

DOCUMENT RESUME

ED 284 404

EC 200 222

TITLE AIDS in Michigan: A Report to Gov. James J. Blanchard.
INSTITUTION Michigan State Dept. of Public Health, Lansing.
PUB DATE Apr 86
NOTE 75p.; Produced by the Public Health Advisory Council and Expert Committee on AIDS.
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS *Acquired Immune Deficiency Syndrome; *Communicable Diseases; Disease Control; Disease Incidence; Educational Policy; Elementary Secondary Education; Health Needs; High Risk Persons; Prevention; Public Education; Public Health; *Special Health Problems; State Government; State Programs
IDENTIFIERS *Michigan

ABSTRACT

This report presents information regarding the incidence, effects, programs, policies, and services pertaining to Acquired Immune Deficiency Syndrome (AIDS) in Michigan. A list of 55 recommendations concerning prevention and control, provider and institutional care, state government policy, and financing precedes sections detailing the current status and possible future impact of AIDS on these areas. The first section of this report is an overview which discusses incidence in Michigan and other areas, deaths from AIDS, high risk persons, treatment and effects of AIDS. A section on prevention and control discusses such activities as surveillance by public health agencies to collect accurate information about AIDS, education for the general public, and epidemic control measures. The third section considers provider and institutional care issues centering around the availability of and access to medical and support services needed by AIDS patients and the educational and inservice training needs of health professionals. The Michigan state government policies and roles are addressed in the fourth section, including discussion of policy effects on state employees, contractors with the government, persons institutionalized in state facilities, the general population, and AIDS patients. The cost of AIDS-related activities and recommended levels of state financial support are discussed in the final section. Appendices contain a glossary, lists of committee participants, and selected references. (CB)

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AIDS

in michigan
a report to Gov. James J. Blanchard

april 1986

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STATE OF MICHIGAN



JAMES J. BLANCHARD, Governor

DEPARTMENT OF PUBLIC HEALTH

3500 N. LOGAN
P.O. BOX 30035, LANSING, MICHIGAN 48909
GLORIA R. SMITH, Ph.D., M.P.H., F.A.A.N., Director

March 18, 1986

The Honorable James J. Blanchard
Governor
State of Michigan
State Capitol Building
Lansing, Michigan 48909

Dear Governor Blanchard:

I am transmitting for your consideration the initial report on Acquired Immune Deficiency Syndrome (AIDS) in Michigan.

Your October 21, 1985, letter directed the Public Health Advisory Council to review the current situation and make recommendations for a comprehensive state policy concerning AIDS. In response, the council created an Expert Committee on AIDS, comprised of 43 leaders in the fields of medicine and law as well as representatives of public agencies, advocacy organizations, and associations of health professionals. The Expert Committee created four subcommittees and began deliberations in December. Acting on the findings and recommendations of the Expert Committee, the Public Health Advisory Council approved this report and its recommendations on March 17.

The recommendations contained in the report reflect the consensus of a wide variety of Michigan experts about the best means to protect the public health from the spread of AIDS. Throughout its deliberations, the committee was fully cognizant of the level of concern of Michigan citizens about this syndrome. The members of the committees also recognized the need to assure that appropriate systems are available in Michigan for the care of people with AIDS.

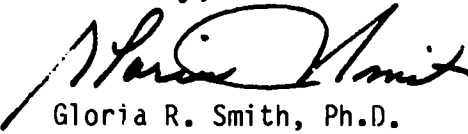
Outstanding leadership and considerable resources have been provided by the private sector for combating AIDS in Michigan, particularly by organizations representing groups at highest risk. While private commitment continues, private resources are being strained. It is clear that additional support from both the state and federal governments is urgently needed to react to this new epidemic.

As you have said, we must guarantee that state and local agencies are doing all they can to protect the health of our citizens through a strong, comprehensive policy regarding AIDS. This report recommends policies to ease public anxiety about AIDS, to motivate individuals to change high-risk behavior, and to meet the medical and support needs of persons with AIDS.

Governor James J. Blanchard
Page 2
March 18, 1986

I am proud of the work of the Public Health Advisory Council, the Expert Committee, and the four subcommittees who participated in this important project. I am also proud of this report. The members of those committees came to this task with differing perspectives and from different backgrounds. Nevertheless, all were sensitive to the complexity of the AIDS issue and to the need for a comprehensive state strategy for dealing with the syndrome. I am confident that, if implemented, the recommendations in this report will help to reassure the Michigan citizenry that the public health is being protected and will make a difference in the lives of many in our state. We will, with the continued assistance of the Public Health Advisory Council, closely monitor new developments concerning AIDS in Michigan and nationally, so that new information can be translated into further policy recommendations when warranted.

Sincerely,

A handwritten signature in black ink, appearing to read "Gloria R. Smith". The signature is fluid and cursive, with a large initial "G" and "S".

Gloria R. Smith, Ph.D.
State Health Director

STATE OF MICHIGAN



JAMES J. BLANCHARD, Governor

DEPARTMENT OF PUBLIC HEALTH

3500 N. LOGAN
P. O. BOX 30035, LANSING, MICHIGAN 48909
GLORIA R. SMITH, Ph.D., M.P.H., F.A.A.N., Director

March 17, 1986

Gloria R. Smith, Ph.D., M.P.H., F.A.A.N., Director
Michigan Department of Public Health
3500 North Logan Street
Lansing, Michigan 48909

Dear Dr. Smith:

On behalf of the Public Health Advisory Council and the Expert Committee on AIDS, we present for your consideration the initial report and recommendations on AIDS in Michigan, requested by Governor Blanchard on October 21, 1985.

This report provides background information and data on the extent of the AIDS problem in our state and makes recommendations for public policy in four broad areas: prevention and control, provider and institutional care, state government policy and financing. Implementation of recommendations will be important to an effective state strategy to confront AIDS and ease the problems of those persons with AIDS.

The recommendations represent the consensus of opinion and comprehensive knowledge of the members of the Public Health Advisory Council and the Expert Committee on AIDS, a representative group of experts in a wide variety of fields. We wish to acknowledge the valuable assistance of the Michigan Department of Public Health and Public Sector Consultants, Inc., which provided staff support.

Thank you for providing us the opportunity to offer analysis and recommendations on this most important public health issue.

Sincerely,

A handwritten signature in black ink, appearing to read "Donald C. Smith".

Donald C. Smith, M.D.
Chair, Public Health Advisory Council
Chair, Expert Committee on AIDS

A handwritten signature in black ink, appearing to read "Charles F. Whitten".

Charles F. Whitten, M.D.
Co-Chair, Expert Committee on AIDS

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 Public Health Advisory Council
 Expert Committee on AIDS
 Invited Observers to the Expert Committee
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EXECUTIVE SUMMARY

Like most Americans, Michigan residents are deeply concerned about the latest infectious condition to threaten the nation: Acquired Immune Deficiency Syndrome, or AIDS. Parents of school-age youngsters, teachers and school administrators, policymakers, business people, health care workers, insurance companies, labor unions, prison guards, hospital and nursing home administrators, and blood donors, among many others, are concerned and anxious about how AIDS is spread and how immediate a threat it is to their health and to the well-being of their families and communities.

As of March 10, 1986, 134 persons in Michigan have developed AIDS; 69 have died. AIDS is a complex defect that destroys the body's natural immunity to diseases. AIDS is caused by the HTLV-III virus, but not everyone who carries the virus actually contracts the fully developed and lethal AIDS. In fact, fewer than 10 percent of those known to carry the virus have developed AIDS, although it should be presumed that anyone infected with the virus is a potential carrier. The long-term consequences of exposure to the virus are unknown.

AIDS cannot be medically prevented by vaccination. Medicine today cannot cure it. The vast majority of adult persons with AIDS are homosexually/bisexually active men and drug users who share contaminated syringes, because the HTLV-III virus is transmitted most easily through semen and blood. Persons will not acquire the virus through normal, everyday, nonsexual activities and contact; studies show that even family members in daily contact with AIDS patients show no signs of infection.

The constitutional and public trust responsibilities to protect the health of its citizens and to prevent unreasonable intrusions into their private lives require state government to respond to the problems presented by AIDS in a carefully considered and responsible fashion.

It is against this backdrop that Governor Blanchard, on October 21, 1985, asked the Michigan Department of Public Health to coordinate the state's efforts and the Public Health Advisory Council to make policy and program recommendations. The Governor requested an initial report by April 1, 1986. In response, the Public Health Advisory Council established an Expert Committee on AIDS and four subcommittees, representing a wide variety of disciplines and perspectives. These groups have been meeting since December 1985 to examine the problems and propose solutions to the complex AIDS dilemma. The groups considered carefully all aspects of the AIDS issue and reviewed national and state data, medical research findings, and perspectives of a wide variety of other bodies studying such issues. Current knowledge, technology, and the scale of the problem shaped the analysis and recommendations, which focus on prevention and control activities, provider and institutional care, state government policy, and financing. Highlights are summarized below.

Mandatory epidemic control measures historically used to curb the spread of infectious conditions are counterproductive in efforts to check the spread of the HTLV-III virus. Unlike polio, for example, AIDS is not preventable by immunization. Unlike syphilis, another infectious condition, AIDS is not

curable. But the virus is not easy to transmit. Therefore, the major public health strategy for prevention and control should be to change behavior that causes individuals to be at high risk of acquiring the virus; education targeted to high-risk groups is the best means currently available to curb the spread of the virus and AIDS. Education of the general public is also important in promoting greater knowledge and understanding of AIDS and in reducing unwarranted fears.

The groups currently at greatest risk, including homosexuals, bisexuals, and intravenous drug users, must be fully informed about the modes of transmission of the virus and given information to motivate them to be cautious and safe in their sexual and other practices. Because of the understandable fear among members of such groups of disclosure of their sexual preference or use of drugs, anonymity and confidentiality are integral to the effectiveness of behavior modification efforts, counseling, and voluntary testing.

To assure continuing and close monitoring of the spread of the virus in Michigan, the Michigan Department of Public Health should continue its surveillance and reporting of AIDS and examine national incidence and prevalence studies. As part of its educational activities, the department should continue to report to the media and public the incidence of AIDS cases in Michigan. The department should also work closely with associations of health professionals to assure the dissemination of knowledge about AIDS.

Because of the disproportionate number of AIDS cases reported in southeast Michigan, the State should promote and support in metropolitan Detroit an expert program for the treatment of persons with AIDS, linked with a statewide network of community hospitals and community-based resources. Consideration should be given to the creation of one or more dedicated long-term care units to assure the availability of long-term care services.

The State should strive to remove barriers to other health care and support services needed by AIDS patients. Examples of health care services are home health, hospice, and dental care; examples of support services are counseling, chore services, and residential care. In some cases, provision of necessary services by professionals such as ambulance crews and funeral directors are jeopardized by inadequate notification of infectious conditions; the Michigan Department of Public Health should resolve questions of inadequate warnings and the need for greater precautionary measures. For these and other health care professionals, the upgrading and dissemination of in-service training programs are needed.

Medical research into the causes and treatment of AIDS is critical, but best funded and coordinated nationally. The establishment of retro-virology laboratory services within the Michigan Department of Public Health is essential for medical researchers in Michigan to access federal research funds.

The Insurance Commissioner should continue to work with life and health insurers and others to assure availability of third-party coverage for AIDS-related treatment and care. The costs of care and its implications for the Medicaid program, third-party payers, and the health care industry must be scrutinized closely.

The Michigan Department of Civil Rights should continue to assure that persons with AIDS and AIDS-Related Complex and persons showing HTLV-III antibody positivity are protected against discrimination in employment, housing, public accommodations, public services, and education. State agencies should not collect identity-specific information about such individuals without clear evidence of need and should review confidentiality standards to assure identity-specific information is accessed only by those with a compelling "need to know." Mandatory testing of confined populations, such as prisoners and residents of mental health facilities, should be considered only in the context of a comprehensive plan deemed useful in containing the spread of the virus.

Students infected with AIDS can safely attend school without endangering others unless they exhibit specific medical or behavioral conditions that present a risk to themselves or others.

To assure the consistency of policy across state department lines, the Michigan Department of Public Health, with the assistance of a broadly representative committee of persons both inside and outside state government, should be charged with reviewing all agency policies and issues involving AIDS.

RECOMMENDATIONS

Prevention and Control

- | | <u>PAGE</u> |
|--|-------------|
| 1. The Michigan Department of Public Health (MDPH) should continue surveillance activities monitoring the occurrence of AIDS cases fitting the standard national case definition. Such activities should include designation of a special AIDS surveillance officer. | 8 |
| 2A. The MDPH should examine the incidence, prevalence, and natural history studies conducted by other states and the National Institutes of Health while compiling and studying the ongoing data being collected within our own state. Such studies should be funded primarily by the federal government. | 9 |
| 2B. The reporting of positive human T-lymphotropic virus type III (HTLV-III) serologic tests and AIDS-related complex (ARC) should not be supported because of its cost and the probability that it would be counterproductive to voluntary testing and would threaten individual privacy and confidentiality. | 9 |
| 2C. Anonymous, batched testing of blood of high- and low-risk groups for prevalence studies and voluntary involvement in AIDS-related research projects should be encouraged. | 9 |
| 3A. The MDPH should direct broad public education campaigns to and produce regular reports about AIDS for the general public; information about the legal rights of persons with AIDS should be included. Distribution should include the news media, libraries, and local health departments. Regular press briefings should be held and surveillance statistics should continue to be provided routinely to the media. | 10 |
| 3B. The MDPH should direct general information and updates to statewide organizations representing labor, business, political activists, civic groups (such as civic clubs, leagues, service clubs, and religious organizations), and statewide, nonhealth trade and professional organizations. | 11 |
| 3C. The MDPH should encourage the production and dissemination of public service announcements. | 11 |
| 3D. The MDPH should work with health agencies in other states to identify, develop, distribute, and purchase printed materials, slides, videotapes, and other media materials. | 11 |
| 4. The MDPH should work with interested groups to develop and implement information strategies aimed at high-risk groups, such as support for a statewide hotline; partial support for community hotlines; and, through contracts with organizations reaching high-risk groups, partial support for targeted educational materials and strategies. | 12 |

