintains its own records of such complaints.

The Attorney General's office or its subcontractor should also monitor and document non-formal complaints of HIV-related discrimination. Sources for such information include the AIDS Action Committee, GLAD, the Department of Public Health, legal service agencies, community organizations, as well as the AG's own local consumer protection offices. These agencies and organizations should be informed of the AG's intent to monitor complaints of HIV-related discrimination, and clients at these agencies and organizations should be made aware that any HIV-related complaints they register will be kept confidential and non-binding.

In addition, the AG's office should work with the MCAD, the Executive Office of Consumer Affairs, and the DPH to establish a consistent protocol for responding to HIV-related discrimination complaints. Persons with HIV who experience discriminatory treatment should be able to contact any of these state entities and receive reliable and consistent legal information and referrals. Such information and referral services to persons with HIV could be provided through a hot line.

2. The Boards of Registration should adopt their AIDS Guidelines as official regulations.

The Boards of Registration should be commended for their foresight and initiative in adopting the Inter-Agency Taskforce's AIDS Guidelines (see Appendix B), however, additional measures should be taken to strengthen the impact of these guidelines on state licensees. The Committee therefore recommends that each of the various Boards of Registration adopt the AIDS Guidelines as part of their respective regulations.

The Boards of Registration diminished the potential impact of the AIDS Guidelines by adopting them as "advisory policies" rather than as official regulations. Official regulations
carry the force of law, while advisory policies do not. Regulations are published in the Code of Massachusetts Regulations, are referred to by licensed professionals, and may be used by the Boards of Registration as the basis for disciplinary action. As a result, regulations serve as both a remedy and deterrent to unethical behavior.

In comparison, advisory policies are not always published and are seldom circulated to licensees. Advisory policies are used primarily by Board members, generally on a post-facto basis. For example, Board members may refer to advisory policies when deciding whether disciplinary action needs to be taken, or when responding to a licensee's question about ethical behavior. As a result, an advisory policy regarding AIDS may have little impact on the day-to-day decisions and activities of state licensees.

3. The Boards of Registration should maintain better communication with state licensees, with a minimum standard of one newsletter every two years. In addition, the Boards should communicate regularly with state professional associations.

Effective communication between the state and its licensees is essential to proper oversight of professional conduct. The state's interests in its licensed professionals do not and cannot end with the issuance and renewal of the license. Licensees should be kept informed of new regulations, of actions by their respective Board of Registration, and of pertinent issues such as AIDS and infection control. The Committee therefore recommends that all the Boards of Registration maintain consistent communication with their licensees through newsletters, memoranda, seminars or other appropriate means.

Many of the Boards of Registration—including those in Medicine, Dentistry and Funeral Services—currently lack regular means of communication with their licensees. According to Judith Meltzer, the director of the Division of Registration, funds necessary for production and distribution of newsletters are unavailable. The cost of distributing a newsletter could be off-set, however, by including the newsletter in the license renewal packets mailed to licensees every two years. More frequent newsletters would be desirable, but one newsletter included with license renewal materials should be the minimum for such communication to licensees.

At this time, the most effective means of communication among licensees is through
professional associations and societies. Many organizations produce journals and newsletters that are distributed regularly to subscribers or members. The state's Boards of Registration should take advantage of the resources of these associations and societies, and should maintain regular communication with these organizations about issues that concern state-licensed professionals.

However, the Boards of Registration cannot neglect their responsibility to communicate with and oversee their licensees. While professional associations and societies may help the Boards communicate with some licensees, none of these organizations is absolutely comprehensive in membership. Moreover, the interests of these organizations may be, and often are, opposed to the interests of the state. Only the Boards of Registration have the ability to reach all state licensees and the authority to represent the state's interests regarding these licensees.

4. The Department of Public Health and local boards of health should conduct consistent inspections of facilities within their jurisdictions.

From the perspective of both the public and licensed professionals, proper infection control is an integral part of preventing discrimination against persons with HIV. The Department of Public Health and local boards of health are responsible for ensuring that the state's medical, dental and funeral facilities are safe and sanitary, and that workers in these facilities adhere to proper infection control procedures.

The Committee therefore recommends that the Department of Public Health and local boards of health conduct consistent and regular inspections of facilities within their respective jurisdictions. Furthermore, facilities failing to meet the state's sanitary standards should be penalized, either through remedial AIDS education for their employees or through suspension of their operating licenses.