- 5A. High-risk populations should be encouraged to seek out voluntary risk-reduction counseling followed by confidential and anonymous testing for HTLV-III antibodies when desired by an individual. The MDPH laboratory should offer the enzyme-linked immunosorbent assay (ELISA) and Western Blot tests on an anonymous basis. 17
- 5B. Mandatory screening, testing, or contact tracing of high-risk individuals should not be implemented because they would be counterproductive and would threaten individual privacy and confidentiality. 17
- 5C. Mandatory screening/testing of low-risk groups, e.g., premarital screening, should not be supported. 17
- 5D. Employers, including health care facilities, should not mandate screenings for employees. Health care facilities should offer voluntary counseling and testing when medically appropriate. 18
- 5E. Mandatory contact tracing should not be supported. Voluntary contact notification should be encouraged. 18
- 5F. The MDPH should work closely with the Michigan departments of Corrections, Mental Health, and Social Services to develop effective policies and plans for confined populations, with an emphasis on disseminating educational materials to staff and institutionalized persons. 18
- 6A. The MDPH should monitor closely laboratory and other testing procedures offered to the public, including new laboratory technologies as they are introduced. 19
- 6B. The MDPH should inform laboratory directors, physicians, and hospitals in the state of its ability to perform Western Blot tests and should provide information about appropriate HTLV-III antibody testing techniques and safety precautions. 19
- 6C. The MDPH should be supported in efforts to develop retro-virology services. The MDPH should pursue with neighboring states the concept of sharing laboratory facilities for cost-effectiveness. 19

Provider and Institutional Care

7. Funeral directors, ambulance personnel, and other health care workers should be notified of infectious conditions. The MDPH should convene meetings of infection control specialists, hospital administrators, funeral directors, ambulance personnel, and other groups to determine how best to provide--whether by law, administrative rule, or voluntary compliance--adequate notification of the presence of infectious conditions and how to take necessary precautions. Such notification should not result in services being withheld by those health care workers. 21

- 8A. The State should assist and fund proposals from selected community organizations to provide necessary quality support services. 23
- 8B. The Michigan Department of Social Services should identify the need for foster care of AIDS patients and remove barriers to and expand access to foster care home settings as well as other residential facilities. 23
- 8C. The Michigan Department of Mental Health should coordinate the provision of psychological and psychiatric services needed by AIDS patients. 23
- 9A. The MDPH should work directly with state professional associations to upgrade and prepackage in-service training programs, patient and/or provider protocols, and education about AIDS. 24
- 9B. The dental, nursing, medical, and allied health professional schools should assess curricula for infection control to ensure adequacy and inclusion of state-of-the-art information. 24
10. The MDPH should work with the professional associations of health care workers, the labor unions representing health care workers, and the employers of health care workers to assure that there are adequate educational and training programs regarding control procedures for all infectious conditions, including AIDS. 25
11. The MDPH should work closely with individual health care providers, institutions, and professional associations to ensure that they are fully informed about AIDS so that they, in turn, render quality care and take desirable precautionary measures. Legal and ethical obligations require health care professionals to render care and service, within their scope of practice and legal standards, to persons with AIDS. 25
12. The State should promote and support in metropolitan Detroit an expert program for the treatment of persons with AIDS, linked with a statewide network of community hospitals and community-based resources. The State should work to stimulate the creation of outpatient community care opportunities through the establishment of networks of community resources elsewhere in the state. The Greater Detroit Area Health Council should be encouraged to continue its assessment of care opportunities in southeastern Michigan. One or more dedicated long-term care units should be considered. 27
13. The MDPH, in cooperation with medical experts in the state, should facilitate collecting and disseminating information about AIDS to health care providers. Such information should be distributed through the professional associations of health care providers, as well as in response to direct inquiries. 28

State Government Policy

14. The MDPH, with the assistance of a broadly representative committee consisting of persons both inside and outside state government, should be charged with ongoing review of all AIDS-related policies of state agencies and cross-departmental issues for the purpose of achieving consistency. 30
- 15A. The MDPH should work with state agencies to provide all employees of state institutions with educational materials outlining current knowledge pertaining to AIDS and with training regarding appropriate infection control procedures. 31
- 15B. Information describing AIDS and its modes of transmission should be made available to all prisoners at state correctional facilities. 31
- 15C. Comprehensive plans to control the spread of the HTLV-III virus in confined populations should be developed by the Michigan departments of Corrections, Mental Health, and Social Services in consultation with the MDPH and with other interested parties, including unions representing affected employees. Mandatory testing of any individual or group of individuals should be considered only in the context of such a comprehensive plan and should be implemented only when demonstrated to be effective in containing the spread of the virus. 31
16. The Michigan Department of Civil Rights (MDCR) should enforce the provisions of the state Handicappers' Civil Rights Act to ensure that people with AIDS, ARC, or HTLV-III antibody positivity are protected against discrimination in employment, housing, public accommodations, public service, and education. The MDCR should publicize its policy regarding the rights of persons with AIDS, ARC, or HTLV-III antibody positivity. 32
17. The MDPH should work with the Michigan departments of Social Services and Mental Health and with the Office of Substance Abuse Services to develop information packages for contracting state agencies to provide to caregivers. 33
18. The Michigan departments of Licensing and Regulation and Public Health jointly should review professional standards for personal service workers to assure that they reflect current information regarding AIDS. Distribution of AIDS-specific information to state licensees is desirable and should be accomplished through general education programs directed at licensees. 34
- 19A. Each department of state government, before obtaining identity-specific information about persons with AIDS, should establish clear evidence that such information is necessary. 35

- 19B. The departments of state government providing custodial care that obtain identity-specific information about persons with AIDS, ARC, or HTLV-III antibody positivity should review their confidentiality standards to ensure that only those persons with a clear and compelling "need to know" have access to such information. 35
- 19C. Whenever personally identifying information concerning AIDS is reported to the MDPH, notice should be given by the personal physician to any individual about whom the information is compiled. Whenever confidential personally identifying information is to be shared among departments of state government, a signed release should be obtained from the individual prior to the transmittal of the information. The individual should have the right to a copy of such information and the names of agencies with whom the information was shared. 35
20. The MDPH should develop legislation or administrative rules to protect against the spread of AIDS through tissue, organ; or bone transplants. The following principles should apply:
- HTLV-III antibody testing of donors is necessary for stored tissues of all types.
 - When fresh organs, tissues, or semen are harvested, HTLV-III antibody testing should be performed, but the need for evidence of a negative test prior to transplantation must be addressed on an individual basis since the condition/need of the recipient and condition of the donor organs vary widely.
 - Appropriate confidentiality standards of donor names and/or test results must be strictly maintained. 36
- 21A. The Expert Committee supports the position of the Centers for Disease Control that students infected with AIDS can safely attend school without endangering others unless they exhibit specific medical or behavioral conditions that present a risk to themselves or others. These conditions should be locally evaluated on an individual basis. 37
- 21B. The Michigan Department of Education (MDE) in cooperation with the MDPH should develop public policy guidelines relating to AIDS that assure public health protection and provide for appropriate educational opportunities for all students. 37
- 21C. The MDE should work with the MDPH to disseminate information about AIDS prevention, transmission, and spread and to dispel unnecessary fears among school employees, parents, and students. 38
- 21D. The MDPH should support the MDE in assuring that school employees infected with AIDS are not restricted from working in the school setting unless specific medical or behavioral risks are documented. Routine AIDS testing is not warranted for students or school employees. 38

Financing

- 22A. The Insurance Commissioner should continue to work with life/health insurers, the Public Health Advisory Council, and representatives of the most affected groups (to be selected by the commissioner) to recommend policies to make available insurance coverage for AIDS-related treatment and care and life insurance benefits. In the interim, persons at risk (whether defined by socio-demographic characteristic, area of residence, or HTLV-III antibody test results) should not be excluded from life and health insurance coverage. Also, until the results of this working group become available, legislative actions in this area are not recommended. In the interim, any use of HTLV-III antibody testing in screening, evaluating, and rating health and life insurance applications and policies is not supported. 40
- 22B. Current third-party coverage for AIDS-related treatment and care should be continued. The State should not mandate insurance coverage for AIDS-related expenses. 40
23. The Michigan Department of Social Services should review, as a component of periodic evaluations, cost-weights for AIDS-related care and make revisions, as appropriate, in accordance with federal and state reimbursement methods. 41
24. Public health prevention and control priorities should be: surveillance; high-risk group education, screening, and counseling; general education; and nonhealth support services. Medical research should have lower priority for state funds since the federal government has primary responsibility for this important activity. Efforts should be made to secure greater research funds. 41
25. Further study of the costs of AIDS-related care in Michigan should be undertaken by the Michigan Department of Social Services, the MDPH, and the Greater Detroit Area Health Council, including analysis of Medicaid data, with special emphasis on determining the costs of the full continuum of care and the relative cost-effectiveness of alternative models of care suitable to the Michigan situation. 42
- 26A. The MDPH should develop a program tailored to educate the general public and high-risk groups. An estimated annual cost is \$1 million. 44
- 26B. The MDPH should develop a program tailored to educate health care providers. An estimated annual cost is \$250,000. 44
- 26C. The MDPH should continue the alternate site counseling and testing program. An estimated annual cost is \$190,000. 45

- 26D. The MDPH should develop retro-virology laboratory services. The first-year estimated cost is \$125,000 and annual maintenance costs are anticipated to be \$90,000. 45
- 26E. The MDSS should support a program tailored to provide adequate support services. An estimated annual cost is \$550,000. 45
- 26F. The Michigan departments of Corrections, Social Services, and Mental Health should continue to monitor the number and rate of growth of AIDS-related cases within their jurisdictions, and MDMH should pay special attention to the rate of increase of HTLV-III-related neuropsychiatric conditions. 45
- 26G. Appropriate state agencies should determine additional funding requirements to carry out these programs. 45

AIDS: AN OVERVIEW

Acquired Immune Deficiency Syndrome (AIDS) is caused by a virus--now known as the human T-lymphotrophic virus type III (HTLV-III) or lymphadenopathy associated virus (LAV)--that impairs the body's ability to fight off certain kinds of illnesses or malignancies. The HTLV-III virus destroys a type of white blood cell (the "T4 helper" lymphocyte) that plays a major role in defending the body against disease. If immune damage is severe, people become susceptible to serious illnesses that would otherwise pose little threat--for example, rare types of cancer (Kaposi's sarcoma) and pneumonia (*Pneumocystis carinii*). About 50 percent of all fully developed AIDS cases reported to date in the United States have resulted in death, and no one is as yet known to have recovered from AIDS, no matter what treatment was received.

AIDS was first identified in the United States in 1981, and since then the number of reported cases has at least doubled every year. It is estimated that between one and two million Americans have been infected by the HTLV-III virus. Only 5 to 20 percent of these are observed to develop full-blown AIDS, although anyone infected with the virus may be able to transmit it. But even a 5 percent rate of symptom development among one million people would yield 50,000 new cases within about 5 years, assuming an incubation period of from six months to five years. This would more than triple the number of cases reported in the United States since 1981 and clearly presages a massive public health challenge. From 20 to 40 percent of those infected by the virus develop what is known as AIDS-related complex (ARC), characterized by chronic lymphadenopathy (swelling of the lymph nodes), weight loss, fever, and/or chronic diarrhea. This condition can persist for years and it can be fatal. It can also be a prelude to the opportunistic infections that mark fully developed AIDS (Table 1).

As of February 3, 1986, 17,001 Americans had been diagnosed as having AIDS, of whom 8,801 had died. In Michigan, the number of cases, though small, has also increased at about the national rate since 1981, as have fatalities (Table 2). Michigan currently ranks about 18th in the nation in number of AIDS cases. The states and standard metropolitan statistical areas with the largest numbers of AIDS victims are listed in Table 3.

AIDS is not confined to the United States. Cases have been reported in 35 other nations, including almost every European country. Some researchers claim to have found the HTLV-III virus--though not necessarily AIDS symptoms--to be strikingly prevalent in a number of African populations. While some argue that this suggests an African origin of AIDS, there is no consensus of opinion.

TABLE 1
 RELATIONSHIPS AMONG EXPOSURE, INFECTION, HTLV-III
 SEROPOSITIVITY, AND DEVELOPMENT OF ARC OR AIDS

| <u>Stage</u> | <u>Meaning</u> | <u>Relationship to Other Stage(s)</u> |
|----------------------------|---|---|
| Exposure | The individual has engaged in sexual or other activity (e.g., needle sharing) through which transmission of the HTLV-III virus is possible. | -- |
| Infection | The HTLV-III virus has been able to enter the body and multiply in the body tissues. | The relationship to exposure is not well understood, although multiple exposure probably increases the risk of infection. |
| Seropositivity | A person's blood contains antibodies to the HTLV-III virus. This means that he or she was infected sometime in the past. Antibody tests cannot, however, determine when a person was infected or if he or she remains infected. | Infection results in the production of antibodies. There may, however, be a 2 to 3 month lag between infection and antibody production. This would account for some falsely negative results in antibody tests. |
| ARC (AIDS-Related Complex) | ARC is caused by infection with the HTLV-III virus, but its symptoms (e.g., weight loss, fever, chronic diarrhea) do not include the opportunistic diseases that mark AIDS. | Estimates of the percentage of seropositive individuals who will eventually develop ARC range from 20 to 40 percent. The lengthy incubation period makes estimates uncertain. |
| AIDS | AIDS is a complex of symptoms marked by one or more opportunistic diseases that are evidence of failure of the body's immune system. | Estimates of the percentage of all infected persons who will eventually develop AIDS range from 5 to 20 percent. The lengthy incubation period makes estimates uncertain. |

TABLE 2

MICHIGAN AIDS CASES AND DEATHS,
1981 TO MARCH 10, 1986

| <u>Year</u> | <u>Cases</u> | <u>Deaths</u> |
|----------------|--------------|---------------|
| 1981 | 2 | 2 |
| 1982 | 2 | 1 |
| 1983 | 12 | 10 |
| 1984 | 40 | 27 |
| 1985 | 71 | 28 |
| 1986 (to 3/10) | 7 | 1 |
| TOTAL | 134 | 69 |

SOURCE: "Michigan Department of Public Health Acquired Immune Deficiency Syndrome (AIDS) Statistics" (Lansing, Mich.: Michigan Department of Public Health, March 10, 1986).

The great majority of adult persons with AIDS in the United States are homosexual or bisexual men, followed by intravenous drug users (Table 4). The HTLV-III virus is transmitted through body fluids, principally blood and semen. Sexual intercourse--with receptive anal intercourse, which damages the rectal lining, carrying the highest risk--is a prime mode of contagion, as is use of shared syringes for intravenous drugs. A small percentage of the cases reported in the United States have been contracted through transfusions of contaminated blood or blood products, including the clotting agents used by hemophiliacs, and through heterosexual contact (Table 4). A significant number of AIDS cases have been reported among Haitians in both the United States and Haiti; Haitian AIDS patients claim to be neither homosexual nor intravenous drug users. A substantial proportion of the Haitian cases have been women, and AIDS seems to be distributed equally between the sexes in Africa. There is evidence that although the number of cases among sexually promiscuous heterosexuals who do not belong to any of the high-risk groups is very small (about 1 percent), the rate of increase is much the same as it is among homosexuals, intravenous drug users, and users of transfused blood and blood products.

Blood tests for antibodies--indicating that a person has been infected with the virus--have been developed. The most commonly used test--the enzyme-linked immunosorbent assay (ELISA)--was developed for use in controlling the spread of the virus through contaminated blood and blood products. Blood screening requires a highly sensitive test; but any very sensitive test will yield many false positives when used to screen populations at low risk. This presents no problem for blood donor screening, where it is better to err on the side of caution, but it does make the test a less than perfect indicator of who is actually a carrier of the HTLV-III virus. Confirmation of the presence of the antibody can be obtained by using the less sensitive, but more specific Western Blot test. To date, no test is available for detecting the presence of the HTLV-III virus itself, only that of the antibodies produced in response to infection by the virus.

TABLE 3
STATES WITH LARGEST NUMBERS OF AIDS CASES

| <u>State</u> | <u>Number of Cases</u> | <u>% of National Total</u> |
|----------------------|------------------------|----------------------------|
| New York | 5,955 | 33 |
| California | 4,089 | 23 |
| Florida | 1,169 | 7 |
| New Jersey | 1,106 | 6 |
| Texas | 981 | 5 |
| Pennsylvania | 393 | 2 |
| Illinois | 392 | 2 |
| Massachusetts | 367 | 2 |
| Georgia | 310 | 2 |
| District of Columbia | 305 | 2 |

CASE RATES BY STANDARD METROPOLITAN STATISTICAL AREA (SMSA)

| <u>SMSA of Residence</u> | <u>Cases per Million Population</u> |
|--------------------------|-------------------------------------|
| New York, NY | 605.7 |
| San Francisco, CA | 590.7 |
| Miami, FL | 333.4 |
| Newark, NJ | 232.5 |
| Los Angeles, CA | 198.1 |
| Elsewhere ^a | 38.9 |
| Detroit, MI | 21.1 |
| Michigan (Total) | 14.6 |
| United States (Total) | 78.5 |

SOURCE: "Acquired Immune Deficiency Syndrome (AIDS) Weekly Surveillance Report" (U.S. Public Health Service, Centers for Disease Control, March 3, 1986).

^aIrrespective of SMSA.

Many questions about AIDS remain unanswered. There is speculation, for example, that prior debilitation of the immune system through disease, drug use, or malnutrition may be an important factor in susceptibility to AIDS. Researchers are not certain that an effective vaccine can be developed, because the HTLV-III virus is prone to mutation. Yet enough is known about the mode of contagion to permit its control, given public education and cooperation. It is impossible to contract AIDS through such contacts as handshakes, toilet seat use, or handling of items used by a person with AIDS, since the mode of transmission is by direct introduction into the blood stream. Multiple exposures to the virus may increase the risk of developing AIDS. The recommended precautions against AIDS--engaging only in safe sexual practices; avoiding sex with persons who might carry the virus; avoiding sex with multiple partners, persons with multiple sexual partners, or intravenous drug users; and rejecting contaminated needles or syringes--can stem the spread of the virus.

TABLE 4

AIDS PATIENT GROUPS

| <u>Patient Groups</u> | <u>United States</u> | | <u>Michigan</u> | |
|---|----------------------|------------------|-----------------|-------------------|
| | <u>Cases</u> | <u>(%)</u> | <u>Cases</u> | <u>(%)</u> |
| <u>Adult/Adolescent</u> (14 years and older) | | | | |
| Homosexual/bisexual men | 12,689 | (73) | 85 | (67) |
| Both intravenous drug user and homosexual/bisexual | --- ^a | --- ^a | 13 | (10) |
| Intravenous drug user | 2,940 | (17) | 12 | (10) |
| Hemophilia/coagulation disorder | 138 | (1) | 5 | (4) |
| Heterosexual contact (case or at risk) | 224 | (1) | 2 | (2) |
| Transfusions; blood or blood products | 277 | (2) | 1 | (1) |
| None of the above; other | 998 | (6) | 5 | (4) |
| TOTAL | 17,266 | (100) | 126 | (98) ^b |
| <u>Pediatric</u> (13 years old and younger) | | | | |
| Hemophilia/coagulation disorder | 11 | (4) | 0 | --- |
| Parent with AIDS/or at increased risk | 189 | (75) | 1 | (100) |
| Transfusions; blood or blood products | 37 | (15) | 0 | --- |
| None of the above; other | 14 | (6) | 0 | --- |
| TOTAL | 251 | (100) | 1 | (100) |

SOURCES: "Acquired Immune Deficiency Syndrome (AIDS) Weekly Surveillance Report" (U.S. Public Health Service, Centers for Disease Control, February 17, 1986); and "Michigan Department of Public Health Acquired Immune Deficiency Syndrome (AIDS) Statistics" (Lansing, Mich.: Michigan Department of Public Health, February 10, 1986).

^a Homosexual/bisexual male intravenous drug users are counted as homosexual/bisexual men in the U.S. figures.

^b May not equal 100 percent due to rounding off.

In fact, AIDS is not easy to get. There is no evidence that living in the same household with a person with AIDS can in itself lead to contagion. On the contrary, fears of its transmission through everyday activities were ameliorated by careful studies, including one of 101 people who live in households in which a person with AIDS also resides. Not one of the individuals showed signs of infection as a result of daily contact. The early fears that AIDS could spread readily are now discounted. Well-documented epidemics that have struck the United States in this century, e.g., cholera, polio, influenza, claimed more lives more rapidly and were far more easily transmitted than AIDS.

At present AIDS can be neither medically prevented nor cured. There is no vaccine to prevent its onset and no cure once it appears. Public health actions must therefore focus on educating the general public and high-risk groups and on motivating individuals to change behaviors that can spread the HTLV-III virus. These are the best means of curbing the spread of the virus until such time as research produces an accurate test for the virus, a vaccine to prevent its transmission, and/or a treatment or cure for the syndrome itself.

AIDS and the reaction to its spread raise a host of public policy questions. Government and public service agencies face problems of how best to counter the widespread ignorance that breeds both panic and failure to take precautions, how to assure that AIDS patients get the treatment and custodial care they need, who should bear the mounting costs of serving AIDS patients, and how to control the spread of infection yet protect the civil rights of individuals. The confidentiality of the results of antibody testing or diagnosis is a particularly significant issue from the public health as well as the civil rights standpoint. Because AIDS is associated with behavior that is not only stigmatized but also illegal (use of illegal intravenous drugs or, in many states, certain sexual practices), the fear that such information might not be kept confidential could deter members of high-risk groups (e.g., male homosexuals or intravenous drug users) from participating in prevention and control programs. Any perceived need to breach confidentiality (e.g., through sexual contact tracing) must be balanced against the vital importance of encouraging voluntary compliance in prevention and control efforts.

The information contained in this overview was drawn from a wide variety of publications. Please see Appendix C for a list of references.

PREVENTION AND CONTROL

Preventing and controlling AIDS involves these activities:

Surveillance by public health agencies is the collection of the number and characteristics of individuals who develop AIDS as defined by the Centers for Disease Control (CDC) in Atlanta. Accurate reporting of the incidence and prevalence of AIDS is critically important for targeting prevention/education campaigns, assessing the adequacy of medical and support services, and informing the medical community and general public of the true scale of the AIDS problem.

Education for the general public, high-risk groups, and health care providers is the single most effective preventive strategy available to curb the spread of AIDS and associated fears. The general public needs to understand that AIDS cannot be transmitted through routine, normal, everyday, nonsexual activities. However, high-risk groups, such as homosexuals and intravenous drug users, must be alert to the risks of engaging in certain activities that are known to transmit the HTLV-III virus. Reaching the high-risk populations is most difficult, particularly intravenous drug users. Special in-service training and education for health care providers are covered in the Provider and Institutional Care section of this report.

Epidemic control measures such as testing, screening, and contact tracing are public health strategies commonly applied to control the spread of communicable diseases. The HTLV-III virus is difficult to transmit, prevails today in only two or three high-risk populations, most likely is communicable for extremely long periods in infected persons, and is neither preventable by vaccination nor curable. In these ways, AIDS differs from other communicable conditions where mandatory epidemic control measures have been useful. Public health experts generally believe that mandatory screening (requiring everyone to be tested for HTLV-III seropositivity) is costly and without significant benefit to low-risk groups. High-risk groups, sensitive to the need for anonymity, are far better reached through encouraging voluntary testing.

PROBLEMS, ANALYSES, AND RECOMMENDATIONS

1. Problem Statement: There is need for a complete assessment of the adequacy of current reporting and surveillance measures to monitor CDC-defined AIDS.

Analysis: Surveillance activities to monitor quickly and accurately the incidence of CDC-defined AIDS in Michigan are essential to respond and to target resources to the emerging needs of those affected. A surveillance system can assist in dispelling rumors regarding transmission of AIDS (reducing inappropriate fear) as well as identifying subpopulations for whom risk-reduction programs are most essential. Legal authority for the Michigan Department of Public Health (MDPH) to collect information regarding CDC-defined AIDS has existed since June 1983. Standardized forms and instructions for AIDS

case-reporting have been distributed to infection control practitioners, chiefs of medical staffs, and administrators of all Michigan hospitals, as well as to local health departments. Checks of death certificates have discovered no previously unidentified cases. Thus, the completeness of CDC-defined AIDS reporting for correctly diagnosed cases appears adequate. The MDPH prepares a monthly statement summarizing AIDS incidence by county. Using federal grant monies, the MDPH has developed a program to stimulate AIDS case-reporting by referral hospitals. In January 1986, an additional AIDS epidemiologist was hired by the MDPH to organize a system of records review, hospital contacts, and report preparation intended to further strengthen the surveillance system. This program is targeted to those Michigan hospitals most likely to see patients with AIDS and should be in place by January 1, 1987.

Recommendation 1:

The Michigan Department of Public Health (MDPH) should continue surveillance activities monitoring the occurrence of AIDS cases fitting the standard national case definition. Such activities should include designation of a special AIDS surveillance officer.

2. Problem Statement: There is need for better information about the size and rate of growth of the population in need of AIDS-related services in order to assess present and future service needs and costs.

Analysis: To make useful estimates of the need for various AIDS-related services and the related costs, accurate information about the current size and the growth of the relevant populations is needed. The MDPH estimates that there will be 90-120 new Michigan AIDS cases in 1986. The department adds, however, that it is difficult and expensive to make more accurate estimates because of the comparatively small number of cases in Michigan and because of the need for more research in the following areas:

- The prevalence of seropositivity in high-risk groups
- The number of persons in high-risk groups
- The proportion of seropositive individuals within high-risk groups who will develop AIDS over time
- The epidemiology of AIDS, including the effect of health status and frequency of exposure on the probability of developing AIDS if infected with the HTLV-III virus

Some have advocated the reporting of all positive HTLV-III serologic tests and cases of ARC to the MDPH. This information might conceivably be useful, but such reporting would discourage voluntary testing and increase concerns about confidentiality. The danger with such an approach is that the epidemic will be pushed underground. Mandating the reporting of voluntary tests would also prove expensive to providers as well as the MDPH. Laboratory testing costs and potential threats to individual privacy and confidentiality must be weighed as downsides of testing. Federally funded prevalence studies have documented and are continuing to document the ratios of HTLV-III

positives and ARC to AIDS. Important studies requiring the participation of over 5,000 high-risk individuals, who are being studied over several years, are being conducted to determine the natural history of and risk factors for AIDS. It is not necessary to repeat these expensive studies. Anonymous, batched testing to establish prevalence of the antibody among high-risk groups is appropriate, and voluntary involvement in research projects should be encouraged.

Recommendation 2A:

The MDPH should examine the incidence, prevalence, and natural history studies conducted by other states and the National Institutes of Health while compiling and studying the ongoing data being collected within our own state. Such studies should be funded primarily by the federal government.

Recommendation 2B:

The reporting of positive human T-lymphotropic virus type III (HTLV-III) serologic tests and AIDS-related complex (ARC) should not be supported because of its cost and the probability that it would be counterproductive to voluntary testing and would threaten individual privacy and confidentiality.

Recommendation 2C:

Anonymous, batched testing of blood of high- and low-risk groups for prevalence studies and voluntary involvement in AIDS-related research projects should be encouraged.

3. Problem Statement: The MDPH needs a strategy for disseminating information about AIDS to the general public.

Analysis: The general public has considerable anxiety about AIDS. A Gallup poll in August 1985 found 62 percent of Americans believing that AIDS will eventually become an epidemic for the public at large; 41 percent were worried that someone they knew would get AIDS.

Health education techniques and principles, derived from previous experience, should shape state strategies to ease anxieties and engender confidence in AIDS prevention and treatment programs. Three characteristics important to successful educational policies and programs are (1) development of educational materials, taking into account the anxiety of the public and incorporating sound health education principles; (2) promotion and distribution of educational programs or materials, ensuring adequate geographic coverage and easy

availability; and (3) quality assurance, evaluating the availability and effectiveness of such programs and materials whenever feasible.

The general public also includes special intermediate groups to whom educational materials should be targeted; for example, teachers, school administrators, legal professionals, and physician office and hospital clerical staffs.

Experience elsewhere shows that the best AIDS education takes place outside an atmosphere of crisis and alarm. For example, school systems, including boards of education, teachers, and parents, should have available to them information regarding AIDS prior to the identification of a local case. The State Board of Education is encouraged to continue efforts to develop school guidelines. The comparatively low incidence of AIDS in Michigan should not be a cause for complacency but should instead stimulate the timely delivery of adequate information and policy development.

The MDPH has established a limited strategy for ongoing education of the general population. The department produces a fact sheet on relevant topics, including a summary of endorsed guidelines and recent literature on AIDS, and critiques of recently issued educational materials on the fourth Monday of each month. The department publishes updated information on reporting of AIDS cases on the second Monday of each month. These reports are distributed to the media, health care provider associations, and local health departments. The department is duplicating slides produced by the CDC, one set aimed at general audiences and another at health care providers; these slides will be distributed to all local health departments. Informational materials are also planned for distribution to providers and to groups representing high-risk populations.