According to representatives of the Department of Public Health, the schedule for licensing facilities operates on a two-year cycle. Inspections are a necessary pre-requisite to licensing, but the Department's limited resources do not allow for such frequent inspections. As a result, facilities often have their licenses extended without being inspected beforehand.
Lack of consistency in the inspection process can be dangerous. Licensed facilities may become lax in their sanitary standards if inspection is delayed indefinitely. Facilities that are mandated to be licensed every two years must be inspected equally often. If such frequent inspections are impossible to conduct, the legislature should appropriate additional funds for the Department and boards of health to fulfill their current responsibilities.

B. Improved outreach to persons with HIV

1. The MCAD should accommodate its complaint resolution process to the unique concerns of persons with HIV.

As mentioned earlier in this report, persons with HIV have unique concerns that may prevent or discourage them from filing a discrimination complaint at the MCAD. Limited financial resources and brief life expectancies are two of the primary concerns facing persons with HIV. At the same time, the MCAD normally awards minimal damages to successful discrimination complainants, and some HIV-related discrimination cases take years to be resolved. In sum, persons with HIV face many barriers and few rewards in the MCAD’s complaint resolution process.

The Committee therefore recommends that the MCAD accommodate its complaint resolution process to persons with HIV. Such accommodation may entail expediting the complaint process, assigning additional staff to HIV-related complaints, and/or increasing the damage awards for successful HIV-related discrimination complaints. As the primary antidiscrimination agent in the state, the MCAD has a responsibility to encourage victims of discrimination to file complaints and to discourage further incidents of discrimination from occurring. The lengthiness and confusion of the resolution process and the minimal damage awards for successful complaints hinder rather than help the MCAD in fulfilling these dual responsibilities.

2. The legislature should consider attaching a limited medical or emergency waiver to the MCAD’s six-month statute of limitations.

Among the various criticisms of the MCAD’s complaint resolution process, the one most
often cited by AIDS advocates and persons with HIV is the six-month statute of limitations. As previously described in this report, medical factors may prevent persons with HIV from filing a discrimination complaint within the designated six-month period. Attorneys at the MCAD are sensitive to these factors but are statutorily unable to consider complaints that exceed this deadline.

The Committee therefore recommends that the legislature consider attaching a limited waiver based on medical or emergency reasons to the MCAD's six-month statute of limitations. Such a waiver would allow persons with HIV and other victims of discrimination to file a complaint at the MCAD despite their inability to meet the six-month deadline. Such a waiver would keep the intent of the statute intact, yet make reasonable accommodation for the unique circumstances of certain persons with HIV and other victims of discrimination.

3. Both the MCAD and Attorney General's office should ensure and publicize that confidentiality is maintained in all cases of HIV-related discrimination.

Confidentiality is often a major factor in the decision of persons with HIV not to file a discrimination complaint. Oftentimes, these individuals are concerned that by filing an employment or public accommodations discrimination complaint, they will be identified as "trouble-makers" and may have difficulty gaining employment or services elsewhere. In addition, many persons with HIV do not want to publicize that they are infected with the AIDS virus.

According to attorneys at the MCAD, formal discrimination complaints may be, and have been, filed and resolved without disclosing the name of the complainant. Similarly, attorneys at the Attorney General's office may investigate and take injunctive action against a discriminating party on the basis of an anonymous complaint of HIV-related discrimination. The MCAD and AG's office should inform persons with HIV and AIDS advocates that such remedial action may be pursued in confidentiality.

4. The MCAD should educate potential victims of HIV-related discrimination about their civil rights through informative brochures and other educational means.

Persons with HIV need to be made aware of the protections accorded them by
Massachusetts and federal laws and the mechanisms by which discriminatory incidents may be remedied. As the state's primary antidiscrimination agency, the MCAD should be a leader in HIV-related antidiscrimination education. Such education should be aimed not only at persons with HIV, but other potential victims of HIV-related discrimination, such as homosexuals, persons of color and intravenous drug users.

The Committee therefore recommends that the MCAD assume primary responsibility for educating persons with HIV and other potential victims of HIV-related discrimination about their right to non-discriminatory treatment in employment and public accommodations. Such education should include information about civil rights, as well as the names and telephone numbers of state agencies that can remedy incidents of discriminatory treatment. In providing this type of education, the MCAD may benefit from working with local media, AIDS advocacy organizations, community health and cultural centers, and local legal service agencies.