Recent experience in New York City and San Francisco makes it clear that it is critically important for public health agencies to be open and responsive to media questions. The effectiveness of educational programs for the general public is directly influenced by the intensity, frequency, and candor of public health contacts with the media.

To reduce costs and increase consistency, the MDPH should work with other state public health agencies as feasible to develop printed materials, slides, and videotapes for both the general population and target audiences.

Recommendation 3A:

The MDPH should direct broad public education campaigns to and produce regular reports about AIDS for the general public; information about the legal rights of persons with AIDS should be included. Distribution should include the news media, libraries, and local health departments. Regular press briefings should be held and surveillance statistics should continue to be provided routinely to the media.

Recommendation 3B:

The MDPH should direct general information and updates to statewide organizations representing labor, business, political activists, civic groups (such as civic clubs, leagues, service clubs, and religious organizations), and statewide, nonhealth trade and professional organizations.

Recommendation 3C:

The MDPH should encourage the production and dissemination of public service announcements.

Recommendation 3D:

The MDPH should work with health agencies in other states to identify, develop, distribute, and purchase printed materials, slides, videotapes, and other media materials.

4. Problem Statement: The MDPH needs a strategy for disseminating AIDS information to high-risk groups.

Analysis: The educational needs of high-risk individuals (e.g., homosexually/bisexually active men, hemophiliacs, intravenous drug users, and their sexual partners) differ from those of the general public. Techniques are available to motivate, facilitate, and maintain behavioral changes. Until a biological preventive measure such as a vaccine is available, only behavioral change can reduce transmission of the HTLV-III virus. Behavioral change is a complex issue; as an example, alteration of long-standing behaviors such as smoking can be extremely difficult. It is therefore reasonable to expect that motivating and achieving behavioral change in individuals at high risk will necessitate the development and delivery of carefully designed programs. Such programs should be based on current knowledge of behavior and health education and should provide both information and support for alternative behaviors perceived to be effective, acceptable to the targeted risk group, and available to the individual.

Advocacy groups for high-risk populations, recognized and viewed as credible by those populations, should carry the major responsibility for educational efforts. The gay community has a number of advocacy organizations such as the Michigan Organization for Human Rights. However, intravenous drug users and significant numbers of minority homosexually active men are not represented or are represented by less well-organized structures, and these groups pose the greatest challenge in developing targeted educational materials. A coalition of the Venereal Disease Action Coalition, Michigan Organization for Human Rights, Wellness Network, Inc., Community Health and Awareness Group,

and Hemophilia Foundation of Michigan has been formed under the name AIDS Coalition Agencies. This coalition also can be a resource for significant educational activities.

In Michigan and elsewhere, hotlines have been established to respond to both informational and counseling needs of high-risk individuals or of those who, although not at high risk, are anxious about AIDS. Wellness Network, Inc. operates a statewide hotline based in Detroit. This statewide, centralized, tollfree (800) hotline, with adequate marketing support, geographic coverage, and quality assurance, is a key resource for high-risk individuals. In addition, local communities should be encouraged to develop their own hotlines to supplement the statewide one. These could provide important information about resources available locally and would minimize the need for centralization of all information in Detroit, a task that seems logistically difficult if not impossible. Ensuring that the people providing information on community hotlines are well trained will be necessary. Financial support for and quality assurance oversight of such hotlines should come from the MDPH.

There is general agreement on the need for educational materials readily understandable in the high-risk groups to which they are targeted. There are concerns about the inadvertent dissemination of such materials to inappropriate groups, such as school-age children. It is recognized that this is a general concern not specific to consideration of AIDS and is a reflection of much broader philosophical and moral issues.

Recommendation 4:

The MDPH should work with interested groups to develop and implement information strategies aimed at high-risk groups, such as support for a statewide hotline; partial support for community hotlines; and, through contracts with organizations reaching high-risk groups, partial support for targeted educational materials and strategies.

5. Problem Statement: There is need to analyze the reliability, costs, and benefits of testing and screening and to develop a state policy regarding epidemic control measures.

Analysis: Reliability of Testing. Two tests are used to find the presence of the antibody indicating exposure to the HTLV-III virus. If an individual tests seropositive (i.e., the test reveals the antibody), it by no means proves the individual has CDC-defined AIDS--the fully developed and fatal syndrome. Approximately 5 to 20 percent of those testing seropositive will have developed CDC-defined AIDS within five years, 20 to 40 percent will develop ARC (AIDS-related complex), and an unknown number will remain unaffected, although longer-term consequences of being infected with the virus are not known.

Both the ELISA and Western Blot tests are excellent laboratory tests. However, whenever these tests or other antibody tests are applied to a human population, a few people test positive even though uninfected and a few people test negative even though infected. Such inaccuracies must be weighed in applying public health principles to controlling the spread of the HTLV-III virus.

Tests may be marketed by private laboratories, and the MDPH has an obligation to assure that new testing procedures and private laboratories offer the public reliable results.

Costs of Testing. The cost to the MDPH laboratory of an ELISA test is about \$6. The Western Blot test costs about \$65. Private laboratory costs for both tests vary. For both tests, at least minimal pre- and post-test discussions with the patient are necessary (likely to cost about \$12) and the time, level of professional involvement, and costs increase dramatically for counseling those whose tests are positive.

Benefits, Objectives, and Target Audiences of Testing. We must recognize that the characteristics of a contagious virus dictate the proper epidemic control and public health measures. Unlike other infectious conditions, AIDS is not currently treatable or preventable by immunization. Therefore, control depends on voluntary and lifelong behavioral changes.

Screening is the testing of population groups to discover HTLV-III seropositives, ARC, and AIDS. Testing is part of a medical diagnosis to determine if an individual is seropositive or has ARC or AIDS.

The benefits of screening and testing differ according to the groups being tested. As with other antibody tests, the predictive value reflects the prevalence of the antibody in the people who are tested. For the low-risk groups, the large number of false positive ELISA tests would be unnecessarily alarming, although confirmation by the Western Blot test would eliminate most false positives; these low-risk people generally are uninfected. For high-risk groups, the combined use of the ELISA and Western Blot tests would disclose a certain percentage of homosexual men and intravenous drug users who test positively and who should receive medical care and counseling about their own health risks and risks of communicating AIDS to others.

ELISA tests can now be handled anonymously by the MDPH laboratory. Western Blot testing is not handled anonymously but is confidential. Both tests should be available anonymously.

Testing is a means to an end: proper medical attention and reducing high-risk behavior. Testing must be viewed as a part of an overall public health strategy to educate high-risk groups and to motivate such individuals to take precautions. Until a cure for AIDS or a technological breakthrough in testing is found, or the spread of the HTLV-III virus becomes more epidemic, mandatory screening and testing cannot be justified in terms of cost. Furthermore, they would likely be counterproductive to the effort to change behavior voluntarily among high-risk groups, including drug users, homosexually active men, and prostitutes.

The CDC recommends that hospitals not perform routine testing of employees but that testing be available to employees requesting it. Because no health care worker has ever transmitted the virus to a patient, the risk of transmission is believed to be exceedingly low. Health care workers must conduct themselves in a manner consistent with knowledge about how the virus is transmitted.

Insurers, wishing to minimize underwriting risks, have expressed interest in screening individual applicants for health care insurance. This issue is discussed in the analysis preceding recommendation 22 in the Financing section of this report. Employers have considered screening potential employees but, as discussed above, such testing would be extremely expensive and largely inconclusive; screening only applicants suspected to be homosexual would raise significant civil rights issues.

Focusing testing on high-risk groups (where the greatest benefits can be derived), raises the troubling question of mandating testing versus encouraging voluntary testing. To many, required testing is synonymous with violating one's privacy by disclosing one's sexual preference or illegal drug use to insurers, employers, and even the general public. The only clear benefit of testing, other than protecting public blood, semen, and organ supplies, is to motivate high-risk and HTLV-III seropositive individuals to adopt behaviors voluntarily that will minimize transmission of the virus and to seek medical help. Mandatory testing encourages such persons to evade the testing for fear of violations of their privacy and civil rights and leaves them less, not more, likely to seek medical help.

The best means available to control AIDS is to educate those at highest risk about their vulnerability; to encourage them to undergo confidential or anonymous testing; to discourage illegal drug use and encourage engaging only in safe sex; to encourage HTLV-III positives to inform sexual partners; and to help those with AIDS receive prompt and continuing medical attention and counseling. Mandatory testing of any population or voluntary testing of low-risk individuals does not achieve the benefits intended and does little, at great cost, to control the spread of AIDS.

Premarital screening is not likely to be effective either in terms of control of the HTLV-III virus or in terms of cost; if the antibody status is known to be positive, the physician should counsel the couple. Proposals to mandate premarital testing would be expensive and largely ineffective.

Contact tracing is a public health strategy that has been used extensively as a disease control strategy with other infectious conditions, e.g., certain types of venereal disease and tuberculosis. Its use in the follow-up of AIDS cases poses a number of problems.

High-risk individuals involved in activities that are illegal in Michigan may not willingly share the names of others involved in these activities. Fear of contact tracing could result in an unwillingness of some individuals to seek treatment for AIDS or a reluctance in some sympathetic providers to confirm the diagnosis. In addition, the long incubation period (one to seven years) and very high numbers of sexual

and needle-sharing partners may make it an impossible task to identify and educate these individuals in a cost-effective manner.

In some instances, however, contact tracing may be effective in interrupting transmission in low-prevalence areas or in locating women of childbearing age who may be infected. In these instances, Rule 325.9004 of the Public Health Code for Class II diseases (of which AIDS is one) already provides the authority to conduct these contact investigations. Mandatory contact tracing of all AIDS cases is not warranted, would not be effective, and would be both expensive and counterproductive. Voluntary contact notification (informing one's sexual partner), however, can be beneficial and should be encouraged.

An acceptable and effective public health approach would be an anonymous system whereby individuals tested as HTLV-III seropositive voluntarily refer for testing and counseling their sex partners or those with whom they have shared intravenous drug syringes. Today in America, the HTLV-III virus is confined largely to homosexual and bisexual men, intravenous drug users, and a few individuals who contracted AIDS through blood transfusions before the virus was identified and corrective action taken. Close and continuing surveillance by the MDPH is the best means of monitoring the spread of AIDS and determining whether or not more intensive control measures are merited. See Table 5 for a report of control measures implemented or contemplated in several states, including Michigan.

Alternate site testing facilities were established successfully in four locations throughout the state to deter high-risk individuals from donating blood at blood donation centers while assuring access to counseling and testing. These alternate site testing facilities should now focus primarily on counseling high-risk group members and other individuals worried about AIDS and secondarily on testing. There is merit to continuing, at least in the short run, support of such facilities.

A troubling issue is the proper response by state and local governments to safeguard the health of confined populations, such as prison inmates and guards and mental health residents and staff. Government has a special responsibility for those confined involuntarily and those under the care and protection of state and local agencies. On the one hand, isolation of individuals known to be infected could reduce the likelihood of transmission to uninfected persons. On the other hand, the costs of isolating all those testing HTLV-III seropositive would be enormous, such isolation could be infeasible in many instances, and confidentiality would be impossible to maintain. Segregation without isolation of those testing HTLV-III seropositive, in fact, could lead to more intense exposure, thereby endangering infected individuals even more. In addition, in a corrections setting, knowledge by other prisoners of the identity of individuals who are HTLV-III positive could pose a serious threat to the safety of the identified individuals unless total segregation could be assured.

TABLE 5

CONTROL MEASURES IN SEVERAL STATES

(as of January 27, 1986)

| | <u>State Law to Report AIDS</u> | <u>State Law to Report ARC</u> | <u>State Law to Report Positive Test</u> | <u>Contact-tracing Laws Requiring Epi* Followup</u> | <u>Premarital Mandatory HTLV-III Test</u> | <u>Required Screening in Prisons</u> | <u>State Laws on AIDS and Prostitution</u> |
|----------------|---|--|--|---|---|--|--|
| MICHIGAN | Yes | No | No | No** | No** | No** | No** |
| Ohio | Yes | Yes | No | No | No | No | No |
| Wisconsin | Yes | No | Yes | Yes | No | No | No |
| Minnesota | Yes | No | Yes | Yes | No | No | No |
| Illinois | Yes | Yes | No | No | No | No** | No |
| Indiana | Yes | No | No | No | No | No** | Pending (Chicago) |
| California | Yes | No*** | No | Self-referral | No | Yes | No |
| New York | Yes | No | No | No | No** | No | No |
| Missouri | Yes | No | No | No | No | No | No |
| North Carolina | Yes | No | No | No | No | No | No |
| Louisiana | Yes | No | No | No | No | No | No |

*Epidemiological.

**Legislation pending.

***Reportable only in Orange County.

AIDS INCIDENCE AS OF 12/17/85
(all reported cases up to that date)

| | | | |
|-----------|-----|----------------|-------|
| Michigan | 102 | California | 3,593 |
| Ohio | 98 | New York | 5,426 |
| Wisconsin | 36 | Missouri | 81 |
| Minnesota | 57 | North Carolina | 88 |
| Illinois | 338 | Louisiana | 167 |
| Indiana | 55 | | |

Several principles should guide AIDS prevention and control policies for institutionalized populations. (1) The primary goal is halting the spread of the HTLV-III virus. (2) A comprehensive plan needs to be developed before any one strategy, such as mandatory screening, is instituted. (3) Measures found useful in stopping the spread of the virus in the general population should be applied to institutional settings. (4) The degree of risk must be as carefully weighed in institutions as it is in the general population before restrictive actions are taken.

There is no fail-safe system to protect public health absolutely, whether inside or outside institutions. As discussed throughout this report, education is the best means of halting the spread of the HTLV-III virus. Educational materials disseminated to institutionalized populations and to staffs in those facilities will likely be more beneficial than other currently available options such as mandated testing and isolation. Transmission is largely dependent on voluntary acts such as sexual intercourse and shared use of syringes; changing behavior remains the best way to curb the spread of the virus.

The MDPH should work closely with the Michigan departments of Corrections (MDOC), Mental Health (MDMH), and Social Services (MDSS) in developing effective plans for confined populations, and such plans can be adjusted to other institutional settings such as local jails. These plans must incorporate educational materials directed to prisoners, residents, and staff.