Printed material about the civil rights of persons with HIV is an essential component of such education, and the Attorney General's aforementioned brochure on civil rights is an ideal model for such educational material. Like the AG's brochure, this brochure should be easy to read and made available in several languages. Moreover, the MCAD's brochure should be distributed in places such as inner-city legal service agencies, community health centers, and AIDS advocacy organizations. Workers at these localities should be trained to respond to client questions about the brochure.
CONCLUSION

At the 100th Shattuck Lecture to the Massachusetts Medical Society, the U.S. Secretary of Health and Human Services, Dr. Louis W. Sullivan, named the nation’s top five health-care priorities: AIDS and HIV-infection, drug abuse, health problems of the poor and minorities, the high cost of health care, and long-term care and health care for the uninsured. The Committee believes that the problems raised in this report touch upon all five of these national health priorities. AIDS and HIV-infection have taken a disproportionate toll on intravenous drug users, the poor and persons of color. As a result, the problems associated with HIV—including HIV-related discrimination—are in many ways related to larger problems with health-care delivery in the U.S. An effective campaign against the AIDS epidemic must work within the context of these larger problems.

At the same time, the Committee believes that small changes in AIDS education and HIV-related antidiscrimination can produce significant improvements in AIDS prevention. As Dr. Sullivan asserted,

Discrimination against those infected with the virus is unacceptable. HIV infection cannot be spread by casual contact. There is no justified medical reason for discrimination. Fear and ignorance must be overcome, not accommodated.

The Committee hopes that this report will assist the state in combating fear and ignorance about AIDS and persons with HIV. By locating, remedying and preventing discrimination against persons with HIV, the state will improve the health and well-being of persons with HIV, licensed professionals and the general public.

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APPENDIX A:
AIDS SURVEILLANCE SUMMARIES

Readers of this report may be interested in the demographic make-up of the current AIDS population. For this reason, the Committee has compiled the following charts to supplement this report.

Chart 1 - compares AIDS transmission categories in Massachusetts and the United States, as reported in the Massachusetts Department of Public Health/Boston Department of Health and Hospital's AIDS Newsletter (July 1989).

This chart shows that while homosexual and bisexual men make up the majority of state and national AIDS cases, intravenous drug users (IVDU) and homosexual or bisexual men who are also intravenous drug users now constitute one-quarter of these cases.

Chart 2 - compares the racial/ethnic background of persons with AIDS in Massachusetts and the U.S., as reported in the Center for Disease Control's HIV/AIDS Surveillance Report (August 1989).

This chart reveals the disproportionate impact of AIDS on communities of color. According to the Massachusetts Department of Public Health, blacks are eight times more likely and Hispanics six times more likely than whites to get AIDS. The increased likelihood of AIDS among blacks and Hispanics can be attributed largely to the problem of intravenous drug use in these communities of color.

Chart 3 - provides a break-down of transmission categories by racial/ethnic background of all persons with AIDS in the U.S., as reported in the aforementioned HIV/AIDS Surveillance Report.

This chart combines the trends exhibited in Charts 1 and 2. While homosexual and bisexual men constitute a clear majority of AIDS cases among whites, intravenous drug users make up a large part of the AIDS population among blacks and Hispanics. These intravenous drug users are considered by many to be the "second wave" of the AIDS epidemic.

Chart 4 - shows the growth in AIDS cases in Massachusetts over a two year period from January 1988 to January 1990 (projected), as reported in the aforementioned AIDS Newsletter.

This chart reveals that Massachusetts' AIDS population is increasing at a rate of over 750 cases per year. This figure translates into just over two new diagnoses of AIDS every day.

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Chart 5 - shows the national diagnosis rate for AIDS since the beginning of the epidemic in 1981. Data for this chart was compiled by the U.S. Centers for Disease Control in its HIV/AIDS Surveillance Report.

This chart reveals the dramatic rate at which AIDS cases are diagnosed in the U.S. Since diagnosis rates measure the number of new AIDS cases rather than the actual number of persons with AIDS, this chart may be misleading. While the diagnosis rate for AIDS has dropped off somewhat in the past year, the number of actual AIDS cases continues to grow.

The slight decrease in the number of AIDS diagnoses over the past year should not be interpreted as a sign that the crisis is over. First, current AIDS diagnosis information may not be completely accurate. More importantly, however, while the AIDS epidemic nears its saturation point in the gay community, the "second wave" of AIDS among intravenous drug users has yet to reach its peak.
Chart 1
Transmission Categories

Other/Unknown 18%
Homo/bi and IVDU 4%
IV drug user (IVDU) 17%
Homo/bisexual male 51%

Other/Unknown 13%
Homo/bi and IVDU 7%
IV drug user (IVDU) 20%
Homo/bisexual male 60%

MA (2,396 cases)  
US (99,936 cases)
Chart 2
Race/Ethnicity of Persons with AIDS

MA (2,396 cases)  US (99,936 cases)
Chart 3
AIDS Transmission, by Race/Ethnicity

Number of cases (Thousands)

Race

- Homo/bisexual male
- IV drug user (IVDU)
- Homo/bi and IVDU
- Other

Total adult cases: 60
White: 50
Black: 10
Hispanic: 5
Other: 0

U.S. Centers for Disease Control, 8/89
Chart 4
Massachusetts AIDS Cases

Number of cases (Thousands)


0  0.5  1  1.235  1.5  2  2.5  3

2.003  2.329

Mass. Dept. of Public Health, 1/88-7/89
Chart 5

U.S. Diagnosis Rates for AIDS

Year (6-month periods)

Number of cases (Thousands)

0 2 4 6 8 10 12 14 16

U.S. Centers for Disease Control, B89
APPENDIX B: AIDS GUIDELINES

Introduction

Early in 1988, the Board of Registration in Medicine participated in Secretary of Consumer Affairs and Business Regulation Paula W. Gold's Inter-Agency Task Force on AIDS Issues, which includes members from 18 licensing boards.

The Task Force developed the following guidelines to help licensing boards anticipate some of the complex issues surrounding this disease. The guidelines address the professional's duty to care, anti-discrimination and confidentiality standards, AIDS education for professionals and the public, infection control and expectations of licensed professionals who are HIV positive. The Board formally adopted the Task Force's Recommended Guidelines as an advisory policy in June, 1988.

A summary and the full text of the Guidelines follows:

Summary of AIDS Guidelines

1. Licensed professionals have a duty to care, treat or provide services to persons with AIDS, ARC or HIV-infection. Exceptions to this obligation may occur in clearly defined, unusual instances but as a general rule, all licensed professionals should be aware of their affirmative duty to treat, care for or deliver services to persons with AIDS, ARC or HIV-infection.

2. Licensed professionals should understand that civil rights laws protect persons with AIDS, ARC or HIV-infection against discrimination and that discriminatory conduct and behavior can subject licensees to discipline and legal action.

3. Licensed professionals should be aware of state law that prohibits health care providers from testing patients for exposure to the HIV virus without obtaining informed written consent, and from disclosing HIV test results without informed written consent.

4. Licensed professionals have an obligation to obtain appropriate education as to the nature of the AIDS virus, its transmission and safeguards against exposure. Minimal education requirements may be necessary in order for licensees to be considered fully competent, as may be recommended by each licensing board.

5. Licensed professionals should take every opportunity to educate the general public in understanding the nature of the AIDS virus, its transmission and safeguards against exposure.

6. Licensed professionals should routinely and nondiscriminatorily take all precautions against exposure and transmission as recommended by the Centers for Disease Control, the Department of Public Health, their licensing board and their profession.

7. Licensed professionals with HIV-infection should especially observe recommended infection control precautions and refrain from practices or procedures where a risk of transmission to patients can occur as identified by the CDC or other public health authorities. HIV-infection should not be ground for licensing board action provided

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the infected licensee observes suitable infection control precautions.

Discussion

A. Duty to Care

AIDS has created anxiety for all types of licensed professionals. This fear can be especially acute for health care and personal service professionals who come into close physical contact with infected individuals.

The best evidence to date, however, indicates that the risk of contracting the HIV virus, even among health care providers, is small and can be minimized by using infection control procedures. Professionals who do not come into personal contact with blood or bodily fluids of other individuals are at virtually no risk of contracting the virus. Consequently, fear of the disease should not be a barrier to caring for or delivering services to persons with AIDS, ARC or HIV-infection.

A professional's license carries with it a duty to provide needed services to the public. Licensed professionals should accord persons with AIDS, ARC or HIV-infection the same respect and quality of service delivered to non-infected individuals and should not deny care or service based on the individual's known or suspected HIV status.