Recommendation 5A:

High-risk populations should be encouraged to seek out voluntary risk-reduction counseling followed by confidential and anonymous testing for HTLV-III antibodies when desired by an individual. The MDPH laboratory should offer the enzyme-linked immunosorbent assay (ELISA) and Western Blot tests on an anonymous basis.

Recommendation 5B:

Mandatory screening, testing, or contact tracing of high-risk individuals should not be implemented because they would be counterproductive and would threaten individual privacy and confidentiality.

Recommendation 5C:

Mandatory screening/testing of low-risk groups, e.g., premarital screening, should not be supported.

Recommendation 5D:

Employers, including health care facilities, should not mandate screenings for employees. Health care facilities should offer voluntary counseling and testing when medically appropriate.

Recommendation 5E:

Mandatory contact tracing should not be supported. Voluntary contact notification should be encouraged.

Recommendation 5F:

The MDPH should work closely with the Michigan departments of Corrections, Mental Health, and Social Services to develop effective policies and plans for confined populations, with an emphasis on disseminating educational materials to staff and institutionalized persons.

6. Problem Statement: There is need for an assessment of the adequacy of Michigan's current laboratory capability in relation to AIDS.

Analysis: The MDPH has the responsibility to oversee closely the laboratory and other testing procedures being offered to the public. Also, new testing techniques will be introduced and will require state monitoring and evaluation.

Since the tests became available in April 1985, six hospital laboratories, three independent commercial laboratories, five blood collection laboratories, and the MDPH laboratory have performed HTLV-III antibody testing in Michigan. Most testing is performed on donated units of blood, although both testing of patients and of concerned individuals in higher risk populations also occurs. Data suggest no unmet needs for laboratory testing of the HTLV-III antibody in the state. Quality control measures include the use of the U.S. Food and Drug Administration's licensed test kits, duplicate testing, and confirmation by Western Blot tests; these measures appear adequate. It is important to note that the MDPH has the capability of performing Western Blot testing. It is apparent, however, that many laboratory directors, physicians, and hospitals are unaware of this capability; it is suggested that the MDPH make their capability widely known and also provide information to laboratory directors about appropriate HTLV-III antibody testing techniques and safety precautions.

The MDPH should be capable of performing retro-viral isolation procedures. Retro-virology services would enhance the clinical and research capabilities in the state. The MDPH should pursue with neighboring states the concept of sharing laboratory facilities offering economies of scale.

Recommendation 6A:

The MDPH should monitor closely laboratory and other testing procedures offered to the public, including new laboratory technologies as they are introduced.

Recommendation 6B:

The MDPH should inform laboratory directors, physicians, and hospitals in the state of its ability to perform Western Blot tests and should provide information about appropriate HTLV-III antibody testing techniques and safety precautions.

Recommendation 6C:

The MDPH should be supported in efforts to develop retro-virology services. The MDPH should pursue with neighboring states the concept of sharing laboratory facilities for cost-effectiveness.

PROVIDER AND INSTITUTIONAL CARE

Provider and institutional care issues center around (1) the availability of and access to medical and support services needed by AIDS patients and (2) the educational and in-service training needs of health professionals. Individuals with CDC-defined AIDS require the same range of health and personal care services as other seriously ill people. Health professionals are concerned about proper isolation of AIDS patients, liability for AIDS transmittals (patient to patient, patient to staff, and staff to patient), reimbursement for care, and proper treatment protocols. Similar concerns also exist for ARC and HTLV-III seropositive individuals.

PROBLEMS, ANALYSES, AND RECOMMENDATIONS

7. Problem Statement: There is need to identify gaps in available health care services along the full continuum of care.

Analysis: Persons with CDC-defined AIDS need the same care as do any other patients with serious illnesses; the comparison most often made is with cancer patients. Inpatient and outpatient, nursing, residential, hospice, in-home, and personal care are all needed by seriously ill persons, including AIDS patients.

The full continuum of care can be divided into medical and nonmedical care. The medical continuum includes outpatient care, inpatient care (including step-down care, acute care, and intensive care), long-term care, hospice care, and home health care. The nonmedical continuum includes residential (including foster) care, independent housing, legal services, employment, advocacy, and activities of daily living assistance.

Hospitals. There is no evidence that AIDS patients in Michigan are precluded by their condition from receiving necessary hospital care, although many AIDS patients are remaining in hospitals past the point of needing acute care for lack of available alternatives such as nursing homes, residential housing, and in-home services.

Nursing Homes. Some patients with AIDS need institutional health services less intensive than those found in a hospital. At present, Michigan nursing homes are not admitting patients with AIDS. Informed guesses as to why suggest that nursing home owners are (1) afraid of losing other patients, (2) concerned about liability if a staff member or another patient contracts the syndrome, (3) necessarily sensitive to staff fears, (4) unsure of care expectations, and (5) concerned about patient characteristics.

Home Health Care. Some home health care agencies care for AIDS patients; others are willing but have not yet had the opportunity; and others may reject them. The major concerns in accepting AIDS patients are (1) fear of acquiring the syndrome, (2) staff reaction to the precautions required for the protection of the patient and the family members, and (3) reimbursement. AIDS patients may be eligible for skilled nursing care benefits; but when skilled nursing care is no

longer required, the in-home personal care, social work, and family support services provided by home health aides may not be covered by insurers. Coverage is available for Medicaid eligible patients.

Hospices. Most of the eighty-nine hospices in Michigan have agreed to take AIDS patients. However, the six-month ceiling on life expectancy poses a problem because it is sometimes difficult to predict the life expectancy for AIDS patients, semiskilled in-home care is not reimbursed, and more staff training is needed. One of two inpatient hospice programs in Michigan does not accept AIDS patients.

Health Professionals. While there has not been a formal survey, there is believed to be no shortage of infectious disease specialists who will treat AIDS patients. However, there is considerable fear and anxiety among the state's dentists. There is some question about whether or not dental schools historically have offered comprehensive training for dealing with infectious diseases. Dentists are concerned about the communicability of the syndrome to themselves, hygienists, and other patients.

There is considerable anxiety, too, among funeral directors and ambulance personnel. Both groups desire consistent and early reporting of the presence of communicable conditions by health care providers. Of 40 ambulance services surveyed by the state association, less than half reported experience in transporting an AIDS patient, but six said they had not been alerted to handling an infectious patient. Florida and Ohio have passed statutes requiring the disclosure of infectious conditions to ambulance crews. Both funeral directors and ambulance service operators indicate that they strongly support the concept of notification. In their view, the concern is the presence of an infectious condition in a patient or a body, not the specific diagnosis. Both groups would prefer to arrive at consistent, voluntary arrangements for timely notification of the presence of an infectious condition. Funeral directors and ambulance personnel should exercise, as should any health professional, significant caution in dealing with any person, given the existence of infectious conditions such as hepatitis B and AIDS.

Recommendation 7:

Funeral directors, ambulance personnel, and other health care workers should be notified of infectious conditions. The MDPH should convene meetings of infection control specialists, hospital administrators, funeral directors, ambulance personnel, and other groups to determine how best to provide--whether by law, administrative rule, or voluntary compliance--adequate notification of the presence of infectious conditions and how to take necessary precautions. Such notification should not result in services being withheld by those health care workers.

8. Problem Statement: There is need for accessibility to support services such as housing, legal, employment, and counseling assistance for CDC-defined AIDS and ARC patients, particularly those who are terminally ill.

Analysis: Housing. Many AIDS patients have lost their residences or require in-home support services. As much as possible, patients should be supported in their homes with personal care and other helpful and necessary services. Some patients, however, have been displaced, are unable to afford housing, or need the companionship found in a residential facility. Efforts are under way to develop Wellness House in Detroit, which when open will provide room and board to six to eight indigent AIDS patients. Such a residence promotes cooperative interaction and emotional stability, while maintaining residents' independence. At a similar home in San Francisco (Shanti Project), the average resident resides in the home for just under three months. Residents are assessed 25 percent of their income to help offset the expenses.

The Michigan departments of Public Health and Social Services (MDSS) should lend support to Wellness House as well as similar residential facilities. Such support should consist of endorsing high quality projects, assisting in private fund-raising, and providing actual support funds on a matching basis to encourage private support and offset program losses.

Foster care placements for both adults and children with CDC-defined AIDS, ARC, or HTLV-III positives are difficult to make primarily for two reasons: (1) providers of foster care are independent contractors privileged to choose to whom they will provide services and (2) providers of foster care are not allowed under the current licensing law to offer continuous nursing care as part of a foster care placement. Steps should be taken by the MDSS to identify the need for foster care placement of AIDS patients and to establish sufficient foster beds to accommodate those in need. Current policies of the MDSS do not discriminate against homosexuals wishing to offer foster care services to adults and children; such applicants undergo the same background checks as do others.

Daily Living. Home-bound patients often need transportation to medical appointments and help with shopping, cleaning, laundry, and other chores. Wellness Network, Inc., has established a buddy system, assigning one volunteer to each AIDS patient to assist with daily chores. As of now, each AIDS patient wishing so may immediately have a buddy assigned to him or her. It is important that this volunteerism be encouraged, and the MDSS should provide financial assistance to such programs to cover minimal operating expenses such as training materials and telephone bills.

Emotional Needs. AIDS patients and their families and loved ones require ongoing emotional support and counseling, both on an individual as well as group basis. As many as 40 percent of AIDS patients have neuropsychiatric problems. Counseling and support can be directed by trained volunteers, but in other cases professional services are needed. The Michigan Department of Mental Health and community mental health boards should coordinate the provision of professional help to

patients in need. The community mental health boards should coordinate such support and work closely with Wellness Network, Inc., and similar volunteer organizations.

Advocacy. Some AIDS patients will require legal and advocacy assistance to obtain social services, social security, and other benefits; to write wills; and to deal with utilities, creditors, and units of government. Legal Aid branches should work closely with community organizations and individual patients to assure this range of advocacy and legal services is available to patients.

Obtaining social services and benefits, which often takes 60 to 90 days, is especially difficult for AIDS patients, as it is for others who are terminally ill and in particular need of urgent care.

Recommendation 8A:

The State should assist and fund proposals from selected community organizations to provide necessary quality support services.

Recommendation 8B:

The Michigan Department of Social Services should identify the need for foster care of AIDS patients and remove barriers to and expand access to foster care home settings as well as other residential facilities.

Recommendation 8C:

The Michigan Department of Mental Health should coordinate the provision of psychological and psychiatric services needed by AIDS patients.

9. Problem Statement: There is need to ascertain how much AIDS-related information is already possessed by institutional and individual health care providers and to ensure needed information is disseminated to providers.

Analysis: Ambulance service operators, police officers, funeral home operators, and dentists have particular need for educational information about AIDS. Few hospitals have ongoing staff education programs. In-service training increases with the number of patients seen. The two or three hospitals in Detroit that see the majority of AIDS patients in the state have the most comprehensive in-service training in Michigan. Home health agencies and hospices also need in-service training materials and assistance.

As suggested earlier, some ambulance personnel, nursing homes, morticians, and dentists either currently or may in the future limit or deny services to AIDS patients. Factual information about the

communicability of the HTLV-III virus is urgently needed by these groups. Following accepted infection-control principles and techniques, such as wearing gloves and masks when dealing with unknown conditions, will protect health care workers, whether dealing with AIDS or any other infectious condition.

The in-service training needs of health care personnel merit the development of educational programs by the MDPH and appropriate professional associations. CDC guidelines must be quickly communicated to the associations and in turn to their members. A library of AIDS-related literature should be maintained by the MDPH for easy access by the professional associations. The MDPH should work with professional associations to develop packaged in-service training programs targeted to specific provider audiences. Finally, the MDPH should sponsor, at regular intervals, seminars updating AIDS information for the leadership of health professional associations.

mentioned, there is some question whether dental schools historically have educated students about precautionary measures to exercise when caring for infectious patients. Newly discovered communicable diseases justify an assessment of the adequacy of medical, nursing, and dental school curricula for dealing with infectious conditions, including AIDS.

Recommendation 9A:

The MDPH should work directly with state professional associations to upgrade and repackage in-service training programs, patient and/or provider protocols, and education about AIDS.

Recommendation 9B:

The dental, nursing, medical, and allied health professional schools should assess curricula for infection control to ensure adequacy and inclusion of state-of-the-art information.

10. Problem Statement: There is need to assess whether or not there are sufficient precautions in place to protect against the transmission of the HTLV-III virus between health care workers and patients.

Analysis: Recent AIDS literature makes two fundamental points: AIDS is difficult to transmit and the protocols and guidelines for hepatitis B are adequate to prevent infection of health care workers. There is no documented instance of a health care worker transmitting the virus to a patient. There is on record one documented case in which a nurse became infected after being accidentally injected with a small amount of blood from an AIDS patient. All other health care workers who have contracted condition have belonged to the high-risk populations (e.g., homosexuals, bisexuals, hemophiliacs, and/or intravenous drug users).

Recommendation 10:

The MDPH should work with the professional associations of health care workers, the labor unions representing health care workers, and the employers of health care workers to assure that there are adequate educational and training programs regarding control procedures for all infectious conditions, including AIDS.

11. Problem Statement: There is need to examine evidence that some health care providers and institutions have declined or are unable to care for AIDS patients.

Analysis: Experience indicates that once AIDS hysteria is successfully combatted, facilities and individual health care providers do not suffer discrimination when they provide care to persons with AIDS, ARC, or HTLV-III positivity. Until both the general public and providers receive information to alleviate concerns about the communicability of AIDS, some providers will be reluctant to give service to persons with AIDS.

Legal and ethical obligations require health care providers to render care and service to persons with AIDS. Ambulance personnel and emergency rooms have served and must continue to serve AIDS patients in life-threatening situations. However, in all situations the care must be appropriate and within the scope and capabilities of the provider.

Without the necessary understanding on the part of the general public and health care providers, it is not productive to mandate that providers render care to persons with AIDS. There appears to be no shortage of hospitals or physicians in Michigan willing to provide care and treatment. However, dental care and long-term care are currently not widely available to meet the needs of persons with AIDS.

Recommendation 11:

The MDPH should work closely with individual health care providers, institutions, and professional associations to ensure that they are fully informed about AIDS so that they, in turn, render quality care and take desirable precautionary measures. Legal and ethical obligations require health care professionals to render care and service, within their scope of practice and legal standards, to persons with AIDS.

12. Problem Statement: There is need for an organized system for the provision of comprehensive, cost-effective, accessible, appropriate, and high-quality care for persons with AIDS.