This legal principle should be observed despite the contrary or possibly misleading advice of certain professional associations concerning the duty to care.

Exceptions to the duty to care can occur, but only in unusual cases and only in certain activities involving close physical contact with the public. For example, some public health experts have questioned whether professionals who are pregnant should treat patients with cytomegalovirus and possibly other opportunistic infections associated with AIDS that could infect the fetus.

Another exception may occur for licensees who are not equipped to manage certain clinical manifestations of AIDS, in which case professionals should still offer non-specialized services.

These exceptions to the duty to care do not apply to most professionals in most situations where the duty to care remains paramount, nor do they affect the delivery of care to HIV-infected patients who are not suffering from such opportunistic infections.

Caring for routine problems associated with AIDS or ARC is a skill all professionals need to master. If care for specialized AIDS manifestations is a skill which an up-to-date professional needs to master, then continuing professional competence would require mastering and offering those skills as well. Therefore, when a person with AIDS develops problems that would normally be in the area of expertise of and be routinely handled by a skilled professional, referral to another professional would be generally not in conformity with the intent of these guidelines. (Please note: This paragraph was modified by the Board before they adopted it.)

Alleged violations of this duty to care will most likely come in the form of complaints raised by the public and other professionals. Such complaints should be promptly investigated by a licensing board. Care should be taken to protect the confidentiality of a complainant with AIDS or HIV-infection.

In the case of health care professionals employed by a health care facility or another professional, a Board should consider cooperating with the employer to ensure resolution of
the duty to care complaint. For verifiable, genuine violations, a Board might recommend remedial AIDS education as a minimal response but more stringent sanctions might be imposed as appropriate.

B. Anti-Discrimination Standards

Licensed professionals should understand that their professional practice is viewed as a "public accommodation" under state and federal civil rights laws. As such, professionals are prohibited from discriminating against handicapped individuals.

The Massachusetts Commission Against Discrimination (MCAD) and the Office of the Attorney General enforce these laws. The MCAD has ruled that individuals known or suspected to have AIDS, ARC or HIV-infection are considered to be handicapped individuals and are protected by civil rights laws. The intent of these laws is to protect individuals against the blatant discrimination and stigmatization experienced by persons with known or suspected AIDS, ARC or HIV-infection.

The MCAD will assist individual Boards that receive complaints of alleged discrimination. The Boards are in a good position to communicate the substance of these civil rights laws to licensees. A Board should also be aware of the potential for disciplinary action against a licensee found to have violated the civil rights of known or suspected persons with AIDS, ARC or HIV-infection.

C. Privacy and Confidentiality

State law strictly controls the confidentiality of HIV test results. The law (M.G.L. c.111, § 70F) prohibits health care facilities, physicians and health care providers from testing for HIV-infection without the test subject's written informed consent. Written informed consent is also required to disclose test results and the fact an individual was tested to anyone other than the test subject. Each release of this information, including medical records that contain HIV test information, must be authorized by a separate written release and must be distinguished from other general releases for medical information. Violations of this law are subject to triple damages under the Consumer Protection Act.

The law attempts to prevent the discrimination and personal harm that can result from the injudicious or even inadvertent disclosure of an individual's HIV status. The law's prohibition against unauthorized disclosure may pose problems within health care facilities and office setting where co-workers might need to know about a patient's HIV status to render proper care.

The law does not prevent professionals from asking patients whether they have AIDS or ARC. Co-workers can share this information just as any necessary diagnostic information would be shared. However, this information is subject to the same laws that protect the privacy of all personal medical information. It is also recommended that only co-treating professionals with a need to know about a person's AIDS or ARC diagnosis should be informed of the diagnosis in order to prevent unwarranted disclosures that might harm the person with AIDS or ARC.

Alleged violations of the test confidentiality law can be referred to the Department of Public Health and the Attorney General which enforce the law. A Board should consider the possibility of disciplinary action against a licensee found to have violated this law on the grounds that the unlawful breach of confidentiality constituted unacceptable professional practice.

D. Education
Education is the best defense against the spread of the HIV virus and the best way to alleviate irrational fears, stereotypes and behaviors that should not be associated with professional conduct. In addition to educating themselves, licensed professionals are in a unique position to educate the public about the nature of AIDS, risk-prone behavior and precautions against exposure.