Analysis: Patients with AIDS could receive needed care through the existing community health care resources available to persons with other medical needs. Some communities, such as San Francisco, have developed a comprehensive system of care. Cost estimates for inpatient care vary according to the differences between the above options. In San Francisco, health economist Peter Arno of the University of California at San Francisco's Institute for Health Policy Studies put the lifetime inpatient treatment cost for an AIDS patient at \$25,000-32,000. Dr. Ann Hardy of the CDC (Atlanta) estimated the national average direct costs for each AIDS patient at \$140,000, most of which was for inpatient care. It is believed that San Francisco has achieved such a low cost because (1) many services are delivered on an outpatient basis and (2) many ancillary services are delivered by volunteer-staffed community-based organizations.

Clinical treatment for AIDS is very complex due to the extremely variable nature of the syndrome. In a recent article, Paul Volberding, M.D., from San Francisco General Hospital, noted three concerns of clinicians: (1) their lack of expertise in treating AIDS, (2) the unexpected, frequent, and severe toxicities of conventional therapies, and (3) the underlying immune system deficiencies that make malignancies and infections more difficult to treat. Effective treatment, in his view, requires a highly competent multidisciplinary team of medical specialists who can recognize and respond appropriately to atypical symptoms.

The Greater Detroit Area Health Council is working cooperatively with southeast Michigan hospitals and health care providers to inventory services available to AIDS patients and find ways to assure that a continuum of care is in place for such patients.

The number of service gaps, especially in the long-term care area, requires attention by state public policymakers. These gaps affect the accessibility and cost-effectiveness of care because of the unavailability of needed alternatives to higher cost inpatient care.

A systematic approach to caring for persons with AIDS is needed. Two options (which are not necessarily mutually exclusive) should be considered: community-based facilities and comprehensive care facilities.

Community-Based Facilities. Integration of AIDS patients into community-based facilities relying upon local infectious disease specialists offers certain advantages to the patient: (1) proximity to home, family, and friends; (2) the ability, if the person is employed, to continue working with a minimal loss of work time; and, (3) in certain areas of the state, lower treatment costs.

The potential disadvantages of a community approach are (1) a narrower range of sophisticated medical resources such as tertiary care; (2) a lack of support services such as crisis intervention networks, buddy systems, and hotlines; and (3) an inability of the community to afford the burden of uncompensated care that AIDS patients often pose for facilities.

Comprehensive Care Facilities. Designated comprehensive care facilities have the following advantages: (1) the presence of sophisticated multidisciplinary treatment teams, (2) a sufficiently large base of clinical experience to offer flexibility in treatment, and (3) access to support networks able to provide assistance with the activities of daily living.

The disadvantages of designated comprehensive care centers are (1) the possible negative connotations of being marked as an AIDS facility, (2) the possibly greater costs of inpatient treatment in a major metropolitan area, and (3) the likely distance from the patient's home and place of employment.

It is felt that Michigan needs a combination of these two options to establish an organized system of care that is comprehensive, cost-effective, accessible, and of high quality. A single expert tertiary care program for the treatment of persons with AIDS should be established in the metropolitan Detroit area, where the majority of AIDS patients are located. This tertiary care program should have the capacity to serve as a consultant to other health facilities and providers, carry out research, and provide professional education. The program should be involved with a network of community hospitals within metropolitan Detroit and throughout the state that also provide inpatient care for persons with AIDS. In addition, the tertiary care program should be linked with community-based resources that make available services such as home health, hospice care, and support services. Moreover, service gaps, such as nursing homes, should be addressed either by the tertiary care program or one or more of the other hospitals. One or more dedicated long-term care units should be created, specializing in the treatment of patients with AIDS. Such a unit could operate in existing but unused hospital space and at far lower cost than if patients remained in acute care beds. The obvious difficulties associated with creating such a unit(s) are our current inability to determine the exact size that might be required at any point in the future and the fact that such a unit provides geographic access only to those reasonably nearby.

Recommendation 12:

The State should promote and support in metropolitan Detroit an expert program for the treatment of persons with AIDS, linked with a statewide network of community hospitals and community-based resources. The State should work to stimulate the creation of outpatient community care opportunities through the establishment of networks of community resources elsewhere in the state. The Greater Detroit Area Health Council should be encouraged to continue its assessment of care opportunities in southeastern Michigan. One or more dedicated long-term care units should be considered.

13. Problem Statement: There is need to ensure that sound information about AIDS is shared regularly with health care providers.

Analysis: Diagnosing and treating AIDS or ARC pose many problems. The AIDS definitions established by the CDC, unless clearly understood by physicians, may lead to incomplete diagnosis. New evidence indicates that in addition to Kaposi's sarcoma (skin cancer) and Pneumocystis carinii (lung infection), central nervous system disorders are associated with the presence of the HTLV-III virus in the cerebrospinal system. Health care providers should be encouraged by their professional associations and the MDPH to remain current on information about AIDS.

Recommendation 13:

The MDPH, in cooperation with medical experts in the state, should facilitate collecting and disseminating information about AIDS to health care providers. Such information should be distributed through the professional associations of health care providers, as well as in response to direct inquiries.

STATE GOVERNMENT POLICY

The constitutional and public trust responsibilities to protect the health of its citizens and to prevent unreasonable intrusions into their private lives requires state government to respond to the problems presented by AIDS in a carefully considered and responsible fashion.

Of particular importance in the development of such policies is their effect on five population groups, each of which has different requirements and demands:

- State employees
- Contractors with the State of Michigan
- Persons who are institutionalized in state-run facilities
- The general population
- Members of the populations who have acquired AIDS

State policy to meet the needs of these sometimes overlapping populations should be consistent across departmental lines but also should recognize special needs and circumstances.

PROBLEMS, ANALYSES, AND RECOMMENDATIONS

14. Problem Statement: There is need for state government policy about AIDS to be consistent across departmental lines.

Analysis: Several departments of state government have already begun developing policy responses to the dilemmas posed by AIDS. In some cases, policies have developed in response to dictates from the federal government (e.g., the Department of Military Affairs); in others, policies have developed in response to specific events; and in still others, a policy-making process is in motion that attempts to guarantee consideration of the viewpoints of a wide variety of disciplines and affected groups. The result could be inconsistent and/or conflicting policies.

In October 1985, Governor Blanchard asked the Michigan Department of Public Health to coordinate the state's efforts to address AIDS and the Public Health Advisory Council to make policy and program recommendations. The creation of the Expert Committee on AIDS by the Public Health Advisory Council has contributed significantly to information-sharing and open communications among departments. This informal mechanism already has contributed to a more consistent policy-setting process than could have been expected absent the action by the Governor.

A more formal process, as implemented in several other states, could assure the delineation of comprehensive and consistent AIDS-related policy across departmental lines.

Recommendation 14:

The MDPH, with the assistance of a broadly representative committee consisting of persons both inside and outside state government, should be charged with ongoing review of all AIDS-related policies of state agencies and cross-departmental issues for the purpose of achieving consistency.

15. Problem Statement: State government bears special responsibilities for protecting the health and rights of persons in state institutions. There is need for comprehensive plans and consistent policies among state facilities for dealing with AIDS-related problems.

Analysis: Currently, some 22,000 Michigan citizens are confined by the State. These include approximately 5,000 persons in mental health institutions, 16,000 in prisons, and 800 in social services residential care centers. In addition, the State shares special responsibilities for approximately 900 persons in Michigan veterans' facilities, 135 in the School for the Deaf, 86 in the School for the Blind, and 309 in the State Technical and Rehabilitation Center.

Because a troubling issue is the proper response by state and local governments to safeguard the health of confined populations, part of the analysis preceding recommendation 5 in the Prevention and Control section of this report bears repeating. Government assumes special responsibility for those confined involuntarily and those under the care and protection of state and local agencies. On the one hand, isolation of individuals known to be infected could reduce the likelihood of transmission to uninfected persons. On the other hand, the costs of isolating all those testing HTLV-III seropositive would be enormous, such isolation could be infeasible in many instances, and confidentiality would be impossible to maintain. Segregation without isolation of those testing HTLV-III seropositive, in fact, could lead to more intense exposure, thereby endangering individuals even more.

There is no fail-safe system to protect public health absolutely, whether inside or outside institutions. As discussed throughout this report, education is the best means of halting the spread of the HTLV-III virus. Educational materials disseminated to institutionalized populations and to staffs in those facilities will be more beneficial than other currently available options such as mandated testing and isolation. Transmission is largely dependent on voluntary acts such as sexual intercourse and shared use of syringes. Behavioral change remains the best way to curb the spread of the virus.

In the absence of policy guidelines from the CDC, the Michigan Department of Corrections has undertaken a systemwide educational program for all staff and its 16,000 prisoners. In addition, evaluation procedures for newly incarcerated prisoners are being revised to improve counseling and education for high-risk groups and to increase the likelihood that those opportunistic infections or diseases associated with AIDS will be detected and treated. Interim guidelines adopted by the Department of Corrections have restricted serologic

testing for HTLV-III antibodies to circumstances in which it is medically indicated for diagnosis or treatment. Segregation of prisoners is imposed only when necessary to provide medical care or to control behavior that places others at risk of infection.

Several principles should guide policies for institutionalized populations. (1) The primary goal is halting the spread of the HTLV-III virus. (2) A comprehensive plan needs to be developed before any one strategy, such as mandatory screening, is instituted. (3) What is useful in stopping the spread of the virus in the general population should be found useful in institutional settings. (4) The degree of risk must be as carefully weighed in institutions as it is in the general population before restrictive actions are taken.

The MDPH should work closely with the departments of Corrections, Mental Health, and Social Services in developing effective plans and policy for confined populations. Such plans can be adjusted to other institutional settings such as local jails. These plans must incorporate educational materials directed to prisoners, residents, and staff.

Recommendation 15A:

The MDPH should work with state agencies to provide all employees of state institutions with educational materials outlining current knowledge pertaining to AIDS and with training regarding appropriate infection control procedures.

Recommendation 15B:

Information describing AIDS and its modes of transmission should be made available to all prisoners at state correctional facilities.

Recommendation 15C:

Comprehensive plans to control the spread of the HTLV-III virus in confined populations should be developed by the Michigan departments of Corrections, Mental Health, and Social Services in consultation with the MDPH and with other interested parties, including unions representing affected employees. Mandatory testing of any individual or group of individuals should be considered only in the context of such a comprehensive plan and should be implemented only when demonstrated to be effective in containing the spread of the virus.

16. **Problem Statement:** There is need for delineation of state policy relating to employee-employer relationships, particularly as it relates to state government.

Analysis: The Michigan Handicappers' Civil Rights Act, enacted in 1976, protects handicapped persons from discrimination in employment, housing, public accommodations, public service, and education, unless it can be demonstrated that such accommodation imposes undue hardship. All employers of four or more persons, including state and local governments, are covered by the act.

The act defines handicap as a "determinable physical characteristic . . . of an individual . . . which may result from disease . . ." The Department of Civil Rights, which administers the act, has stated that it will accept and process complaints from persons alleging unlawful discrimination based on AIDS, since AIDS appears to be within the statutory definition of a handicap. It is likely that alleged discrimination based upon ARC and HTLV-III antibody positivity would also be subject to the Handicappers' Civil Rights Act.

In addition to the fear of discrimination, concerns have been expressed by state employees regarding health and life insurance benefits. The Michigan Department of Civil Service recently reviewed state employee health benefits and life insurance and determined that AIDS-related illnesses and medical treatment are covered by both the state's health and life insurance policies.

Recommendation 16:

The Michigan Department of Civil Rights (MDCR) should enforce the provisions of the state Handicappers' Civil Rights Act to ensure that people with AIDS, ARC, or HTLV-III antibody positivity are protected against discrimination in employment, housing, public accommodations, public service, and education. The MDCR should publicize its policy regarding the rights of persons with AIDS, ARC, or HTLV-III antibody positivity.

17. **Problem Statement:** There is need for state contractors who provide care in settings such as foster care homes, halfway houses, and substance abuse clinics to be provided with AIDS information and policy direction.

Analysis: A substantial number of caregivers provide direct services, lodging, and other care under contract with state agencies such as the Department of Social Services (foster care homes), the Department of Mental Health (community mental health clinics), and the Department of Public Health (substance abuse clinics). Concerns for themselves, their employees, and other patients or residents must be addressed through informational materials developed by the appropriate contracting agency with the assistance of the MDPH.

Throughout this report, education is identified as the best means currently available for controlling the spread of the HTLV-III virus. Appropriate educational materials broadly disseminated through the state's contractor system will encourage voluntary behavioral change and will do far more to check the transmission of the HTLV-III virus than can be accomplished through mandatory testing or isolation.

As is true of other populations, blanket mandatory screening of all contractor employees, foster care homeowners, or clients and residents is not cost-effective and could be counterproductive. However, contract caregivers should be alert to individuals exhibiting high-risk behavior and should suggest that their clients seek medical advice as to the advisability of testing.

The MDPH should work closely with the contracting agencies of state government to develop appropriate educational and informational materials for contractors, employees, and patients and residents.

Recommendation 17:

The MDPH should work with the Michigan departments of Social Services and Mental Health and with the Office of Substance Abuse Services to develop information packages for contracting state agencies to provide to caregivers.

18. Problem Statement: There is need to develop AIDS policies for licensees of the State who are not health care providers, but whose occupations involve close personal contact with their clients.

Analysis: The Michigan Department of Licensing and Regulation licenses a number of health care occupational groups. Recommendations for dealing with AIDS-related prevention and control for those groups are dealt with in recommendations 9, 10, and 11 of the Provider and Institutional Care section of this report.

The Department of Licensing and Regulation also licenses a number of other occupations that involve close personal contact with clients, such as barbers, cosmetologists, and myomassologists. In addition, the Department of Licensing and Regulation licenses marriage counselors and registers social workers, groups which engage in counseling services that might be needed by a person with AIDS or ARC or who has been identified as HTLV-III antibody positive.

While there is no evidence of transmission of the virus between clients and personal-service workers, the CDC has recommended that all personal-service workers be educated about the transmission of bloodborne infections, including the HTLV-III virus, and that licensure requirements for such occupations should include evidence of such education.

Special efforts to assure that personal-service workers are provided with appropriate educational materials regarding AIDS, ARC, and HTLV-III positivity are warranted.

Recommendation 18:

The Michigan departments of Licensing and Regulation and Public Health jointly should review professional standards for personal-service workers to assure that they reflect current information regarding AIDS. Distribution of AIDS-specific information to state licensees is desirable and should be accomplished through general education programs directed at licensees.

19. Problem Statement: There is need for a complete review of state government's confidentiality standards to assure that the rights of persons with AIDS, ARC, and HTLV-III positivity are adequately protected and that the public health is maintained.

Analysis: Voluntary testing, education, behavior change, and notice to sexual partners are essential to successful control of the HTLV-III virus. Such voluntary compliance can be inhibited if strict confidentiality of the identities of AIDS, ARC, and HTLV-III seropositive persons is threatened. Confidentiality is particularly important in public health efforts to control AIDS because of public fears of AIDS and the discrimination and social stigma visited upon people who contract the syndrome.

The MDPH and other state agencies need to maintain accurate information on the spread of AIDS in Michigan. In addition, agencies exercising custodial care may need to maintain medical records on prisoners, patients, or clients.

At present, the MDPH requires a complete epidemiological report on persons with AIDS but does not require reports of ARC or HTLV-III seropositivity. For information reported to the MDPH to be accurate, it is critical that every local public health department be provided with clear guidelines regarding what constitutes CDC-defined AIDS. Such guidelines are essential so that clear instructions on reporting requirements can be given to the provider community and providers do not report cases of ARC or HTLV-III antibody positivity.

Where medically necessary, identity-specific information for ARC and HTLV-III positivity may be appropriate for state agencies that exercise custodial care responsibilities over individuals. Persons with access to such information should be required to adhere to strict confidentiality standards.

For the general population, any collection of personally identifying information regarding AIDS by state agencies should be governed by a standard that prohibits it unless there is a clear and compelling need to serve an individual with AIDS, to protect the health of persons who may be at risk of contracting AIDS through body fluids, or to protect public health.

When any personally identifying information about AIDS is reported to a state department, notice should be given to the individual by the person reporting it and the individual given the right to obtain a copy of such information. In addition, whenever such information is shared by one state department with another, the individual should be provided with notice and the opportunity to obtain a copy.

When personally identifying information is collected, there also is a duty to restrict access to only those persons within state agencies who have a compelling need for the information in order to protect the health of the individual with AIDS or to protect the health of persons who might contract it through body fluids.

Recommendation 19A:

Each department of state government, before obtaining identity-specific information about persons with AIDS, should establish clear evidence that such information is necessary.

Recommendation 19B:

The departments of state government providing custodial care that obtain identity-specific information about persons with AIDS, ARC, or HTLV-III antibody positivity should review their confidentiality standards to ensure that only those persons with a clear and compelling "need to know" have access to such information.

Recommendation 19C:

Whenever personally identifying information concerning AIDS is reported to the MDPH, notice should be given by the personal physician to any individual about whom the information is compiled. Whenever confidential personally identifying information is to be shared among departments of state government, a signed release should be obtained from the individual prior to the transmittal of the information. The individual should have the right to a copy of such information and the names of the agencies with whom the information was shared.

20. Problem Statement: There is need to develop and disseminate standards for private and public agencies that store human tissues, organs, and semen.

Analysis: When considering the issues involved in transplantation, a distinction must be made between tissues and organs that can be stored,

such as sperm and bone, and those that cannot, such as kidneys and hearts. Different policies may be appropriate for each.

Major tissue and sperm banks, through the American Association of Tissue Banks (AATB), have recently implemented standards of HTLV-III antibody testing. An inspection and accreditation program is being developed for member tissue banks. Adherence to standards may become a requirement for AATB membership, but membership is voluntary. It is not anticipated that the Food and Drug Administration will promulgate rules for HTLV-III testing in tissue banks in the near future.

Information is not currently available about the number of artificial inseminations performed each year. However, industry standards for artificial insemination using stored frozen semen are comprehensive regarding HTLV-III antibody testing. The donor is tested at the time of donation. The semen is then frozen and quarantined. After two months, the donor is tested again and if he still tests negative, the stored semen is released from quarantine.

In bone banking, there are instances in which bone removed during a surgical procedure is recycled into bone powder for later use. While there are protocols for proper preparation and quality assurance, including HTLV-III antibody testing, such protocols may not always be followed. The AATB plans a major educational effort to upgrade surgical bone retrieval and processing procedures. The principles involved in safeguarding the blood supply are applicable to tissue, organ, and semen protection.

Recommendation 20:

The MDPH should develop legislation or administrative rules to protect against the spread of AIDS through tissue, organ, or bone transplants. The following principles should apply:

- HTLV-III antibody testing of donors is necessary for stored tissues of all types.
- When fresh organs, tissues, or semen are harvested, HTLV-III antibody testing should be performed, but the need for evidence of a negative test prior to transplantation must be addressed on an individual basis since the condition/need of the recipient and condition of the donor organs vary widely.
- Appropriate confidentiality standards of donor names and/or test results must be strictly maintained.

21. Problem Statement: There is a need to develop consistent policies regarding AIDS for public school students and employees in Michigan.

The lack of information about the nature of AIDS, its spread, and its prevention have led to unnecessary fears and anxiety in schools.

Analysis: Instances of AIDS hysteria have occurred in other states when students with AIDS have entered schools. In some situations, the students who were denied access to schools were not infected themselves but had siblings or parents suspected of having AIDS.

Michigan currently does not have a diagnosed case of AIDS in a public school. It is important to put in place now education programs and policies to protect the public health as well as the rights of students and school employees who may be infected.

There is no reason to believe that AIDS can be spread in the normal interactions between school staff and students or between students. No special screening programs are necessary to test students or school employees for AIDS. Normal sanitary procedures and precautions for handling body fluids and blood are sufficient to protect against the potential spread of the HTLV-III virus.

Cases of AIDS in the school setting should be evaluated individually at the local level. Decisions regarding the appropriate educational and care settings for students or staff with AIDS should be based on the medical and behavioral condition of the individuals. These decisions should be made by a local evaluation team that includes the affected individual's physician; public health personnel; a parent or guardian, in the case of a student; and personnel associated with the proposed education setting.

Basic information about AIDS, its prevention, and its spread should be disseminated through teacher training and in classroom and public education settings. A better understanding of the issues will be useful in dispelling some of the fears associated with AIDS and in reducing the potential for AIDS hysteria.

Recommendation 21A:

The Expert Committee supports the position of the Centers for Disease Control that students infected with AIDS can safely attend school without endangering others unless they exhibit specific medical or behavioral conditions that present a risk to themselves or others. These conditions should be locally evaluated on an individual basis.

Recommendation 21B:

The Michigan Department of Education (MDE) in cooperation with the MDPH should develop public policy guidelines relating to AIDS that assure public health protection and provide for appropriate educational opportunities for all students.

Recommendation 21C:

The MDE should work with the MDPH to disseminate information about AIDS prevention, transmission, and spread and to dispel unnecessary fears among school employees, parents, and students.

Recommendation 21D:

The MDPH should support the MDE in assuring that school employees infected with AIDS are not restricted from working in the school setting unless specific medical or behavioral risks are documented. Routine AIDS testing is not warranted for students or school employees.

FINANCING

Federal government participation in funding AIDS-related activities is likely to be limited to medical research; the states will be left on their own to finance treatment for the indigent, regulate insurance coverage, maintain surveillance, and provide education to the general public and high-risk groups. The costs of AIDS-related activities and recommended levels of state financial support are discussed in this section.

PROBLEMS, ANALYSES, AND RECOMMENDATIONS

22. Problem Statement: There is need to determine if third-party payers are contemplating changes in coverage for AIDS-related care (e.g., premium rates or denial of coverage).

Analysis: Group plans, which are not generally medically underwritten (that is, insurers do not assess applicants' health risks), currently account for approximately 85 percent of traditional private health insurance nationwide. Coverage for AIDS is not excluded from such policies except in cases in which a form of treatment is deemed experimental and policies stipulate that experimental treatment is not covered. While the Michigan insurance industry indicates no intention of initiating medical underwriting of group coverage, projections of mounting costs for AIDS-related health care have aroused concern about individual insurance policies, which generally are medically underwritten. Insurers assert the necessity of having as much medical knowledge as possible about applicants in order to assess risks accurately. Further, they are concerned about potential "adverse selection"; that is, that persons who test positive for the HTLV-III antibody will buy large amounts of insurance without revealing the results of the antibody test to the insurers. Critics of insurers' use of HTLV-III antibody screening (or detailed questioning about lifestyles and sexual practices) argue that if an applicant tests positive, coverage may be denied, premiums may be set prohibitively high, and/or inadequate confidentiality safeguards may lead to discrimination in other contexts. They also point out that at present the ELISA HTLV-III antibody test often yields falsely positive results. Attaining greater accuracy in antibody testing entails the expense of a series of ELISA tests and use of the Western Blot test, which is not widely available and costs at least \$65 to perform. Some Michigan insurers say that they do use this more rigorous testing procedure. Even true positive findings of the antibody, however, do not mean that the individual will ever experience an illness or require medical treatment related to the virus. Therefore, critics allege, testing does not provide a sound basis for underwriting decisions.

Insurers have a legitimate interest in assessing their financial risks. It can also be argued that, as with such serious illnesses as heart disease or cancer, those who are at higher risk should bear a greater share of insurance costs. It would be highly undesirable, however, to create a class of uninsurable people or to underwrite policies on the basis of insufficient medical evidence or tests that are unreliable or that cannot predict future medical needs.

Blanket exclusion of AIDS-related information from underwriting, on the one hand, or use of questionable practices to exclude from coverage those who may be at risk of AIDS, on the other, are extremes to be avoided. Alternatives must be sought that protect the legitimate interests of those at risk of AIDS and also of insurers. Pooled risk insurance for those who can reliably be demonstrated to be at risk, for example, should be considered. Six states already have such pools, and twenty others are considering them. Questions of confidentiality and of who will bear the costs of a reliable regimen of blood screening must also be addressed.

There is, at present, no evidence that third-party payers are contemplating denying coverage to those at risk of AIDS or excluding coverage for AIDS-related expenses from group or individual health policies. The insurance industry's interest in using HTLV-III antibody testing in assessing applicants does suggest the potential for future exclusions or limitations of coverage. It would be premature, however, to assume the need for the State to mandate coverage before other means of ensuring maintenance of third-party coverage have been explored.

Recommendation 22A:

The Insurance Commissioner should continue to work with life/health insurers, the Public Health Advisory Council, and representatives of the most affected groups (to be selected by the commissioner) to recommend policies to make available insurance coverage for AIDS-related treatment and care and life insurance benefits. In the interim, persons at risk (whether defined by socio-demographic characteristic, area of residence, or HTLV-III antibody test results) should not be excluded from life and health insurance coverage. Also, until the results of this working group become available, legislative actions in this area are not recommended. In the interim, any use of HTLV-III antibody testing in screening, evaluating, and rating health and life insurance applications and policies is not supported.

Recommendation 22B:

Current third-party coverage for AIDS-related treatment and care should be continued. The State should not mandate insurance coverage for AIDS-related expenses.

23. Problem Statement: There is need to examine how AIDS-related treatment is classified in terms of diagnosis related groups (DRGs).

Analysis: Some observers have suggested that the state Medicaid DRG cost-weights currently applied to AIDS-related health care do not adequately reflect the actual costs of treatment. Medicare also uses DRG classifications in determining reimbursement, but it is federally administered and its classification system and cost-weights are not subject to revision at the state level.

Recommendation 23:

The Michigan Department of Social Services should review, as a component of periodic evaluations, cost-weights for AIDS-related care and make revisions, as appropriate, in accordance with federal and state reimbursement methods.

24. Problem Statement: There is need to examine how public funding in Michigan should be allocated among various AIDS-related activities (e.g., education/prevention, research, screening and counseling, care and support services).

Analysis: A comprehensive approach to funding AIDS-related activities is needed that recognizes the interdependence of its components. Medical care and treatment will always be the highest priority, the financial burden for which falls on government (Medicare and Medicaid), private insurers, and private payers. Preliminary data from Michigan indicate that Medicaid bears at least part of the costs for about 45 percent of AIDS patients. However, the state Crippled Children's Program now bears the costs of treatment for AIDS or ARC contracted from blood or blood products administered to pediatric hemophilia cases. Great importance must also be given to surveillance (on which all other activities are based); to screening, counseling, and education/prevention programs for high-risk groups (which could have an immediate effect on contagion and future costs of care); to education/prevention programs for groups at lower risk and the general public (which are an essential part of a full AIDS-control program); and to nonhealth support services, such as counseling and advocacy services. A lower state spending priority is medical research. While medical research seeking a cure and a vaccine for AIDS is vitally important, these endeavors can best be funded and coordinated on a national basis by the federal government. Limited state funds may be needed to enable Michigan researchers to participate in federal and private clinical research efforts.

Recommendation 24:

Public health prevention and control priorities should be: surveillance; high-risk group education, screening, and counseling; general education; and nonhealth support services. Medical research should have lower priority for state funds since the federal government has primary responsibility for this important activity. Efforts should be made to secure greater research funds.

25. **Problem Statement:** Information is needed concerning the costs of the full continuum of AIDS care, including information about the costs of alternative models of care and their applicability in Michigan.

Analysis: Nationally, estimates of the costs of AIDS-related hospital care vary widely, from the CDC estimate of \$140,000 per patient to estimates as low as \$25,000-32,000 per patient for care at San Francisco General Hospital. Actual costs differ in part because the typical length of hospital stay varies considerably. Length of patient stay depends on such factors as differences in the prevalent clinical manifestations of the disease, patient management practices, and the availability of nonhospital-based care. San Francisco General Hospital has been able to reduce costs of inpatient care by establishing a specialized multidisciplinary AIDS unit, including an outpatient clinic and an AIDS inpatient unit. This approach may not be cost-effective, however, in a decentralized approach to care where many hospitals are each serving only a small number of AIDS patients.

Preliminary data from Michigan indicate the average Medicaid expenditure for 20 months of care is \$52,230 per case. The Hospital Financial Management Association and the Greater Detroit Area Health Council plan to survey the six southeast Michigan hospitals that together serve nearly 90 percent of Michigan's AIDS cases. Costs studies are hindered, however, by the lack of AIDS- and ARC-specific ICD-9 (International Classification of Diseases [9th edition]) codes. Costs also go beyond hospital care. The most often cited studies do not include estimates of expenditures for home health care, outpatient care, medication, and laboratory work. (The Michigan Medicaid study covers the full continuum of care, although there are no data for covered home health care because no payments have been made to date in this area.) Better estimates of the costs of all aspects of AIDS-related care in Michigan are necessary to establish present and future funding needs and to assist in designing a cost-effective model of care compatible with the scope and nature of the manifestation of AIDS in Michigan.