AIDS education for the professional should minimally include an understanding of what the HIV virus is and how it is transmitted, infection control methods and the psychological and sociological impacts of AIDS on individuals and society. In addition to considering whether this minimal education should be a matter for continuing education, licensing boards should consider what additional education its licensees should possess to care for, treat or deliver services to persons with AIDS, ARC and HIV-infection.

Licensing boards should become familiar with AIDS educational resources that are available to their licensees. They should also consider whether board-approved teaching and training programs should include AIDS education and infection control procedures in curricula and training programs. Boards might consider including a section on AIDS and infection control in the licensure examinations which they administer.

The Governor's Task Force on AIDS has urged that all professionals take every opportunity to educate the public. The Department of Public Health has promulgated regulations that require AIDS education at all family planning and drug treatment clinics and when physicians perform blood tests for marriage licenses. Professionals should provide education whenever appropriate and include explanations of precautions that reduce the risk of exposure to the virus. Professionals should also correct misinformation about AIDS and help allay fears that contribute to stereotypes and stigmatization associated with AIDS.

E. Infection Control Procedures

Licensed professionals should routinely use infection control procedures recommended by the Centers for Disease Control (CDC), the Public Health Service, Department of Public Health and other agencies whenever they are likely to come into physical contact with any individuals where bodily fluids, particularly blood, might be exchanged.

These procedures not only protect against HIV transmission, but also more virulent and contagious viruses like Hepatitis B. Several licensing boards, like Acupuncture and Electrology, have adopted mandatory equipment sterilization procedures for their licensees. Other Boards might consider infection control standards appropriate for their licensees.

In the absence of adopting infection control regulations, all licensing boards should strongly advocate their use and expect licensees to seek infection control education.

F. HIV-Infected Licensees

The Centers for Disease Control (CDC) have found no evidence that HIV-infected health care professionals have transmitted infection to patients. The CDC has stated that a risk of transmission would exist in situations where there is both (1) a high degree of trauma to the patient that would provide a portal of entry for the virus (e.g., during invasive procedures) and (2) blood or serous fluid from the infected health care professional might gain access to the open tissues of a patient as could occur if the professional sustains a needlestick or scalp injury during an invasive procedure.

HIV-infected professionals must observe the infection control precautions that apply to all health care professionals, regardless of whether they perform invasive procedures: (1) all professionals should wear gloves for direct contact with mucous membranes or nonintact
skin of all patients and; (2) professionals who have exudative lesions or weeping dermatitis should refrain from all direct patient care and from handling patient-care equipment until the condition resolves.

Licensed professionals with HIV-infection have an obligation to take preventive steps that protect the public from any risk of infection. Infection control precautions should be strictly observed by HIV-infected licensees. A Board should consider taking stringent disciplinary action against licensees who fail to meet this expectation.

An HIV-infected licensee should also refrain from practices and procedures where a risk of transmission exists as identified by the Centers for Disease Control and other public health authorities. Licensees should not, however, be disqualified from practices, procedures and activities that do not pose a genuine risk of transmission.

It is still open to further consideration under what circumstances infected licensees might have to disclose their HIV status. However, infected licensees should be aware that boards will carefully scrutinize any conduct or behavior which even potentially jeopardizes public health and safety.
APPENDIX C:
ACKNOWLEDGMENTS

In doing its analysis of discrimination, the Committee interviewed and consulted many people throughout the state. Among these were dozens of persons with AIDS, ARC or HIV-infection who, for reasons of confidentiality, are not included in the following list. The Committee is deeply indebted to all the individuals and organizations who contributed their time, knowledge, and suggestions for this report.

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Massachusetts Dental Society
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Massachusetts Department of Public Health
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   Sarah Bachrach
   Janet Bath
   Anne DeMatteis
   Henya Handler
   Beverly Hayes, former Director, AIDS Office
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Massachusetts Department of Public Health/ Boston Department of Health and Hospitals, AIDS Surveillance Program
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Massachusetts Division of Registration
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Massachusetts Executive Office of Consumer Affairs and Business Regulation
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Massachusetts Funeral Directors Association
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Massachusetts Medical Society
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Bob Ward

Massachusetts Office of the Attorney General
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PWA Coalition of Western Massachusetts
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APPENDIX D:
LIST OF REFERENCES


Richardson, Jean J., Thomas Lochner et al. "Physician Attitudes and Experiences Regarding the Care of Patients with Acquired Immunodeficiency Syndrome (AIDS) and Related