Nonhealth support services, such as counseling, advocacy, residential facilities, and assistance in daily living, are needed. These are detailed in the analysis of recommendation 8A. State funds totaling \$550,000 have been estimated as necessary to support such activities.

Recommendation 25:

Further study of the costs of AIDS-related care in Michigan should be undertaken by the Michigan Department of Social Services, the MDPH, and the Greater Detroit Area Health Council, including analysis of Medicaid data, with special emphasis on determining the costs of the full continuum of care and the relative cost-effectiveness of alternative models of care suitable to the Michigan situation.

26. Problem Statement: There is need for funding to implement the recommendations contained in this report.

Analysis: This report contains recommendations in a number of areas that require funding and staffing support by various state government agencies, especially MDPH.

Surveillance activities are addressed in recommendations 1, 2A, and 2C. Existing resources and federal funds have been made available to the MDPH to address recommendations 1 and 2A. This support is expected to continue. A grant application has been submitted by the MDPH to the Centers for Disease Control to address anonymous, batched testing (recommendation 2C).

Information and education activities for high-risk groups and the general population are spoken to in recommendations 3A, 3B, 3C, 3D, 4, 5F, 15B, and 18. A total of \$1 million is estimated to be the amount needed to address these recommendations adequately. State funding, totaling \$361,100, to address these recommendations has been recommended in the Governor's FY 1986-87 budget. In addition, the MDPH has applied for a grant from the Centers for Disease Control requesting \$270,000 to be used for the design, implementation, and evaluation of health education activities. Additional state funding will be needed to supplement these two sources.

Information and education activities for health care providers are addressed in recommendations 5F, 6B, 9A, 10, 11, 13, 15A, and 17. A total of \$250,000 is estimated to be needed to address these recommendations adequately. This funding would supplement resources provided by health care professional organizations, health care facilities, and agencies of state government. Of the estimated \$250,000 needed to carry out these activities, \$25,000 is recommended in the Governor's FY 1986-87 budget.

Encouraging high-risk groups to undergo voluntary testing is spoken to in recommendation 5A, and the existing capability of the MDPH and other laboratories is adequate to meet this need. The MDPH laboratory estimates it can perform an additional 30,000 ELISA tests and 1,000 Western Blot tests in FY 1986-87 at a cost of \$242,000. Counseling and anonymous testing in the alternate site testing facilities is an important component, which needs to be maintained. Federal funds have supported this effort but are not expected to continue; estimated annual state funds totaling \$190,000 will be required.

The development of retro-virology laboratory services is addressed in recommendation 6C. The first-year start-up costs of such services are estimated at \$125,000. Annual maintenance costs after the first year are expected to total \$90,000. Such resources would allow for the analysis of three to four specimens daily. No existing resources currently are available to carry out this activity.

The development by the Michigan Department of Social Services (MDSS) of adequate support services is spoken to in recommendation 8A. A residential facility to house six to eight indigent AIDS patients, as well as similar projects, is expected to require \$500,000 for acquisition and the first year of operation. Assistance with daily

living activities such as transportation and chore services are being handled primarily through the volunteer efforts of groups such as Wellness Network, Inc. However, minimal operating expenses need to be funded from a stable source. An estimated total of \$50,000 is needed for this effort. No resources currently exist to support the various facilities and services described above.

Development of an expert program for the treatment of persons with AIDS, coupled with a statewide network of community hospitals and community-based resources and including one or more dedicated long-term care units, are addressed in recommendation 12. The costs for such a program are not yet known. To a certain extent, implementation of recommendation 25 will facilitate finding answers to costs questions. In addition, the efforts of the Greater Detroit Area Health Council should be encouraged as a means of implementing recommendation 12.

Various state departments have specific responsibilities for AIDS-related care and education. The MDSS bears responsibility for financial assistance to the indigent and medically indigent (through Medicaid) and for the administration of foster care. Numbers of AIDS patients are eligible for MDSS programs by virtue of their eligibility for federal Supplemental Security Income benefits. To date, the Michigan Department of Corrections has encountered three cases of AIDS and five cases of ARC among inmates. The Michigan Department of Mental Health has had one patient diagnosed with AIDS (after leaving MDMH care). It has been pointed out that AIDS infection can result in neurological impairment and that this may give rise to an increasing number of AIDS-related psychiatric cases and a greater burden on Michigan's facilities for the care and treatment of mental illness. Some observers estimate that as many as 40 percent of all AIDS patients now suffer neurological impairment. MDMH, MDSS, and MDOC do not foresee financial problems in dealing with AIDS patients in the near future.

Other state agencies, such as the Michigan Department of Education, with significant responsibilities for AIDS may need to adjust their budgets to provide support for educational and other services.

Recommendation 26A:

The MDPH should develop a program tailored to educate the general public and high-risk groups. An estimated annual cost is \$1 million.

Recommendation 26B:

The MDPH should develop a program tailored to educate health care providers. An estimated annual cost is \$250,000.

Recommendation 26C:

The MDPH should continue the alternate site counseling and testing program. An estimated annual cost is \$190,000.

Recommendation 26D:

The MDPH should develop retro-virology laboratory services. The first-year estimated cost is \$125,000 and annual maintenance costs are anticipated to be \$90,000.

Recommendation 26E:

The MDSS should support a program tailored to provide adequate support services. An estimated annual cost is \$550,000.

Recommendation 26F:

The Michigan departments of Corrections, Social Services, and Mental Health should continue to monitor the number and rate of growth of AIDS-related cases within their jurisdictions, and MDMH should pay special attention to the rate of increase of HTLV-III-related neuropsychiatric conditions.

Recommendation 26G:

Appropriate state agencies should determine additional funding requirements to carry out these programs.

APPENDIX A

GLOSSARYAcquired Immunodeficiency Syndrome (AIDS)

A serious condition caused by the human T-cell lymphotropic (HTLV-III) virus (see below). It is characterized by a defect in immunity against disease. People who have AIDS are vulnerable to certain serious illnesses that are not a threat to anyone whose immune system is functioning normally. These illnesses are referred to as "opportunistic" infections or diseases.

For medical and public health scientists to count cases of AIDS uniformly for epidemiologic purposes, the U.S. Public Health Service Centers for Disease Control (CDC) has developed a standard national definition that classifies a case as AIDS if any of several opportunistic diseases are present without other explanation. It is estimated that 5 to 20 percent of those infected with the virus that causes AIDS will go on to develop an illness that fits the standard national case definition within five years. Note that clinically oriented health professionals often use the term AIDS to refer to the full spectrum of illnesses related to infection with the virus causing AIDS, not just to those illnesses included in the standard national case definition.

AIDS Carrier

One who is infected with the HTLV-III virus. Carriers can infect others, but do not necessarily become ill themselves. Essentially, any person with laboratory evidence of exposure to the virus (i.e., seropositivity) is considered a possible carrier.

AIDS Related Complex (ARC)

A condition caused by the same virus that causes AIDS. It is characterized by a specific set of clinical signs and laboratory abnormalities. Symptoms can include lymphadenopathy (chronically swollen lymph nodes), weight loss, fever, chronic diarrhea, encephalomyelopathy, dementia, general malaise, and other conditions. It can persist for years, be a prelude to the rare types of cancer and pneumonia that mark full-blown (i.e., CDC-defined) AIDS, or resolve spontaneously. It can also be fatal in itself. From 20 to 40 percent of those infected with the HTLV-III virus eventually develop ARC.

Alternate Site Testing

Sites other than blood donation centers where persons at high risk for AIDS are encouraged to receive information about being tested and be tested for exposure to the HTLV-III virus. Counseling and testing services are provided free to those who cannot afford to pay for them or make a donation. These test sites were set up so high-risk individuals would not be tempted to donate blood in order to be tested. In Michigan, alternate site testing information is available through all local health departments and through Wellness Networks, Inc., via a statewide telephone hotline.

Antibodies

Unique protein substances present in the blood that the body produces in response to infectious agents or toxins. The presence of a particular antibody is therefore evidence of exposure to a particular infectious agent or toxin.

Asymptomatic

Being infected with a disease-causing agent, but without having symptoms of the disease.

Centers for Disease Control (CDC)

An agency of the U.S. Public Health Service responsible for monitoring communicable diseases, developing disease control strategies, conducting applied research, and disseminating up-to-date information about diseases to public health and health care professionals.

Diagnosis Related Groups (DRGs)

A method of classifying illnesses by types of diagnosis and treatment, used by Medicare and Medicaid to determine payments to hospitals. A relative cost-weight is calculated for each DRG, which, in conjunction with each hospital's cost factors, determines the amount paid for each hospital stay. Hospitals are paid this amount regardless of the actual costs incurred for each episode of hospitalization.

ELISA (or EIA) Test

The acronym for Enzyme-Linked Immunosorbent Assay, a type of test for the presence of antibodies in the blood. In the context of this report it refers only to tests for presence of antibodies to the HTLV-III virus.

The ELISA test was designed to screen blood donors to prevent the spread of AIDS through contaminated blood or blood products. For this reason, it is highly sensitive. However, when used among populations at low risk for AIDS, such as volunteer blood donors, as many as 19 of 20 positive results are incorrect. Fortunately, a confirmatory test, the Western Blot test, can be administered to those testing positive by the ELISA test. The Western Blot test (see below) can classify the vast majority of those testing falsely positive. The ELISA test may rarely give falsely negative results, meaning there is an extremely slight risk of accepting donations of contaminated blood.

Epidemiology

The branch of public health science concerned with the spread and distribution of disease, the scientific basis for disease control strategy, and the evaluation of disease control program effectiveness.

Hemophilia

An hereditary disorder characterized by inadequate amounts of blood clotting factors.

High-Risk Groups

In the context of this report, people who are at high risk for AIDS include homosexual or bisexual men, intravenous drug users, hemophiliacs who have received clotting factor concentrates not processed to inactivate viruses, heterosexual contacts of the above groups, and children born to women who carry the HTLV-III virus.

HTLV-III Virus

The abbreviation for human T-cell lymphotropic virus, the virus that causes AIDS. Its name comes from the fact that the virus attacks the T-4 lymphocytes, white blood cells that play a major role in defending the body against infection. The virus is also called lymphadenopathy associated virus (LAV).

HTLV-III Antibody Test

Blood tests to detect the presence of antibodies to the HTLV-III virus. The confirmed presence of such antibodies is presumed to be evidence of HTLV-III infection. (See ELISA and Western Blot.)

ICD-9

The abbreviation for International Classification of Diseases (9th Revision), the disease classification system developed by the World Health Organization for coding diseases and conditions in hospital records.

Intravenous Drug User

One who uses drugs that are injected into the body. Users of illegal intravenous drugs, e.g., heroin, may share equipment with others and thus risk infection.

Kaposi's Sarcoma

A type of skin cancer. It is one of the more common of the opportunistic diseases that occur in people with AIDS.

Low-Risk Group

In the context of this report, persons not belonging to high-risk groups (see above) and thus at extremely low risk of contracting AIDS.

Medicaid

A health care program that is state administered and uses a combination of state and federal funds to pay for predefined medical care for individuals classified as needy or medically indigent. The Medicaid program is authorized by Title XIX of the Social Security Act.

Medicare

A health insurance program for all people 65 years old and older and some under age 65 who are disabled. Medicare is a federal program authorized by Title XVIII of the Social Security Act.

Morbidity and Mortality Weekly Report (MMWR)

The weekly scientific publication of the U.S. Public Health Service Centers for Disease Control that provides health care providers and public health professionals with timely information and recommendations about current public health problems.

Morbidity

A measure of the occurrence of a disease. The morbidity rate is the number of persons who become ill per unit of population during a given time.

Mortality

A measure of the number of deaths from a disease. The mortality rate for a particular disease is the number of deaths per unit of population during a given time.

National Institutes of Health

An agency of the U.S. Public Health Service with a major responsibility for performing and funding health-related research.

Opportunistic Infection or Disease

An infection or disease that strikes those whose natural resistance to disease has been damaged. AIDS impairs part of the body's natural immunity to some diseases and renders one susceptible to some specific serious illnesses that would otherwise pose little threat.

Pneumocystis Carinii Pneumonia

A type of pneumonia caused by a protozoan parasite that occurs primarily when the body's natural abilities to fight disease have been weakened. It is the most common life-threatening opportunistic infection that strikes people with AIDS.

Retrovirus

The family of viruses that includes the virus that causes AIDS, the HTLV-III virus.

Safe Sex

Sexual behavior that minimizes or eliminates the risk of transmitting the HTLV-III virus.

Serology

The study of the liquid portion (serum) of the blood. This is the part of the blood in which antibodies are found. A serology laboratory generally is one that performs antibody testing.

Seropositivity

The presence of a specific antibody in the blood. One is seropositive for the HTLV-III virus if the antibody to the HTLV-III virus is present in the blood.

Screening

Testing of well persons to determine the presence of a characteristic that is associated with risk of disease. In the case of AIDS, testing the blood of members of specific populations (e.g., blood donors) to determine who has antibodies to the HTLV-III virus and may harbor the virus.

Symptomatic

Showing evidence of disease other than the presence of antibodies in the blood; for example, in the case of AIDS, exhibiting weight loss, chronic swelling of the lymph nodes, and/or one of the opportunistic diseases to which those with AIDS are prone.

Tertiary Care

The most sophisticated level of health care. For example, tertiary care hospitals are nearly always major medical centers that usually have residency, fellowship, and post-doctoral educational components and that carry out clinical research.

Virus

A submicroscopic infectious agent capable of growth and multiplication only in living cells.

Western Blot Test

A confirmatory blood test for the presence of HTLV-III antibodies. It is more difficult and expensive to perform than the ELISA test, but is less likely to indicate falsely the presence of the antibodies. It is used to confirm the results of ELISA tests. However, 5 to 10 percent of those who are actually HTLV-III positive will test negative by the Western Blot test. It is therefore not useful as an initial screening test, nor is it truly confirmatory.

APPENDIX B

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Wayne Living Center
Michigan Nurses Association

Michael Spaulding
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Robert Tell
Greater Detroit Area Health Council

Hollis Turnham
Citizens for Better Care

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Lynne Zimmerman
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Michigan Association of Ambulance Services

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Center for Health Promotion
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Michigan Department of Public Health

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Mark Bertler
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Michigan Department of Mental Health

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Michigan Public Health Association

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Medical Services Administration
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Insurance Bureau
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Life Association of Michigan

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APPENDIX C

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